

# Design Considerations for Semi-Automated Tracking: Self-Care Plans in Spinal Cord Injury

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## ABSTRACT

Self-care in Spinal Cord Injury (SCI) is highly complex and individualized. Patients struggle to adapt to life with SCI, especially when they go home after rehabilitation. We conducted a field study to understand how self-care plans work for patients in their lived experience and what requirements there might be for an augmentative system. We found that patients develop their own self-care plans over time, and that routinization plays a key role in SCI self-care. Importantly, self-care activities exist in different states of routinization that have implications for the technological support that should be provided. Our findings suggest that self-care can be supported by different types of semi-automated tracking that account for the different routinization of activities, the collaborative nature of care, and the life-long, dynamic nature of this condition. The findings from our study also extend recent guidelines for semi-automated tracking in health.

## Author Keywords

Self-care plans; self-monitoring; semi-automated tracking; quantified self; context-aware environments; disability; rehabilitation; requirements; user needs.

## ACM Classification Keywords

H.5.3. Group and Organization Interfaces: Computer-supported Cooperative Work.

## INTRODUCTION

Spinal Cord Injury (SCI) causes complete or partial loss of movement (paralysis) and sensation in specific areas of the body, and affects organ function. Rehabilitation in the hospital, in the immediate aftermath of an injury, often extends over several months. Following rehabilitation, care must be maintained over one's lifetime. Adapting to life with a spinal cord injury is challenging, especially when patients leave hospital and have limited access to professional support. To guide the care at home, clinicians provide patients with a care plan at the time of hospital

discharge, which outlines the important care-related activities. In talking to patients and clinicians, we observed that patients rarely find these care plans work for them, and clinicians report that patients tend not to follow their care plans. We also observed that, given the nature of SCI, which we detail below, self-care is complex and highly individualized. In light of these observations, we embarked on a study to understand (1) how care plans work for patients in their lived experience, and (2) if we could use low-cost personal sensing technologies to augment self-care through improved monitoring and personalization.

In our study, we found that patients and their caregivers find it difficult to translate what they learned in the hospital – and what is outlined in the care plan – to the home environment. Moreover, the personal priorities and preferences of the patients dictate which self-care activities they focus on and how they choose to do these. Importantly, we found that for these reasons, patients tend to develop their own self-care plans over time, and that they do so in collaboration with their caregivers and with intermittent input from clinicians. These self-care plans are dynamic; they are continuously updated based on changing needs and priorities.

As we detail in this paper, our findings suggest that the formulation and execution of self-care plans could be effectively supported through semi-automated tracking of self-care activities. Choe et al. [3] recently defined semi-automated tracking as “any combination of manual and automated tracking approaches,” and described design considerations for these types of approaches. Our work directly extends their design guidelines. Specifically, we elaborate on semi-automated tracking for situations where self-care is long-term and dynamically evolving and where multiple and often interrelated care activities occur over time. In SCI, as well, self-care is accomplished collaboratively with caregivers and clinicians. We show that, under these circumstances, semi-automated tracking needs to be constantly mediated and tailored. For SCI, tracking should support the appropriate prioritization of self-care activities, provide the data and the collaborative tools that are necessary to effectively routinize and maintain self-care activities, and help to identify breakdowns in routinized activities.

In this paper, our contributions are three-fold: (1) we examine how our participants deal with their clinicians' care plans and create self-care plans for themselves, thereby enhancing the understanding of user practices and

needs, (2) we uncover the design requirements for helping a group of patients with a complex, chronic condition. By doing so, (3) we extend recent design guidelines for semi-automated tracking in health. While the context for our study was SCI, we believe that our findings are likely to inform the support of collaborative self-care in other chronic conditions as well.

In the next section, we first provide an overview of related work. We follow with a brief background on SCI and associated self-care needs before describing our methodology and findings.

**RELATED WORK**

**Care Plans and Self-Care Plans**

A ‘care plan’ is created by clinicians to denote the care that is to be provided to a patient, and serves as a medium of communication and coordination for enabling continuity of care across clinicians [1]. At the same time, in long-term follow-up, care plans are used to provide guidance and resources for patients to obtain and maintain care in the outpatient setting [7].

Self-care encompasses the activities people do for managing a chronic condition as part of their everyday lives [13]. The goal is to influence the course of the condition to achieve a satisfactory quality of life [14]. Practices around self-diagnosis, self-management, self-medication, and self-monitoring are all part of self-care [15]. Self-care and self-management tend to be used interchangeably in CSCW/HCI; in this paper we follow the convention of Nunes et al. [14] and use *self-care* to include so-called self-management tasks.

Self-care plans consist of a set of goals along with actionable steps towards achieving those goals. Figure 1 [12] shows a high-level self-care plan for SCI. Clinicians have found self-care plans to be helpful for patients for many chronic conditions (e.g. [8,9]).

For an extensive review of the research on self-care technologies, see Nunes et al. [14]. They noted that technologies can foster reflection and awareness through health and contextual information, suggest care activities or treatment adjustments, enable the sharing of care activities with caregivers, enhance collaboration with clinicians, and facilitate peer connections and support. They continue, “an HCI lens ...is critical for ensuring technologies are designed and evaluated with a deep understanding of everyday practices. (p.39)” In this paper, we examine what is required to facilitate the use of self-care plans.

**Self-Tracking Support for Self-Care**

Self-tracking platforms, whether stand-alone mobile or pervasive environments, have been used to collect health related data (e.g. symptoms and outcomes) to provide information about one’s health condition and feedback on self-care practices [e.g. 2]. They have also been used to track contextual information to facilitate awareness and reflection on one’s activities, breakdowns in routines, and environmental factors that influence self-care [e.g. 11]. Self-care technologies have supported tracking either by allowing manual data entry, such as self-reporting of one’s mood or stress level in bipolar disorder [2], or through automated data collection, such as measuring blood glucose levels with a glucometer in diabetes [11]. Choe et al. [3] have recently argued that semi-automated tracking approaches may better support self-monitoring given the complementary benefits and limitations of manual and automated tracking (i.e. burden of data capture vs. awareness or engagement). They identified data capture feasibility (including data type and capture frequency), the purpose of self-monitoring, and the user’s motivation level as key parameters to consider in designing semi-automated tracking systems. We will return to Choe et al. in more detail in our Discussion, extending their argument.

**SELF-CARE IN SPINAL CORD INJURY**

In a spinal cord injury, signals between the brain and the body are disrupted. The higher the ‘level of injury’ (i.e. the higher the injury is located along the spinal cord, or the closer to the neck), the more dysfunction the injured person will have. SCI causes complete or partial paralysis and loss of sensation in the parts of the body below the level of injury. In *paraplegia* the lower half of the body is affected, including both legs and possibly parts of the trunk. Individuals with paraplegia have control over their arms and hands. In *quadriplegia* (also known as *tetraplegia*) both the upper and lower parts of the body are affected, including all four limbs and the trunk. Depending on the specifics of the injury there may be a degree of control over certain parts of the body (e.g. elbows, wrists, hands), so the exact effects of SCI differ from person to person.

Spinal cord injury causes chronic health problems that must be managed through self-care. Among the most common issues that need to be dealt with are:

- *Loss of control over bladder and bowel functions.* Individuals with SCI are usually unable to control bladder and bowel functions at will. They must develop programs to empty the bladder (via catheterization) and

<b>7:30am – 8am</b>	Wake up	
<b>8am-8:30am</b>	Cath (ISC); If in Bed, roll & reposition (R&R) If in chair, pressure relief	Catheter; gloves; urinal
<b>8:30am-9am</b>	Take medications; Eat breakfast If in chair, pressure relief	Medications
<b>9am – 9:30am</b>	Perform bowel program If in chair, pressure relief	Assistance to transfer to commode; gloves; suppositories
<b>9:30am – 10am</b>	Bowel program (continued)	
<b>10am-10:30am</b>	Get dressed and transfer to wheelchair ; Check skin	
<b>10:30am-11am</b>	If in chair, pressure relief	

Figure 1: High-level self-care plan for skin care, medication, and toileting (from [12], p. 52).

bowel (via bowel stimulation) regularly to avoid unwanted accidents and potentially serious complications (such as infections). Proper nutrition, hydration, and medications are also part of these programs.

- *Pressure sores.* Pressure sores result from constant pressure on the skin from lying or sitting in one spot for a long time. Individuals with SCI are particularly disposed to getting these as they are often in a wheelchair or in bed. A pressure sore may vary from a red spot on the skin to a deep wound down to the bone caused by skin breakdown. If a sore does not heal properly it can lead to severe complications (e.g. infection or amputation) and even death. To prevent pressure sores the person's weight must be shifted on a regular basis, which is called 'pressure relief.'
- *Problems with breathing and other respiratory issues.* Individuals with higher levels of injury may have difficulty breathing and coughing. Some injuries require the use of a ventilator (a mechanical breathing device) constantly or for varying periods during the day. Individuals may need assistance with coughing to clear secretions produced by the body. Cough assistance may include manual help by a caregiver or use of a device that facilitates coughs.
- *Spasticity.* Many people with SCI experience unusual muscle stiffness (spasticity), the symptoms of which may include involuntary movements, such as the sudden flexing or extending of a leg or muscle spasms. Spasticity can prevent normal movement and limit range of motion, thereby affecting daily activities. It can be painful, and it can affect sleep quality. Regular stretches and range-of-motion exercises are the most important ways to counter these changes. Medications may also be used to help alleviate the problems.

Ultimately, self-care in SCI is complex. Each affected individual must manage many activities, either independently or with the assistance of caregivers. Self-care activities include not only different types of physical care, but also medication adherence, exercise, nutrition, sleep, and stress relief, among others. Self-care is also highly individualized; different parts of the body are affected depending on the location of the injury on the spinal cord, and even in similar injuries patients experience chronic issues differently. Both emotional wellbeing and social context, including working with caregivers, critically influence the management of self-care activities. Besides helping to address the issues described above, caregivers – often family members as well as hired caregivers – assist with activities such as feeding, bathing, grooming, transfers (e.g. transferring the person from bed to wheelchair), and household tasks, depending on the person's needs.

Mastering the relevant knowledge and skills for self-care, adapting to life with a spinal cord injury, and maintaining care over time are all challenging. The period immediately following rehabilitation in the hospital, when people first

go home, is particularly difficult as people struggle with radical changes to the ways they were accustomed to doing things. Caregiver support, often throughout the lifetime of the individual, is critical. At the same time, clinicians with different expertise are intermittently involved in aspects of care. Clinician support often includes Physical Medicine and Rehabilitation (PM&R) doctors (the lead specialists for SCI), Primary Care Physicians (PCPs), urologists, respiratory therapists, occupational therapists, physical therapists, home care nurses, as well as physician assistants and nurse practitioners.

Next, we present a scenario founded on a composite persona that we developed from our data to give a flavor of one's life with SCI and illustrate self-care activities. We use a composite persona to protect the privacy of our participants, since details of individual cases are unique.

### **Sarah's Life with Spinal Cord Injury**

Sarah was 22 years old when she fell during a hiking trip and suffered a spinal cord injury that caused quadriplegia. This sudden change in her life was devastating to Sarah. She could no longer walk. She had some control over her arms, but had dexterity problems with her hands and fingers. After three months of rehabilitation in the hospital she moved back in with her parents. At first, Sarah felt helpless and self-conscious about her dependence on others, especially her parents.

For both Sarah and her parents, adapting to life at home was hard. Without the structure, assistance and clinical oversight they had in the hospital, they had to devise their own ways to manage the care. They had to plan every day with Sarah's care needs in mind. Both parents had to work, but fortunately their jobs provided some flexibility. The family hired caregiver support by posting ads on nursing school bulletin boards. Nursing students would come for about 9 hours on weekdays, each running a 3-hour shift. When the students were unable to fulfill their shifts or when additional help was needed, Sarah's sister, other family members, or friends would try to step in. Otherwise, a parent would have to stay home with her. Her parents also assisted Sarah with the self-care activities at night.

For Sarah, a typical day began at 7am with the arrival of a student-caregiver. The caregiver helped transfer Sarah out of bed and into the bathroom that was renovated to include a roll-in shower. The family decided to schedule her bowel program on every other day, so on those days the caregiver assisted her with the program (some days it worked better, but they weren't always sure why), then gave her a shower and helped her get dressed. With the encouragement of her sister, Sarah eventually decided to learn how to do her catheterization for the bladder program. She saw this as a step to gain more independence and self-confidence. She practiced every day with a caregiver nearby.

After she completed her morning care activities, which took 2 to 3 hours, Sarah had breakfast. She then used her tablet to study for an online course she had recently enrolled in. She was determined to train for a job that

would allow her to work with her disability. Her hope was to eventually get her own place and live life on her own terms like her friends. She was so focused on her studies that she often worked for several hours until a caregiver brought her lunch or she was jolted by a muscle spasm. On some of these occasions – mostly, if she got a spasm – she would realize that she had not done pressure relief as her doctor had instructed her to do. Sometimes her caregiver would ask whether she had done pressure relief recently, but caregivers were inconsistent with their observations of her activities as they were generally focused on their immediate tasks, such as carrying out household chores. She once developed a pressure sore on her buttocks, which required wound care directed by her doctor.

Twice a week Sarah went to physical therapy in the afternoons. On other days, if she felt up to it, she would use the specially outfitted van to go to a local rehabilitation center's gym. Sarah found physical therapy difficult. She felt that she worked very hard but the results were barely noticeable. Her therapist assured her that she was making progress, but Sarah often felt very tired and disheartened.

Her parents, while wanting to encourage Sarah, worried about whether she was eating and drinking enough to sustain all her efforts. They became more concerned after she got a urinary tract infection, which they believed she might have acquired during her efforts to learn how to use a catheter. When this happened, Sarah's doctor instructed her to increase her water intake, but she abandoned the extra effort after the infection cleared. She wanted to focus on her studies and the exercises she wanted to do to support her movements; she did not pay attention to her water intake unless she noticed that her urine had become darker. Her caregivers each focused on their own shifts; they did not track Sarah's overall fluid intake over the course of the day. Her parents wondered if Sarah's fatigue was at least in part caused by insufficient hydration, especially since she had begun sleeping much better at night after her doctor prescribed a medication to address the muscle spasms that would interrupt her sleep.

## **METHODOLOGY**

Due to the condition, access to participants was a challenge especially in their home environments for this study. To understand collaborative self-care practices in SCI and what requirements there might be for an augmentative system, we conducted semi-structured interviews with adults with SCI, caregivers, and clinicians. We interviewed three individuals with paraplegia, five individuals with quadriplegia, and an individual with a low-level injury that did not cause paralysis. We interviewed four parents of individuals with quadriplegia, and a paid nurse caregiver of an individual with quadriplegia. We also interviewed two PM&R doctors, a primary care physician who works with individuals with disability, two occupational therapists, a rehabilitation nurse, and a rehabilitation engineer who helps people with disability with assistive technologies. We supplemented these interviews with three others – a patient

and two parent-caregivers – where the person with the medical condition had a neuromuscular disorder or a brain injury that resulted in similar care needs. The interviews focused on important care issues in SCI, care-related activities and the difficulties with managing these activities, care plans, social context (e.g. working with caregivers and clinicians), and the use of technology for self-care. Interviews lasted between 1 to 2 hours.

To triangulate our data, we held a 50-minute focus group on how technology might support care-related activities and routines. The group included four of our interviewees (two individuals with SCI or other disability, and two parent-caregivers), a community partner with experience in disability issues in school districts, and an information technology expert at a large medical center. We also reviewed approximately 250 posts and 8 hours of video from four SCI forums (the Christopher and Dana Reeve Foundation, the Northwest Regional Spinal Cord Injury System, SPINALPedia, and CareCure) to gain additional insights on relevant self-care activities, common medical and social problems, aspects of working with caregivers, the nature of the rehabilitation process over time, tools and technologies (e.g. wheelchairs, home modification, transportation), and caregiving. In addition, we participated in 4 professional meetings that centered on technological support for SCI self-care.

For our analysis, we used Clarke's Situational Analysis [5], an updated version of Grounded Theory. In addition to the standard Grounded Theory induction methods, Situational Analysis adds more formal analyses for social context, specific situations, and common narratives. We discussed the data in weekly project meetings, analyzing and coding interview and focus group data in an iterative manner to identify emerging themes. We iteratively considered the themes as well as the links among themes, and used memos to refine our findings. During our analysis, we checked our emerging understanding against the data, and particularly against the presence of any negative cases.

This project was reviewed by our Institutional Review Board. In this paper, we use pseudonyms for all participants. Some quotes have been slightly edited for clarity. Next we present our findings.

## **FINDINGS**

### **Care Plans in SCI**

When a spinal cord injury first occurs, the patient spends some time in critical care followed by several months at a rehabilitation unit. The focus of rehabilitation is to gain back as much function as possible, and to learn how to do self-care given the conditions imposed by the injury. For the clinical team, a central goal is to teach the patient and caregiver(s) the relevant self-care activities, how to do these or how to assist, and common health issues of which they should be aware. At the time of hospital discharge, people are provided with a care plan by the clinicians. Care plans are largely standardized with some room for

customization. Dr. Scott, a PM&R doctor, explained how care plans are created:

*The physician would probably tell the nurse “The usual,” or “The usual except for skin [care] in this patient.” ...While historically.. [noticing that] every patient is unique, the current thinking is, particularly around complex disease and certainly with hospitalized patients and some evidence, that standardization improves quality and safety.... So it may be ‘suppository [in the] evening.’ [If] this patient wants to do their bowel program in the morning, you can just cross [it] off. But you don't forget to order the suppository in the bowel program; it's right there.*

As Dr. Scott describes above, usually nurses create the care plans for patients based on doctors' directives. Although there is some customization to the patients based on prevalent issues (e.g. skin care) or preferences (e.g. bowel program in the morning), care plans generally contain information the clinicians deem most important:

*The actual practice would be probably a written protocol for the really important things. A person with high-level quadriplegia will probably have a written trach [breathing tube] protocol for trach care. There will probably be a written bowel and bladder program. There would be probably a verbal pressure relief program. (Dr. Scott)*

However, we found that while people with SCI and caregivers use the information in care plans as guidelines, they do not closely follow these plans once they are home. Instead, they focus on some self-care activities and largely neglect others. They follow some clinician recommendations and deviate from others. They come up with self-care activities that were not considered in their care plan, and they do activities differently at home than how they did these in the hospital. In effect, over time, they formulate and execute self-care according to their circumstances, priorities, and preferences; essentially, they develop their own self-care plans.

### **Self-Care Plans in SCI**

An important reason for why people do not closely follow clinicians' care plans is that they find self-care at home to be significantly different from what they practiced in the hospital. Charlie, who has quadriplegia, described how some of his self-care was different at home:

*You're going from a scheduled environment in the hospital to your home, and you can do whatever the hell you want. I could sleep for eight hours... and not have to worry about someone checking in or rotating me or anything like that....*

Charlie's sleep schedule at home is very different from what it was in the hospital. At home, he does not worry about asking a caregiver to turn him at night (i.e. to do a 'weight shift'), an activity that the clinicians believe is important for pressure relief. A standard clinician recommendation is to do a weight shift in bed every two hours to prevent pressure sores. However, many patients lament the interruption to their sleep. Charlie did not choose this activity as one of his self-care priorities. We

found that prioritizing activities (e.g. “sleep” over “weight shift”) and focusing on a subset of them at any given time is common among people with SCI. Charlie has to pay more attention to pressure relief when he gets a pressure sore, which has happened on occasion. Hence, priorities shift from time to time.

While personal priorities and preferences affect which self-care activities people choose to focus on and how they do these, the different circumstances and resources at home – compared to the hospital – often require people to develop new ways of doing self-care activities as well:

*I think the biggest thing is the bowels, because [in the hospital] you have all the supplies and everything you need, where[as] here, especially in my situation, I have to be a little more resourceful. (Charlie)*

For Charlie, quoted above, bowel management is important, but he had to formulate his own program at home because he could not obtain the supplies that were available to him at the hospital. For him and his caregivers, this self-care activity involved trial-and-error as they tried to develop a program that worked.

Caregivers can get actively involved in formulating self-care plans. Lara, a parent-caregiver, noticed that her son was not getting enough nutrition when she read through the notes that hired caregivers kept of their shifts:

*As I was reading through I just said to [my son], “I don't think that you're eating enough. Are you eating enough?” He said, “No, I'm really not.”.. And so, I said to the staff “... I want you to just note in your journal if [he] has breakfast, lunch or dinner with you.” Because it's a reminder, an accountability factor to them, because they may see [him] once a week, they may see [him] twice a week. They're not thinking, “Has [he] eaten?”*

Lara noted that tracking daily food intake – not calorie counts per se, but whether or not a meal was eaten – helps them to decide whether supplemental nutrition is necessary.

Clinicians also provide input on self-care plans, albeit intermittently and sometimes remotely. Examples include prescribing specific exercises for physical therapy, overseeing pressure relief and wound care when a pressure sore emerges, or suggesting adjustments to or alternative supplies for bowel programs. However, we found that clinicians overwhelmingly prefer only to be made aware when their help is needed – as opposed to having to monitor the patients constantly. Their aim is to get the patients to a point where they do not have to be seen often:

*I would like [the patients] to know more about bladder management and bowel management and pressure reliefs than I do. I'd like them to take care of those things and not need me a whole lot. I mean if we do things right, you want them to be independent and not needing to see their doctor. (Dr. Williams, PM&R doctor)*

The doctors we interviewed said that the ideal follow-up would be an annual visit with the patient to monitor certain

care issues regularly; bladder and bowel management, skin issues, spasticity, pain, and equipment issues (e.g. wheelchairs) are among the ones they identified. From the doctors' perspective, then, what is ideal is minimal oversight while being alerted to potential issues in a timely manner. Instead of having to monitor a constant data stream, they want to get involved when they must attend to a problem. Importantly, all of the clinicians we interviewed identified – even assumed – caregivers as being essential to effective self-care, and stated that they make a point of asking for caregiver input as well as the patient perspective. For example, Dr. Scott noted that in clinic visits he likes to ask both parties about their concerns:

*Because I still want to start with your perspective of where you are... And if you're a spinal cord patient with a caregiver, sometimes they see things that you don't know. So what are your caregiver's concerns? What are your concerns?*

Our data show that self-care in SCI is collaboratively achieved through self-care plans that dynamically develop and change over time. While the specifics of a self-care plan vary from person to person – based on their needs, priorities, preferences, circumstances, and resources – the effective execution of a plan commonly involves the routinization of self-care activities to different degrees. Routinization helps to ensure that the activities get stabilized and are done, but it also serves the critical role of providing a sense of control for patients over their lives and their choices. Our participants universally noted the central role of routines in managing self-care activities, and online forum entries also provide ample evidence for the need and desire for routinization; in SCI, life is organized around self-care activities. In fact, participants have stated attachments to routines, and an unwillingness to change these unless there is a need.

### **Routinization of Self-Care Activities**

In our analysis, we found that activities can be categorized based on their degree of routinization, which has implications for different types of technological support. Here, routinization means that there is an established pattern to the activity that enables it to be performed without persistent attention or scrutiny. Routinization usually happens as a process. We found that activities can be stabilized as routines, activities can be in the process of being routinized, and activities can fail to be routinized even when they should be. We note that these are analytical categories. In practice, activities can appear to be in-between or even in multiple categories. Any specific activity may be in different categories for different people. Nonetheless, we found these categories to be useful in our analysis of design requirements.

#### *Activities That Are Stabilized As Routines*

At home, people with SCI and caregivers completely routinize many self-care activities of their choice. People differ in their choices; different activities may be routinized in different households. A prime example of an activity

most people want to routinize, and routinize early on, is the bowel program. Because individuals with SCI are unable to control bowel functions at will, they must develop programs to empty the bowel regularly. Otherwise serious complications may occur, or a bowel movement may occur at an unwanted time and place, which – as our participants have noted – carries undesired social consequences.

People find it important to track whether a routine is working and how each aspect affects the outcome. A bowel program involves medications, a process for bowel stimulation at the desired time, as well as hydration and nutrition components, such as eating fibrous foods or drinking a hot beverage at a specific time to help with stimulation. For example, Bill, an individual with paraplegia, set the routine of having breakfast and hot tea half an hour before his program. A bowel program is often time consuming; it can take anywhere from 30 minutes to several hours to complete. In addition, it usually necessitates the help of another person and must therefore be scheduled at a time when a caregiver is available. While family members can and do learn how to assist with these programs, some people prefer help from a hired caregiver given the highly personal nature of this self-care activity. We found that the norm is for individuals with SCI to schedule caregiver assistance for bowel programs either every day or, quite commonly, every other day. Furthermore, because the activity is so time consuming, people usually schedule it for early morning or the evening as not to have it interfere with the rest of their day. Therefore, this activity, with all its aspects, is often routinized and remains so unless it is somehow disrupted.

#### *Activities That Are Being Routinized*

Routinizing self-care activities can take considerable effort. Our participants universally noted that establishing self-care routines at home involves a lot of “trial-and-error.” Again, people's experiences differ; an activity could be easy to successfully routinize for one person and not be so for another. Jane, a parent-caregiver, described how they worked to find an effective hydration routine:

*When we got home we bought tons of bottled water, and for a while it was just "Hey Jim, you need to drink some water." And it got to a point where, one, he got tired of everybody asking him to drink water. Two, it made sense to me that it eventually just got in his head; it seemed like every time you came to give him some water he felt like he had just drunk some even if he hadn't... So I started thinking about what the doctor told me about how much water he needed to drink each day... I think he said 60 or 70 ounces... I started thinking "Well, he takes pills three times a day. What if he drank x amount of water each time, he'd at least get his minimum amount of water."*

In the quote above, the caregiver explains how they first decided that a hydration routine was necessary, and how they established an initial routine. At first, it was difficult to keep track of the water intake. Multiple caregivers would offer water to Jim at different times, and it came to a point

where he could not even remember the last time he had drunk. Moreover, over time, Jim began to tire of people asking him to drink all the time and he was not as willing to comply. Jane, his caregiver, explained that the initial routine had to be developed further. First they started using wider straws to reduce the strain of drinking. Later, Jane adjusted the amount due to ongoing urinary tract infections:

*So, I found the right straw, then it was a matter of finding the right container... I started off at about 24-ounce containers but we were still having issues with UTIs... And I'm like "I've got to get more water in him...." We got a different bottle and I increased it to 30 ounces.*

This routine provided a structure for Jim and his caregivers to track the hydration activity. Later, Jim himself added another component to the routine to solve the problem of getting thirsty at night: he got a hydration bottle developed for cyclists for hands-free hydration to keep next to him on his bed where he could easily reach for more water.

As in this example with hydration, we found that self-care activities commonly go through several iterations before they are routinized in an effective way. Multiple parties – the individual, caregivers, and clinicians – are involved. In order to figure out what works, people may need quantitative data (e.g. amount of water per day), subjective data (e.g. difficulty using a narrow straw), or both.

#### *Activities That Should Be Routinized But Are Not*

Individuals with SCI do not always routinize important self-care activities even though doing so would likely make self-care more effective. They do not, for example, always do clinician-recommended activities consistently, even when they are aware of the benefits of doing so. In these cases, the lack of routine is often because completing the activity is bothersome, the consequences are not salient, or the activity is, by nature, one that people easily forget.

An activity that tends to fall into this category for many people is pressure relief. The standard clinician recommendation is to do pressure relief at least every 15 minutes during daytime. Dr. Williams, a PM&R doctor, stated that he believes it should actually be done much more frequently, noting that uninjured individuals unconsciously “squirm” to shift their position habitually. Individuals with SCI can do pressure relief themselves by tilting backwards and forwards in the wheelchair (power wheelchairs, which many people use, have a button for tilting automatically), but it is not an unconscious activity for them because of the nerve damage caused by injury. They do not feel discomfort or pain from constant pressure, and they also cannot see for themselves that a pressure sore is emerging because these are generally located on the back of the body. They must therefore remember to complete this activity regularly, throughout the day.

We found that pressure relief is one of the most neglected self-care activities, according to the clinicians we interviewed. The individuals with SCI and caregivers we interviewed noted that it is common to go for hours without

doing any pressure relief. For instance, Charlie does it whenever he remembers, and Jim does it based on his feeling for when his body needs pressure relief. Some people remember to do pressure relief when they randomly move and begin to experience spasms, realizing then that they have been immobile for some time. Interviewees stated that disruptive reminders provided every couple of minutes are not an effective mechanism to help routinize this activity, although several of them noted less disruptive reminders (e.g. a light instead of an alarm) might work better. In general, people tended to default to completing this activity on an ad hoc basis.

Our findings indicate that pressure relief becomes a priority when a pressure sore emerges. Hence, one way in which people approach the issue of pressure relief is to be diligent about identifying and tracking the progress of pressure sores. Since pressure sores tend to occur on the back of the body, it is usually up to caregivers to notice and to help keep track of pressure sores. Some caregivers routinize this activity to keep on top of it; a common routine is to check the body for sores once in the morning and once at night when the person is getting dressed and undressed. Karl, an individual with quadriplegia, described his parents to be “like hawks,” watching every day for any changes. However, Dr. Scott, a PM&R doctor, worries about caregiver diligence, especially with paid caregivers:

*We've heard the caregivers are quite uneven unless you pay them a lot (laughs). So there's a tendency for these to go ignored until they're serious... If I were really going to be aggressive on this, and knowing the fluctuation of skill of caregivers, and I'm setting up the ideal program, I would say “I want a picture of the patient's [buttocks], the cheeks spread at the vulnerable area, every month.” And I'm going to play a little bit with the color balance of what you're shooting with, because a redness of color is critically important...*

As in this example, the clinicians are interested in some low-level monitoring for self-care activities that they know are not consistently being done by patients and caregivers. At times, the clinicians want more objective data, such as pictures of a sore instead of a caregiver's description. Sometimes complications like these prompt patients and caregivers to routinize activities going forwards.

#### **Temporal Patterns of Routinization**

As described above, for any person, we found that self-care activities tend to be in different states of routinization. A person may have completely routinized some of their self-care activities whereas they are in the process of routinizing others. Moreover, for any person, activities move between different states of routinization over time. We observed two important temporal patterns in routinization; both occur after a routine has been established and is stable.

*Evolving Routines.* The first pattern consists of activities progressing from one routine to another in an iterative manner; there is an evolution, perhaps gradual, into a more preferable or effective routine. (Each “stage” in this

progression, however, can be stable for a time.) We saw this above with Jim's hydration routine. In these cases, it may be important to track how an activity and its outcomes are going to assess effectiveness, suggest improvements, and to stabilize the activity as a routine.

*Disrupted Routines.* The second pattern is where an activity has been routinized and become stable, but the routine gets disrupted and stability must be reestablished. A routine may be disrupted due to a complication or a new symptom (e.g. a sleep schedule gets disrupted due to painful spasms) or changes in other routines (e.g. a sleep schedule gets disrupted because the person needs more ventilation support at night). The disruption of a routine, especially if it was a particularly effective one, can cause inconvenience and considerable unease; as we mentioned, having control over routines is particularly important to individuals with SCI. Losing control results in a struggle to either reconstruct the routine or, if that fails, to recreate a new routine that may or may not work better than the original. If the cause of the disruption is temporary, it may not be difficult to reestablish a routine. For instance, controlling painful spasms with medication may enable a return to the original sleep schedule. If the disruption is permanent, people may go through trial-and-error to find a new routine that works. The most complicated cases are where interdependent or overlapping routines affect one another. In those cases, tracking may help to balance the routines, for example, in finding the optimal settings for the ventilator to enable the person to sleep better.

## **DISCUSSION**

To summarize, for our participants with SCI, self-care plans were an adaptation of clinical care plans. These self-care plans reflect the personal priorities and preferences of the patients. Patients develop, or attempt to develop, routines to handle the necessary self-care activities over time, and they do so in collaboration with caregivers and with intermittent input from clinicians.

Furthermore, self-care in this complex, chronic condition is long-term and dynamically evolving, with multiple and often interrelated care activities occurring over time.

### **Using Semi-Automated Tracking**

As mentioned, people with SCI often desire to completely routinize many of their self-care activities. Since this allows a sense of control over their lives and ensures that activities get done more effectively, technical support for care activities would be useful. Prior work in other domains has shown that goal setting, activity tracking, and feedback can be effective at promoting behavior change and establishing new habits [6].

Self-care activities are often routinized with a specific goal in mind. Once a goal is set, an augmentative system should allow tracking for purposes of awareness and assessment so that an effective routine can be set. Choe et al. [3] lays out a number of design guidelines for semi-automated tracking, as the Related Work section mentioned. They argue, for example, that self-tracking usually leads to behavior

modification, often in a positive direction; awareness and self-assessment promote change. It has been shown that manual tracking increases, whereas automated tracking may reduce, awareness, accountability, and engagement [10]. Choe et al. [3] also noted that people's motivation levels can inform the type of self-tracking that could be more effective. In their view, high-burden manual tracking is more appropriate for highly motivated individuals.

On the other hand, as Choe et al. [3] noted, some automation can make data collection easier, leaving time and energy for other self-care activities. Automation can also help where multiple people are partially engaged in the tracking of an activity.

### **Routinization and Self-Tracking**

However, we also found that routinization is seldom complete for people with SCI. Some self-care activities do have stable routines, but others do not. Routines break down, or patients decide to do the activities differently. We believe the kind of routinization for any given activity would likely affect the kind of self-tracking that would be helpful. Our analysis of technology's potential to support self-care therefore turns toward the support for different states of routinization of activity.

#### *Routines Being Established*

Establishing routines often involves an iterative process based on trial-and-error; there is a role for technology to help scaffold routinization. This is similar to many self-tracking situations [4]. We believe some amount of manual tracking could provide benefit in establishing new routines by engaging people in the process, making them more aware of important factors and of progress. As mentioned, Choe et al. noted that high-burden manual tracking might be more appropriate for highly motivated individuals. Since people with SCI and caregivers are often highly motivated to establish working routines, manual tracking seems appropriate from this perspective as well. Furthermore, manual tracking can increase accountability; we previously described a situation where a parent-caregiver asked the paid caregivers to note in their journal whether a meal was eaten during their shift. The purpose of this intervention was to promote accountability for the paid caregivers who largely focused on their own shifts and did not pay close attention to related activities undertaken by others on the care team.

On the other hand, while establishing some routines, automation may be helpful as well. We described examples related to hydration above. In these cases, some amount of automated tracking could help to provide a better overall picture of the activity by countering the fragmentation of data collection.

#### *Stabilized Routines and Watching for Breakdowns*

Once a routine is stabilized, the focus can shift to maintenance. It is not necessary to have constant awareness and assessment; patients and their caregivers can switch attention to other self-care activities instead. For stable routines, a system that shifted towards largely automated



tracking could still help. A system could help the care team know when a breakdown in the routine occurs, when the routine becomes ineffective, or when there are consistent, significant deviations. Tracking could help to identify where and when a breakdown occurs, as well as alert the patients. It could also potentially trigger the appropriate caregivers and clinicians. While clinicians were adamant they do not want detailed data streams, they would like complications or significant deviations to trigger an alert.

#### *Evolving Routines*

Patients and caregivers sometimes want to identify routines that work better than the current one. While evolving a routine is in some ways similar to establishing a new one, we believe it is not in fact the same problem. People already have a routine that works for them; they want to improve it. In these cases, the ability to accurately compare the effectiveness of routines would be helpful. Since automated tracking may enhance data accuracy, measuring outcome variables using automated tracking would be beneficial. On the other hand, manual tracking would be useful to engage care team members in the process of discovering which health or contextual parameters to adjust in the routine.

#### *Support for Non-Routinized Activities*

Our findings showed that some activities may resist routinization indefinitely. This is the difficult case in supporting activities, since it is usually the case that routinization is not a priority for the individuals. In these cases, where motivation is generally low, we believe that support should tip towards increased automation or low-level manual tracking. In this paper, we provided the example of pressure relief as an activity that is not routinized by many people. As in that example, where the activity became high priority when a complication (i.e. pressure sore) occurred, people may use proxy measures for the effectiveness of their self-care practices. As well, manual tracking could be tied to other routines; in that example, checking for pressure sores could be done once or twice a day when getting dressed or undressed, i.e., as part of a less burdensome self-care activity.

Alternatively, given the collaborative nature of care, technology could provide additional support to members of a care team where an activity is not a priority for some but is a priority for others. Also, depending on the particular situation, manual or automated tracking of other people's activities could help to monitor outcomes for a non-routinized activity.

#### **SCI and Design Considerations Extending Choe et al.**

Our study indicates that SCI is a complex, long-term chronic condition that could benefit from semi-automated tracking. Above, we have discussed several places semi-automated tracking could be effective in providing support for self-care activities in SCI. At the same time, our analysis of SCI self-care suggests that there is complexity in providing this technological support. Here we draw back and discuss what these complexities say in general.

First, in SCI, self-care must be maintained over one's lifetime. Over time, people's priorities, preferences, and even circumstances change. Previously established routines may stop working, and new self-care activities or routines may become necessary as well. Hence, both the content and execution of self-care plans are dynamic, and it will be crucial to adapt semi-automated tracking based on the changes that take place. In situations where a chronic condition exists over a long period of time, activities may need to be supported in different ways at different times by semi-automated tracking.

Second, in SCI, multiple self-care activities must be managed simultaneously, and each of these activities may require different kinds of semi-automated tracking based in part on their state of routinization. This multiplicity of activities could lead to an overload of data and requests for data, and so a balance must be struck so that the individual with SCI and other members of the care team are not overwhelmed in their tracking efforts for self-care. It is more burdensome, for instance, to do most things by manual tracking. In situations where many self-care activities co-exist and outcomes are often interdependent, system support for semi-automated tracking will require the ability to understand the state of multiple self-care activities at any given time and adjust accordingly.

Third, in SCI, self-care plans and associated activities and routines are actively mediated and tailored by the different parties involved. In situations with care teams and important social context to the self-care, semi-automated tracking choices for each activity will need to take into account the particular social context to enable coordination and effective role distribution for self-care tracking.

#### **Future Work**

Based on the findings of our study and our subsequent analysis of requirements for supporting tools, we are working on a system that utilizes what we call *Continuous Mediated Tailoring* for supporting SCI self-care:

- Both manual and automated tracking approaches should be employed to allow tracked activities to shift in and out of focus as dictated by their routinization status. This must be modified over time as required.
- We must allow *tailoring* to enable members of a care team to create, adapt, and specify aspects of a personalized and dynamic self-care plan.
- Tailoring must be supported in *continuous* and *lightweight* fashion, allowing changes to the self-care plan to be negotiated and effected at any time.
- Feedback and reflection tools will be provided to allow care team members to monitor the routinization status of varied activities, in order to inform the need for adaptation of the self-care plan.

Our prototype system includes facilities to allow members of a care team to create aspects of a personalized and dynamic self-care plan; automated and lightweight manual activity tracking to capture activity and related outcomes in

an ongoing fashion; and feedback, prompting, and alerting facilities to engage caregivers, clinicians, and the individual with SCI in the execution and monitoring of plans.

## CONCLUSION

Based on a field study, we described how individuals with SCI adapt the self-care practices they learned at rehabilitation to their lived experience at home, and how they develop their own self-care plans over time in collaboration with their caregivers and clinicians. Our study shows that the self-care activities that are components of these self-care plans exist in different states of routinization with implications for the kinds of semi-automated tracking support that could be provided. Our study extends recent guidelines for semi-automated tracking in health by unpacking some of the complexities present in long-term, constantly evolving, collaborative self-care.

As with any interpretivist work, we cannot easily generalize to other conditions and situations. However, we believe that the analytical distinctions and design considerations we have uncovered serve as theoretical generalizations [16], and so extend to many other complex, long-term chronic care situations.

## ACKNOWLEDGMENTS

We thank Michelle A. Meade, the TIKTOC Advisory Council, and the SocialWorlds and Interaction Ecologies research groups for their support. We are grateful to all our participants for sharing their experiences. This project was funded by the Craig H. Neilsen Foundation (Grant #324655) and the National Institute on Disability, Independent Living, and Rehabilitation Research (Grant #90RE5012).

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