

Socio-technical Design for the Care of People With Spinal Cord Injuries

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1 Introduction

Spinal cord injury (SCI) is a difficult, complex, and chronic condition. Injuries commonly result in paralysis and loss of normal function. Currently, there is no known cure. For those with an injury, managing one's health and mitigating secondary conditions is often physically and psychologically hard. Care must be maintained over one's lifetime.

Managing a SCI is complex and highly individualized (Hammond et al., 2009; Maddox, 2007). Each affected individual must master a range of self-care skills, including physical self-care, exercise, medication adherence, healthy eating, stress management, and emotional self-awareness (Meade and Cronin, 2012; Nunes et al., 2015). Mastering such a range of skills can be challenging, especially when patients leave the rehabilitation unit and have little access to professional support.

Much of the long-term burden of care falls on the patient and her family. Care can include help with continence and even breathing, help with the necessary exercises to maintain physical tone, and even making sure that helpers and supplies show up. Every patient is different and requires customized care at some level (Hammond et al., 2009).

Self-care is obviously centered on the patient herself. (Self-care and self-management tend to be used interchangeably in the Human-Computer Interaction literature; in this chapter, we follow Nunes et al. (2015) and use *self-care* to include so-called self-management tasks.) Assistance with care is often provided by a group of people we will call "caregivers" and will describe more fully below. This group includes spouses, parents, and siblings. Some families are able to hire aides, that is, health care helpers, people with relatively low-skill levels who can assist the individual and/or family in assisting with or completing required tasks at home. Helpers may come from an agency, but they may also be college students and volunteers. Family members are often prominent in assisting with care.

While SCI is a unique condition in some ways, its problems mirror other conditions. For example, the elderly often require similar care, although cognitive declines may limit their ability to direct care and participate in their self-management as

fully as some patients with SCI. SCI is a particularly fruitful domain in which to develop and examine the potential for technical augmentation, due to the complex, collaborative nature of care and the strong need for customization to the individual.

To help people with SCI, we designed a system called SCILLS (pronounced “skills”, short for the Spinal Cord Injury Living and Learning System), to be described below. From the beginning, it was designed as a technical system that had to fit in the specific social context of SCI. However, we did not anticipate how much that specific social context would interplay with the specific technical requirements. This chapter describes the rationale and design outcomes for SCILLS.

In the chapter, first we describe a standard scenario of use. We then follow with a description of our envisioned system, along with the design rationales for the system. We then describe our initial formative evaluation of the design. We learned a considerable amount from the formative evaluation, and after describing the evaluation, we survey the lessons learned as well.

2 Spinal Cord Injury

Individuals have different care needs based on the level of SCI and the completeness of injury. In SCI, the higher the level of injury (the closer the injury is to the neck area along the spinal cord) the more dysfunction the patient experiences and the more they require assistance with care activities. The spinal cord is enclosed by the spine (i.e., backbone), which is organized from top to bottom into the cervical, thoracic, lumbar, and sacral regions. Nerves originating at specific levels of the spinal cord go to specific areas of the body, each nerve exiting the spine between specific vertebrae. These nerves are numbered from top to bottom (one being at the top). Injuries are signified by their location: C1 through C8 (cervical or neck injuries), T1 through T12 (thoracic or upper-back injuries), L1–L5 (lumbar or mid-back injuries), and S1–S5 (sacral injuries).

For SCI, it is also important to note that injury may be “complete” or “incomplete.” In a complete injury, there is no sensation or movement below the level of injury. In an incomplete injury, there is some function below the injury and the lack of function may not be symmetric; for example, there may be more movement in one limb **more** than the other ([What You Need to Know About Spinal Cord Injuries, n.d.](#)). Both complete and incomplete injuries can occur at any level of the spinal cord.

Complete, cervical injuries cause quadriplegia (also called tetraplegia), **including** paralysis, and loss of sensation in both the upper and lower extremities and the trunk. C1–C4 injuries (high cervical injuries) are the most severe. With the exception of some control in the neck, both the upper and lower body is affected. Individuals may not be able to breathe without a ventilator. People with high cervical injuries require 24-h assistance with care activities, although they may still be able to use powered wheelchairs on their own.

With C5–C8 complete injuries (low cervical injuries), there is more function in the upper extremities. In C5 injuries, there is shoulder and biceps control, but no control below the

elbow. In C6 injuries, there is also wrist control but problems with the hands. At these levels people are able to do some self-care activities with assistance. With C7–C8 injuries, one becomes able to manage many self-care activities, but there may still be dexterity problems with the fingers. Individuals can get in and out of beds and wheelchairs without assistance. While relatively able to care for themselves independently (e.g., eat and dress), like with most spinal cord injuries they do not have bladder or bowel control. They need several hours per day of assistance with various self-care activities.

Thoracic (T1–T12) and lumbar (L1–L5) injuries cause paraplegia, **including** paralysis, and loss of sensation in the lower extremities. People with paraplegia can use a manual wheelchair and modified car. They can be independent in self-care activities, including managing their bowel and bladder on their own, which at these levels of injury still lack normal function. People often need help with housework. Lumbar (L1–L5) injuries allow for some hip and leg control. People with these injuries can complete almost all tasks independently except for heavy housework.

We designed SCILLS to help SCI patients and caregivers.¹ SCILLS helps people with SCI acquire self-care skills through a clinician-managed virtual coaching program. Based on discussions with domain experts, we envisioned a particular use, which we next review.

3 Scenario

In a diving accident, Tim suffered a C6 SCI, meaning that he was unable to control his legs, hands, bladder, and bowels and had only limited control of his arms. He spent 2 months in the hospital, where he worked with rehabilitation clinicians.

As his discharge date approaches, Tim's nurse, Kevin, meets with Tim and his mother, Sharon,² and introduces them to the SCILLS system. The nurse shows them how to create a Self-Care Plan (simply called a Plan in SCILLS) for Tim, which is a list of what he should do and how to carry out the activities. Kevin shows them how to track plan progress and access information digests. Kevin suggests some reminders, alerts, and triggers for bladder and bowel activities. These reminders, alerts, and triggers work on data being returned about what Tim is doing. Kevin also sets up information digests that would be useful for bladder and bowel management.

Upon returning home, Tim's mother, Sharon, helps Tim by setting up a plan using Kevin's recommendations. She adjusts the reminders about bladder and bowel management, knowing that Tim is a late riser. Sharon also selects two information digests that were recommended: one that provides several different stories about how individuals with SCI were able to find bladder management programs that worked for them, and one that discusses strategies for effective communication with one's health care provider. (In an actual scenario, there would be many more activities being done and facilitated.)

Throughout the weeks that follow, Sharon uses SCILLS to follow the plan and track progress and adds elements to the Plan, including items for performing skin checks, taking

medication, and performing stretching exercises. She also fine-tunes the settings on her version of the self-care plan to optimize the effectiveness of the reminders and to lower the burden of data entry. After a month, it is time for Sharon to return to work, so she hires a crew of three home care helpers. They will work in shifts to help care for Tim. The helpers received basic training in home health care, but only one of them has experience specifically working with individuals with SCIs. Sharon trains the helpers, including how to use the SCILLS components, and nervously returns to work.

After a week, Sharon reviews the plan's progress and observes that medication and bowel management are on track but that, while Tim and the helpers were successful at performing bladder management according to schedule, they found wetness indicating bladder accidents. To understand this better, Sharon modifies the self-care plan to monitor Tim's fluid intake on an hourly basis while awake. When Sharon clicks the "accept" button, the modified self-care plan goes to Tim's care manager and physician for potential review.

While this scenario covers only a small portion of care, it illustrates key aspects of the envisioned use of SCILLS. Sharon could compose a customized self-care plan for Tim and his helpers based on her intimate knowledge of Tim's condition, personality, and lifestyle. Feedback about the aspects of the plan that worked well and those that did not helped Sharon tailor the plan in ways that could support Tim's progress. Other capabilities of SCILLS not highlighted in this scenario include providing alerts and data to clinicians, reuse of others' self-care plan elements, and the ability to author more complex plans including, for example, conditionals.

We next describe the SCILLS system.

4 SCILLS, the Spinal Cord Injury Living and Learning System

In this section, we provide an overview of our initial design for SCILLS. SCILLS is currently in its second iteration of design, having gone through over a year of design, prototype construction, and formative evaluation.

Previous studies found that mobile software systems can help patients adhere to recommended treatment programs and develop self-care skills outside the clinical setting (Ding et al., 2010). However, the complexity of comprehensively managing a SCI or disease introduces new challenges. First, it is seldom feasible to try to master all needed skills immediately. Overwhelming the patient with tasks and responsibilities can increase stress and impede learning (Boschen et al., 2003; Fisher et al., 2002). This suggests that software to support skill development must be dynamic, adapting to the patient's level of mastery. Second, the complexity and individuality of different people's rehabilitation needs, environmental context, and care support system suggests that patients and clinicians will need to work together to customize and evolve self-care plans that work for the individual. For the patient to effectively participate in the design and implementation of their care program, it is critical that they understand not just *what* actions need to be taken, but also *why* and *how*.

4.1 Prior Work

A number of projects have explored using mobile technology to provide coaching and support to individuals with chronic conditions and disabilities. An application area that has received a great deal of attention is medication adherence (e.g., Choi et al., 2008; Lundell et al., 2007). While gains in adherence can be obtained through improved scheduling alone (Siek et al., 2010), it has been shown that leveraging user context, including location and activity, can improve the effectiveness of medication reminders significantly (Kaushik et al., 2008). Additionally, sensing technology can help with tracking medication adherence (McCall et al., 2010), playing a valuable role in evaluating the effectiveness of reminder systems as well as helping to moderate their operation. Systems to promote medication adherence, however, are just one component of the larger domain of *virtual coaching*, which comprises systems "aimed at guiding users through tasks for the purpose of prompting positive behavior or assisting with learning new skills" (Ding et al., 2010). While

coaching systems have been explored most thoroughly in the domain of supporting people with cognitive impairments (e.g., [Boger et al., 2006](#); [Mihailidis et al., 2008](#); [Pollack et al., 2003](#)), they have also been examined in other domains related to physical rehabilitation ([Liu et al., 2010](#)) and management of chronic disease ([Quinn et al., 2008](#)). In their survey of virtual coaching systems, Ding et al. argue that the critical considerations when designing such systems include self-monitoring approach, context awareness, interface modality, and coaching strategy ([Ding et al., 2010](#)). Importantly, they argue that sensing and inference are critical enabling technologies for both assisted self-monitoring and context-aware reminders, both of which are important for the success of mobile virtual coaching systems.

The complexity and diversity of SCI manifestations argued that the personalization of virtual coaching protocols would be critical. While prior systems for reminding and coaching provided interfaces to allow users to initialize and update details of their prescriptions or care plans ([McCall et al., 2010](#); [Siek et al., 2010](#)), these assume only simple data input would be required (e.g., dose and frequency). At another extreme, Autominder learns specific user activity patterns so that it can help the user accomplish them later when the user’s cognitive function has been reduced ([Pollack et al., 2003](#)). This approach does not work in cases where the activities requiring assistance are new or where a potentially lengthy training period is not feasible. We favored a third approach, which seemed more promising for the domain of SCI coaching – end-user customization by the person with SCI and his care providers. The [Memory Aiding Prompting System \(MAPS\)](#) ~~MAPS system~~ adopts just such an approach, developing a “meta-design” environment in which caregivers with special knowledge of cared-for individuals with cognitive impairments are empowered to create custom “scripts” that allow the impaired person to perform personally meaningful activities of daily living ([Carmien and Fischer, 2008](#)). MAPS uses a “film-strip–based scripting metaphor” to allow care providers with little technical know-how to create complex multimedia scripts, though other metaphors have been explored to help nontechnical users create context-aware rules ([Dey et al., 2006](#); [Rodden et al., 2004](#); [Truong et al., 2004](#)).

Our review of the prior literature, preliminary interviews, and discussions with domain experts led us to the design of the SCILLS system, described next.

5 System Description

The critical abstraction in the SCILLS system overall is a Care Plan. We describe that next, and follow with brief overviews of the important components of SCILLS—the care plan language, the Patient Coach (PCoach) application, and Clinician Builder (CBuilder) application (see [Fig. 1.1](#)).

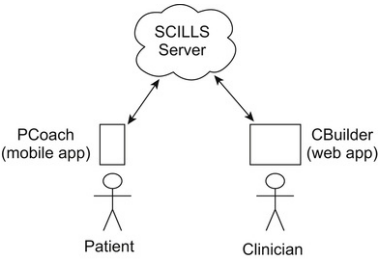


Figure 1.1 General architecture of the SCILLS system. *SCILLS*, spinal cord injury living and learning system.

At the heart of SCILLS are self-care plans (sometimes called care plans, self-management plans, or treatment plans). Self-care plans are sets of goals with a step-by-step breakdown of how to achieve those goals. [Fig. 1.2](#) shows a sample, high-level self-care plan:

7:30am – 8am	Wake up	
8am-8:30am	Cath (ISC); If in Bed, roll & reposition (R&R) If in chair, pressure relief	Catheter; gloves; urinal
8:30am-9am	Take medications; Eat breakfast If in chair, pressure relief	Medications
9am – 9:30am	Perform bowel program If in chair, pressure relief	Assistance to transfer to commode; gloves; suppositories
9:30am – 10am	Bowel program (continued)	
10am-10:30am	Get dressed and transfer to wheelchair ; Check skin	
10:30am-11am	If in chair, pressure relief	
11am-11:30am	If in chair, pressure relief	
11:30am-noon	If in chair, pressure relief	
noon-12:30pm	Cath (ISC); If in chair, pressure relief	Catheter; gloves; urinal
12:30pm – 1pm	Medications and lunch If in chair, pressure relief	
1pm – 1:30pm	If in chair, pressure relief	

Figure 1.2 High-level self-care plan for skin care, medication, and toileting (Meade, 2009, p. 34).

A physician may sketch out a self-care plan with relatively few details. These instructions are often elaborated by a lower-level clinician, such as an educator, nurse, or occupational therapist and might look like that in Fig. 1.2. As well, these lower-level clinicians may directly engage the patient with the necessities of their care. Regardless, each step in Fig. 1.2 would be further elaborated at some point—and perhaps multiple times as the patient and caregiver come to understand the condition and the clinicians come to understand the patient and caregiver.

For SCILLS to provide sufficient assistance, using sensor-based monitoring and planned reminders, self-care plans have to be described in a way that can be automated. We began by designing a special purpose-language (Maloney et al., 2010), the Self-Care Plans for SCILLS (SCP4S) language. SCP4S is the glue for all of the components described above and provides the abstractions necessary for the performance of the overall system.

- SCP4S includes characteristics of the three essential roles in the patient's situation: the patient herself, the caregivers, and clinicians. The language (a fragment of which can be seen in Fig. 1.3) had to be able to detail rules that would include:
- the activities that the patient would be learning or doing, including the necessary prompts and reminders for those activities,
 - the measurement of those activities,
 - the timing of those activities, and
 - the feedback on the monitoring of those activities to the caregiver and/or a clinician



Figure 1.3 This mockup shows a fragment of a self-care plan to prompt the user once a day to record his weight. The variable weight is defined elsewhere as being of type number, so the user will be prompted to enter a number. This request also recommends an information digest about healthy eating.

The language also had to include the ability for users to demark key elements of the patient's physical and sensor environment, since this is critical for monitoring. Finally, self-care plans also need to incorporate a limited amount of data about the patient's social environment (e.g., the roles and/or people who would be available as caregivers or clinicians). Note that we assumed that the self-care plans would be constantly evolving, and therefore the language had to be carefully constructed

to make this easy.

Self-care plans, after being created and described in natural language and/or in the SCILLS plan language, have to be presented to the patient and/or caregiver. This is the role of the Patient Coach (PCoach) application. From the viewpoint of the user, PCoach is the most important part of SCILLS. It allows patients to view a schedule of activities, review information about their health conditions and recommended treatments, enter self-monitoring reports, and receive reminders for incomplete actions. Additionally, PCoach was designed to facilitate communication among the patient, caregivers, and clinicians, by allowing the patient or a caregiver to make changes to the schedule and plan (which are then communicated to the

clinician for review), suggest information or videos about the activities, update plan progress by checking off completed actions, with optional comments, and enter questions, problems, or barriers encountered as a way to trigger further conversation with a care provider—perhaps at a later date. PCoach relies on a ContextEngine, which monitors contextual information provided by sensors.

In addition, SCILLS has an application, CBuilder, that allows clinicians to create and edit self-care plans, attach relevant information resources for patient education, monitor patient progress through self-monitoring reports and updates of completed actions, and respond to patient questions and problems.

6 Formative Evaluation

Following the standard Human-Computer Interaction iterative cycle ([Shneiderman et al., 2017](#)), we wanted the SCILLS system to be designed, developed, and evaluated through interactions and repeated testing with both patients and clinicians, ensuring that the system would be developed and tested in the appropriate environment of use, making SCILLS be useful for and usable by members of the target audiences. The standard iterative design cycle used by many, if not most, HCI/CSCW projects has been found to be highly effective in creating usable and useful designs.


Therefore, we began with a two-fold approach, first studying some relatively simple tasks we wished to support: we chose (based on our readings on SCI care and initial conversations with patients, caregivers, and clinicians) hydration, exercise, and eating healthily. Drinking fluids is important for individuals with SCI, and we believed it could be measured using existing sensors such as smart water bottles. Drinking fluids is best monitored in conjunction with toileting, to make sure the two are in balance. Since we felt toileting would be harder technically, we examined hydration in detail. We also chose to consider pressure relief and pressure sores, as clinicians told us this was a critical activity that people did not always do. Pressure sores are caused by constant pressure on the skin from lying or sitting in one spot for a long time, and individuals with SCI do not check their skin as often as clinicians would prefer. At the same time as the formative evaluation, we developed a first-round prototype of the SCILLS language, SCP4S, as well as a simple plan editor.

What we found, in short, was that our initial assumptions, although aware of the importance of the patient and caregiver's social context along with their required coordination with clinicians, were naive and limited. In addition, as we began to construct our prototype language, we uncovered a number of limitations that were largely socio-technical in nature and which deepened our understanding of the requirements for the SCILLS system.

Below we discuss the findings from the interviews. We will then follow that by unpacking the contextual issues for the technical system.

6.1 Examination of Activities

SCI causes chronic health problems that must be monitored and managed on a daily basis. We conducted 21 interviews with people with SCI, caregivers, and clinicians (plus another

three with people dealing with related conditions). Our interviews attempted to determine the basic issues in the activities, any problems routinely encountered, and the feasibility of helping patients or caregivers with those activities. As mentioned, we focused on three common activities, but the interviews ranged over other activities as well. The interviews were approximately 1  in length, and with permission, were audio-recorded and transcribed. We used Clarke's Situational Analysis ([Clarke, 2005](#)), an updated version of Grounded Theory, to analyze the data. Any participant identities or quotes used here have been made anonymous.

6.1.1 Bladder and Bowel Functions

People with SCI are usually unable to control bladder and bowel functions at will. They must develop programs to empty the bladder and bowel regularly to avoid unwanted accidents and potentially serious complications. Effective bladder and bowel programs are intrinsically related to careful management of hydration and nutrition as well.

The fear with both bowel and bladder programs is that an accident will occur at an unwanted time or place unless the activities are regularly scheduled and successfully completed. Larry, who has been a peer mentor to other individuals with SCI for many years, noted that one of the topics newly injured people are most interested in is the bowel program. This is due to psychosocial reasons, and because it involves trying different approaches until a favorable routine is established:

...the bowel program I think is the hardest because sometimes it doesn't work. And no matter what you do it's not working. Whether you're using a suppository, or you're doing digital stimulation, or you're doing both, and you [have to] invest more than an hour or two into just going to the bathroom.

As Larry mentioned above, in the case of a bowel program there is the need to establish a process for bowel stimulation (via medications or other means) that is time consuming. A routine can take anywhere from 30 to 60 min to several hours to complete. In addition, for those with higher level injuries, a bowel program usually necessitates the help of another person and must therefore be scheduled at a time when a caregiver is available. Family members can and do learn how to help with bowel programs, but some people prefer help from a hired caregiver because of the highly personal nature of the activity. For example, Tina—a caregiver—stated that her son with quadriplegia (tetraplegia) specifically requested that his parents not get involved, delegating the task to a hired caregiver. On the other hand, Tina also noted that even with caregivers the bowel program “is a *big* issue. Because that's something obviously nobody has been used to doing.”

Megan, an individual with quadriplegia—explained how her bowel routine developed through trial and error once she got home from the hospital after rehabilitation. She eventually arrived at a routine that has been working for her very effectively:

[I]n my situation I have to be a little more resourceful.... You take a little juice basically, you take it in a little tube, squirt it in there and then in about 30 min you're going. And it takes care of it so much easier than anything else.

Much like the bowel program, many people tend to routinize the bladder program early on as well. Bladder-care routines also evolve over time through intermediate, increasingly

favorable routines that bring stability to the activity. Commonly, catheterization is at first done by a caregiver, and people try to work out the optimal schedule to avoid accidents. Megan explained that in the beginning her mother usually did her catheterization. Later on, Megan decided she could learn how to catheterize herself despite having dexterity issues with her hands:

And then the other thing was cathing. Because at the time when I got home I wasn't cathing myself... And early on [my mother] was ... the one doing a lot of it, which was, you know, get me up in the morning, cath me. ...But as time went on I learned I can do it and did it.

6.1.2 Hydration

Our participants noted that proper hydration is crucial for a number of reasons, including avoiding fatigue or complications such as urinary tract infections. People with SCI are generally aware of the importance of hydration and develop routines to try to maintain sufficient fluid intake.

Recommendations by experts concerning the amount of daily hydration vary considerably. Some professional societies recommend 2–3 L a day, an SCI nurse on a forum commented that the human body needs about 9 cups of fluid for women and 13 cups of fluid for men, and Greg—a Physical Medicine and Rehabilitation (PM&R) doctor we interviewed—explained how the amount of hydration has to be personalized:

Most of that stuff that's in the general public knowledge about hydration is just inaccurate... You know, it would be really dependent on their bladder program... What are their volumes? What's the frequency of their catheterization? If they're quadriplegic, are they having any symptoms of dysreflexia? And then are they having any issues related to urinary tract infections? Then also like I said, accidents.

In the quote above, the doctor points out some of the complexities in hydration routines (bladder output and frequency of catheterization), as well as some complications that commonly disrupt these routines (e.g., autonomic dysreflexia, urinary tract infections). Hydration, in general, is quite contextualized. It depends on the types of fluids a person drinks (e.g., alcohol, juice, or water), the ambient temperature (hot or cold), and the amount of activity the person is engaged in. Instead of measuring, people with SCI often inspect the color of their urine to determine whether they are properly hydrating.

We found that people develop hydration routines over time that are stable, but that these routines have to be reconstructed or recreated if there is a disruption. For instance, a common response to a urinary tract infection is to increase hydration to help clear the

infection. Once the infection clears, people may revert back to their original routine. They may also permanently change their routine, although whether or not the new routine is more effective than the original may not be readily apparent. For instance, evidence from SCI forums indicates that for some people drinking cranberry juice or taking cranberry pills helps to prevent urinary tract infections, while for others these turn out to be ineffective. On the other hand, at times routines change more permanently after a disruption. Coronary problems tend to require individuals to decrease their fluid intake, as do bladder accidents that may happen.

6.1.2.1 Pressure Sores. *(This should be subheading "6.1.3 Pressure Sores")* As mentioned, pressure sores are caused by 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 bed or in a wheelchair. A pressure sore may vary from a red spot on the skin to a deep wound down to the bone. If a sore does not heal properly it can lead to severe complications (e.g., requiring amputation) and even death.

Pressure relief involves the shifting of one's weight on a regular basis, which is critical to prevent the formation of pressure sores. The standard recommendation is to do pressure relief at least every 15 min during daytime. Greg, a PM&R doctor, stated that uninjured individuals unconsciously "squirm" to shift their position frequently. Individuals with SCI can do pressure relief themselves by tilting backward and forward in the wheelchair, but it is not an unconscious activity for them because of the nerve damage caused by injury. They often do not feel discomfort or pain from constant pressure, and they also cannot see for themselves that a pressure sore is beginning to emerge because these are usually 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 activities despite clinicians' warnings. In addition to clinicians' observations from experience, individuals with SCI and caregivers noted that it is common to go several hours without doing any pressure relief. James, the father of an individual with quadriplegia, noted that his son would sit for hours without moving, only to realize he has not done pressure relief when something causes him to "spasm out." Other caregivers and individuals with SCI, as well as clinicians, have noted that people often do not do pressure relief as instructed. However, disruptive reminders provided every couple of minutes are not deemed as an effective mechanism to help routinize this activity. Megan, for instance, commented that she would be "annoyed" if she were constantly interrupted, even by a caregiver. It is indeed the case that many individuals default to completing this activity on an ad hoc basis instead of setting alarms to remind them every few minutes.

6.1.3 *(This should be subheading 6.1.4. (See previous instruction, which created a subheading 6.1.3.))* **Other Activities**

There are many other issues for people with SCI including problems with breathing and other respiratory issues (sometimes requiring the use of ventilators and cough assistance), as well as muscle stiffness and involuntary movements (spasticity). Sleep hygiene and chronic pain are often problems, and depression and isolation can be issues. Over time, the sedentary lifestyle, as with other people, may lead to bone density loss, obesity, cardiovascular disease, and diabetes. The muscle problems may lead to a limited range of motion. As well, for individuals with paraplegia, shoulder injuries mount over time, since the shoulders are strained with manual wheelchair use.

In addition, each person with SCI must manage a number of activities, either independently or with the help of caregivers, related to physical care (e.g., skin care, bladder, and bowel management), medication adherence, exercise, nutrition, and hydration. Besides the common issues described above, everyday activities such as feeding, bathing, grooming, and household tasks may require considerable effort and potentially caregiver help. Transfers (e.g., between a bed and a wheelchair) may be required depending on the person's needs.

6.1.4 The Social Context of Care

These activities are not usually done in isolation. People with SCI work with family or hired caregivers, critically influencing the management of self-care activities. The age of the injured person and time after a traumatic injury affect dependence on caregivers: children and those who are newly injured tend to rely more heavily on caregivers. Individuals gradually take more responsibility for self-care, although reliance on caregivers for certain activities may be permanent depending on the level of injury. Caregiver arrangements vary and are often associated with the availability of funds. Family members are usually closely involved in the care process regardless, with parents and spouses taking the lead. However, hiring outside caregivers for a few hours per day or per week is common.

In addition, clinicians continue to oversee medical care and provide recommendations—which become part of the self-care plan—on an outpatient basis. Notably, for those with access to specialty centers, doctors specializing in physical medicine and rehabilitation, urologists, occupational therapists, physical therapists, rehabilitation psychologists and rehabilitation engineers continue to be centrally involved. Depending on the needs of the individual, other specialists (e.g., respiratory therapist, dietitian, social worker) may also be involved.

At the same time that their care team is a network of people, a key concern of many individuals with SCI is to manage as much of their care as possible to become as independent as possible. However, mastering the knowledge and skills to achieve maximum independence can be challenging, especially when individuals leave the hospital after months of rehabilitation that immediately follow their injuries. Once they leave the hospital, individuals with SCI and caregivers tend to develop care routines that they prefer and stay with them.

In summary, activities done by people with SCI about their own care are often highly situated. To a large extent, this is the norm—people develop stable routines that work well enough and can readily adapt to the contingencies at hand. These routines therefore deal with the basic situational context of activities. For the three activities examined, the routines may need to be adjusted (and often are), but they are not constantly changed except under unusual circumstances. (Sleep and pain may cause substantial changes to routines to find new and even temporary solutions.)

7 Technical Lessons

As we conducted our formative interviews, we also constructed several prototypes of our language and editing system. This language, as mentioned, was to be the glue between the coaching and clinicians. It tied together the kinds of data desired, the desired functioning of sensors, and the actions to be taken with sensor and user data.

We found that we could construct such a language; however, we believe that one would need to be careful in its uses. In short, if there is a gap between the capabilities of available sensors and the complex, situated social context, then the software **that maps mapping** sensed values to system actions also explodes in complexity. This is especially true when the software must make inferences based on data that is incomplete or partial. Furthermore, any system

employing noisy sensors in the tracking of users with clinical oversight (as was originally envisioned for SCILLS) runs the risk of producing more errors than patients, caregivers, or clinicians would tolerate.

While constructing a technical infrastructure to support the social requirements of use, including measurement, calculation, and alerting, we found four rough categories based on the adequacy of sensors for the activity in question: activities for which there exists a sensor that accurately measures that activity. Completely accurate sensors that measure the activities of importance are currently rare. Even many simple activities either do not have the right sensors available for their detection and measurement, or the activities are sufficiently simple that people can do them largely without the need for clinical intervention. However, our participants were all highly motivated, and it may be that automatic monitoring could help those who are less motivated. Furthermore, automatic monitoring may help look for breakdowns people are having in an activity (e.g., problems with sleep).

An example of a sensor that (very nearly) solves the hydration problem is Uchek.² This sensor can detect urine color, which is the basis for the relatively straight-forward heuristic that people with SCI use. Uchek simply measures the color of one's urine based on taking a urine sample, testing it with a known color strip, and then holding a cellphone up to the color strip. As noted above, the standard heuristic people with SCI are trained to use and do use is to note the color of the urine. If it is sufficiently dark, the person with SCI is not hydrating adequately. Although we have not yet tested this, the heuristic should be relatively straight-forward to program, given a sample, color strip, and cellphone.

Note that the use of this sensor would require the participant or caregiver be motivated enough to collect the data in this fashion reliably and over time. This is particularly an issue since it is simpler to not **avoid getting get** a urine sample and **using use** a color strip. Nonetheless, one could easily imagine this sensor leading to a system **like that is** our goal—relatively easy to use and a highly reliable instrument.

In this case, our language and system merely needs to provide clinicians with a template to set alert conditions. For people with SCI and their caregivers, they may wish a visualization application to see how they are doing.

There is a class of activities for which no sensor can exist by definition, because at least part of the activity or state is subjective. Example conditions include pain and sleep. While sleep duration can be adequately measured with sensors, subjective sleep quality cannot. Pain is highly subjective. In these cases, an augmentative system might be able to partially monitor the person's ongoing conditions, but some amount of manual data entry will be required. This condition has the standard motivational issues of on-going data entry found in personal informatics applications (Epstein et al., 2015; Li et al., 2010). People with SCI and their caregivers may wish a visualization application to see how they are doing. Clinicians may find it more straight-forward to directly ask about the condition during medical appointments, although for people who see their physician only yearly, distance monitoring, and/or alerting might still be valuable.

here is a class of situations where no sensor exists to reliably monitor an activity, but manual data entry can be simple. In some situations, just asking whether the activity has occurred may be adequate. An example of this is checking for pressure sores. Manual data entry could occur from caregivers or from the patient, and if reliably done, this would be adequate for distance monitoring. (Of course, in this situation the question of reliability is paramount.)

Io sensor can adequately measure an activity, even though the condition is not subjective. An example of this might be hydration before the Uchek sensor. This is an interesting condition to explicate, since it shows the complexity of using a combination of sensors to measure an activity.

Initially we attempted to use the MyHydrate water bottle [m33](#)³ as our sensor for hydration. The MyHydrate water bottle [promised promises](#) to be “smart,” but its functionality at the time was to simply measure how many fluid ounces it contained. Using any water bottle like it to measure hydration would place severe restrictions on the person with SCI. To have adequate measurement, he/she would need to take all fluids through the smart water bottle. Alternatively, we would have to find ways to wire each cup and other drinkware, which is not currently feasible. Thus this approach failed to achieve *sensor completeness*. [\(Please insert new paragraph\)](#)

Even if this smart water bottle or other smart drinking utensils were used and the amount of fluid could be measured adequately, a considerable amount of data entry would still need to be done by hand. One might want to drink outside of one’s standard utensils; the person with SCI might drink a bottled soda or beer while out with friends. As well, different drinks have different properties. The substance might be a diuretic, for example, tea. Diuretics have very different hydration properties from water (they dehydrate), so that information would need to be entered by hand or any calculations of hydration would be incorrect. Thus this approach also failed to achieve *data completeness*. [\(Please insert new paragraph here.\)](#)

In addition, the calculation of hydration from the input side is far more complex than measuring the output. Even if data collection proceeded as one hoped, confounding issues might include whether the person left the house and went to a store by car, encountering four additional temperature exposures of various durations (home to car, car, car to store, store, with repetitions). In the depth of a cold winter or hot summer, these changes can be significant. Moreover, the calculations would need to be personalized to the person’s bodily characteristics. Every person’s metabolism is different. This approach also failed to achieve *computation completeness*. [\(Please insert new paragraph here.\)](#)

One might contrast the complexity of automatic activity inferencing and calculation with how relatively easy it is for people with SCI to calculate hydration level as part of their normal practice. Much care goes into teaching the patient what this means in specific situations and what to do about it. Like [Goodwin’s \(1994\)](#) competent practitioner, a patient (and any caregivers) must be taught to work out hydration and dehydration. They are taught, or come to understand, the color of the urine, [and](#) how to contextualize that including how to consider the ambient atmospheric temperature and other aspects of diet (e.g., an alcoholic drink while socializing). An alert, for example, to drink 200 mL every 2 h would be robotic and not situated. Even with the best of intentions, such an alert is likely to be ignored, since visual inspection would inform the patient that hydration is a problem or not.

To summarize, we have not yet found a situation where meaningful self-care activities can be measured automatically with a strong level of reliability, a high level of usability, and/or a level of clinical comfort. We have found situations, however, where a combination of manual and sensor-based monitoring could lead to a better understanding [of](#) people’s activities. Because this is a research project, we have bracketed off question of installation and maintenance (e.g., ongoing calibration, network installation) from concern.

8 Reflections on Socio-technical Design

Our project demonstrates important characteristics about the beginning of socio-technical efforts. Designing a socio-technical system is to design to a moving target. Partly, it is an effort to understand the social environment as a set of ongoing negotiated and constructed practices. For us, our design had to take into account the care practices and the kinds of caregiver networks and so we focused our efforts there. When designing, initially the social environment is relatively stable and appears as a set of constraints on the design. But as well, designs have to also understand the technical possibilities, either of particular systems or of technical environments. The technical systems are often givens, but for us, they could also be constructed. [\(The sensors lay outside of our design capabilities and therefore are given rather than under our control.\)](#)

Therefore, the story of SCILLS to date has been one of trying to understand the current practices of SCI patients, caregivers, and clinicians, as well as the capabilities and constraints of potential sensors and software platforms. As one can easily deduce, the project (at the time of writing) is at an early stage of development.

The state of understanding for SCILLS currently—where the details of the technical platforms and potential capabilities are still becoming clear while the complexity of the social context has been detailed—is not uncommon in socio-technical design. The considerations obviously differ from project to project, but uncovering and understanding the co-design space is common. The hard problem in socio-technical design is not in understanding the requirements of multiple, conflicting, or overlapping social contexts or the technical capabilities of various system components—although these are very difficult—but understanding *how the two will join together over time*. (See the analysis in [Ackerman, 2000](#) for why this is difficult.). That is, one must understand the *socio-technical trajectory problem* in design. If one assumes there is an embeddedness ([Bjørn and Østerlund, 2015](#)) or entanglement ([Barad, 2007](#)) between the social context and artifacts (where the social context includes but is not

limited to specific practices), then clearly there is a state where some artifact has not yet been entangled in a specific group's practices and then another state where it has been. How one gets from a separate social and technical to this embeddedness or entanglement needs to be studied.

Developing theories of socio-technical design cannot be limited to understanding how things became the way they are. In retrospect, the decision points in designs seem obvious or at least understandable. Guiding design is important. Few studies examine the messiness of design in the early stages. At the beginning of design projects, there are technical capabilities and there are social practices, but they have not yet combined. The difficulty in the design process is finding the new possibilities within the constraints that either exist or could exist.

While several academic areas look at socio-technical design, none have a good answer about how to carry out this step. For example, [STS The Science, Technology, and Society \(STS\) academic area](#) looks at how systems relate to their social contexts, often at a macro-scale (but see e.g., [Jackson et al., 2012](#); [Vertesi, 2008](#)). The classic Latour study Aramis ([Latour and Porter, 1996](#)) describes the socio-technical trajectory problem in the context of the history of a high-speed train design. HCI and CSCW look at what people do and believe strongly in iterative cycles of analysis and design. HCI and CSCW have an assumption that the social and the technical come to be intertwined, but they do not study the process by which that intertwining occurs. A newer area, found intertwined within CSCW and in organizational behavior and communications, calls itself socio-material studies ([Leonardi and Barley, 2008](#)) and is concerned with what we call socio-technical design here. For socio-material studies, technical capabilities enable or constrain changing social practices, and changing social practices drive new technical investigations and design. This newer area aims to understand the design process better. The theoretical framework is appropriate, but to date only some studies have studied how to formulate the early stages of design. [Bjørn and Østerlund \(2015\)](#), for example, examine designing medical practices, argue that one should explicate the bindings between artifact and practices and then systematically relax and tighten the bindings.

We cannot offer any complete solutions here; indeed, we found ourselves casting about for a method to rationalize our design process. However, in retrospect, creating a detailed matrix of technical affordances offered by the sensors (i.e., what they did) along with the social requirements should have been our first step. In our case, there were social requirements that were absolutely required and some that were preferred. In many cases, from a usability perspective, the care practices of the people with SCI and their caregivers cannot be easily changed because their lives are very dependent on the continuity of their routines. It might be possible to substitute care practices, but this would [be have been](#) a substantial effort. On the other hand, the care practices of clinicians, that is the kinds of alerts and data they might receive, are strongly preferred and in most cases required. For both, it was possible to try new practices within a prototype so as to examine their future potential. When we finally sat back and created such a matrix, we discovered that we could not adequately support the care practices with the sensors that were available, but with some additional manual data entry, we could provide alerting and tracking facilities. We are now constructing such a facility.

In conclusion, SCILLS was initially based on our preliminary analysis of the needs of people with SCI as well as our understanding of the current state of the technical art, as might have been expected. As we carried out the project, as described in this chapter, we discovered how far apart the social and the technical still were. This is also as expected. The details matter. What we want to highlight here is the process of moving from a general conception of the social requirements and technical affordances to having experience with the details. HCI/CSCW has methods for pulling out the details of the social context; we followed them here. It still needs methods for pulling out the details of the technical environment.

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Footnotes

¹People with spinal cord diseases or some neuromuscular disorders have care needs that are closely comparable to those of individuals with SCI. Some individuals with conditions other than SCI were included in our work; however, we primarily report on those with SCI unless noted.

²<https://www.wired.com/2013/02/smartphone-becomes-smart-lab/>.

³<https://www.myhydrate.com/>.

Abstract

The Spinal Cord Injury Living and Learning System helps spinal cord injury (SCI) patients to acquire self-care skills through a clinician-managed virtual coaching program. It does this within a “smart” sensor-rich environment that helps monitor people with SCI and provides feedback to them, their caregivers, and clinicians. In this **chapterpaper**, we discuss the basic design of the system, the requirements analysis and formative evaluation, and the technical lessons learned. We note the issue of sensor completeness and computational completeness in the technical design. We close with an analysis of what it means to design within a rapidly changing technical environment, one where the capabilities and constraints are unclear. The problem, as we discuss, is understanding how the social requirements and the unclear technical will join together over time, which we call the socio-technical trajectory problem in design.

Keywords: Care plans; Caregiving; Patient-clinician communication; Personalized health care; Pervasive environments; Self-care plans; Self-management plans; Sensor environments; Socio-technical design; Spinal cord injury patient tracking; Ubiquitous computing

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