Supporting Collaboratively Constructed Independence: A Study of Spinal Cord Injury

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Independence is a central concern for people in the care of many chronic conditions. It is often viewed as a goal that can be facilitated with the use of patient data. It is also viewed, especially from the medical side, as something an individual achieves. However, in the lived experience, independence is often a set of collaborative practices. In this paper, we unpack findings from an interview-based study of Spinal Cord Injury (SCI) self-care. We found that independence - both functional and in the form of effecting agency - must be co-constructed by the choices and activities of the care network, including the person with disability, caregivers, and clinicians. This collaboratively shaped independence also affects potential collection and use of data in support of self-care. We describe how collaboratively shaped independence informs requirements and constraints for the design of sensor-based networks for self-care in long-term chronic disability.

CCS Concepts: • **Human-centered computing → Collaborative and social computing → Collaborative and social computing theory, concepts and paradigms** → Computer supported cooperative work

KEYWORDS

Self-care; self-management; self-care plan; self-management plan; self-care routines; patient support; caregiver support; care network; independence; context-aware environments; pervasive environments; disability; rehabilitation; medical informatics.

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1 INTRODUCTION

Self-care encompasses the activities people do to manage a chronic condition as part of their everyday lives [32], where the goal of self-care is to influence the course of the disease or disability to maintain a satisfactory quality of life [33]. Our work attempts to augment self-care with pervasive technologies, such as sensor-based systems [10].

Achieving or maintaining independence has been a focus of CSCW / HCI studies on supporting self-care (e.g., [20]). The existing literature suggests that independence is a construct with at least two dimensions: the ability to do an activity without physical assistance (physical or functional independence) and having control over decision making in self-care and life choices (independence through agency). So far, studies have focused on key considerations such as privacy (e.g., [35]) and remote caregiver support (e.g., [30]) in helping individuals attain or retain independence, where independence is largely a characteristic or circumstance of the individual (e.g., aging in place). In this paper, through a study of spinal cord injury (SCI) self-care, we show that in long-term chronic care, independence is collaboratively achieved by a care network through individual and collective approaches to care and coordinated actions. Further, we believe the collaborative nature of independence has important implications for sensor-based, pervasive systems support for self-care.

Spinal cord injury is a particularly rich context for investigation, since independence is of central concern. SCI causes paralysis and loss of sensation in specific areas of the body and impairs organ function. Currently, there is no known cure for SCI. The first few months after an injury are critical for gaining back as much of the lost function as possible and patients usually spend this time in rehabilitation at a hospital or specialized center. Besides physical therapy, a major focus of rehabilitation is learning and practicing how to do self-care activities to prepare the person for going home. Due to the condition, individuals often need ongoing caregiver assistance for self-care activities and family members commonly participate in their self-care training. In previous work [10], we have shown that self-care at home might be effectively supported by semi-automated tracking of self-care activities that accounts for the different states of routinization of these activities. In this paper, we expand on our previous finding of how self-care activities, which collectively constitute individualized self-care plans, are collaboratively developed, routinized, and executed by individuals with disability and members of their care networks. Specifically, we show the relationship between self-care plans and the desire for independence from the viewpoint of collaborative care, and how this raises previously unexplored considerations for how to support chronic care like that in SCI.

In this study, our contributions are twofold:

(1) In the context of SCI self-care, we provide an analysis of independence as a collaborative construct, thereby enhancing the understanding of user practices and needs.

(2) We describe implications for the design of sensor-based data flows for self-care support that the collaborative co-construction of independence implies.

While the context of our study was SCI, and SCI is unique in some ways, we believe that an understanding of independence as a collaborative construct is likely to inform the support of collaborative self-care in other kinds of long-term care conditions. There are, for example, significant similarities in care practices and goals for independence across a spectrum of developmental disabilities.

In the next section, we first provide an overview of related work. This is followed by a brief background on self-care in SCI and our methodology for this study. In the findings, we

illustrate how independence is co-constructed in the context of spinal cord injury. We consolidate our findings in the discussion to highlight what constitutes collaboratively constructed independence and to describe implications for the design of sensor-based support.

2 RELATED WORK

Activities to manage symptoms, treatments, psychosocial issues, lifestyle changes and daily living (e.g., bathing, feeding) are all part of self-care in chronic illness and disability [33]. Self-care and self-management tend to be used interchangeably in CSCW/HCI; we follow Nunes et al. [33] and use self-care to include so-called self-management tasks.

It has been recognized that self-care is often a collaborative activity between patients and caregivers [32]. To date, most of the work involving caregivers has focused on "primary caregivers;" usually parents, children or spouses who tend to be the most involved in the care of the person. For example, Mynatt et al. [30] presented a system to help adult children monitor their elderly parents remotely. Toscos et al. [45] examined how parental monitoring affects parent-child relationships in type-1 diabetes. Other types of caregivers have been considered in the literature to a lesser degree. Miller et al. [27] more broadly considered "informal caregivers" to include any non-professional person, often a family member or friend, who helps with some aspect of care. Their study, however, focused on the roles these caregivers adopt in the inpatient setting. Foong and Zhao [17] examined the needs of volunteer caregivers at nursing homes who helped care for patients with dementia and who lacked the familiarity primary caregivers had with the unique needs of the individuals. Finally, some studies have looked at paid, professional caregivers; for example, Müller et al. [29] detailed how caregivers in an institution managed wandering dementia patients.

As well, most research to date has focused on patient-caregiver dyads, with notable exceptions. In their study of elderly care, Consolvo et al. [15] identified the need to support the entire "care network" of an individual, which includes all the different types of caregivers (e.g., family, friends) and healthcare providers. Their data did not include healthcare providers; however, through interviews with the elderly and caregivers they identified care coordination as the central concern for caregivers in these networks. Importantly, they argued that the focus of supporting care coordination in networks should be the person, instead of a shared objective such as keeping the person healthy. They noted this shift in perspective emphasizes issues such as emotion, trust, and privacy. In this paper, we focus on the issue of independence as collaboratively achieved by members of care networks in spinal cord injury.

Danholt and Langstrup [16] have also argued that self-care is "a practice that is thoroughly sociotechnical, material, distributed, and de-centered" (p. 513), and that there is no 'self' in self-care. They argue that self-care involves multiple actors and forces, including the condition itself, which constitute an infrastructure in which care is accomplished. We see self-care technologies as an actor in the infrastructure of care.

2.1 Supporting Self-Care through Technology

Technical support for care includes monitoring of patients by doctors in the home and support for self-care, including support for patient-caregiver dyads. We consider here support within a home environment.

In medical informatics, and to a lesser extent within HCI, there is an extensive literature on monitoring of patients by clinicians. This literature tends to focus on the technical (e.g., architecture) details of networking or sensor flows (e.g., [5,13,19,22,24]). One of the early and on-going lines of investigation has been to design technology to facilitate medication adherence [9] or more broadly to assist individuals to follow and execute the steps recommended by health professionals [23]. Recently, more focus has been shifted to "concordance" [3] to encourage patients to take control and to enhance communication and collaboration with clinicians. Within this literature are also studies about user interfaces for monitoring including visualizations [38] and clinician consoles [34].

Patient-generated data and home health monitoring have created new opportunities. At a basic level, a series of applications allow patients to self-enter data or collect data through consumer electronics on, for example, nutrition [38], mood, and emotional state [7]. This data can be provided to doctors and other clinicians, but it can also be used for self-tracking and sense-making [23]. Collecting and reflecting on such data empower patients to find their voices [4] and learn from the perspectives of health professionals [36].

There has been considerable interest in the CSCW/HCI community in designing technologies to support self-care. A recent review of the literature [33] outlined the main research trends in this body of work. Above, we have already mentioned several of the trends, including fostering awareness and reflection by making health and contextual data available to the person (e.g., [25]) and suggesting care activities or treatment adjustments (e.g., [6]). Other work ties together peers for support (e.g., [28]) or allows self-reflection for support (e.g., [18]). The work that most closely influenced our work here includes sharing information with caregivers (e.g., [45]) and enhancing collaboration with healthcare providers (e.g., [1]). For example, Tixier and Lewkowicz [44] and Tixier et al. [43] described awareness support for the entire care team for dementia patients. The effort was to support caregivers and the people with dementia in maintaining their independence. The system was an asynchronous shared notebook-like repository of activities that supported caregivers and clinicians alike. Other work has also supported the care network. Barish et al. [7] supported data collection among caregivers sharing it with clinicians, but there was little, if any, support for independence. Taylor et al. [40] examined design requirements for data within care networks, but included only the carers and not clinicians. With these exceptions, and a few others (e.g., [26]), studies have focused on supporting a patient-clinician or patient-caregiver dyad, rather than a network of individuals participating in care. We take inspiration from Tixier and Lewkowicz and Tixier, et al.'s emphasis on care networks and maintaining independence of people with dementia, and extend it to consider new forms of data and sensor-based data collection.

2.2 Supporting Independence in Care Networks

There has also been interest in CSCW/HCI for supporting independence through technology, particularly in the literature on aging in place for the elderly. This body of work focuses on enabling elders to continue to live in their own homes while being monitored by caregivers. The work of Mynatt and colleagues was described above. In another study on balancing privacy and awareness, Birnholtz and Jones-Rounds [8] found that the elderly and caregivers rely on attributes of the physical environment, routine conversations and activities, and technological mediation (such as safety systems or turning off one's phone). In recent work, Caldeira et al. [11] argued for balancing self-tracking of health information and monitoring by

caregivers or clinicians to promote independence. These studies have examined aging in place either for people living in their own homes or living independently in a community environment with little assistance, if any at all. Hence, all were considered "independent" individuals. The studies also focused either on the elderly and their caregivers, or the elderly and retirement community staff, in comparison to considering broader care networks. These studies did not examine independence specifically in chronic care situations.

Other work in CSCW/HCI have looked at independence in chronic care situations where there is a higher degree of caregiver involvement in the conduct of daily activities. Hong et al. [20] examined support for independence for individuals with autism, who often need prompts to perform daily tasks and have difficulties with developing adaptive self-care and social skills. Hong et al. developed *SocialMirror*, a system that connects people with autism to a trusted social network of family, friends, and professionals (i.e. a care network) to seek advice on everyday life skills. In their study with caregivers and young people with autism who were transitioning to adulthood, they found that helping the individuals with autism in elaborating problems and structuring their schedules through system design could help to increase their independence. This context of chronic care and independence is significantly different from SCI, the focus of our study, due to the presence of cognitive difficulties which add a layer of complexity to the analysis of agency.

One study that aligns well with our work from this perspective is Nunes et al.'s [31] examination of agency in the context of Parkinson's disease, which also involves physical disability. Their focus was the patients' and carers' (i.e. whom we have referred as caregivers) interactions with their doctor, specifically with respect to expressing issues of concern, evaluating movement, discussing treatment adjustments, understanding what to expect, and getting inappropriate medications adjusted. The authors found that patients and carers were very active in exercising their agency in their interactions with their doctor, but that this required the doctor to allow a non-paternalistic interactional dynamic that supported the expression of agency. The authors also conducted a review of self-care technologies for Parkinson's patients to interact with doctors and found that technologies can promote a more limited participation in care; for example, technologies did not allow patients to signal the need for treatment adjustments, lacked variety in tracking and logging features, and in some cases eliminated discussions with doctors. In this study, we extend Nunes et al.'s work by examining independence – encompassing agency and functional ability – as a collaborative construct of care network members, including a closer look at the role of caregivers in the person's independence; in Nunes et al.'s study, the patients and carers are in a way grouped together in their interactions with doctors.

While the studies described above focus on the independence of the elderly person or the individual with chronic condition, de Carvalho et al. [12] have recognized the importance of supporting the independence of informal carers (e.g., family members), noting that the dependencies that caregiving brings upon them are often taken for granted. They build on Tellioğlu et al.'s [41] work on the conceptualization of independence in informal caregiving – specifically, what independence means from the caregivers' point of view – which has four dimensions: independence with respect to action, finance, decision, and emotion. De Carvalho et al. show that independence in action, decision, and emotion could be supported through coordinated care, where technology can support coordination with the person who receives the care, or coordination with others involved in the care of the individual. Importantly, the

authors note that while dependency has been defined as an individual attribute rather than a social relationship where all actors contribute to the construction of the situation, dependency is social in the context of caregiving. We build on this notion, showing how independence is constructed for people with disability in the context of collaborative care that includes the participation of different types of caregivers and clinicians, and how, in fact, tensions may arise from conflicts in the care network.

We note that, in the medical literature, the view of independence has shifted over time from largely focusing on functional independence – for which standard evaluation tools like the Functional Independence Measure (FIM) have been developed – to the recognition of self-determination and autonomy as a form of independence of equal importance. In this paper we show that, in the context of SCI, independence as a construct that encompasses both functional ability and agency, is collaboratively shaped by the activities of care network members, which has implications for the design of technological support for self-care.

In the next section, we first provide a brief background on the context of the study.

3   SPINAL CORD INJURY BACKGROUND: SELF-CARE IN SCI

Depending on its location on the spinal cord, an SCI causes paralysis and loss of sensation in specific areas of the body. In *paraplegia* the lower half of the body is affected, including both legs and possibly parts of the trunk. People with paraplegia have normal arm and hand function. In *quadriplegia* (otherwise known as tetraplegia) both the upper and lower limbs and the trunk are affected. However, depending on the specifics of the injury, there may be a degree of control over certain parts of the upper body (e.g., elbows, wrists).

SCI also affects organ function. It almost always causes loss of control over bladder and bowel functions. Therefore, people with SCI must develop programs to regularly empty their bladder (usually via catheterization) and bowel (via bowel stimulation) to avoid accidents and complications. Spasticity, or unusual muscle stiffness, is also common in SCI and can cause muscle spasms that can be painful. Spasticity can limit range of motion (i.e. movement around a specific joint or body part). Individuals with SCI need to do stretches and range of motion exercises to counter these changes. Finally, people with more severe injuries can have trouble breathing, in some cases requiring ventilator support either temporarily or permanently.

A lot of SCI self-care involves prevention of complications. For example, hydration is critical for preventing urinary tract infections that are common. In another example, people with SCI must shift their weight frequently in the wheelchair or in bed to prevent pressure sores (i.e. bedsores) that can lead to severe complications and even death. Prevention is also key for avoiding health issues over the long-term, many of which have to do with a sedentary lifestyle. Examples include posture problems, shoulder wear-and-tear from wheelchair use, obesity, diabetes, and bone density loss.

Besides these issues, self-care involves the activities of daily living, including feeding, bathing, grooming, and transfers (e.g., between a bed and wheelchair). As well, there are important activities that are not required on a daily basis but are essential for health care. Examples include meal preparation, shopping, housework, and transportation.

Given the range of issues, and because the effects of spinal cord injury differ from person to person, self-care is complex and highly individualized. As we will show, caregivers play a central role and clinicians also provide assistance even after post-injury rehabilitation is

complete. The activities and choices of people in these care networks help to construct the nature of independence for people with SCI.

Next, we describe our methodology.

4 METHODS

In order to gain a variety of perspectives about SCI and its self-care, we conducted semi-structured interviews with adults with SCI, caregivers, and clinicians. Due to the condition, access to people with SCI and caregivers was a challenge for this study. For recruitment, we used both snowball sampling and the database of a past SCI study at our institution where individuals had explicitly listed interest for being re-contacted with information about future studies. Table 1 summarizes the distribution of our study participants. One of the occupational therapists we interviewed was also caregiver to a person with quadriplegia who is not a participant in our study; the interview focused on both caregiver and therapist roles. We supplemented our SCI interviews with four others where the person with the chronic medical condition had care needs almost identical to those with SCI. These medical conditions included cerebral palsy, neuromuscular disease, stroke, and a genetic syndrome.

Table 1. Study Participants

Participants with disability	Caregivers	Clinicians

Individuals with SCI:
  5 with quadriplegia
  3 with paraplegia
  1 with chronic health issues
    but no paralysis
 	
Other chronic conditions:
  1 person with disability due to
    cerebral palsy
  1 person with disability due to
    a genetic condition
	5 family members of people
	  with quadriplegia
	  (includes: 2 mothers,
	  2 fathers, and 1 spouse*)
	
	1 paid home nurse who is
	  caregiver to a person with
	  quadriplegia
	
	1 parent of a person with a
	  neuromuscular disorder
	
	1 parent of a person who had
	  a stroke
		2 rehabilitation doctors
		2 occupational therapists*
		1 rehabilitation nurse
		1 respiratory therapist
		1 clinical psychologist
		1 rehabilitation engineer
		1 primary care doctor

* One of our interviewees was both the spouse of an individual with quadriplegia (who is not a participant in our study) and an occupational therapist who works with individuals with SCI. This interviewee is included in both the caregiver and clinician columns above, noted by the asterisk.

As we detail in our findings, self-care in SCI involves care networks of caregivers and clinicians that provide critical support to the individuals with disability. Due to access issues, in most cases we were not able to interview multiple people with different roles in a care network (e.g., the individual with disability, a parent, a clinician, and a friend), but in a few cases we were able to interview people who belonged to the same care network. These include: a person with quadriplegia and both their mother and father; a second person with quadriplegia and their mother; a third person with quadriplegia and both their father and a paid nurse caregiver.

We were also able to interview an individual with disability caused by a genetic syndrome and a clinician who provides treatment to this individual. In this case, permission was obtained from the individual with disability to interview the clinician and we were put in contact with the clinician by the individual. Other clinicians in the study were recruited separately (i.e. they were not members of our participants' care networks) because of privacy (HIPAA) constraints. Regardless of whether we were able to interview multiple people from the same care network, in each interview we collected data about the care network in which the participant was involved and how the participant collaborated with other members for self-care. This data was very detailed. In cases where we interviewed multiple people from the same care network, we triangulated data within the network as well.

The majority of our participants with a disability (SCI or other) were young adults in their 20s, with our oldest participant being in his early 50s. Seven of our participants with a disability were male and four of them were female. All participants with a disability had a high school education at the minimum, four of them having earned their diploma after their injury or illness. In addition, all individuals with disability except an older participant were either taking college courses online, physically attending college classes and working towards a degree, or were employed (one self-employed, others hired) at the time of their interview. The demographics of the individuals whom the caregivers we interviewed cared for were similar; all but one were young adults in their 20s. These young adults were either taking college-level courses, physically attending college, were employed, or had specific plans for self-employment at the time of the caregiver interview. Indeed, the motivation and courage of our participants with disability and those for whom the caregivers cared have inspired and shown us how important it is to provide support; we believe this is an area in which CSCW/HCI can play a valuable role.

All interviews were at least an hour long. Some of our participants were quite engaged and voluntarily extended their interviews. Our longest interview took about three hours over two days. In the interviews with people with SCI or comparable disability, we focused on background information about the chronic condition, self-care activities and how these are managed in everyday practice, description of the care network, working with caregivers and clinicians, technology use, and independence. In the interviews with caregivers, we focused on the needs and difficulties of the caregivers, description of the care network, working with other caregivers and the person with the injury or other chronic condition, care activities and how these are managed in everyday practice, technology use, and independence. In the interviews with clinicians we focused on the key health issues in SCI, self-care needs, working with people with SCI and caregivers, and independence in SCI. The clinicians we interviewed all had expertise in working with individuals with SCI and other chronic conditions that cause comparable disability. They provided critical background information on the condition and its medical and psychosocial challenges, had much insight into patient-caregiver dynamics, and were very knowledgeable about issues around independence as they saw promoting independence as an essential part of their work. While most clinicians relied on their overall experience with their patients in these interviews, as mentioned above, in one case we were able to interview a clinician about their work with one of our participants with disability. That interview allowed us to ask questions about the clinician's understanding of the patient's care network (who is involved and their roles) and self-care needs, as well as specific examples of the clinician's data needs and how data sharing occurs in the care network.

In addition to our interviews, we held a 50-minute focus group on how technology, in particular, might support self-care activities and routines. The participants were individuals who were specifically interested in the topic area, who were invited affiliates of a research center that focuses on disability and technology research at our institution. The focus group helped us to learn from individuals who were invested in thinking about technology support in care practices and who readily exchanged experiences and ideas. 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.

All interviews and the focus group discussion were audiotaped and transcribed. For our analysis, we used Clarke's Situational Analysis [14], an updated version of Grounded Theory. Situational Analysis places an emphasis on understanding the lived experience of participants. In addition to the standard Grounded Theory induction methods, it adds more formal analyses for social context, specific situations, and common narratives. It also adds an emphasis on multiple centers of narrative and intentionality. We discussed the data in weekly project meetings, iteratively identifying and coding the emerging themes and any links among them. We checked our data for the presence of negative cases and used memos to refine our findings.

This study was reviewed by our Institutional Review Board. In this paper, we use pseudonyms for all participants. For clarity, we removed filler words (e.g., um, uh) and false starts and repetitions (e.g., "And, and, and then") from quotes.

5   FINDINGS

In previous work [10] we detailed the central role of personalized self-care plans and routines in SCI, and how care could be effectively supported by semi-automated tracking that accounts for different states of routinization of self-care activities. Below, we provide only a brief summary of self-care plans and routines for context. We then illustrate how independence is constructed around these through the actions and choices of individuals in care networks. We return to the significance of this co-construction to the use of sensor-based technology for self-care in the Discussion.

5.1   Self-care Plans and Routines in SCI

We have previously described how, after they are discharged from post-injury rehabilitation in the hospital, people with SCI develop their own self-care plans at home instead of following the care plans initially created for them by doctors and nurses. They develop these self-care plans over time and with the active participation of their care networks, including clinicians, who are aware that care plans prepared at the time of hospital discharge are rarely followed closely. We found that people develop their own self-care plans in part because self-care at home turns out to be very different from how clinicians had them practice it in the hospital prior to discharge. This is due to differences in resources, circumstances, and context in the home environment compared to the highly resourced and strictly regimented hospital environment. However, as we will show in this paper, people also develop their own self-care plans because they want to formulate and execute self-care according to their own priorities and preferences, thereby exercising independence.

We found that, at home, self-care plans are often written in part or in full (on paper, in spreadsheets, or on a whiteboard) in various levels of detail to serve as reminders and to keep track of activities. Figure 1 shows an example self-care plan. Common components of self-care plans include specific activities (e.g., catheterization or pressure relief) and the timing of these activities (e.g., day/time), while they are also implicitly prepared with consideration of who should take part in each (e.g., the paid nurse who comes in the morning will assist with the bowel program in place of a parent). Over time, many of these activities become routinized, the details associated with them are internalized, requiring less explicit tracking unless a breakdown occurs in the routine.

In the following sections, we gradually unpack how independence is shaped through collaborative practices in the lived experience of self-care in long-term disability.

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	

Fig. 1. High-level self-care plan for skin care, medication, and toileting (from [26], p. 52, © Michelle Meade).

5.2 The Simplified View: Independence as a Goal or Characteristic of the Individual

In this section, we present two real-case scenarios from our data to illustrate the two types of independence – functional independence and independence in the form of effecting agency – as viewed as an accomplishment or characteristic of the individual with disability alone. We recognize that, in reality, in most situations it is almost impossible to separate these categories of independence; they are often closely intertwined. However, we use these as analytical simplifications to build towards a more complex description of independence as a collaborative achievement.

5.2.1 Scenario 1: Robbie Works Towards Increased Functional Independence. When a person has functional independence for an activity, they can do that activity without physical assistance. Examples include being able to dress oneself or to do self-catheterization. The extent to which functional independence may be achieved is largely limited by the constraints of the injury.

Robbie is a young adult with quadriplegia. He loved the outdoors and had a very active lifestyle before he got a spinal cord injury from a hiking accident. He lost a lot of muscle mass in the months following the injury because he was not physically active anymore. In his interview, he talked of his frustration from being unable to exercise like he used to. He was aware of the long-term risks from his newly sedentary lifestyle, including obesity and bone density loss, that could further limit his functional independence. To counter these

issues, Robbie did a variety of exercises to increase strength in his upper body where he had some control, to maintain his weight, and to prevent bone loss and muscle atrophy:

> "Since I don't stand up typically on my own the bones are bound to get more brittle and the muscles are bound to atrophy, so this [contraption] helps with keeping the muscles strong, keeping the bones dense. ...I do shrugs – I have ankle weights over there and weights that I can grip with these assistive gloves – and I do curls, and I also raise my arms out to the side [for] lateral raises. I began to work with these elastic bands for resistance training for my shoulders. My arms are now strong enough that I can do those exercises and actually get some kind of gain out of them, whereas before I could barely move my arms when I came home, so it's been a progress to get to this point. Those are the exercises that I do from day to day."

In this example, Robbie has identified a series of activities he wants to focus on and has developed a routine that he personally follows to keep healthy and improve his functional independence. As in this case, once a person with disability identifies a goal they try to implement an activity or activities to achieve it. They track these activities for progress and often establish a routine. As in Robbie's case, supporting the person in this process through self-care technology would require standard functionalities such as goal setting and activity tracking.

5.2.2 Scenario 2: Robbie Identifies His Self-Care Priorities and Routines, Thereby Effecting Agency. Having control over decision making with regards to self-care and life choices is a fundamental form of independence. In this study we saw that such control becomes an even more central concern when functional independence is limited. Our data showed that, for people with significant physical disability, the ability to control other aspects of their lives is a primary source of independence. This was particularly evident in relation to formulating and executing self-care plans according to one's own priorities and preferences.

Let's return to Robbie's case. Robbie had a number of goals that were central components of his self-care plan. We already mentioned physical activity to increase his functional independence. Another goal he was paying close attention to was watching his nutritional input and maintaining his weight. His mother, interviewed separately, noted that this was a definite priority for Robbie:

> "He is a real stickler with his weight for a couple of reasons. He knows diabetes is, [that] he is susceptible to that. He also knows that if he gains weight he won't fit in his chair. So he's been very meticulous about that."

Robbie's interview corroborated his mother's observation. He talked extensively about nutrition and what he did to maintain his weight. He also talked about watching his posture in the wheelchair, as posture problems are a significant issue for people with SCI. These were among Robbie's identified self-care priorities. On the other hand, some self-care activities that are common in SCI were not a priority of his on a daily basis, and he did not closely track them or develop detailed routines. For instance, he did not care much for routinely doing and tracking pressure relief (to prevent pressure sores):

> "I mean, I just kind of keep a mental note of it and try to just remember, based off looking at the clock you know."

In this example, we see that Robbie's priorities and preferences play a central role in his self-care. He is in charge of decision making on what aspects of his life to improve. We found this to be universally true for all cases in our study; the desire to control self-care plans and routines was a definitive finding in all our interviews. Our participants, or the individuals they assisted in self-care, had clear preferences for the self-care activities they

wanted to focus on (and would at times largely ignore others), and they were very particular about the ways in which the activities should be done (e.g., how to do stretches, the order in which activities should occur) and even the person who should assist them if assistance was needed. George, a primary caregiver parent, noted that a psychologist had informed him that this tendency was common, especially among people with more widespread paralysis:

> "In fact, the psychologist I talk to … he says that's one of the psychological fallouts, wanting to control their routines. They really get set in routines, and don't like their routines disrupted once they become a quadriplegic."

The above suggests that supporting this kind of agency-based independence for people with disability through a self-care technology would most likely require an ability for the person with SCI to customize goal setting and tailor activity tracking. Since even among people with similar physical disabilities and overall care needs the focus of self-care differs significantly, being able to support a range of goal setting and activity tracking will be key. While a generic list of activities and goals could be accounted for in a system, people must have the ability to customize beyond these.

5.3 The Context of Self-Care Is Collaborative

Our interviews showed us that, in SCI, self-care involves a dynamically changing care network that includes different types of caregivers and clinicians, with the individual with SCI being part of and at the center of the network. We found that the care network's structure and its members' coordinated actions and approaches to care shape what independence looks like in the context of care. This is not dissimilar to care networks found in other chronic conditions where the patient needs substantial assistance (e.g., [42,44]), but we need to provide an overview of the care networks we found in SCI for our findings about independence to have context. In this section, we first describe the structure and dynamics of care networks that emerged from our data. We will then show how independence is collaboratively shaped in the course of self-care.

5.3.1 The Structure of Care Networks. Our participants described care networks that included primary caregivers, secondary caregivers (both paid and unpaid), as well as clinicians of different specialties and social service providers.

Primary caregivers, among all caregivers, assumed the most responsibility in these care networks. In our participants' networks, the primary caregivers were either a parent or the spouse. They occupied a central position alongside the person with disability; as George, one of the primary caregivers we interviewed described it, "*the buck stop[ped] with*" them. We found that other caregivers in a network were often as accountable to the primary caregiver as they were to the person with SCI because of their often-substantial involvement in self-care practices and their role in managing secondary, paid caregivers' employment. These were also the caregivers with whom clinicians usually interfaced.

Secondary caregivers were commonly employed to assist with self-care, particularly in the home and other non-clinical locations (e.g., school). Our participants hired anywhere from 2 to 15 secondary caregivers at any given time. Although nurses were among the choices (and often employed through agencies), our participants have commonly hired college students or others such as members of their church. Depending on the needs and circumstances of the person with disability, caregivers were hired for anywhere from a few

hours of help per week to 24/7 assistance in shifts. Not all individuals with disability employed caregivers consistently. For example, one of our participants with paraplegia reported loss of secondary caregiver support due to loss of income.

Our participants also had family members or friends who provided additional support when needed. These unpaid secondary caregivers were often described as "the back-up" caregivers. For instance, some of Robbie's friends have learned how to assist him with his bladder program and with eating and drinking when they go out together. Jim is another young adult with quadriplegia, and his siblings have learned how to assist with all of his self-care activities that require support in case they need to step in at any time.

Care networks in SCI also include clinicians and social service providers. Physical Medicine and Rehabilitation (PM&R) doctors (the lead specialists for SCI), physical therapists, occupational therapists, urologists, primary care physicians, respiratory therapists, rehabilitation psychologists, and social workers were among the members of care networks described to us.

5.3.2 The Dynamic Nature of Care Networks. We found that these care networks change dynamically over time; people join or leave the network, and alternate between having a more central or peripheral role. This evolving nature of the networks was most striking to us with respect to caregivers. A common complaint was high turnover rates among paid secondary caregivers, which our participants primarily attributed to low wages or life events (e.g., graduating from college, giving birth). Our participants almost unanimously noted how difficult it is to find and maintain long-term support from skilled paid caregivers. George, a primary caregiver, described the difficulty they had as they tried to build their support over several years to include multiple caregivers to cover multiple shifts:

> "The length of time between losing a nurse and finding a nurse sometimes could be 30, 60, 90 days, because it was very difficult to find nurses who were working in home care, who would fit the criteria which you're looking for, that were available... While you're building up to get to four or five nurses it's like you get one, you lose one."

Our participants also reported rapid turnover rates for paid secondary caregivers. For example, Aaron, a young adult who requires 24/7 support, had different caregivers almost every school semester because he hired students whose schedules changed each term.

With the high turnover rates for paid secondary caregivers, the primary caregivers and other family members and friends had to provide the necessary support to keep up with self-care activities, increasing their involvement if the care network lost members. Primary caregivers, and in some cases unpaid secondary caregivers as well, also developed broader knowledge and a wider range of skills to assist with self-care so that crucial knowledge would not be easily lost from the network due to turnovers. However, while the long-term commitments of these caregivers were generally more stable, those components of care networks also changed, or our participants expected change. For example, Jim's sister (a secondary caregiver) moved out of town. Larry got divorced, whereas Charlie got married; one losing and the other gaining a primary caregiver.

While the evolving nature of care networks was particularly striking from the perspective of caregiver membership, we found that the networks were also dynamic with respect to clinician involvement. Physical therapists and occupational therapists were mostly engaged in the first few months following hospital discharge, when patients were in outpatient rehabilitation. Rehabilitation doctors, who come on board immediately after an injury and

continue to follow people in the outpatient setting, also became less engaged over time, eventually seeing patients once a year (if at all), whereas people with SCI more often saw their primary care physicians even for problems associated with their injury. Participants with respiratory problems often felt closer to their "vent team" than any of their other providers and remained in contact with them more regularly.

In the next section, we illustrate how independence is collaboratively constructed in care networks as they work to formulate and execute self-care through self-care plans and routines.

5.4   Independence is Collaboratively Shaped in the Care Network

In this section, we will return to and re-examine Robbie's case by looking at how independence is collaboratively constructed in his care network through self-care practices and attitudes towards self-care. At the time of his interview, this care network included both parents, with his mother taking the lead as primary caregiver, several paid secondary caregivers (depending on who the agency had available to send, which could be different each time) who came by to assist with self-care activities several days a week, his physical and occupational therapists, as well as his rehabilitation doctor, family doctor, and other family members and friends whose involvements were less frequent.

Let's look at some areas of self-care that Robbie chose to focus on. One of these, as we mentioned previously, was posture. As Robbie explained, this was initially not something that he prioritized. It became a priority over time as the physical therapists he worked with intermittently reminded him and provided guidelines on what he should do. Eventually, watching out for and correcting posture issues, as well as preventing related problems, got incorporated into his self-care:

> "For the longest time I would sit around and drive around at a slightly reclined position. In rehab the PTs would emphasize to me like every now and then the importance of eventually building up to sitting completely, like with the chair completely flat and upright, as opposed to tilted back a little bit, which is a habit that I got into. Luckily now I'm starting to put a lot more thought and effort into keeping my chair totally upright. It's tough because I don't have very good core strength anymore, so it's tough to sit completely upright…"

Robbie stated that building up to a better posture and for longer periods of time is a process where "*some days it's better than others.*" This is a long-term goal for him. As in this case, our data showed that articulating self-care priorities and identifying a related set of goals is often a process that is accomplished by the care network through one-on-one and at times collective deliberation. The care network can influence a person's priorities and goals, while leaving the final decision to the individual with disability.

It is important as well that care network members accept an individual's identified priorities and goals and help the individual with these. We saw an example of this with another one of Robbie's priorities: nutrition intake and weight control. This goal was embraced by his primary caregiver, who also saw it as an opportunity to give control to her son over an area of his life:

> "At mealtime I let him decide what he wants to eat. I don't [interfere], you know, I want him to have as much power as he can have."

Once a goal is determined, members of the care network then fulfill different roles in helping the person map the goal to a self-care activity or set of activities, and in assisting them in accomplishing or tracking those activities. As we mentioned previously, many self-care

activities are eventually routinized. Our data clearly showed that people with SCI tend to get very particular about their routines. This is an important means of control, and therefore of independence, for them. Care network members not only help the person develop routines, but they allow for independence by strictly adhering to these routines as they assist the individual with SCI. These routines include not only what activity is done and when, but who assists with the activity as well. We found this to be another way in which care networks help to construct and support independence, as it makes it possible for activities to be delegated to specific individuals. For instance, we found that individuals with disability often prefer activities of a more personal nature (e.g., bowel programs or showering) to be assisted by paid secondary caregivers rather than parents or their spouse; young people wanted independence from their parents, whereas change in relationship or intimacy was a concern for spouses. Like others, Robbie preferred paid caregiver assistance with some personal activities. In comparison, having the assistance of friends in some activities (e.g., eating and drinking) allowed him independence to enjoy social relationships with peers without parental or paid support.

We found that primary caregivers play a critical role in training other caregivers in the care network – most extensively the paid secondary caregivers who are frontline in daily care – in the individual's activities and preferred routines. We also found that, the role of training caregivers may be done collaboratively by the individual with SCI and the primary caregiver, or that the individual may assume the responsibility for training over time by providing express direction. Caregivers help to construct independence in an important way by learning and following these directions:

> "It's just a lot of personal preferences that I end up teaching them. It's not customary to people with spinal cord injuries. A lot of things that I teach them are just ways that I like people to help me out. I like to get stretches done in the mornings and at night before I go to bed, and there are certain ways I like the stretches to be done. There's a certain order when I'm in the shower that I like people to help me, in terms of where they wash me first and last. Yeah, just small things like that." (Robbie, individual with quadriplegia)

Caregivers also help to construct independence by allowing the person to try to do activities on their own, whether this is an attempt to open their pillbox by themselves or to manage their self-care:

> "In the beginning we had to be really involved with his medical care, his health care. Now we've pulled out of it, he directs all that." (Clara, Robbie's mother)

Our data showed that, as much as they withdrew from assisting with self-care activities on a daily basis, primary caregivers were very much concerned with keeping an eye on the big picture of care. They wanted to ensure that activities were getting done, and that they were being done in safe ways. For this information, they depended on the person with SCI or the caregivers they employed. The fact that self-care activities were distributed among multiple caregivers, who also moved in and out of the care networks frequently, was challenging. Moreover, following the big picture of care became even more challenging as primary caregivers willingly decreased their involvement over time to allow the person more independence. Robbie's father, interviewed at a later time, noted that while as parents they had significantly withdrawn their involvement, it would give them peace of mind to know that everything was going well with his care:

> "It's kind of like his information, right? But if he would allow us to see it, or at least [to] have something like that (care management application) would be good for tracking just to look at trend data. You can look at trends, whether something's changing."

Let's now more explicitly unpack how independence is collaboratively shaped in the example from Robbie's self-care. First, the attitudes of care network members towards self-care play a critical role. Care network members actively seek to understand and at times influence what Robbie's priorities are. There is ongoing deliberation involved in this, and an overall self-care plan emerges over time based on these priorities. Furthermore, through the training of the paid caregivers, first by the primary caregiver and later by Robbie, work is done to ensure that self-care activities get done in alignment with Robbie's preferences. All of these are important for Robbie to have agency over his self-care. As we described earlier, having control over self-care and life choices is a fundamental form of independence.

At the same time, functional independence is also shaped by the collaborative practices in the network. It is not sufficient for Robbie to identify an area in which he would like to see improvement. He needs to know what he could do to increase functional independence in a chosen task or to prevent further physical problems (e.g., issues related to posture). Physical and occupational therapists play a crucial role in this. Since knowledge and skills vary among care network members, the collaborative way of identifying and tracking a set of goals related to the self-care plan is important. The set of outcomes to be tracked have to be agreed upon as well. Robbie is also given opportunity to practice doing activities on his own (e.g., opening pill bottle), instead of being assisted by default, which helps to increase functional independence.

Supporting independence within a care network is more complex than the simplified scenarios we provided in previous sections. Goal setting and tracking are collaborative and require deliberation. Depending on their roles, each member of the care network is interested in different outcomes and they can be variably involved in tracking (e.g., unlike the person with disability and primary caregivers, physical therapists are likely not interested in goals related to social interaction, such as how much a person leaves their house and socializes with others, which some of our participants had). The primary caregiver is more concerned about the overall picture of self-care than being involved in some of the specific self-care activities on a daily basis. The primary caregiver is also concerned with safety in self-care, which could severely impact independence. On the other hand, paid and unpaid secondary caregivers each have their own tasks, which can vary based on how much time they spend with the person with disability, and their own knowledge and skills; there is a distribution of responsibilities with respect to self-care activities. Furthermore, when they are newly hired, paid secondary caregivers require guidance in what activities to do and how to do them as part of the individual's preferred routines.

In the next section, we move beyond an individual case to a broader set of findings related to the dynamics of collaboratively shaped independence in care networks.

5.5 Tensions in the Care Network Affect Collaboratively Shaped Independence

For our participants, care networks were often actively supportive of independence, both functional and in the form of effecting agency. However, we also found places where there might be pushback against the priorities or preferences of the person with disability. At times, people with SCI could find themselves in conflict with their caregivers. We discuss two of these tension points, caregiver conflicts of interest and the need to maintain a balance between independence and care.

5.5.1 Caregiver Conflicts of Interest. A source of tension in care networks that influences collaboratively shaped independence is caregiver conflicts of interest. At times, we saw that caregivers asserted their own viewpoints or priorities, or indicated that they would. We saw this in primary caregiver interviews in particular. Even caregivers most openly supportive of independence can at times overrule the preferences of others in the care network.

For instance, our data provided ample evidence that Peter's care network was one in which specific attention was given and effort was made to help him have the kind of independence that he prefers. However, Peter's primary caregiver also described in detail how she deliberately and rigorously monitored his nutrition, in part because his weight also affected her potential to assist him in self-care:

> "Portion size is really important with him, because he does not move around a lot. ... And if he gains weight it's around his middle, which just makes him moving even harder. [Be]cause there was a while he weighed like 145, it made it hard on me trying to move him [be]cause he couldn't help as much. ... So yeah, I'm the food police. Everyone knows that mom is the food police."

In the quote above, the primary caregiver's reference to "everyone" is to other members of the care network, most notably the paid secondary caregivers. In her interview, she further explained that *"everybody knows what mom thinks is a good snack"* (fresh fruits and vegetables, as opposed to candy, which her son liked) and acknowledged that "*a lot of people don't get and maybe don't like*" the fact she so closely monitors her son's nutrition. However, the secondary caregivers followed her direction in this matter. In cases where there is a misalignment between the perspective of the primary caregiver and the individual with disability, it is possible that the person with disability will be overruled. This is further evidence that hierarchical relationships in care networks can influence the collaboratively shaped independence and carries implications for data control.

5.5.2 Maintaining Balance Between Independence and Care. We know that individuals with disability articulate priorities and establish a set of preferred routines; they have their own ways of doing and tracking self-care activities. However, self-care, as we have shown, happens with the participation of care networks where members have distinctive roles. We found that members of care networks at times require or prefer self-care related data at different levels of granularity to fulfill their roles. Misalignments in preferred data granularity can be challenging if one party in the network relies on another for information.

For example, for Jim, an individual with quadriplegia, it is not essential to know how many times he uses a machine for a self-care activity called 'cough assist' on any given day, whereas his clinicians would like to have this information:

> "I usually say, "Two to five times a day", because that's about how it is. I don't really know. I know for sure I do it twice a day, but then some days it's more, some days it's less. I don't really know. I don't really track it like that. My clinicians would like to."

We found that clinicians in these care networks are quite particular about how they would like to receive self-care data. In a way similar to primary caregivers, they work to accommodate the priorities of the individual with disability but also want to be alert to potential complications so that they can interfere in a timely manner. However, unlike the primary caregivers who are interested in following the big picture of care, the clinicians do not want or need to receive a continuous stream of data. Rather, they want to be alerted to anomalies that could indicate an emerging complication:

"I think for the general things for self-management, it's probably more important for the caregiver and the patient [to have daily patient data]. But how useful it's going to be for providers? I just don't see much utility in that. But if the computer could say anytime this person complains about this [issue], or the blood pressure is above this level or below this level, or there is a temperature reading above this level, those are things that would pop up as an alert for the providers, I think that would be probably a much better way to approach the question." (Joe, primary care doctor who works with individuals with disabilities.)

Our interviews have shown that misalignments exist between the clinicians' preferred data granularity and what was or could be tracked by other members of the care network. Examples include data on the time and degree of pain that is experienced, data related to sleep hygiene, and pressure relief measurements in wheelchairs. Overall, considerations of data granularity can impinge on the independence of the individual with disability by affecting control over data or routines for data collection.

6   DISCUSSION

In this paper, we showed how self-care highlights ways in which independence is collaboratively co-constructed for Spinal Cord Injury and similar disabilities.

We showed that articulating self-care priorities and identifying a related set of self-care goals is often a collaborative process accomplished through one-on-one and at times collective deliberation among the person with disability, caregivers, and clinicians. Structuring self-care around priorities and preferences is a central means for attaining and maintaining both functional independence and a sense of agency, and the care network is critical in this process. Based on their knowledge, skills, and incentives, members of care networks participate in shaping self-care, and in the course of that help to shape what independence looks like for the individual.

In the following, we consolidate the findings so as to identify specific design implications:

A. The drive for independence influences the shape and evolution of self-care plans in SCI and most likely similar conditions. However, this can be done only in conjunction with others, both caregivers and clinicians. And for people with SCI, independence can only be achieved collaboratively.

B. Both functional independence and independence to assert agency play important, but different, roles in shaping the nature of care, especially the prioritization of care activities and the development of routines.

C. SCI care takes place within a complex and ever-changing network. Both caregivers and clinicians can change, and caregivers' responsibilities shift over time.

D. Over time, the individual with SCI often gains greater independence by increasing their involvement in directing their own care. The primary caregiver yields control (willingly, to support the individual's independence), but wishes to remain aware of the "big picture" of care and health status.

E. Despite a shared desire to support the individual's independence, there are tensions that influence self-care plans and routines. Individuals with disability have needs and preferences, but so do caregivers, and clinicians need to effectively monitor care. Everyone in the network, in fact, must maintain their own independence and agency.

F. Maintaining independence over time requires ongoing attention, work, and negotiation by everyone, or nearly so, in a care network.

Given the findings, what are the implications for the design of sensor-based technologies? In the next section, we return to our initial goal of deriving implications for the design of sensor-based support for self-care within the SCI context.

6.1 Design Implications for Sensor-Based Technology

Home health monitoring and other forms of sensor-based interventions have received a great deal of attention in both the medical and CSCW/HCI literatures. The rapid proliferation of sensing technologies that can passively and continuously observe context-, activity- and health-related phenomena allow individuals to capture phenomena that are impossible to observe directly, easily forgotten, or exhibit patterns that are difficult to identify. However, to date, much of the work in sensor-based support has focused on supporting individuals who are pursuing self-knowledge or well-defined goals, providing assistance to the caregiver-patient dyad, or on providing more data to support clinicians' care.

Our study highlighted the issues in providing an alternative venue for sensor-based technologies, namely supporting complex care networks involving diverse stakeholders with diverse motivations. Finding A (the drive for independence) argues that for the support of people with SCI, and most likely people with similar chronic conditions, maintaining independence is paramount. This argues heavily against a standard medical informatics viewpoint, where data is sent automatically from the home to support the clinician-patient pair. The canonical application of providing patient data to a doctor or other clinician for monitoring, for example if an anomalous health incident were occurring or the patient were deteriorating, is more complicated than might appear at first blush. Sending patient data to a doctor would seem like an easy decision, since it would allow one to monitor the health of an SCI patient. If we ignore the problems of sensor-based systems – what Ackerman et al. [2] called *data completeness* and *computational completeness* inherent in the current incapability of sensors to accurately and reliably provide the necessary data for the computation of many important biological and behavioral actions – then it would appear, at first blush, that only good outcomes are possible. The patient might lose some privacy, but it would be for their own good. Findings (A, the drive for independence) and (B, types of independence) argue that CSCW/HCI should, instead, centralize the person with SCI (and later findings also argue for including the entire care network) so as to promote both functional independence and agency in care.

Centralizing the person with a chronic condition is not a trivial imposition. Having clinicians set care plans and data access is straightforward, but lacks the negotiation that may be necessary. The mere imposition of care plans and any resultant monitoring could be detrimental to the strong sense of agency that individuals desire. For some people with SCI and for their sense of autonomy, they will need to be able to disseminate data as they choose. They will want to choose the timing and granularity of data release. They may even wish to hide aspects of the data, whether or not clinicians or other members of the care network think this prudent. We note that this is relatively easy to do without automatic capture of data, since patients are relatively free to disseminate whatever data they wish. In certain circumstances, they may get caught – as when they get pressure sores or are dehydrated – but if their condition does not deteriorate, they may choose to provide only overviews, only good days, or

even "good data." Sensor-based systems can overturn this control, and this needs to be considered in designs. As we note below, this control will need to be highly nuanced.

Finding B (development of independence) suggests that sensor-based systems need to be flexible enough to accommodate changing priorities and routines [21]. It also suggests that the governance of self-tracking systems (e.g., what to track, how to track it, what to do with the data) ought to be seen as a distinct concern from the sensor-based technologies for monitoring, tracking, or data reflection. The current literature also does not specify requirements for how the flows should be controlled when looking at the entire care network. Findings C (dynamic care networks) and D (shifting responsibilities) also argue that the control will need to be dynamic, since clinical conditions change and so do the makeup (and responsibilities) of care network members. Again, control over data flows will need to be highly nuanced.

As well, findings C (dynamic care networks) and D (shifting responsibilities) strongly argue for how important the entire care network will be for data sharing and data flows. While dyadic relationships are simpler to model and control, they are not the entire picture. Trying to create *agency within a care network raises many difficult issues, especially when allowing for the awareness and coordination* that is necessary in a care network. Findings E (tensions in the care network) and F (ongoing negotiation) argue that the tensions of having many people with disparate roles and agendas pushes against a simplified view, again often found in the medical informatics literature, where patients merely want to provide their doctors or other clinicians with as much data as the clinician can handle. In our participants' view, instead, patients may want to present a self-representation that is adequate for their purposes. As above, they may wish to present themselves as "good patients" to clinicians even when they miss some daily tests (such as skin checks). They may wish to present themselves as dutifully concerned with their health even when they go off-diet or imbibe too much. The ability to create these self-representations, and the actual actions that may be in tension with them, are what feed patients' sense of autonomy. This becomes even more urgent, as finding (E, tensions in the care network) notes, when family members or friends are involved.

We do not want to minimize the need for awareness and coordination, as Tixier and Lewkowicz [44] so well pointed out. In their study of the elderly, clinicians and caregivers alike had to provide one another with informal summaries of the daily care activities so as to maintain awareness. Our participants similarly had a variety of informal and formal arrangements for providing awareness to at least the person with the disability and/or primary caregivers. Awareness, for our participants, could be result of deep coordination, or fragmentary or disjoint. However, we note that awareness based in detailed data can bring privacy issues that can violate one's sense of autonomy.

As findings E (tensions in the care network) and F (ongoing negotiation) also point out, agency is not just for the individual with SCI. *Everyone in the care network requires support for their own sense of autonomy.* This aligns with the work of de Carvalho et al. [12] and Tellioglu et al. [41] on supporting the independence of caregivers. Primary caregivers must not only understand the activities of others to provide the best care, they must also maintain their own lives as best as possible. Paid secondary caregivers, and even unpaid secondary caregivers, must weigh patient care against their own needs and careers. Similarly, clinicians must also weigh patient care against their own shortages of time and financial responsibilities. This again requires nuanced control over data.

Where do all of these implications lead us, then? We believe this argues for two basic requirements [37] for system implementation:

First, many of the implications from our findings argue for a very nuanced control over the data access and data flows that a sensor-based system might provide. Only the person with SCI can properly balance the need for others' awareness and coordination, whether that of a family member, paid caregiver or clinician, with his/her own sense of self-agency and self-control. Therefore, a person with SCI will need the ability to easily control and visualize data flows. This, of course, is not trivial. Based on the findings above, the system must allow for the setting of sharing policies by actor (or by role), the visualization of the resultant data flows (along with the ability to test what policies will do using real data), the ability to share policies since most people will not wish to write their own policies (or even think of sharing as policies), and the negotiation of that data sharing over time as conditions change. People find it particularly difficult to predict what setting their data sharing preferences will do. Visualizations that help people understand what the data flows will look like, with specific data sharing preferences, may be critical.

This concern over a detailed control of sensor-based data and data flows results not just from an abstract sense of privacy, but as being essential to care. Care, for our participants, included control over one's agency as a patient, as a family member, and so on.

Second, it is unlikely that any technical means of providing control or governance over one's data will be right all the time. Since each individual in a care network needs their own autonomy and the care network characteristics change over time with new people or new care needs, that an occasional clash or misunderstanding will occur should not be surprising. This was documented as early as in Strauss et al.'s Social Organization of Medical Work [39], which detailed how a patient's wishes contravened what her husband wanted and what her doctors thought best, but it has often been forgotten in discussions of medical technologies for monitoring. As in Strauss et al., to provide for the coordination and functioning of the various actors, a negotiated order is required. To provide for autonomy of all parties in the care network, the provision of data must be a negotiated order among the actors in the care network. In the more complicated provisions for agency within a care network structure, data sharing and data control must become a communicative activity, one with technical support for ongoing negotiation.

We are currently making progress towards the construction of a framework with these functionalities.

7   CONCLUSION

In this study, we examined self-care for individuals with spinal cord injuries. We found that independence is a central concern in SCI, and that it has two dimensions: learning and maintaining the physical capabilities to do activities without assistance and asserting a measure of agency over self-care decision making. Importantly, we found that independence is a collaborative construct, heavily influenced by the coordinated activities of the care network and its members' approach to and active help in self-care. We also found that the care network is dynamic in terms of specific members, roles, and activities. The presence of a care network, its importance in maintaining both functional and agential independence, and the dynamic nature of the care network all influence the nature of data sharing and access from sensor-based systems. Moreover, because everyone in a care network must also weigh their independence, data provision is often not straight-forward. We found that sensor-based systems to provide data access and data flows must provide for user control over those flows.

Our methodology had limitations. As we mentioned previously, recruitment was a challenge for us due to the nature of SCI. Recruitment efforts showed "study fatigue" experienced by individuals with disability because they are not infrequently asked to participate in studies. The difficulty and sensitive nature of the condition itself, as well as geographical dispersion, pose additional challenges. We also would have liked to interview more members belonging to the same care network. However, we found that recruiting a group of connected individuals is oftentimes more difficult; some people in the care network are willing to participate while others are not. We did not want to make this a condition for participation given the other challenges with recruitment. The inclusion of clinicians in the care network further adds HIPAA considerations (e.g., the individual with disability must first agree to participate and grant the clinicians permission to disclose information). We believe that the care network is an important unit of analysis, especially in long-term illness or disability, and how to recruit networks as participants to learn how to better support them is an important challenge for CSCW/HCI. However, we believe we recruited a reasonable cross-section of people with SCI, their caregivers, and clinicians.

Our findings are also limited to the particular context we studied and are therefore not broadly generalizable. However, while the context of our study was SCI, we believe that similar kinds of concerns will exist in other chronic care situations. For instance, our supplemental interviews suggest that people with developmental disabilities, disability from stroke, and certain neuromuscular conditions that impose similar constraints and self-care needs have similar care networks and concerns of independence.

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