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Decisions and Dilemmas in Everyday Life: Daily Use of Wheelchairs by Individuals with Spinal Cord Injury and the Impact on Pressure Ulcer Risk

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Abstract

Individuals with spinal cord injury (SCI) use wheelchairs for mobility and for full participation in their daily activities. The use of wheelchairs, however, can increase the risk of pressure ulcers. This study focused on wheelchair users' perceptions of the interplay between their wheeled mobility and the development of pressure ulcers by performing a secondary analysis of data gathered during a 2-year ethnographic study of 20 community-dwelling adults with SCI. Data from a subset of these individuals are described; each of these stories contains a pressure ulcer risk episode related to wheeled mobility or cushion use. Identified risk episodes were associated with wheelchair selection, wheelchair adjustment, habituation to new equipment, lifestyle choices, and challenging life contexts. Examples highlighted the crucial relationship between individuals' minute-to-minute decision-making and pressure ulcer risk.

Keywords

daily routines; paraplegia; pressure ulcers; spinal cord injury; tetraplegia; wheelchair; wheelchair cushion

For the majority of people with spinal cord injury (SCI), a wheelchair is not only their primary means for mobility but also represents the base from which they act in the world. Their daily routine typically begins with an early transfer into their wheelchair, where they remain for most, if not all, of the day. Full engagement in daily pursuits while spending most waking hours in a wheelchair carries with it multiple, often inconspicuous, dangers for individuals with SCI. Pressure ulcers are one such danger.

Due to paralysis, lack of physical sensation, and impaired control of bowel and bladder functioning, pressure ulcers are a ubiquitous threat to individuals with SCI.[1–3] The severity of this threat obliges people with SCI to conduct their daily activities with a heightened awareness of how their minute-by-minute choices may affect their skin integrity.[4] The most common areas for skin breakdown for people with SCI are the ischii, sacrum, coccyx, trochanters, and heels; significantly, the first three of these areas are in contact with parts of the wheelchair.[5] Despite the prolonged amounts of time people spend in wheelchairs, and the correspondence between common pressure sore locations and areas of contact with the wheelchair, there has been little focus in the literature on the ways in which individuals with SCI use their wheelchairs impact pressure ulcer risk. An increased understanding of how mobility devices are used in the context of the individual's daily life could be used to inform clinical practice. Such findings could have implications for both the prescription of these devices and the design of educational and rehabilitation programs for people with SCI. There could also be implications for wheelchair design.

Impact of Pressure Ulcers

Pressure ulcers are wounds created by unrelieved pressure and/or shearing forces on an area of skin, resulting in tissue destruction. These wounds are common secondary medical complications for people with SCI. Among this population, currently believed to number between 225,000 and 300,000 individuals living in the United States, the annual incidence of pressure ulcers has been estimated to be between 23% and 40%, with a lifetime incidence of approximately 95%.[1,6–9] A study by Fuhrer and colleagues [7] found the prevalence of pressure ulcers among community-dwelling adults with SCI to be almost 33%. An individual who develops one serious pressure ulcer is significantly more likely to develop subsequent ulcers,[1,7,10] making the prevention of an initial ulcer even more important.

The impact of pressure ulcers on a person's health and quality of life can be significant, particularly in the case of the more serious stage III and stage IV ulcers in which underlying tissue and support structures are damaged. One study of the incidence of rehospitalization after traumatic SCI found that pressure ulcers were the second most common cause of rehospitalization at 1-, 10-, 15-, and 20-year intervals after the injury and the leading cause of rehospitalization at the 5-year interval.[11] Septicemia, which is strongly associated with the presence of pressure ulcers, is the third leading cause of death among people with SCI.[12] Pressure ulcers are believed to be a contributory factor in the deaths of more than 7% of those with SCI.[1] Therefore, understanding the factors that contribute to the formation to pressure ulcers is essential.

A long list of factors contributing to an individual's risk of developing pressure ulcers has been identified in the literature. These risk factors include paralysis; loss of sensation; bowel and bladder dysfunction; nutritional status; medical co-morbidities; demographic characteristics; psychosocial issues such as depression; and tobacco, alcohol, and recreational drug consumption.[1,4,7,10,13–15] However, the particular contribution of wheeled mobility equipment use to the formation of pressure ulcers is seldom explored from the perspective of the person's lifestyle issues and activity choices.

Wheelchair Use and Pressure Prevention Practices

One study focusing on pressure relief practices in daily routines and its relationship to skin breakdown was conducted in Taiwan.[16] This study examined the sitting and pressure relief practices of 20 community-dwelling manual wheelchair users with SCI by installing cushion sensors on wheelchair seats and then remotely monitoring the time participants spent in the wheelchair. The researchers also gathered data on the frequency of pressure releases performed. Data were collected over a 1-week period. Results showed that individuals spent an average of 9.2 hours per day in their wheelchairs, a significant amount of time. Additionally, the participants performed pressure reliefs on average only 9.4 times each day, a rate of approximately once each hour they were seated in wheelchairs rather than the two to four times per hour commonly advocated. Another study of health behaviors of SCI adults reinforced the latter point; among the 410 participants studied, weight shifts while seated in a wheelchair were one of the least frequently practiced health behaviors.[17] A number of other researchers[18–20] have also noted the low frequency of pressure reliefs performed by wheelchair users.

Most individuals with SCI are provided with their first wheelchair and cushion shortly after their initial injury. Typically, a therapist recommends a selection of wheelchairs and the consumer has the opportunity to try each of them for a few days during the acute rehabilitation stay. After such trials, a permanent wheelchair and cushion are ordered. However, these trial periods generally take place in the hospital setting rather than in the consumer’s home environment where the equipment will actually be used, often leading to a poor fit with the home and community environment. Wheelchairs, the most important mobility device for the person with SCI, can become the most significant barrier to full participation when poorly matched within a particular context. Consistent with this notion, individuals with SCI have identified their wheelchairs as the greatest factor limiting full participation in daily life.[21]

In this article, we address the ways in which everyday use of mobility equipment, particularly wheelchairs, contributes to the risk of pressure ulcer development. To do so, we examined data gathered during a 2-year ethnographic study (the Pressure Ulcer Prevention Study [PUPS])[4,22] of adults with SCI carried out by a team of researchers and clinicians from the University of Southern California and Rancho Los Amigos National Rehabilitation Center.

Method

Data analysis for the present study consisted of a secondary analysis of qualitative information collected during an ethnographic project that focused on the role that lifestyle choices play in the formation of pressure ulcers.[4] This secondary analysis specifically focused on the role that mobility equipment plays in the development of pressure ulcers.

Twenty adults with SCI participated in the original study (i.e., the PUPS study). All but one of these participants had a traumatic SCI; the remaining participant’s spinal cord was damaged as a result of transverse myelitis. Participants were recruited from a specialized pressure ulcer management unit where most treated individuals had undergone at least one surgical repair of a pressure ulcer. The sample was purposive; it was selected to maximize diversity on a range of characteristics and to include persons at a very high risk of pressure ulcer development. Participants ranged in age from 28 to 77 years at study outset, and they were all at least 1 year post injury. The sample included 14 men and 6 women and was ethnically diverse (see Table 1).

Data collection

The current study was a secondary analysis of data collected in the PUPS study. These data were collected through a combination of methods, including participant observation and structured and unstructured interviews. When possible, interviews were also conducted with care attendants, family members, and health care professionals involved in the participants’ care. Although most data collection was carried out in the participants’ homes, researchers also accompanied participants on community outings and to health care appointments. Some interviews were conducted in hospitals and care homes. The number of times each participant was interviewed ranged from 3 to 23, with an average of 11.5 data collection sessions per participant. The average length of time each participant was involved in the study was 18 months.

Data analysis

All interviews and field notes were transcribed verbatim and thematically coded using Atlas.ti software23 by the PUPS team. For the present analysis, the original, raw transcripts of each of the 20 participants were read and coded by two of the authors (Fogelberg and Blanche) with the specific intent of identifying issues relating to mobility and mobility equipment. These codes were then reviewed in an attempt to identify patterns within the data and to detect common themes. When multiple themes appeared to be related to one another, a meta-code was assigned to describe that thematic category. These categories are described below and illustrated with quotations. Although the transcripts of all 20 participants were reviewed, the Results section focuses on those participants whose data most effectively illustrate the themes identified. The names of these participants are pseudonyms previously assigned by the PUPS team. The quotations have been edited for clarity and to remove any potentially identifying information.

The present analysis builds on previously published findings from the PUPS study team. Specifically, there are two main concepts that were used to understand the formation of pressure ulcers in the context of daily life. For a full account of these concepts, please refer to Clark et al.4 The first concept relates to the interplay of factors that affect a person's risk of pressure ulcer development. Those factors that exacerbate risk are referred to as *liabilities* and those that mitigate risk as *buffers*. Any given factor's influence on pressure ulcer risk was found to be highly context dependent; factors that acted as buffers in some contexts were liabilities in others and vice versa. For example, paid employment appeared to provide a buffer against pressure ulcer development for some individuals; one participant was pressure ulcer–free for almost three decades and experienced his first significant skin breakdown only after his loss of employment left him spending long periods of time in bed. Another participant, however, routinely developed pressure ulcers in part because her job required her to spend significant periods of time at her office. Paid employment could therefore be considered something of a mixed blessing for those with SCI.

The second key concept that emerged from the original PUPS study is that of a *change event*, a new or altered factor in the person's life circumstances that contributes to *a pressure ulcer risk episode*, which is a period of heightened risk of incurring a pressure ulcer. Change events identified in the PUPS data included such things as the employment of a new caregiver, relocation to a new home, or the loss of a job.

Our analysis is based on the hypothesis that wheelchairs, pressure-relieving cushions, and other mobility aids can act as either buffers or liabilities with regard to pressure ulcer risk. Furthermore, we hypothesized that the introduction of, adaptation of and to, and everyday use of mobility equipment are examples of change events that may lead to pressure ulcer risk episodes. Although it is tempting to conceive of risk as resulting from dramatic, out-of-the-ordinary events, our analysis of the data was based on the belief that the mundane, everyday use of wheelchairs can lead to pressure ulcer risk episodes.

Results

The themes that emerged from our analysis suggest the existence of liabilities that have received little attention in the SCI literature and that constitute ongoing potential risk episodes for developing skin breakdown. These risk episodes can be organized into two main categories: (a) selecting and adjusting to the wheelchair and changing habits, and (b) ongoing use of the wheelchairs (see Table 2). The first category, choosing and adjusting to the wheelchair, concerns both the interaction between health care providers and participants during the selection of the wheelchair and the participants' initial period of adaptation to the wheelchair. This category underscores the importance of participants' tacit knowledge about their bodies as well as their seating needs in the wheelchair selection process. The second category, integrating the wheelchair into daily life, centers on the ongoing uses, both customary and idiosyncratic, of wheelchairs. Within this category, a variety of factors emerged that related to the participants' lifestyles, including modifications they made to their wheelchairs, unusual ways in which they used wheelchairs, and choices they made regarding how long to remain in their wheelchairs. Often, these choices emerged as a balance between the conflicting desires to care for their health and to fully participate in life. Finally, instances in which the use of wheelchairs failed to go as planned, including occasions when equipment malfunctioned or participants found themselves in unexpected contexts, will be discussed.

Selecting the wheelchair

The participants in this study reported choosing equipment for a variety of reasons, including aesthetics, comfort, mobility, and the desire to prevent pressure ulcers. For most participants, the equipment under discussion in this study was not the initial postinjury wheelchair. In many instances, the participants had specific ideas about the type of wheelchair that would serve their functional and lifestyle needs, and these ideas informed the wheelchair selection process. In other cases, the participants had minimal input in choosing their wheelchair. Instead, the wheelchair was chosen on the basis of health care providers' clinical judgments.

Initial selection of the wheelchair—Chris's story illustrates one way in which the process of wheelchair selection can impact pressure ulcer risk. Chris was injured at the age of 17 when he dived into a river. Several years after his initial injury, he had a lengthy hospital stay. When hospital personnel decided it was time for him to be discharged, they asked him to choose a new wheelchair. Chris was ambivalent about the prospect of being discharged and felt pressured to make a quick decision about the wheelchair. Faced with making a decision in these circumstances, the wheelchair's appearance emerged as a deciding factor. He did not want a chair that would look too bulky and old fashioned.

> Chris: And he [the therapist] goes, "Here, try this chair." And then I got into it. And it was bigger for me, but … I liked the way it looked, and I go, "Okay, I'll just take that one."… [but] I didn't want a chair that *looked* like it reclines.

In the previous excerpt, this participant's decision about the wheelchair appears to have been made without taking into consideration all of the factors that later contributed to the formation of pressure ulcers. Once the chair was at home, Chris realized the chair was too big to move around and he had difficulty learning to maneuver it effectively.

> Chris: Because it was wider and I was running into things, I couldn't do things and [I hit] corners as well. I didn't have the feel of it. It felt bulkier [than his old chair].

The wheelchair Chris chose was unmanageable for him, and the frequent collisions he described had the potential to damage his skin. The wheelchair was considered a contributing factor to a medically serious pressure ulcer that he later developed. This ulcer required surgical closure and a stay of several months in the hospital for healing. Another wheelchair had to be ordered for him at a considerable cost.

The link between Chris's choice of a wheelchair and his subsequent development of a pressure ulcer was relatively straightforward. Steve's story illustrates a more subtle connection. He was in his early 30s at the time of his injury and had spent much of his life as a member of a street gang. Although he had left the gang before acquiring his SCI in a road traffic accident, after completing his rehabilitation Steve returned to his previous habit of spending long periods of time on the streets of his neighborhood, drinking, and socializing with friends. With this in mind, he had asked for a shiny blue wheelchair.

> Steve: I like to be out at night, and you know [a blue chair] would help the reflection off the headlights of cars you, know when, when I'm crossing the street or whatever. I'm always in the street. I don't like being on the sidewalk around here.

However, when the wheelchair was delivered to his house, he realized it was not the color he wanted. Steve chose to keep it, in part because the wheelchair he had been using up to that point was broken. Steve's desire for a specific color of chair was not only based on his aesthetic preference but also on his desire for increased safety while on the street. A blue wheelchair would have made him more visible after dark.

In this example, the relationship between Steve's choice of wheelchair and his pressure ulcer risk is less obvious. However, his desire for a brightly colored wheelchair was based on his intention to spend long periods of time in the wheelchair at night on the street. In later interviews, Steve noted that the relatively cold night air increased the frequency with which he experienced muscle spasms, which are known to be correlated with pressure ulcer development. He also described drinking alcohol while socializing with his friends on the street, another factor known to increase pressure ulcer risk. He requested a wheelchair that would enable him to reenter an environment that would place him at high risk of ulceration.

Tacit knowledge—Some participants reported knowing how their body felt when sitting in the appropriate equipment; however, they did not consistently articulate these insights to the person ordering the wheelchair. In some cases, if they had been vocal about their concerns they could have prevented the formation of a pressure ulcer. Helen's story provides an example of this type of tacit knowledge. Helen was a 57-year-old grandmother at the time of her study participation, and she had her SCI since she was in her early 20s. She described knowing, in a tacit way, when her body position could contribute to the formation of pressure ulcers. In one exchange, Helen talked about how she had previously developed "blisters" (possibly stage 2 pressure ulcers) as a result of incorrect positioning in her wheelchair and an associated sense of discomfort. She then described a more recent episode in which she recognized the discomfort associated with incorrect positioning:

> Helen: Like yesterday when I was sitting, I was too far to the right…. [Y]ou know [after] so many years in the chair you know what's going on.

Helen's many years in a wheelchair gave her the experience to realize when her positioning put her at risk of developing a pressure ulcer and to know what she needed to do to reduce this risk.

Chris, the participant who initially did not want a reclining chair because of the way it looked, later became convinced that the unwanted chair placed him at an increased risk of pressure ulcer development. During the study, he developed a pressure ulcer and explicitly stated his belief that it was caused by the wheelchair:

> Chris: [It's] happening again [an ulcer developing]. I think it's the recliner chair. I think I need to be in my [old] chair. I didn't have a problem when I was in that

> [previous] chair, but then you put me in a… recliner and then all of a sudden I break down. Why?

Chris had been ambivalent about the new wheelchair from the beginning. Although both Helen and Chris knew what they needed, the outcomes were very different. While Helen trusted her instincts and articulated her needs, Chris overrode his instincts in a rush to reach a decision about his wheelchair.

Adapting to a new wheelchair—The study participants often took several months to become accustomed to a new wheelchair and integrate it fully into their daily routines. In some cases, initial concerns about the new equipment were well-founded. In other cases, repeated use of the wheelchair made participants aware of the benefits and disadvantages of the new wheelchair.

After Chris developed a pressure ulcer because of an ill-fitting wheelchair, hospital personnel ordered a new one for him. Although he was not convinced that this new wheelchair was going to prevent future ulcers, he complied with the therapist’s selection. After receiving his new wheelchair, Chris continued to feel ambivalent about it.

> Chris: They said it [the new wheelchair] was the newest thing out. So I said, Okay. I have to be in one [a wheelchair], I’ll take that one. But I’m going to go home and I’m going to get back in my old one.

He took the wheelchair home and took some time to adjust his movements to the new equipment. Eventually, he became accustomed to the new wheelchair:

> Chris: Because … after adjusting to the change, now I don’t want to get [out of the new chair], because I notice the ride was a lot better, the suspension is phenomenal on this thing, it’s like car suspension. And I don’t bounce around in this chair like that one.… [I go] over bumps and I just keep going. I don’t have to stop to readjust my whole body.

In this instance, Chris did not initially appreciate the benefits of his new wheelchair, but he eventually grew comfortable with it and recognized its positive value. The new wheelchair’s improved suspension helped mitigate Chris’s pressure ulcer risk by maintaining him in an appropriate position. He needed time to let go of his attachment to his previous wheelchair and transition to his new, more technologically advanced wheelchair.

Integrating the wheelchair into daily life

Once the participant had selected and accepted the wheelchair, there were two main types of risk that contributed to the formation of pressure ulcers: lifestyle factors and problems related to the context in which participants found themselves. The specific lifestyle factors we are concerned with in this section include instances in which participants needed to make ongoing decisions about whether to focus on adhering to their pressure ulcer prevention routines or becoming fully engaged in significant, meaningful activities. At times, participants knew how to decrease their pressure ulcer risk but chose to ignore it for a more satisfying life. This category of risk also included making adjustments to the wheelchair to make it better fit the participants’ personalities, their functional use during daily activities, or their comfort. The second category, problems relating to context, included episodes related to specific challenging situations such as being placed in a nursing home, becoming homeless, experiencing major traveling delays, or spending time in jail.

Lifestyle factor: wheelchair adjustments—The participants performed a number of adjustments to their wheelchairs and other equipment. These adjustments were seldom identified by health care providers and created daily potential risk episodes. Some of these adjustments were harmless, for example, placing a license plate in the back of the wheelchair, decorating the wheelchair, or adding Velcro to an armrest for attaching a cell phone. Other adjustments were more insidious and created risks for pressure ulcers. Ken's story provides an example of a wheelchair cushion adjustment that resulted in a pressure ulcer. Ken immigrated to the United States from Cuba when he was a teenager and quickly became involved in gang activities. He incurred his SCI as a result of receiving a gunshot wound when he was 23 years old. When it was time to change his cushion, Ken disregarded his therapist's advice to have the wheelchair cushion cut in the clinic. Despite being fully aware of the therapist's recommendation, he decided to have his mother cut the cushion at home instead. He developed a pressure ulcer as a result of this adjustment.

In other situations, the participants were unhappy with their wheelchair, either because it was not the wheelchair they had ordered or because they wanted the wheelchair to better reflect their personality and fit their lifestyle. Steve, who spent a great deal of time socializing with his friends, wanted to lower his wheelchair to give it a sleeker appearance. He proceeded to lower the back wheels but was unable to lower the front ones, leaving the seat uneven. The following excerpt illustrates that point:

> Steve: No, see? I lowered the rod. I lowered the wheels. …So, I brought it up to make it lower, but it went lower from the back and the front stayed the same, so I have to figure out how to lower the front so they'll even out.

In this case, after the interviewer pointed out that sitting on an uneven surface could contribute to the formation of a pressure ulcer, Steve realized that his wheelchair adjustments had been a bad choice. At that point, however, the adjustments were irreversible.

Lifestyle factor: unusual wheelchair uses—To incorporate the wheelchair into their lifestyle, participants also used the wheelchairs in unusual ways. For example, some participants would sleep in the wheelchair and others would use the wheelchair as a substitute car to travel long distances. Participants often used their reclining wheelchairs to take a nap. Many of them depended on other people for their transfers, and even with help transfers were long and difficult. Because participants often stayed all day in their wheelchairs, they would commonly use them as makeshift beds, reclining for longer periods of time than necessary to relieve pressure from sitting. These prolonged periods of reclining often led to naps or long periods of sleep. While bottom cushions are designed to support the full weight of the body while in a seated position, back cushions are thinner and do not provide adequate full body weight relief for prolonged periods of reclining. As a result, the participants increased the risk of developing an ulcer on the back and the vulnerable sacrum/coccyx area.

On other occasions, participants could not use public transportation due to either lack of money or lack of appropriate transportation available to transport a wheelchair. As an alternative, they would occasionally choose to ride their chair for long distances, exposing themselves to significant pressure ulcer risk. Charlie, who was mentioned previously, used his power wheelchair as a means of transportation when he did not have money for the bus, sometimes travelling several miles.

Like Charlie, Brenda also used her wheelchair as an alternative to a car. Brenda was a 47-year-old woman who struggled to maintain a positive outlook on life despite multiple hospitalizations due to medical complications of her SCI. In discussing her criteria for choosing whether to use a manual or a powered wheelchair, Brenda noted that:

> Brenda: If you are going to walk a long distance, instead of having someone to walk me, I can… power myself. You can charge [the chair] up… [and] it will go 10 miles off of one charge, when it is fully charged. So you know you can go a long ways if I have enough power.

As even the most highly powered wheelchairs are not able to travel at speeds comparable to those of a car, such extended journeys would entail the person remaining in the chair for a dangerously long time, in addition to the other multiple dangers such a trip would likely involve.

Lifestyle factor: trading health for full participation—Often participants pushed the boundaries of what was safe, stretching or bending health-related recommendations to meet a goal, participate in social activities, or simply enjoy life more fully. The recommendation most frequently stretched in this way related to the amount of time participants would spend sitting in the wheelchair.

Bending the rules is especially pertinent in view of the fact that many individuals become injured as young adults. Like many young adults or adolescents, some of the participants tended to underestimate the risks they were taking in order to live in the moment. Many of the participants experienced a conflict between the desire to achieve significant life goals and the need to spend time off of the wheelchair in order to prevent pressure ulcer formation.

One example of bending the rules can be found in Ken’s story. After incurring his SCI, Ken turned his back on his previous gang activities and became committed to his religion and to completing his education. He desperately wanted to finish the semester despite having a pressure ulcer, so he would disregard the doctor’s recommendations in order to stay in class.

> Ken: See, [the doctor] says [I should] recline maybe [every] fifteen minutes. I don’t do it, because I just sit for a long time…one hour, two hours, and then I recline back, and rest about thirty minutes.

Ken’s ulcer worsened as he chose to ignore his medical team’s advice, and he experienced multiple additional pressure ulcers because of his reluctance to cut short his school days to enable proper pressure relief.

Judy, a successful professional with a demanding, office-based job, faced a similar dilemma when a friend came to visit and Judy wanted to make the most of the time they were spending together:

> Judy: A couple of Saturdays ago [my friend] came down and I was at 8 hours [sitting in the wheelchair]…. [W]e were able to throw that [a trip to the store] into the mix, which [was] nice. And that is one of the days I did stretch [my sitting time] a little bit longer than 8 hours. I don’t think it was much more than 9. It was closer to 9 hours. But it wasn’t my usual 12 to14 hours.

Although she was clearly aware of the length of time she was spending in her wheelchair, Judy appeared to have been more focused on “getting things done” than on limiting her sitting time. Her “usual 12 to 14 hours” in the wheelchair far exceeded the recommended sitting time and placed her at risk of pressure ulcer development.

Steve summed up the dilemma of balancing health and life satisfaction succinctly when he described his own situation:

> Steve: Na, I don’t think I’m taking care of myself the way I should be taking care of myself, but I’m living (laughs).

Balancing life satisfaction and the need to limit time spent sitting in the wheelchair was an understandable theme among the participants. It involved participants' pursuit of social and professional activities that allowed them to live a more enjoyable life at the risk of developing pressure ulcers. Teaching individuals with SCI to balance these competing aims in a more deliberate and overt manner could potentially decrease the risk of pressure ulcers.

Malfunctions—Malfunctioning equipment led to risk episodes by increasing stress, confusion, and accidents that heightened the chance of incurring pressure ulcers. For example, such malfunctions contributed to Charlie's pressure ulcer risk. Charlie was a 48-year-old immigrant from Southeast Asia who sustained his SCI as the result of a gunshot wound during a robbery. His electric-powered wheelchair often malfunctioned and would simply stop moving. The wheelchair would only begin working again after he turned the power off and on several times. On one occasion, it quit working while he was in the middle of crossing the street, and he was trapped in the crosswalk when the traffic light changed. In the end, he needed the help of a passing pedestrian to finish crossing the street. After this incident, Charlie often worried about the prospect of his wheelchair malfunctioning and leaving him stranded and dependent on the goodwill of strangers. Understandably, such concerns frequently lead Charlie to limit the range of activities he became involved in, diminishing his quality of life.

At times, participants became aware of malfunctioning equipment when it was too late to prevent an injury. Chris realized one of his back casters had become fixed and unable to pivot only after seeing the back of the chair in the reflection of a window. Because of his tetraplegia, he was unable to look under and behind the chair in order to inspect it properly. A regular equipment inspection by his caregiver could have possibly prevented his subsequent fall.

> Chris: I went to a meeting and I go, "Something's wrong." I went and I looked in the reflection of a window. And I saw my wheel and I would go forward and it wasn't rolling, it wasn't pivoting. It was just dragging. And I was like, "oh, no, that wheel's broke…. Well, I better be aware of that"… So I went out and I was going up my garage that [was when I] went down.

A significant proportion of participants in this study had very limited financial resources. When mechanical problems arose, they resorted to simple, immediate solutions to stay mobile. Their equipment was often in need of repair, adjustment, and cleaning. At times, participants had to improvise in making their own repairs, occasionally using bits of spare wire and makeshift tools to do so. Predictably, these repairs were often far from ideal and resulted in such problems as seating asymmetries and broken footrests. These factors contributed to the development of skin breakdown or worsening of an existing ulcer. The same participants spent large amounts of time in their wheelchairs, sometimes because they were homeless or because they lacked reliable caregiver support to return to bed when needed. The combination of malfunctioning wheelchairs and extended periods of time spent in them created a major liability, particularly for those participants with lower socioeconomic status.

Unplanned situations—The wheelchairs became essential parts of the person when they were trapped in unplanned or undesirable situations. In those cases, the role of the wheelchair as an essential part of the person helped the participant deal with the event. The situations identified in this study included being stranded at an airport, being homeless, living in a nursing home, or being in jail. Because of safety issues, it was evident in some cases that separating from the wheelchair was not a choice. Robert, a 45-year-old man, traveled frequently. On one trip, he was stranded in an airport for 12 straight hours.

> Robert: And I stayed in one airport for twelve hours, and I slept maybe six or seven hours in one position, and that's not good…. That has a lot to do with it [the pressure ulcer].

Robert had other choices available to him, such as asking for assistance, but he decided that sleeping in the wheelchair was the most comfortable and convenient option for him at that particular time. As a result of this decision, he developed a pressure ulcer. Robert also stayed in a nursing home for a few months. While living there, he would frequently become bored and use his wheelchair to "wander" around the surrounding neighborhood. He stated:

> Robert: I couldn't stay in the nursing home all day, and [be around] nothing but old people. And there [were] three young guys there, and we stayed going all day, stayed riding all day…. All I did was spend the night in that place. In the day time, I'd take my medication with me and I'd be gone all day.

Partly as a result of his wanderings, Robert developed a pressure ulcer.

Wheelchairs also functioned as living spaces, particularly when the participants were homeless or in jail. Charlie lived on the streets for a number of weeks, and during that time he was mugged and had his cushion stolen. While he was homeless, he lived in constant fear that his wheelchair would also be stolen. The fear of having his means of transportation taken from him, and the need to have a place to sleep, led Charlie to use his wheelchair as a personal living space. Like Charlie, Steve also experienced frequent periods of homelessness, and when he could not sleep on one of his friends' sofas he would simply sleep in his wheelchair. During these periods of homelessness, he was in his wheelchair 24 hours a day. In Steve's case, he would even spend nights with his girlfriend sleeping on his lap, further increasing the pressure on his buttocks. The combination of using the wheelchair for sleeping long hours and the lack of hygiene created the ideal conditions for the development of a pressure ulcer and a consequent infection.

Discussion

Recently, researchers have shifted focus away from identifying isolated risk factors, attempting instead to discover patterns of factors associated with pressure ulcer development.[3,4] These lines of research suggest that rather than studying the number of weight shifts and skin checks performed by those with SCI, further developing our knowledge about other risk factors, such as sleeping in or living in the wheelchair, and passing this information on to consumers may prove to be a more effective prevention strategy. These researchers suggest that a greater understanding of the lifestyles of individuals with SCI may play an important role in designing more effective pressure ulcer prevention interventions.

This study offers evidence that, despite the attention provided in acute care settings when ordering a wheelchair for individuals with SCI, there are many lifestyle factors that need to be considered to minimize development of pressure ulcers. Individuals with SCI continue pursuing their significant life goals and in this quest encounter ongoing challenges to which they need to adjust. However, in the case of the person with SCI who is prone to the development of pressure ulcers, the wheelchair functions as an integral part of their lives. As such, the wheelchair can either empower the individual to attain a sense of greater accomplishment and well-being or act as a hindrance that will limit their achievements and possibly further damage their health.

In the analysis of the individuals' stories, it became apparent that because of the time participants spent in them, the wheelchair functioned more as a living space that was occupied day in and day out rather than simply as a means of transportation. As such, the wheelchair became a part of who the participants were, a representation of their identity, and both a place of comfort and a potential liability. Wheelchairs acted as buffers and liabilities in the lives of individuals with SCI. Wheelchairs acted as buffers when the individuals and the wheelchairs were well-matched, as in the last wheelchair ordered for Chris, and they acted as liabilities when used in ways that created risks of pressure ulcers that contributed poor health.

The participants' stories illustrate some important points on the relationship between the use of wheelchairs and pressure ulcer risk. First, it is important to view wheelchair use from the consumer's perspective as well as from the professional's concerns. For example, the possibility that wheelchairs will be used for sleeping in, traveling long distances, or as makeshift living spaces needs to be considered when establishing the risk of pressure ulcer development for a person with SCI. Such a position is in full agreement with Chaves and Boninger's21 assertion that the input of the wheelchair user and full consideration of the discharge context is crucial for the right wheelchair-person fit. Second, the constellation of risk factors that are embedded within an individual's lifestyle must be considered when ordering a wheelchair. Finally, it is vital that wheelchair users understand the importance of proper wheelchair maintenance and repair and that they have access to appropriate resources for these purposes; there is significant scope for health care providers to assist in this task.

Conclusion

Individuals with SCI enjoy the freedoms that new technologically sophisticated wheelchairs and their accessories afford them. At the same time, they must face the constant risk of developing pressure ulcers while using wheelchairs. In this study, we examined the relationship between wheelchair use and the development of pressure ulcers. Analyzing the stories of 20 individuals, we examined pressure ulcer risk in relation to wheelchair use. These incidents were associated with problems related to wheelchair selection, adjustment, habituation to new equipment, lifestyle choices, and challenging life contexts.

Pressure ulcers are generally viewed as stemming from a failure; this may be a failure of the individual to adhere to medical advice, failure of health care providers in their care of patients, or failure of equipment to adequately protect the person with SCI. Undoubtedly, each of these types of failures was present in the data we examined. However, we would also argue that the data suggest that pressure ulcers often emerge even in the absence of such gross failures, when a series of steps in the rehabilitation process appear to have been successfully navigated. Specifically, although wheelchairs are selected and equipped with a view to minimizing the person's risk of pressure ulcer development, they may become a liability when used in the context of the person's life.

The limitations of the study lie in the fact that it is based on a limited number of participants who were selected nonrandomly and who were at the high end of the pressure ulcer risk spectrum. Additionally, the study is limited by its reliance on self-report; what participants thought was the cause of their pressure ulcers may not have been the true cause. Nevertheless, the findings point to the significant role of equipment use in the formation of pressure ulcers and importance of considering lifestyle issues when ordering equipment. In the future, these findings should be included in the intervention process. The next challenge is to find ways to collaborate with individuals with SCI to help them use their equipment in a way that contributes to building successful routines and habits and allows full participation in life.

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Table 1

Participant demographics

Pseudonym	Gender	Ethnicity	Age at study commencement	Age at injury	Level of injury	Complete/incomplete	Education (highest level)	Wheelchair
Aaron	M	AA	43	19	L3	I	Some HS	Manual
Alley	F	C	77	44	T5	Com	Col	Power
Alma	F	C	37	5	C1	Com	Col	Power
Billy	M	H	30	21	T10	Com	HS	Manual
Brenda	**F**	**AA**	**47**	**33**	**C7**	**I**	**Some Col**	**Power**
Charlie	**M**	**A**	**49**	**43**	**T10**	Com	**Trade school**	**Power**
Chris	**M**	**C**	**40**	**17**	**C5**	Com	**Col**	**Reclining**
Dave	M	C	43	16	T10/T11	Com	Grad	Manual
Frank	M	AA	31	24	T4	Com	HS	Manual
Gary	**M**	**AA**	**28**	**22**	**T12/L1**	Com	**Some HS**	**Manual**
Helen	**F**	**H**	**57**	**21**	**C5/C6**	Com	**JH**	**Power**
Howard	M	C	62	60	C5	Com	Col	Power
Judy	**F**	**C**	**51**	**43**	**C5**	Com	**Col**	**Tilt-in-space**
Ken	**M**	**H**	**35**	**23**	**C4**	Com	**Some Col**	**Power**
Mitch	M	AA	49	14	C6	Com	Col	Power
Odel	M	AA	46	28	C4	Com	Some Col	Reclining
Rachel	F	AA	28	27	C5/C6	Com	Some Col	Power
Robert	**M**	**AA**	**45**	**39**	**C7**	**I**	**Some Col**	**Tilt-in-space**
Steve	**M**	**H**	**33**	**30**	**T8**	Com	**Some HS**	**Manual**
Tom	M	H	41	31	T6	Com	HS	Manual

Note: Participants listed in bold type are discussed in the current analysis. M= male; F = female; AA = African American; A = Asian/Pacific Islander; C = Caucasian/not Hispanic; H = Hispanic/Latino; Com = complete; I = incomplete; JH = junior high; HS = high school; Col = college or university; Grad = graduate degree.

Table 2

Wheelchair-related change events and associated risks

Selecting the wheelchair	
Change event	***Potential risks***
Initial selection	Clinician's wheelchair selection is in conflict with participant's needs and/or wants
Tacit knowledge	Participant's tacit knowledge about his or her needs may or may not be communicated to person ordering the wheelchair
Adapting to a new wheelchair	Participants may need a period of time to adjust to a new wheelchair
Integrating the wheelchair into daily life	
Change event	***Potential risks***
Lifestyle factor: wheelchair adjustments	Participant making adjustments that change the seating dynamics
Lifestyle factor: unusual uses	Using wheelchairs for purposes they were not designed for
Lifestyle factor: trading health for enjoying full participation	Staying long hours in the wheelchair to accomplish goals
Malfunctions	Malfunctioning equipment may directly or indirectly increase pressure ulcer risk
Problems in context	Using the wheelchair in novel environments