



Article

The Perceived Role of Healthcare Providers and Systems in the Development of Secondary Health Conditions among Adults with Spinal Cord Injury

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Abstract: Individuals with spinal cord injury (SCI), with high healthcare utilization rates and costs, require special attention and tailored care protocols to meet their healthcare needs. This qualitative study collected narrative information from adults with SCI and their family members and/or caregivers to examine the perceived role of healthcare providers and systems in the development and treatment of secondary health conditions (SHCs). After personal information was collected, individuals participated in focus groups which were recorded and transcribed; transcripts were then reviewed, cleaned, and uploaded to NVivo10 software to facilitate the analysis. An initial stage of coding was conducted which identified potential categories and themes; afterwards, the perceived role of healthcare providers in the development and management of secondary health conditions (SHC) was prioritized and transcripts were re-coded. Two overlapping themes emerged: (1) Iatrogenic and nosocomial factors; and (2) Relationships with healthcare providers. Iatrogenic and nosocomial factors had three subthemes: (1) Misdiagnosis; (2) Perceived mistreatment or mistakes made during treatment; and (3) Unintended consequences of medical treatment; while three subthemes were identified for Relationships with healthcare providers: (1) Respect; (2) Knowledge and experience; and (3) Patient Expertise. To improve safety, reduce healthcare costs, and facilitate more favorable perceived outcomes for individuals with SCI, healthcare providers, organizations and systems need to implement principles of high reliability organizations to improve outcomes through the treatment and prevention of SHC.

Keywords: spinal cord injury; secondary health conditions; high reliability; quality of care; veterans



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1. Introduction

Increasingly, healthcare organizations are seeking to improve the safety of both patients and employees by adopting the models and principles of high reliability organizations (HROs) [1]. HROs defines organizations that have created environments and consistent systems to both accomplish their goals and avoid potentially catastrophic errors [1]. While a full explanation of HROs is beyond the scope of this paper, in brief, high reliability healthcare (HRHC) hospitals and systems reflect consistent characteristics and develop training, processes and environments to optimize patient safety and ensure the best possible care to each patient at each interaction [2,3]. Optimizing safety is a way of improving the healthcare experience of those seeking care and improving the perceptions of the quality of the healthcare system. This may be particularly challenging when working with individuals with low prevalence, but high impact conditions, where HROs may lack the experience and particular knowledge needed to optimize outcomes.

Spinal cord injury (SCI) is a complex neurological condition that both mirrors the characteristics of HRHC systems and represents a diagnosis that requires consistent training

and standardized processes by both individuals and systems in order to avoid potentially catastrophic errors. Maintaining health with SCI requires constant vigilance to avoid secondary health conditions (SHC), which may occur at any time after SCI onset, develop quickly, and have life-changing consequences. The best health management reflects a partnership between individuals with SCI, caregivers and healthcare providers working in both outpatient practices and within hospital and healthcare systems [4,5]. Moreover, because of the high rates of hospitalization among adults with SCI, and the associated high costs for those stays, it is critical to integrate or provide mechanisms to incorporate training and standardized processes into the operational practices of healthcare systems [4].

While the incidence of traumatic SCI is just 54 per million people in the United States each year [6], the costs associated with living with SCI are high and vary based on age at injury, severity of injury and life expectancy. For instance, published estimates range from \$1.2 million in terms of lifetime costs for a 50-year-old with level D SCI to \$5.1 million for a 20-year-old with high level (C1–4) tetraplegia (AIS ABC) [6]. Higher costs are related to higher injury levels, more frequent SHC, and associated increases in urgent, non-planned healthcare utilization, particularly hospitalizations [6]. In fact, one study in which administrative billing data were used found that 69% of the costs of hospitalizations and emergency department (ED) visits were incurred by only 16.5% of the participants [7].

Additionally, the most common SHCs after SCI require medical treatment or hospitalization that incur expenses and may contribute to further health problems [8]. Research studies have found that between 18–59% of persons with chronic SCI are hospitalized one or more times in any given year [9,10] with lengths of stay and associated costs corresponding to the severity of condition. Of note, one 2011 study found that adults with SCI hospitalized for skin conditions spent an average of 19.8 days in the hospital and reported an average charge of \$75,872; those hospitalized for UTIs had an average length of stay of 7.3 days and an average charge of \$24,007 [9]. These findings underscore the importance of high-quality healthcare and creating an environment where people seek out high-quality services both for the treatment and prevention of future complications.

Despite the high rates of SHC and hospitalization among adults with SCI, it appears that relatively few systems have been established—outside of SCI Medicine—to manage the health of these highly complex patients. As such, adults with SCI who are discharged from the rehabilitative or specialty hospital and return to the community for care by primary care providers and home healthcare agencies many wind up at EDs and find themselves re-hospitalized in non-rehabilitation units. Here, they meet with clinicians and systems that are often not trained to manage their specific concerns and do not have processes in place to proactively manage their health. It is this lack of training and the absence of established processes, then, which could potentially lead to the development of SHC or more catastrophic events.

Unfortunately, while the side effects of medication and SHC of SCI is well documented within the field of SCI Medicine [8,11], relatively little research is available which examines the role of providers and systems-level factors that can influence their development and the results rarely connect the development of SHC to modifiable actions of providers and health systems.

Our purpose was to examine the role of health care providers and systems in the development of SHCs after SCI as perceived by adults with SCI or by a family member or caregiver. Therefore, we investigated the experiences of those with SCI and their perceptions of the role of healthcare in determining their health outcomes. Data were extracted from a larger qualitative project designed to enhance the understanding of the factors associated with the rapid development of multiple SHCs from the perspective of those with SCI. Both this study and the larger project seek to inform the development of intervention strategies as well as the decision-making and systemic changes that are needed to reduce the occurrence of SHC and to improve the experiences of people with SCI with the healthcare delivery system.

2. Materials and Methods

Participants consisted of adults with SCI in the United States, their families, and caregivers. Eligibility criteria were as follows: (1) traumatic SCI with residual impairment, (2) 18 or older, (3) minimum of 2 years post-injury, (4) wheelchair as the primary mode of mobility, and (5) significant recent history of health problems, defined as endorsement of a minimum of two SHCs or a combination of at least one SHC and at least one treatment indicator (e.g., hospitalization or physician visit). After receiving Institutional Review Board approval, civilians and veterans with SCI were recruited through research registries and membership lists of the primary investigator and Paralyzed Veterans of America (PVA), an organization serving veterans with spinal cord injury and disease (SCI/D). Participants were asked to identify a family member or caregiver who was familiar with their SCI complications and who may be willing to participate. Participants were offered remuneration for their participation (\$75 for interviews, which were not part of the current analysis; \$250 for in-person focus groups; \$125 for virtual groups). For this study, data consisted of narratives from twelve focus groups of adults with SCI ($n = 44$) and three focus groups of family members or caregivers ($n = 10$). The majority of participants were male (70.5%; Table 1) and white non-Hispanic (63.6%). The average age was 57 years, with an average of 25 years having passed since SCI onset. The majority of participants had thoracic injuries (46.5%, followed by low cervical (C5–C8; 30.2%), and high cervical (C1–C4; 16.3%). Detailed demographic data for caregivers/family members are not available.

Table 1. Demographic and injury related characteristics of adults with SCI (spinal cord injury).

	Participants with SCI $n = 44$
Sex	
Male	70.5
Female	29.5
Race/ethnicity	
Non-Hispanic White	63.6
Non-Hispanic Black	27.3
More than one race	9.1
Injury severity	
C1–C4	16.3
C5–C8	30.2
Thoracic	46.5
Lumbar	7.0
Age (Mean% (SD))	57 (12.2)
Years since injury onset (Mean% (SD))	25 (11.5)

Informed consent was obtained prior to participation. Focus group protocols consisted of semi-structured questions and follow-up prompts designed to gather participant perspectives on the history and sequence of SHC and factors associated with the improvement or spiraling of the SHC. Questions were developed based on a literature review and input from individuals with SCI and their families. The focus of the global study was the development of SHC. The topics covered included: (1) health status and course of change over time, (2) SHCs, including occurrence of multiple SHCs, (3) health behaviors, such as routine behaviors done to prevent SHCs and maintain health, (4) psychological factors, including characteristics that may affect approach to prevention and treatment of SHCs, and (5) socio-environmental factors, such as socioeconomic status and physical environment. While specific areas associated with the development of SHC were suggested, participants were encouraged to identify and discuss factors that influenced their health, leading to the observed findings regarding perceptions of the healthcare system. Of note, this study only focused on the responses associated with healthcare systems and providers and their relationship to SHC.

Focus groups were professionally transcribed then reviewed, cleaned and uploaded to NVivo qualitative software. All coding, initial and in depth, was conducted using NVivo software (Version 10) (QSR International: Burlington, MA, USA). Initial coding, conducted in the manner described by Charmaz [12], was broad and inductive, driven by the data rather than any preexisting ideas or coding frameworks. Potential categories and themes were discussed among project investigators, resulting in the role of healthcare providers in the development and management of secondary health conditions being prioritized. All transcripts were then re-coded (MM and KR). The analysis drew on the work of Braun and Clarke's reflexive thematic analysis approach, which supports attending to people's views and experiences and the examination of data that are richly detailed and nuanced [13]. Coding was conducted separately by two investigators. The process of analysis was iterative and continually evolved. It moved between the identification of codes and patterns in the data and the development of themes and sub-themes and the sorting of associated narratives [13]. Themes, categories, and interpretations were rigorously discussed, developed, and revised until a consensus was achieved. Findings and interpretations were discussed among the research team and reconsidered as needed. All participant names have been changed to aliases to protect the confidentiality and identity of the participants.

3. Results

This study examined the role of health care providers and systems in the development of SHCs after SCI as perceived by adults with SCI and their family members or caregivers. The following two overlapping themes emerged from the qualitative analysis of focus group narratives: (1) Iatrogenic and nosocomial factors; and (2) Relationships with providers. Iatrogenic and nosocomial factors had the following three subthemes: (1) Misdiagnosis; (2) Perceived mistreatment or mistakes made during treatment; and (3) Unintended consequences of medical treatment; while the following three subthemes were identified for Relationships with providers: (1) Respect; (2) Knowledge and experience; and (3) Patient Expertise. In the following, a distillation of representative participant perspectives related to each theme is presented.

3.1. Theme 1: Iatrogenic and Nosocomial Factors

Iatrogenic events are diseases, disorders, or symptoms inadvertently induced by a healthcare provider, diagnostic procedures, or medical treatment. In contrast, nosocomial conditions are infections and other health conditions acquired during hospital stays. In their narratives, both participants and caregivers clearly discussed their perceptions that healthcare providers, systems, and procedures were a cause of the SHC and associated negative consequences. Responses were grouped into the following three subthemes: misdiagnosis; mistreatment; and unintended consequences of treatment.

3.1.1. Subtheme 1A: Misdiagnosis

Narratives within the subtheme of misdiagnosis included participant descriptions about a failure to properly assess and identify the cause of a symptom or problem. One participant explained how numerous doctors failed to test for medical conditions and relied on the participant to supply that information.

Wesley: I guess when they trying and look in my foot, they would say, "Are you diabetic?" I say, "No." And I guess that's why 'cause the wound wouldn't heal. So every doctor I went to, how long have you had this wound? And then the next one say, "Are you a diabetic?" I say, "No."

Facilitator: And they keep testing you for it?

Wesley: I don't even think I have been tested for it.

For one participant, misdiagnosis led to potentially life-threatening complications.

Shane: *Well, my local doctors kept telling me I was constipated. But there was a massive abscess growing in my colon . . . And it ruptured one day in class when I was at college . . . And nearly bled out.*

Facilitator: *Misdiagnosis?*

Shane: *Yeah. I mean, I went to three doctors and they all told me the same thing. None of them took an X-ray.*

Leroy: *Were they specialists?*

Shane: *They wouldn't send me to a specialist.*

3.1.2. Subtheme 1B: Perceived Mistreatment or Mistakes Made during Treatment

For this theme, participant narratives alluded to the neglectful behavior of healthcare providers—including home caregivers—and its relationship to SHC. Examples of this subtheme included dropping patients and not performing necessary therapies or assistance, including failing to turn patients when hospitalized. A representative example of narratives under this subtheme (below) was provided by a participant with SCI who described how medical professions did not listen to his/her concerns about the improper use of equipment, which ultimately led to a more severe problem.

Wesley: *I had an issue . . . Well, a nurse was coming out to put a wound bag on my foot. So, she came, she put the wound bag on and kind of explained to me, how this thing is supposed to work. It was some type of sponge, like inside the wound with the . . . It's supposed to, basically, suck out the moisture, basically. So, of course, I can hear the thing pumping, and I'm looking at my foot, and I could see it's not draining through the thing . . .*

So, of course, I mentioned it to them and they said, Well, the nurse, she knows what she's doing, or whatever. So, of course, I didn't mess with her, so every time she would come change it, the foot would look worse . . . And I would try to tell them that, you know . . .

So, . . . when the doctor seen it . . . Of course, my baby toe, it gots to go. I guess the doctor was going to get something to, cut out the baby toe. And he looked at it, and he just started pulling on it and he just pulled it off. . . . he just pulled it off with his hand. He didn't even cut it. But then, the fact is, if she would've came out there and that wound bag was properly done, it wouldn't even had an issue. I had an issue on the bottom of my feet, but now I got an issue on the bottom and the top, now, because of the wound bag.

Another participant explained how he received mistreatment from multiple doctors.

Wayne: *I had that problem, but I went to three urologists before I found the one to help. The first one, he did a . . . What you call it? Microwave treatment on me, and he just . . . He really screwed me up.*

Ruben: *Microwave?*

Wayne: *What they do is they shrink your prostate. And it's sort of like a heat treatment. And after the treatment, I kept getting blockages. You're sitting there and you full, your bladder's full of stones. You keep telling me that it's gonna come out and then you gotta be catheterized and . . .*

He did a surgery on me, trying to open me up, and that didn't work. So then I wound up going to another urologist. He wanted to put a bag on me. And my son told them, "No, we're not going that route". So then I went to the third urologist. Then he went in and did some treatment on it. And then he did a MRI, and they found out that my spleen and my pancreas . . . They had to remove part of my pancreas and my spleen.

3.1.3. Subtheme 1C: Unintended Consequences of Medical Treatment

The third subtheme was unintended consequences of medical treatment. While the most frequent responses in this area were associated with the negative side effects of

prescription medication (including opioid medications), other negative impacts included consequences of hospitalization, including MRSA, pressure sores, and infections. As one participant stated:

Harry: . . . a lot of things that I've learned that some of the medications that we take for a long period of time could cause secondary problems from that. So, a lot of medication I just stopped taking once they said, Well, you know if you take this for a long time, this could damage your kidneys. So, I said, Okay, well, let's just stop taking that, then, because my spasms is not that bad where I'm gonna take a chance on damaging my kidneys. So, let's stop taking it. The same thing with ibuprofen; I was taking that for pain. I had a shoulder issue. Of course, taking that for a long period of time will cause problems, so, they changed that.

Similar sentiment was echoed by another participant with SCI who discussed difficulties with stopping certain medications.

Sheryl: Once I left there and came home, the biggest thing I had to contend with on top of the limited movement was the constipation from the prescriptions they, the medication they gave me while I was in. Through the IV and of course you come home with these gigantic horse antibiotic pills. I'm getting over pneumonia now just dealing with the constipation which is always a problem. I really, I know the medication is probably helping, but I always feel this dread that I know when it's over the constipation is back.

Infections related to treatments or medical devices were mentioned by several participants. One shared the following statement:

Festus: And then I couldn't get my urination under control, so I was using a catheter there and finally I decided I'd go in for a suprapubic and I went in and they put the first one in, but once you know I got another infection, so the doctors did a second suprapubic and once you know before I left the hospital I was running a fever and I had gotten an infection again and this was a second tier infection and I don't know how they rate them, but when they first started giving me the antibiotics it wasn't the right one, so they had to turn-around and keep me even longer.

Additionally related to infections, participants shared concerns about the potential for nosocomial or hospital-acquired infections.

Shaun: About six years ago in 2011 I was diagnosed with MRSA due to open sores and I also had strep and a couple of other unknown bacteria that caused major infection, where I had to get most of my pelvis and both legs amputated to spread everything from spreading and death. . . .

Louis: Was that hospital born MRSA and some of the other infections?

Shaun: I believe so. It had to do with all the open surgeries I've had. It started it as an open sore on my backside that would heal and go away, I've had skin grafts and about twelve to thirteen detriments in both pelvises and it won't go away. Nothing confirming exactly where it's from.

It is worth noting that in each of these cases, the perceptions of what occurred and why it occurred—that is, as a result of factors within the control of providers and healthcare systems—influenced the reactions of participants and created a fear of being treated. Whether or not the healthcare provider or system is actually at fault does not change this.

3.2. Theme 2: Relationships with Providers

The second overlapping theme was Relationships with healthcare providers. Narratives associated with this theme reflected both positive and negative experiences and their associations with the development of SHC and included three subthemes: respect, knowledge and experience, and patient expertise.

3.2.1. Subtheme 2A: Respect

A common topic that was brought up by both adults with SCI and caregivers was respect. Respectful relationships were characterized by feelings of being listened to and whether providers were invested in the long-term health and quality of life of patients. In contrast, both the patients and caregivers participating in this project expressed feelings of betrayal and spoke to the negative consequences that arose when they and their experience were ignored.

Family member: . . . for us over the years I think we've learned to be more, to insert ourselves more into the conversation. I guess we certainly want to hear what they have to say, but we also believe sometimes that we need to be heard as well., certainly we just started them the majority of the time because they are the professionals and they, they should know that . . . the time that sticks out in my mind where my husband where the doctors wouldn't listen to me., it was when he was going in for kidney stone surgery evolving. And I explained to them that they should not put my husband on his stomach because he cannot breathe when he's laying on his stomach. And they basically said, oh, you Ms. [name removed]. You know, we know what we're doing . . . it'll be fine. Don't worry. Well, they did put him on his stomach, did they, before the surgery where they inserted a drainage tube and she came out in retrospect, he was definitely in shock, you know, because he was just looking to just was freezing. And he said to me, I am, I can't, you know, I just want, I just can't breathe. I don't know what's going on. He was breathing. But long story short, you had the surgery the next day and six months later he was discharged from the hospital after coding twice and left with a drain that he did not go in with. Oh, I know. It was just, it was just a series of episodes that happened after that. And a large part of it was just not listening.

A key element of respect was listening to patients and their families. While with individual providers in outpatient settings, there are opportunities to make choices and find new physicians, the same choices do not exist in inpatient settings and patients and families have to manage and communicate with whoever is on call.

Bethany: I have my regular MD. She's my regular doctor, my primary doctor, is awesome. She's the one that stepped up to the box in life and said I'm not giving you anymore of these pain pills, there's gotta be an alternative route around it, you're only 38 years old and you keep this up and you won't have a liver, you won't have kidneys and that will function when you're 60 years old.

Facilitator: But it sounds like she did it with respect- with the sense of not blaming you, not saying your being, that you're just here to be pill sinking, but that we are addressing [crosstalk 01:06:05].

Bethany: Very respectful, very respectful in a very professional way at, if she had moved to the other side of the world and kept her practice open? I would follow her to the end of the Earth until- She's awesome. She actually cares, the same doctor that when I go in for any kind of hospitalization, she sees her patients every day in the hospital, regardless where they are, to where I know it's rare. That, a lot of physicians don't care. I don't believe about their patients as much as a piece of paper, or she sees you as a human being, and respects that, that's what you are, and tries to conduct personal, at a personal level of respect and honesty. That, without her I'd probably still be pushing pills every day and not seeing the other alternatives in life to pain relief and healthy living.

It should also be noted that respectful relationships appeared to correspond with the willingness of participants with SCI to follow recommendations and make behavioral changes. This is illustrated in the narrative provided below from a female with SCI.

Bethany: I do work with my doctor. He had texted my . . . it's a diabetic index number. I don't know what it's called, but my index number was 6.6. He said, "That's a little high. You've opened up the door of heading towards getting diabetes."

Facilitator: *The A1c?*

Bethany: *Yeah, the A1c level, that's right. I immediately made changes to the type of bread that I ate, things with more complex carbohydrates. I still drink diet soda. I switched from regular soda with sugar in it to diet soda. My numbers came down pretty quickly.*

3.2.2. Subtheme 2B: Knowledge and Experience

The knowledge and experience of providers and systems in working with and treating individuals with SCI was consistently identified by participants. Comments ranged from finding the right specialist to the importance of educating new providers about SCI in how to work with them. This later perspective can be seen in comments such as “*New doctors, you have to teach them more.*” Other representative statements include:

Facilitator: *Have you felt that you've been treated differently or that doctors have not known how to treat you?*

Camille: *Yeah, especially when you go to the ER They just they don't know . . . you really need a specialist, 'cause they don't know . . . or I don't know. I don't know how to put it in words.*

Of course, this is not always the case.

Helen: *No. They don't treat me any different than they do other patients. Every time I've had to go to the hospital, the ambulance guy that was in there with me called in and said however old I was at the time, a quadriplegic that tends to bleed, and everybody has always just treated me well in the emergency room. Last year when I had to go and stay, those few days that I had slow blood, all the nurses and everybody just . . . I don't have any complaints at all.*

The comments of other participants helped to identify the importance of knowledge about health management after SCI when interacting with other elements of the healthcare system and not necessarily with the physician.

Benny: *It really is the nurses . . . the nurses that come to see you from the nursing agency. Because they're the gateway to the doctor. If you get good, decent nursing, they can explain to the doctor if they doctor's not knowledgeable. And the nurses are good enough.*

Finally, many participants spoke to the importance they place on regularly connecting with an SCI specialist in order to appropriately manage their health.

Albert: *Getting to the specific care that you're talking about. Spinal cord injuries is a specific injury. A lot of health care providers, they might have general knowledge but a lot of your health care . . . it's important that you see a health care provider, I think, that's specifically for spinal cord injuries like [redacted], at least once a year. So that you can stay calibrated.*

3.2.3. Subtheme 2C: Patient Expertise

Finally, several participants discussed the need to for healthcare providers to recognize their expertise and lived experience. The quotes below are from four different participants but reflect the nuances of this subtheme.

Randy: *Sometimes my doctor, I mean, you tell him one thing, he don't know too much about spinal cord people. I have to go to Atlanta and they know it all down there . . . I tell you if you have a bladder infection, you need to come up there and check. I said, “Look, just call me the pills. I know what I got and what I don't got.” If my pee is real dark, I know I got a bladder infection.*

Benny: *My primary physician, she retired, so I had to switch. But, all my doctors and stuff, they're right in this area. Everybody was in the [same] complex. And as it went on and she retired, I had to switch. But then you have to acclimate your new doctor to what's going on with you. It's all about the conversation. Once I found a new doctor, I*

tell them, Hey, I got a spinal cord injury. This is why I do this. And this part of my body you can't be messing with like you do the left side.

Kaedon: I've had home health before. Some of them I loved because they were open-minded and they didn't try to act like they knew how I felt. But then there were some that I could not stand because they thought that they knew what was best for me, but they had not walked in my shoes, or rolled in them should I say.

Empathy and not acting like they know more than we do since we live with it. Some people have this . . . some people in the health profession have this attitude that the patient doesn't know best but we know our bodies better than we do since we're dealing with the stuff that they're not.

4. Discussion

The management of SCI is complex and requires the coordination of patient health behaviors with the support of knowledgeable care and evidence-based protocols to ensure optimal outcomes and patient safety and satisfaction. Results from this study speak to the importance of healthcare systems and providers creating cultures that respect the experience and expertise of patients and family members while developing the protocols, knowledge, and collaboration needed to prevent iatrogenic and nosocomial conditions.

In the general population [14], iatrogenic events are often drug-related and include adverse drug reactions (e.g., nausea or anaphylaxis), withdrawal or rebound due to sudden drug stoppage, drug-related damage to the organs or central nervous system (e.g., hepatic damage, seizures), and drug-induced psychiatric syndromes (e.g., hallucinations, paranoia). The role of medical professionals in perpetuating iatrogenic events may be related to error or negligence, fear of malpractice, insufficient information on adverse drug effects, over medicalization, and commercialization influenced by pharmaceutical companies [15]. From the perspective of the individual with SCI, these events represent significant setbacks and contribute to a health decline, as indicated by the strong relationship between the onset of SHC and diminished life expectancy [16,17]. It is particularly noteworthy that septicemia is the cause of death with the most significant standardized mortality ratio, in a comparison of people with SCI in relation with the general population [18]. This is particularly relevant because people in the current study raised concerns about iatrogenic causes related to infection and often, perhaps even typically, attributed these to the quality of care.

Of course, the context of these events should not be forgotten. Treating people with SCI can be extremely difficult. Patients rely on medical professionals for improvement in ways that may not be feasible or realistic. Moreover, the nature of SCI is such that symptoms and side effects looked for to diagnose conditions in the general population may be masked. Therefore, a broken bone might not cause pain but may result in increased blood pressure, immobility, spasticity, and even mortality [19,20]. Without either expert knowledge or standardized processes and protocols which prioritize skin checks, catheterization, and x-rays to identify and treat high frequency conditions of pressure ulcers, autonomic dysreflexia and fractures in Emergency Departments, the risks of undiagnosed conditions and severe errors increase. Similarly, protocols that operationalize the health management of individuals with SCI who are hospitalized and provide sufficient staff to maintain schedules of turning, pressure relief, bowel programs and bladder management will be more successful in preventing SHC.

Nosocomial conditions are infections and other health conditions acquired during hospital stays. In the United States, nosocomial infections occur in approximately one of every thirty one hospitalized patients [21]. Due to the high number of procedures and hospital stays, individuals with SCI are at increased risk of exposure to bacteria, viruses, or fungal parasites [22] which can then result in nosocomial infections, including urinary tract infections [23,24], pneumonia [25,26], gastrointestinal infections [27,28], and bloodstream infections [29–31]. Given the high rates of re-hospitalization, hospital-acquired infections, such as MRSA, might be expected in this population; however, this does reduce the importance of recognizing risk and developing processes to reduce or minimize negative

outcomes as well as the need to communicate with patients and their families about such observations.

While some research has identified iatrogenic problems during surgery as a cause of SCI [32], there has been little discussion of how the SHCs of individuals with existing SCI can result from misdiagnosis, inappropriate treatment, and the negative, unintended consequences of medications and other health-related treatments. By collecting the perceptions of adults with SCI and their caregivers about the contribution of iatrogenic factors in the development of SHC for individuals with SCI, this study highlights areas that can be targeted to improve the quality of care and enhance health outcomes for individuals with SCI. That is not to suggest that participant perceptions are fully accurate, but rather that, from the perspective of those with SCI, such events are all too common and have devastating consequences. This further undermines the confidence they have in the healthcare delivery system.

We did not begin this study with the intention of looking at iatrogenic causes, but rather at those factors leading to the development of multiple SHC and the potential of negative health spirals, which were previously defined as the co-occurrence of two or more SHCs, “where health may deteriorate rapidly and result in life threatening or life-changing circumstance” [33]. Nevertheless, these stood out as the primary themes generating a great deal of concern and complications for participants.

This study emphasizes the importance of respectful, patient-provider relationships in which the patient feels listened to and valued. The narratives not only articulate how such relationships promote adherence with medical guidance, a frequent finding in the medical literature [34], but they also speak to the problems that occur when the expertise that individuals with SCI and their families have developed is not taken into consideration in medical decision making.

4.1. Implications

Findings from this study support the need to integrate the principles and key concepts of HROs into the care of individuals with SCI—not just by those working in SCI medicine but by healthcare systems. As implied by the definition, healthcare systems need to be aware of the danger of causing iatrogenic and nosocomial SHCs in individuals with SCI to that they can identify problems in their systems and develop protocols and processes to eliminate severe errors and assist in preventing the development of SHC for adults with SCI.

As such, using the language and key concepts of HROs, this study serves to increase “situational awareness” that will hopefully serve to enhance sensitivity to operations—that is, the degree that errors will be identified and fixed. It aims to reinforce the Reluctance to simplify as SCI is a complex condition that requires a number of teams that are able to develop complex and adaptive systems. Healthcare providers and systems need to recognize and defer to the expertise within the teams that are developed—including the expertise provided by patients and families—and include patients and families as part of the decision-making process. Finally, rehabilitation for patients with SCI works to instill both a preoccupation with failure associated with a lack of health management behaviors and a sense of resilience when creating systems and moving forward, and healthcare providers and systems need to do the same.

More specifically, findings from this study point to several areas needing improvement in the healthcare delivery system while articulating areas of strength. First, consistent care and service delivery are needed. More coherent and structured systems of care for individuals with SCI should be better developed to provide consistency during follow-up, which is required to help avoid and contain the development and spiraling effects of SHCs. Relatedly, specialty services and care providers with significant experience in treating people with SCI are needed. This relates to the continuum and quality of care. Opportunities exist to utilize technology to better prevent and monitor SHC. Engaging the individual in the development and implementation of the treatment plan is necessary. This

requires respect for the individual and providing them with the ability to monitor his/her own health and to make critical observations regarding health status and needs for care.

Individuals with SCI who experience negative health spirals are clearly frustrated with the system of healthcare delivery and their individual experiences. Those with better experiences identify respect as a major factor in the quality of their outcomes. This counterbalances some of the negative experiences that are attributable to iatrogenic and nomothetic conditions. Although the perceptions may reflect different degrees of correspondence with actual contributory causes, many of the issues brought up appeared to be well grounded, given the nature of the adverse health outcomes. Clearly, the findings suggest the need for an improved sensitivity to the needs of those with SCI among a wide array of providers and the need to establish a respectful interaction that considers the experience of people with SCI, their families and personal care assistants. It is noteworthy that the high costs of SCI escalate due to recurrent issues and negative health spirals among a relatively small portion of people with SCI. For instance, the aforementioned research based on actual billing data indicated that 69% of health care costs from ED visits and hospitalizations were incurred by only 16.5% of the study cohort [7], and establishes the background from which to interpret the current findings, as the perceptions of study participants clearly indicate their repeated contact with the healthcare system without resolution.

4.2. Methodologic Considerations

The qualitative method is ideally suited for the identification of themes and patterns of contributory factors to the development of multiple SHC and effects that can lead to life-changing and life-threatening circumstances. It establishes the foundation for additional research that quantifies the themes, which requires quantitative methods with larger participant cohorts. From the perspective of sample size, the current study had a relatively large sample for a qualitative study ($n = 44$ adults with SCI completing focus groups plus family/other reporters = 28). However, the study only included the narratives of family members/caregivers of adults with SCI who were still alive; as such, it does not reflect the experiences of those whose SHC resulted in death.

All data were self-reported, as is inherent to qualitative research, so no external validation of the reports occurred. The focus groups were conducted within a short timeframe, so the data are not intended to be longitudinal. Longitudinal research would better identify changing trends and the development of multiple SHCs.

4.3. Future Research

Better quantification of each of the observed themes using larger participant cohorts is required. This research should seek representative participant samples and use quantifiable self-report assessments that can be directly compared across studies.

5. Conclusions

The results in this study identified the perceived association between the development of SHC and iatrogenic and nosocomial factors, as well as the importance of the relationships between those with SCI and healthcare providers. It clearly indicates that people with SCI attribute some SHCs and the extent to which they result in complications and new problems to healthcare providers and a lack of understanding of their needs. To improve outcomes, high reliability healthcare organizations should consider investing in and implementing methods for monitoring the appropriateness, success, and unintended consequences of treatment strategies, as well as methods for listening to and respecting patient concerns and experiences.

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