
Understanding the Changing Health Care Needs of Individuals Aging With Spinal Cord Injury

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Background: Individuals over age 65 are projected to account for over 20% of the general population by 2030. This trend is reflected in an increase in the age of individuals sustaining traumatic spinal cord injury (SCI). Based on current evidence, there is concern regarding the needs of older individuals aging with SCI and current health care services. Research is limited regarding factors that contribute to health status and treatment outcomes associated with aging 5 or more years post SCI. **Objective:** The purpose of this qualitative study was to explore changing health care needs of individuals aging with SCI and their caregivers and to identify the environmental supports and barriers to achieving long-term health and treatment outcomes. **Methods:** This was a phenomenological study utilizing semi-structured interviews. Inclusion criteria were age greater than 60 years old and 5 years post SCI. Between October 2014 and January 2016, 41 individuals with SCI and eight caregivers participated in the semi-structured interviews. Emergent themes and quotations were noted and analyzed using established methods. Triangulation was used to establish rigor and trustworthiness. **Results:** Data analysis of the interviews revealed four themes (health literacy, health services, changes with age, and environment) and 10 subthemes. **Conclusion:** Rehabilitation programs should consider the health literacy of older individuals with SCI and their caregivers. Similarly, these programs should be designed to allow them to identify and utilize resources in solving barriers to everyday participation. Further investigation is required to examine the macro-environmental influences (systems and policies) on the changing health care needs of individuals aging with SCI. **Key words:** aging, environmental supports and barriers, health care, health literacy, health status, interviews, older adults, outcomes, traumatic spinal cord injury

Individuals over 65 years old are projected to account for over 20% of the general population in 2030, an increase from 13% in 2010 and 9.8% in 1970.¹ This aging trend is reflected in an increase in the age of individuals sustaining traumatic spinal cord injury (SCI).² Older individuals are increasingly sustaining traumatic, incomplete cervical injuries.³ Studies indicate that SCI alters the process and effects of aging by impacting multiple factors related to physical and mental health and quality of life (QOL).⁴⁻¹⁰ There is concern about the needs of older individuals aging with SCI and current health care services.² Hammel et al¹¹ documented the need to evaluate the impact of the environment on participation at the community and societal levels.

Significant changes when aging post SCI are found in the areas of employment, social life, sex life, and health.¹² Individuals who sustain SCI over the age of 65 demonstrate increased dependency on caregivers and experience the highest annual mortality rates within the SCI population.^{2,4} Caregivers of aging individuals with SCI experience increased physical and mental stress and are challenged by comorbidities.¹³ Groah et al⁴ highlight an inherent complexity in these individuals due to the interaction between factors related to aging and those related to SCI. This perspective implies that needs are contingent on the unique experience and context of the individual with SCI. Maintaining health, maximizing function, and improving level of

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activity and participation constitute three major rehabilitation goals for people aging with SCI.⁴ Age is a significant factor in determining health care utilization.¹⁴ There is a tendency for rehabilitation professionals to view SCI as an acute event rather than a life-long process.¹² Research emphasizes factors that influence health status and treatment outcomes.² The common target of this research has been the acute health care needs of individuals with SCI as they relate to age at time of injury. While there is research describing the changing health care needs of individuals aging with SCI, this study specifically looked at individuals who sustained injury at age 60 or older.

The purpose of this qualitative study was twofold: to explore changing health care needs of individuals aging with SCI and their caregivers and identify environmental supports and barriers to achieving those long-term outcomes. This study aims to provide information on the changing health care needs of this population from the perspectives of individuals living with SCI and caregivers.

Methods

Design

This was a phenomenological study utilizing semi-structured interviews with individuals who had sustained traumatic SCI and their caregivers.

Participants

Participants and caregivers were recruited through a quarterly newsletter published by the Regional SCI Center of the Delaware Valley (RSCICDV). Inclusion criteria of participants included age greater than 60 years old with SCI and 5 years post injury. Of the 61 individuals with SCI recruited to participate, 41 individuals with SCI and eight non-paid family caregivers participated in semi-structured interviews (**Table 1**).

Procedure

A literature review was conducted to identify health care needs of individuals aging with SCI; these results informed the development of the interview questions. The research team reviewed

Table 1. Participant demographics

Age, mean (range), years	73.4 (61-89)
Mean time since SCI, years	10.8
SCI level of injury	
Tetraplegia	54%
Paraplegia	31%
Unknown or not identified	15%
Total no. of caregivers	8 (3 male, 5 female)
No. of participants with spouse as caregiver	6
No. of participants with nonspousal caregiver	2 (1 son, 1 granddaughter)

all potential interview questions until consensus was achieved (**Table 2**). Institutional review board (IRB) approval was obtained and recruitment continued until data saturation. Data collection occurred between October 2014 and January 2016. Team members, all of whom were faculty or graduate occupational and physical therapy students, were assigned sample methodology and research readings prior to participating in training sessions by the lead author. Electronic data analysis programs were not used in this study. The team participated in data collection and analysis.

Interviews

Two pilot semi-structured interviews were conducted by trained investigators to verify content validity and clarity of intent. Questions were refined, clarity of intent was verified with the participants, and questions were finalized. Informed consent was obtained prior to the interviews. All in-person interviews except three via telephone (due to distance) lasted 60 to 90 minutes.

Data analysis

Data analysis began after completion and transcription of the first 10 interviews and continued until saturation was achieved. Using accepted methods of data analysis,¹⁵ emergent themes and subthemes were identified in order to understand the participants' natural context and experience. After individual analyses were completed, the entire team met and discussed

Table 2. Interview questions

Topics	Participant questions
Health status	<ol style="list-style-type: none"> 1. Describe your health today. 2. Has there been a period since your injury that you noticed a dramatic shift in your health? 3. Describe your diet. How has it changed in the last 5 years? 4. How has your physical and mental health status changed over the past 5 to 10 years? 5. Did you have preexisting conditions before your injury? How has your SCI affected this condition(s)? 6. How many times have you been hospitalized in the past 5 years? 7. Describe how you take care of your skin on a daily basis. Has this changed in the last 5 years? 8. Have you had to seek medical attention for your skin?
Health services	<ol style="list-style-type: none"> 1. Tell me about the health services you receive. 2. Which health care professionals are on your current professional team? <ol style="list-style-type: none"> a. Which have you seen regularly? b. Have those professionals changed in the past 5 years? 3. Do you attend the follow-up clinic at Magee Rehab? <ol style="list-style-type: none"> a. If not, describe why you do not use the clinic. 4. What health care services do you seek outside of your home? <ol style="list-style-type: none"> a. Which do you receive in your home? b. Are there any other modes of communication that you use to contact your health care team, such as telephone, telecare, email? 5. Over the years, have you noticed a change in the services that are covered by insurance? <ol style="list-style-type: none"> a. How do you feel about that?
Energy	<ol style="list-style-type: none"> 1. Describe your energy level today. <ol style="list-style-type: none"> a. Is it the same day to day? b. How does it change throughout the day? 2. The literature states that fatigue is one of the most common symptoms reported for people aging with spinal cord injuries. How has your level of energy changed over the past 5 years? 3. Describe how you have had to change your activities because of your energy level in the last 5 years.
Activity and participation	<ol style="list-style-type: none"> 1. What types of activities do you participate in? 2. How has your SCI affected your participation in activities outside of the home in the last 5 years? 3. Describe your exercise routine. Has it changed over the past 5 years? 4. How do you get around? 5. Describe any changes in your level of independence with any ADLs? 6. Has your ability to transfer changed in the past 5 years? (If yes, describe the changes.) 7. Are you working? Describe any changes you've needed to make in the workplace, or with the work tasks you do.
Minimal significant change	<ol style="list-style-type: none"> 1. Are there any small significant changes in your functional status that you have experienced in the last 5 years that you would like us to be aware of? 2. Describe how you think rehabilitation can better serve your needs as you age with SCI.
Social	<ol style="list-style-type: none"> 1. Who are the important people in your life? <ol style="list-style-type: none"> a. What are some key influences they have had on your life in the past 5 years? Since your injury? 2. Who do you interact with socially? <ol style="list-style-type: none"> a. Where do you socialize? 3. How have your social interactions with family and friends changed? 4. How have your supports changed over the years? 5. Describe the quality of your life in the past 5 years. <ol style="list-style-type: none"> a. What makes you happy? b. What makes you feel good? c. What makes you feel bad?
Mentorship	<ol style="list-style-type: none"> 1. Over the years have you found yourself seeking out others with SCI for support? 2. The literature talks about mentorship. Did you have a mentor who worked with you after your injury? <ol style="list-style-type: none"> a. How did that experience impact you? 3. Did you/Are you mentoring someone with an SCI? <ol style="list-style-type: none"> a. Why did/didn't you do it? b. What was that experience like? c. What are the benefits of being a mentor? 4. Now that you are older, how can you benefit from a mentor?

Table 2. Interview questions (CONT.)

Topics	Participant questions
Participant needs	<ol style="list-style-type: none"> 1. Are you the primary caregiver for _____? 2. How long have you been providing this care? 3. What type of assistance do you provide (transfers, ADLs, bowel/bladder, shopping, finances, etc)? 4. Over the last 5 years, what services, assistance, or assistive devices have you needed to help you with your caregiving? <ol style="list-style-type: none"> a. Describe how you got these services (social support, professional services, assistance for everyday living, paramedic services, lifts, wheelchair, etc). 5. Describe _____'s health today. 6. Over the past 5 years what changes have you noticed in health insurance coverage? 7. Over the past 5 years what changes have you noticed in _____'s energy level? 8. Over the past 5 years what changes have you noticed in _____'s independence level? 9. Over the past 5 years what changes have you noticed in _____'s activity participation? 10. Over the past 5 years what changes have you noticed in the number of caretaking hours? 11. Describe how you think rehabilitation should change to better serve the needs of those who are aging with SCI. 12. Describe any other small but significant changes in _____'s ability to participate in activity.
Caregiver needs	<ol style="list-style-type: none"> 1. Describe your health today. 2. Over the last 5 years what services have you sought out for your own health? <ol style="list-style-type: none"> a. Describe how you got these services (psychological support for stress, depression, life satisfaction, or QOL). 3. What are your concerns regarding the next 10 years?

Note: ADL = activities of daily living; QOL = quality of life.

themes. Upon achieving consensus of the thematic codes, an individual team member resumed data analysis followed by an additional team review for theme formation or revision. Rigor and trustworthiness were achieved through both member checks of the transcripts and triangulation through iterative data analysis by the team.

Results

Health literacy

Health literacy refers to “the degree to which an individual has the capacity to obtain, communicate, process, and understand basic health information and services to make appropriate health decisions.”¹⁶ It includes knowledge of mechanism of injury, rehabilitation and medical process since injury, insurance coverage, and any health concerns.

One subtheme was the existence of a continuum of individuals with and without a high degree of health literacy (**Table 3**, subtheme a). Two areas of health literacy that demonstrated this continuum for individuals with SCI involved knowledge of their medications and rehabilitation importance. Some individuals acknowledged the need to take several medications but were unable to recall or provide documentation of a medication routine. As

far as rehabilitation, few individuals participated in an occupational therapy (OT) or physical therapy (PT) program or regular exercise.

Another subtheme of health literacy was the degree of problem-solving capabilities among respondents (**Table 3**, subtheme b). There seemed to be a significant difference in internal motivation as it related to problem-solving capabilities.

Health services

Health services refers to “all services dealing with the diagnosis and treatment of disease, or the promotion, maintenance and restoration of health.”¹⁷ This theme encompasses patient perception of quality and satisfaction with health services, professional perception of patient's functional ability, and patient's perception of personal and caregiver's needs. One subtheme involved participants' perception of access to health services (**Table 4**, subtheme a). Several respondents expressed the need to prioritize their health services based on health insurance and reimbursement. It seemed that they needed to choose between obtaining their medications and receiving OT, PT, or other services due to finances.

An additional subtheme for health services was the respondents' perceptions of health care

Table 3. Health literacy theme and subthemes of barriers impacting individuals aging with spinal cord injury

Theme	Subthemes	Participant quotes reflecting subthemes
Health literacy	a. Continuum of health literacy	<ul style="list-style-type: none"> • “With medications or it. I mean I have a copy somewhere but you know. I can’t list them all out. I don’t even know half the names of them you know.” (WS 77-83) • “Even if I do the exercises twice that day it still it tightens you up, it’s like you have to move, you have to really move... It seems like you have to do them like every hour or something because otherwise you stiff right away.” (VP 1187-1188 & 1202-1204) • “Yeah. When the doctor...when the surgeon told me, ‘you’re not going to walk again and here’s the reason’ and he gave me, I guess what I needed. I needed the scientific basis, being a scientific-type person, and he explained what was going on in the spinal cord and why things don’t happen and all the, the scar tissue and the interfering molecules and whatnot.” (AB 2170-2177)
	b. Degree of problem-solving skills and abilities	<ul style="list-style-type: none"> • “I always describe having a disability as having to problem solve pretty much every day. In some little way, somebody with a disability has to problem solve.” <i>Raising a 5-year-old son</i> – “How do I change him? How do I get to be able to change him? How do I pick him up? How do I carry him? How do I protect him?” Learned to problem solve as a phys-ed teacher and has applied that to raising his son; has taken advantage of what he’s learned from his disability in how he designed his house and taking care of his son. (RW) • “Well first of all I can’t reach anything...I liked my life better before obviously.” (JS)

professionals since their SCI (Table 4, subtheme b). Respondents acknowledged that individuals with SCI are a different patient population with specific needs, and trained SCI rehabilitation specialists are limited.

A final subtheme involved a disconnection and lack of collaboration between respondents and health care providers (Table 4, subtheme c). It seemed that providers were not listening to the respondents in terms of rehabilitation goals. Some respondents actually discussed the need for advocates for individuals with SCI due to this disconnect. They commented that it is even more important to have advocates after their initial acute rehabilitation than with aging with an SCI.

Functional changes with age

Whereas the entire study is an exploration of the overall effects of aging with an SCI, this theme is specific to functional changes. One subtheme of functional changes with age involved changes in health status (Table 5, subtheme a). Health status is “often summarized by life expectancy or self-assessed health status, and more broadly includes measures of functioning, physical illness, and mental well-being.”¹⁸ Changes were noted along a continuum of diminished to improved health status regarding energy levels, sleep patterns,

memory, bowel and bladder control, and additional comorbidities. One significant change in health was an increase in falls, which is also common for those aging without SCI. Another change related to changes in skin integrity and how to manage them, especially due to increased potential risks as a result of the SCI. Finally, a disconnect was noted between what typical changes were due to aging alone versus having an SCI. Some respondents were able to note that certain changes in energy levels were due to aging alone.

Change in level of participation was another subtheme (Table 5, subtheme b). The central concept of participation is being a part of informal and formal activities. Formal activities include concrete rules and goals and informal activities involve little to no planning.¹⁹ A continuum of change was noted and included topics of socialization, activities of daily living/instrumental activities of daily living (ADLs/IADLs), employment, and physical activity. Certain respondents and caregivers were motivated in terms of participation whereas others were not.

A final subtheme was future orientation (Table 5, subtheme c). The definition of future orientation is the “image that individuals have for the future” and “provides the grounds for setting goals and planning.”^{20(p3)} It appeared that there was not a consensus among respondents and caregivers

Table 4. Health services theme and subthemes of barriers impacting individuals aging with spinal cord injury

Theme	Subthemes	Participant quotes reflecting subthemes
Health services	a. Perception of access to health services	<ul style="list-style-type: none"> • “If I went for therapy, they would drop my homecare. So it’s like, okay what do you do? I need the homecare... so now I can’t go to physical therapy, because if I go outside the home, then they figure I can do it.” (VP 689-691 & 696-697) • “There’s things in here that I know I could do to make her twice as healthful. But it’s the money.” (JS Caregiver 574-575) • <i>Discussed difficulty with payment and access to adult day care services:</i> “...since I was so close to retirement we I had saved money for retirement so that put us into a disadvantage from a financial thing to get anything else, any other kind of financial help from what we were looking for.” (TB 216-218)
	b. Perception of self and caregiver’s needs & prioritization of needs by health care professionals	<ul style="list-style-type: none"> • <i>In regards to experienced rehabilitation facilities:</i> “They’re not completely... staffed properly...and some of the folks really don’t know what they’re doing.... are not trained enough to deal with a spinal person with spinal cord ...with spinal cords, it’s just uh, we’re different, we’re a different, we’re a different beast so to speak... we need diff-different things to be done to us, done, done for us.” (MC 381, 427) • “She should be having physical therapy three times a week... There’s girls that come here that are very good with her but they’re not physical therapists and if you don’t watch how you bend her leg you can break it.” (JS 382 & 398-399) • “Well that’s thanks to my OT. I never knew what she was gonna have me doing. It was always a surprise. She had me washing the dishes one day. Set up on the table, took me down this street, in this of course. I said ‘Oh my God’. But she always had something different for me to do. It wasn’t just come in and stretch your body.” (JS PG 6)
	c. Provider perceptions of individuals’ abilities and the resultant disconnect in the plan of care	<ul style="list-style-type: none"> • “And I said, to my wife, I said, ‘I don’t really need this anymore’ and I kind of stopped—but ----- rehab over there, insisted that I continue using the walker so I went over there and I, and I showed them that I didn’t need it. I would walk all over the place carrying it so they wanted to graduate me to a cane (pause) so they gave me a cane and they showed me how to walk with that and now I was walking with that and uh, they says, ‘ok you can stop using the walker and you can use a cane.’ Well I never used the cane.” [C: Ok.] S: “I just refuse—I just refused to use it. And I went along fine until like I said five months ago.” • “If it isn’t a comfortable relationship I move onto another Doc...for lots of patients, they’re not really too communicative. They are intimidated by a doctor, uh, they don’t ask the questions, they try and fake it and what they need is, they need umm, almost like an advocate, not, not necessarily a doctor, but somebody to be an intermediary, so that they can make sure that their issues are raised and, and, and I wind up doing that with some of the patients at ----- . And I’m there to do it, but once people leave the hospital and as you get older it gets harder. Yeah, the health care system doesn’t provide for that so, especially for people who are at the lower end of the education spectrum who are not real communicative, umm who may have injuries that are more pronounced, umm you know, you need to be able to break through it...And it is not their fault, they work at it, but it is just the way the system is set up.” (SS 156-184)

with perceptions of their futures. Motivation and resources greatly influenced respondents’ perceptions. Some respondents never really thought about the future whereas others were more motivated to improve their lives.

Environment

Environment was the final theme that was addressed by respondents. Subthemes included both non-human and human environments. Changes in the non-human environment

were defined as modifications to the physical environment and/or adaptation to the activity (occupation) performed by an individual to promote health, welfare, and safety of the participant. For many respondents, several of the changes in the non-human environment after injury were directly related to their homes and improvement in accessibility and functionality (Table 6, subtheme a). The respondents discussed how this led to a financial burden.

Human environment was another subtheme and is defined as the various types of support

Table 5. Functional changes with age theme and subthemes of barriers impacting individuals aging with spinal cord injury

Theme	Subthemes
Changes with age	<p>a. Perceptions of health status (age vs SCI)</p> <ul style="list-style-type: none"> • <i>In response to question regarding fall frequency:</i> "...in the beginning, when I first came out of [the Rehab Hospital], I had uh, no falls. And then, probably (pause) oh, maybe 5-6 years down the road I started stumbling, uh, maybe once a year... twice a year. This past year was probably the worst. I've had, uh, some real bad ones. Uh, and, it, it got to a point where when, being aggressive, the falls never bothered me. 'Oh well, ...' and get up and keep going. But anymore, I'm just, I'm just getting ...from the falls, I've had some, like I've had my head hit, cut open about three times I think...from falling. And I'm just, I don't wanna do it anymore...and it's, and it's slowed me down an awful lot." (JM_SC 302-19) • "...skin problems. I've had some skin breakage, which happens cause your circulation is uh poor. And we had an issue there where you're like what do you do? Who do you call? The rehab hospital says make sure you keep checking for it. Which we did. And then when it happened...Down there where it happened the whole team of people that look at you and they had a nurse that would specialize in that. And she would recommend stuff. But at home you have the family doctor and he had a visiting nurse come out and we started a routine, but you're like alright I found the problem, what do I do now?" (TB 304-310) • "I don't think it's changed. I can't, ya know, I got, I'm the same energy level that I had uh, I mean less because of my age, I think, yeah. But other than that, I don't think it... I still do the same things that I did before." (WS 496-502) • "My health today is pretty good. The occasional UTI, um...still a...shoulder I'm rehabbing...uh, more aches and pains coming on as I'm aging, um...older nerves, slight damage in both elbows to the ulnar nerve." (AB 481-483)
	<p>b. Level of participation and potency of replacement activities</p> <ul style="list-style-type: none"> • "Well, my social activities have really changed a lot because I can't get, I can't be there to a lot of places, and a lot of times, well like, for instance, we were at eh (pauses) a wedding recently and we got there and I sat down and I couldn't move around to see the people I wanted to see...And I had to wait 'til they came to me... so that, that cut down the amount of interaction I had with people...I can't move around like I used to." (MC 381-391) • "The sex. Is that good enough?...that's about the only thing that's changed. Uh, he has slight limitations. His hands don't work and stuff at times. Um, and you know, he's coming along. It's much better than it was when...12 years ago when he first got hurt." (GD caregiver): reports changes to sexual activity; difficulty with hands with buttons, zippers. (GD 15-9) • "You probably don't want to hear it again. To me, I'm devastated that I'm like this. I can't function, you know. The worst part um is my bowels." (SW 300-303) • <i>SCI effect on participation in last 5 years:</i> "When you really come down to it but my balance problem is what holds me back. (Pause) But I do things outside, uh ya know uh even though I walk with a cane, I can still uh do some stuff in the garden, I got uh I got a pool out back that I have to take care of. (Laughs) And that's got uh I clean that with a chair. Ya know, I take the chair and sit in the chair and clean it. And do things like that. I find a way to do things, ya know. (WS 608-619) • "I want to do more... I don't want to sit around." (AB 633 & 635-636)
	<p>c. Future orientation</p> <ul style="list-style-type: none"> • "I have no anticipation or concern about the future." (WM) • "You just can't stagnate... You can't live with what's in the past, you can only go forward, but if you sit there and just dwell on the past, then that's all you're gonna do is just be in the past." (VP-Caregiver 1941, 1948-1950). • "I'd say the mental issue is probably the biggest thing, the biggest challenge so far... I went from kinda optimistic last year to then as time marched on and found out what was really available to reality, you know...The reality is that things aren't, we don't see anything on the horizon that's gonna make my situation any better." (TB 304-310)

Table 6. Environment theme and subthemes of barriers impacting individuals aging with spinal cord injury

Theme	Subthemes	Participant quotes reflecting subthemes
Environment	a. Non-human: includes built environment factors (architectural, accessibility, geographic factors, access to assistive technology)	<ul style="list-style-type: none"> • “So the roll-in shower...it’s not an assistive device, but we redid the house. We redid the bathroom so that I could use it.” (AB 1779-1780) • “We bought this home and made \$60,000 in modifications to make it handicap accessible and we are chewing up our savings...And there’s no opportunity to get to make that up. So we’re losing money, we’re getting bills and it just keeps weighing on you. Home modifications and financial expense.” (TB 262-263) • <i>Respondent built a handicap accessible home after his injury:</i> “Uh, we’ve added some railings to the house, where I can go and use both railings, I can climb, I can go up the steps.” (MS 1109)
	b. Human: includes social & attitudinal factors	<ul style="list-style-type: none"> • “Especially after my--initially after my injury. Um I felt as if I needed to show my family um that (pause) they didn’t have to take care of me.” <i>He wants his family to know that he is okay and he can take care of himself; he wants his friends to know:</i> “I want them to know that I can meet them there.” (RW) • “...he’s doing it because he knows I don’t, I can’t, I’m ill, if I didn’t have this accident, if I was sick, he would do it for me... you know, that’s one of those, that, that kind of relationship we have... where if I need, he’ll do for me. If he needs, I do for him. <i>Talks about his relationship with his neighbor; he used to drive him when he had a CVA and now the neighbor helps MS out. He also describes other neighbors who come over to sit and chat with him on his patio.</i> (MC 1311, 1326, 1356) • “If you don’t do those things, you’re not giving her good care. You have to be nurse aid and rehab person and mentor and you know, husband.” (VP-Caregiver 1709-1710) • “Because if something happened to me tomorrow, there’s nobody to take care of her.” (JS Caregiver 640 & 643)

Note: CVA = cerebrovascular accident.

provided by others. It is generally classified into three major categories: emotional, instrumental, and informational support.²¹ Human environment included caregiving and receiving, social support including family and friend relationships, and mentorship. It appeared that respondents relied heavily on their caregivers even though they did not want to have to do this (Table 6, subtheme b). Caregiver overburden was discussed throughout the interviews from the perspectives of both the individuals with SCI and the caregivers.

Discussion

To understand the changing health care needs of older individuals aging post SCI and caregivers, it is important to analyze experiences and identify environmental supports/barriers to achieving long-term outcomes. This study reinforces, expands, and adds to the literature regarding the changing

health care needs of individuals aging with SCI. Health care services should focus on enhancing and applying patient and caregiver health literacy to everyday activities. Active engagement in health promotion may improve recipients’ future problem-solving skills to deal with environmental barriers and increase participation.

Findings are consistent with current literature, except for the addition of the health literacy theme. Participants describe a continuum of health literacy: There are those who are more knowledgeable and those who are less knowledgeable. Similarly, participants’ responses describe a continuum in the degree of problem solving. This highlights the need for the health care provider to assess patient and caregiver health literacy and provide opportunities to demonstrate these skills. Health care professionals should provide additional opportunities to practice and discuss outcomes of problem solving to potentially empower long-term skills.

The findings of this study expand the knowledge of environmental influences and reinforce the findings of more recent research in the past 2 years. Hammel et al¹¹ described four themes identified by individuals with disabilities within environmental supports and barriers to participation as the built environment, the natural environment, assistive technology, and transportation. Whereas, additional environmental supports and barrier subthemes identified in this study included the human and non-human environment.

Health literacy

Research shows that health literacy and rehabilitation are linked by common emphasis on the capacity, functioning, participation, and empowerment of the patient.²² Advanced age, over 65, has been identified as a limiting factor.²² A cross-sectional study of people with SCI identified communication with health care professionals as being associated with levels of participation and functioning and perceptions of well-being.²³

Health services

A prevalent portion of health services was the lack of comprehensive coverage for both home health and outpatient therapy services. However, under Medicare, individuals with an SCI are only eligible for either one. Because many of these individuals require home health in order to complete their ADLs, they often do not receive therapy services due to reimbursement limitations.

In addition, individuals with SCI may have limited access to health care services secondary to low income, low functional ability, and geographic factors. Guilcher et al¹⁴ compared socio-demographic characteristics and utilization of a physician and emergency department visits for non-traumatic and traumatic SCI 1 year after acute rehabilitation. Those individuals who had a non-traumatic SCI experienced fewer acute rehabilitation days compared to those with traumatic SCI. The results also indicated rural-dwelling individuals faced several environmental barriers limiting access to community services.¹⁴

Those aging with SCI face many environmental barriers to health services including insurance coverage, income, functional ability, rural living, and, according to one participant, poor service from health care professionals. Pershouse et al⁷ reported a solution that suggested health care professionals should engage in the early phase (onset of injury) by educating patients about maintenance and mitigation strategies to sustain their meaningful life roles. In addition, Zinman et al²⁴ determined that participation in therapeutic education can improve the well-being in an individual with SCI and reintegration into communities. The findings of our study reinforce the importance of providing patient-centered, long-term reassessment of levels of function and requirements needed for everyday participation.

Change in health status/energy with aging

A prominent item that appeared in our study was the presence of repetitive injuries related to long-term wheelchair use and other adaptive equipment as well as the incidence of falls. An implication for future therapy is that greater emphasis should be placed on ongoing balance interventions for individuals with SCIs during and after immediate post-SCI rehabilitation. This study coincides with the changes in health status associated with aging with an SCI as in previous studies. These changes include upper extremity conditions, deconditioning, bowel and bladder difficulties, spasticity, pain, fatigue, osteoporosis, and diabetes.⁴⁻¹⁰

Change in level of participation

Recent literature regarding the levels of participation disparities among individuals aging with SCI suggests that continued participation in meaningful activities in/outside the home supports positive adjustment to SCI.^{25,26} Prior literature supported that the presence of resources, social support, and continued involvement in leisure activities as individuals age with SCI correlated with higher QOL.²⁷ Barclay et al²⁶ concluded that adequate financial resources and social support contributes to participation in meaningful

activities, whereas physical environment and lack of social supports were identified as barriers to participation.

Our study has demonstrated a need for greater rehabilitative emphasis on modifying preexisting leisure activities or exploring new ones following SCI. Additional emphasis should be on providing individuals with SCI and caregivers strategies to overcome environmental barriers. Williams et al²⁸ found in a recent study that despite physical therapists placing a high level of value on physical activity, active promotion of engagement in physical activity remains absent from practice with this population. They recommend that health care professionals (physical therapists) begin to promote and prescribe physical activity as an integral component of practice.²⁸

Similarly, our results suggest the need for greater long-term involvement of health care professionals after initial discharge. However, our findings indicate more disparity among the levels of change in participation, and we were unable to directly associate these changes in level of participation to life satisfaction and QOL.

Based on previous literature and the results of our study, individuals aging with SCI may benefit from increased involvement of health care professionals after discharge in order to increase awareness of systems, health and social policies, and other available resources. Future research may indicate the incorporation of telerehab and outreach group programs to assist individuals in staying active within the community.

Future orientation

Although not a potent theme, some participants gave voice to the presence of or lack of a future orientation. This theme requires additional data and analysis to further understand the implications of this orientation.

Environment

This study differentiated coding of the data between human and non-human environments, but this was not found in the literature. The literature does not use the term *human environment*²⁹ often

to describe caregiving and social environment. Human environment²⁹ defined as “friends/peers”²⁹ does appear in relation to factors that influence community participation and QOL in individuals with SCI who use wheelchairs.²⁹ The literature prefers the term *caregiving*²⁹ to describe ideas similar to our theme of human environment.²⁹ Two studies demonstrated that social integration, receiving social support, and experiencing negative social interactions independently influenced the impact of SCI caregiver burden.^{13,30}

These findings resonated with Hammel et al's¹¹ more detailed factors and had great applicability to rehabilitation practice and education of rehabilitation professionals. Prior to their study, a limited number of environmental factors such as transportation, assistive technology, and social supports were described in the literature as barriers or supports to participation in individuals experiencing SCI.¹¹

Hammel and her colleagues¹¹ proposed a conceptual framework that described the relationship between eight environmental factors (human and non-human) and participation. Those factors were the built environment, natural environment, assistive technology, transportation, information and technology (IT) access, economics, social support and social attitudes, and system, services, and policies. Our findings resonated with those of Hammel et al and further contributed to the body of knowledge of environmental influences on participation for individuals aging with disability, such as SCI.

Study limitations

This qualitative study was limited to a small, convenience sampling of individuals who received rehabilitation through the RSCICDV. Caregiver interviews were conducted with the participant present. This could have contributed to the veracity of the caregivers' responses. In future studies, participant and caregiver interviews should be conducted separately. Thematic differences between participant and caregiver interview responses did not emerge from the data, however this should be further investigated in future

studies. A recommendation would be to interview caregivers separately from the SCI participant.

Conclusion

This study highlighted and supported previous findings reporting the changing needs of individuals aging with SCI. Our findings suggested that contemporary rehabilitation for individuals with SCI consider the health literacy of the patients and their families at all phases of rehabilitation. Similarly, rehabilitation programs should be designed so that patients and families practice, at all phases of rehabilitation, identifying and using resources in solving barriers to everyday

participation in health promotion and other meaningful activities. Further investigation is required to elucidate our understanding of the macro-environmental (systems and policies) influences on the changing health care needs of individuals aging with SCI.

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