The Impact of Health Behaviors and Health Management on Employment After SCI: Physical Health and Functioning

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Background: Research has shown that employment following spinal cord injury (SCI) is related to health and functioning, with physical health and functioning after SCI frequently identified as a primary barrier to employment. **Objective:** To examine the relationship between employment and behaviors associated with the management of physical health and functioning as described by individuals with SCI who have been employed post injury. **Methods:** A qualitative approach using 6 focus groups at 2 sites included 44 participants with SCI who had worked at some time post injury. Heterogeneous and homogeneous groups were created based on specific characteristics, such as education, gender, or race. A semi-structured interview format asked questions about personal, environmental, and policy-related factors influencing employment after SCI. Groups were recorded, transcribed, and entered into NVivo before coding by 2 reviewers. **Results:** Within the area of behaviors and management of physical health and functioning, 4 overlapping themes were identified: (1) relearning your own body and what it can do; (2) general health and wellness behaviors; (3) communication, education, and advocacy; and (4) secondary conditions and aging. Specific themes articulate the many types of behaviors individuals must master and their impact on return to work as well as on finding, maintaining, and deciding to leave employment. **Conclusions:** Individuals with SCI who are successfully employed after injury must learn how to perform necessary behaviors to manage health and function in a work environment. The decision to leave employment often appears to be associated with secondary complications and other conditions that occur as persons with SCI age. **Key words:** employment, health behaviors, self-management, spinal cord injury

Employment is fundamental to adult life and is related to health, life satisfaction, and longevity.^{1,2} However, spinal cord injury (SCI) is associated with unacceptably low employment rates, often lower than 30%.^{3,4} One of the most consistent findings regarding employment following SCI is its relationship with health and functioning. Numerous studies link secondary conditions (including pressure ulcers, urinary tract infections) and hospitalizations with poorer employment outcomes.⁵⁻⁷ Physical health and functioning is frequently identified by individuals with SCI as a primary barrier to employment.^{8,9} Krause⁸ found that reasons for unemployment were related to energy, health, and health considerations, and the reported barriers generally increased across

age cohorts. Liese, MacLeod, and Drews⁹ found that health and physical limitations were one of the most commonly reported barriers to employment for Utah residents with SCI. Other studies have noted that aging and experiencing secondary conditions are related to lower earnings and an earlier end to the work life for individuals with SCI than for the general population.^{7,10,11} Furthermore, gainful employment has been found to be associated with a decreased risk of excess mortality among those with SCI.¹²

While behavioral factors have been linked to morbidity and mortality after SCI, they are rarely addressed when discussing employment. Specifically, the theoretical risk and prevention model (TRPM), as articulated by Krause et al,^{13,14}

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notes that the health behaviors engaged in after SCI can either protect against or increase the risk of secondary conditions. In particular, smoking, binge drinking, and prescription medication use have been identified as risk factors while numbers of hours out of bed each day, exercise, and diet appear to be protective.^{15,16}

Despite the identified link between physical health and employment after SCI, research is lacking in identifying the health behaviors and health management strategies that are critical for maintaining employment. The purpose of this study was to articulate the relationship between employment and the management of physical health and functioning from the perspective of individuals who are living with SCI and who have worked or continue to work after injury. This article particularly focuses on the health behaviors and health management issues that individuals with SCI identify as impacting their work lifecycle. These insights can then be used to develop interventions, programs, and policies to support employment after SCI.

Methods

Institutional review board approval was received prior to study initiation. Participants were identified through a 35-year longitudinal study of SCI and community resources.¹⁷ All participants were a minimum of 10 years post injury at the time of the study and had worked at some time post injury. Attempts were made to recruit a stratified sample based on time in employment post injury (those employed for at least 10 years after SCI vs those who were employed at some time post injury but unable to maintain employment), gender, race, and education (high school vs some college or more).

Six focus groups were conducted consisting of between 4 to 9 individuals each for a total of 44 participants. Focus groups were conducted at 2 sites – Minnesota (MN) and Georgia (GA). In general, individuals with a high school education or less were invited to be part of a blue collar group while those with a college education were invited to participate in a white collar group. One group (in GA) consisted solely of individuals from racial-

ethnic minority backgrounds while another group (in MN) consisted solely of females; these groups were specifically organized to allow the unique issues and experiences of these traditionally underserved populations of individuals with SCI to be articulated. Other groups had a mixed composition, including males and females as well as individuals from both majority and minority racial-ethnic backgrounds. Previous research has indicated the benefit of including both heterogeneous and homogeneous groups due to advantages regarding the diversity of opinions expressed.¹⁸

Participants ranged from 30 to 73 years old (average, 52.2; $SD = 10.05$) with an average age at injury of 21.57 years ($SD = 9.76$) and time since injury ranging from 14 to 58 years (average, 30.66; $SD = 2.83$). Level of injury ranged from high-level tetraplegia to incomplete paraplegia allowing ambulation. Women accounted for 30% of participants; individuals from racial and ethnic minority backgrounds accounted for 27% of the sample. Half of the participants were currently working, 23% were not working at the time of the focus group, and 27% were retired. **Table 1** provides details to link narratives with participant characteristics.

Each focus group had 2 facilitators, followed a semi-structured format, and lasted between 2 and 3 hours. The core of the focus groups consisted of questions designed to elicit information about the personal, environmental, and policy-related factors that influenced job attainment, maintenance, and advancement following SCI. In addition, participants who had left employment were queried about associated factors and decisions.

Focus groups were audio- and video-recorded; the tapes were sent to a professional transcription service. Completed transcripts were reviewed for accuracy and completeness; errors were noted and corrected, and “cleaned” transcripts were entered into NVivo qualitative software. Transcripts were reviewed multiple times before being coded by 2 authors (Meade and Reed) to extract topics, themes, and patterns from the source documents. Aliases were assigned for de-identification of participants.

Given the volume of narrative, this article presents a distillation of perspectives highlighting

Table 1. Participant demographics and injury characteristics

Alias	Site	Group ^a	Gender	Decade injured	Age at injury ^b	Current age, years	Time since injury, years	Race/ ethnicity	Current work status	Impairment level
Aaron	MN	WC	M	1980s	YA	51-60	31-40	non-Hispanic, White	Working	Tetra C6
Al	GA	MG	M	1990s	A	51-60	11-20	Hispanic	Not working	Para
Allen	GA	BC	M	1990s	T	31-40	21-30	non-Hispanic, White	Working	Tetra
Alton	GA	MG	M	1980s	A	51-60	21-30	African American	Working	Tetra
Arlene	MN	WG	F	1950s	T	66+	51-60	non-Hispanic, White	Retired	Tetra
Benjamin	MN	BC	M	1970s	YA	61-65	31-40	non-Hispanic, White	Working	Tetra
Bill	GA	WC	M	1970s	YA	60-65	41-50	non-Hispanic, White	Retired	High tetra
Brent	GA	BC	M	1980s	T	31-40	21-30	non-Hispanic, White	Not working	TBI/para
Brian	MN	WC	M	1980s	YT	41-50	31-40	non-Hispanic, White	Working	Para
Charlie	GA	MG	M	1980s	T	41-50	21-30	African American	Not working	Para
Chester	MN	WC	M	1970s	T	51-60	31-40	non-Hispanic, White	Retired	Tetra
Dora	MN	WG	F	1970s	YA	51-60	31-40	non-Hispanic, White	Working	Tetra
Edmund	GA	BC	M	1980s	YA	51-60	31-40	African American	Working	Tetra
Ellis	MN	WC	M	1960s	YA	66+	41-50	non-Hispanic, White	Retired	Para
Eloise	GA	BC	F	1970s	T	61-65	41-50	non-Hispanic, White	Not working	Para
Frank	MN	BC	M	1980s	T	41-50	21-30	non-Hispanic, White	Working	Para
Jason	MN	WC	M	1980s	A	51-60	21-30	non-Hispanic, White	Retired	Tetra C5
Jeannette	MN	WG	F	1950s	YC	51-60	51-60	non-Hispanic, White	Retired	Para
Jeffrey	GA	BC	M	1990s	YA	31-40	11-20	non-Hispanic, White	Working	Tetra
Joanne	MN	WG	F	1990s	YA	41-50	21-30	non-Hispanic, White	Working	Tetra
Joey	GA	WC	M	1990s	T	41-50	21-30	non-Hispanic, White	Working	Para
Joshua	MN	WC	M	1970s	T	51-60	31-40	non-Hispanic, White	Working	Tetra C4
Karl	GA	MG	M	1990s	A	61-65	11-20	African American	Retired	High tetra

(Continued)

Table 1. Participant demographics and injury characteristics (CONT.)

Katrina	MN	WG	F	1970s	YA	66+	41-50	non-Hispanic, White	Retired	Para
Kevin	MN	WC	M	1960s	T	61-65	41-50	non-Hispanic, White	Retired	Para
Larry	MN	BC	M	1970s	T	51-60	41-50	non-Hispanic, White	Working	Tetra
Lisa	GA	BC	F	1980s	T	31-40	21-30	non-Hispanic, White	Not working	Para
Louis	GA	MG	M	1990s	YA	31-40	11-20	African American	Not working	Tetra
Max	GA	WC	M	1980s	A	60-65	31-40	non-Hispanic, White	Working	Low tetra
Milton	GA	MG	M	1990s	T	21-30	11-20	African American	Not working	Para
Nicolas	MN	BC	M	1960s	YC	41-50	41-50	non-Hispanic, White	Working	Para
Pam	MN	WG	F	1980s	T	41-50	21-30	non-Hispanic, White	Working	Para
Peggy	GA	WC	F	1970s	YC	41-50	31-40	non-Hispanic, White	Working	Para
Raymond	GA	BC	M	1980s	YA	61-60	21-30	African American	Not working	Para
Richard	MN	WC	M	1970s	YA	51-60	31-40	non-Hispanic, White	Retired	Tetra C5
Ronnie	GA	BC	M	1980s	T	41-50	21-30	non-Hispanic, White	Working	Tetra
Roy	MN	WC	M	1970s	T	51-60	31-40	non-Hispanic, White	Working	Para
Sabrina	MN	WG	F	1990s	A	66+	21-30	African American	Retired	Para
Sheryl	MN	WG	F	1980s	YA	41-50	21-30	non-Hispanic, White	Not working	Para
Stanley	GA	WC	M	1980s	A	60-65	21-30	non-Hispanic, White	Retired	Para
Susan	GA	MG	F	1990s	A	51-60	11-20	African American	Not working	Para
Vernon	GA	MG	M	1990s	YA	41-50	21-30	African American	Working	Low tetra
Victoria	GA	WC	F	1990s	T	31-40	21-30	non-Hispanic, White	Working	Para
Yukami	GA	MG	F	1990s	A	41-50	11-20	Asian American	Working	Para

Note: F = female; GA = Georgia; M = male; MN = Minnesota; Para = paraplegia; TBI = traumatic brain injury; Tetra = tetraplegia.

^aFocus groups: WC = white collar; BC = blue collar; WG= women's group; MG = minority group

^bAge groups: YC = young child (0-5); YT = tween/young teen (11-15); T = teen(16-19); YA = young adult (20-25); A = adult (25 to 50); OA = older adult (51+).

one of the issues that emerged – the relationship between the behavioral management of physical health and functioning and employment as expressed by study participants. Narratives related to management of emotional health and employment were not included and will be addressed in a future article.

Results

Narratives fell into 4 overlapping themes: (1) relearning one's own body and how to do things; (2) general health and wellness behaviors; (3) communication, education, and advocacy; and (4) dealing with secondary conditions and aging with SCI. Most themes reflected issues that varied based on severity of injury as well as stage of employment.

Relearning one's own body and how to do things

After SCI, participants indicated that they had to relearn how their body worked, what was possible, and how to do things before thinking about returning to work. They needed to figure out how to function in their everyday lives given their various levels of impairment and develop daily routines that would support employment. As noted by one participant (Vernon): “If you don't know your body, who else is going to know it? And how are you going to explain what's going on?”

In the narrative below, Bill – a male in his 60s with high-level tetraplegia – tells of his reaction when asked about returning to work. Stanley, also in his 60s, joins in the conversation, sharing his perspective and experiences:

Bill: *I remember being in the rehab center back in 1970. The social worker talked to me about completing my education and going back to work. I was blown away. I was like I don't even know how I'm going to get up out of bed. How am I going to get from Point A to B independently transportation wise? Back then, the van lifts and accessible transportation was practically non-existent. There were fundamental questions about even if I can get prepared to go, how am I going to make that happen? But down the road, I learned ways I could do things.*

Stanley: *I remember vividly 25 years ago, it took me 2 or 3 hours to get up and dressed, an hour to get downtown, 11 o'clock, and so tired after 2 o'clock, went back home. In that transition, you don't know if you're going to work or not, do you want or not want to work, are your skills the same in the chair? There are a lot of things you have to look at. For me,*

it was a back-to-work mentality, but it took me a good year before I could function normally of what you had before the injury. It takes time. It wasn't about the work. Yes, I'm going back, but will you handle the day-to-day routines versus the work routines and the end-of-the-day routines. You know until you try it.

The importance of relearning your body and the time involved was heard in other groups as well. Yukami, an Asian American female in her 30s with paraplegia, shared her experience.

It took around a year and a half to get okay. I had to figure out how to regulate my body. You deal with ICs [intermittent catheterizations] and bowel and bladder issues, being able to transfer, having access to a car. It took that long to manage to feel normal. You have to have good time-management skills especially at the front end to make sure you're successful....

Later, she talked about how determining your endurance is critical in making an informed decision about obtaining full-time versus part-time employment and possibly losing social security income and health care coverage.

Several participants talked about delaying their return to work until they had time to feel comfortable with how they functioned at a wheelchair level.

Joey: *...the question about going back to work wasn't a question. It took me adapting to the new normal using a chair, surgeries, and get health back. When I met with the employer and HR [human resources], they said come back when you're ready.*

For some, the delay to return to work meant letting go of previous employment.

Alton: *I made a decision. The objective that you try to get back to work is 60 days or 90 days? I said heck no, I'm not going back to work. That's the decision I made; so even though the company wanted me back to work, I said no. I'm glad I said no, I'm not going back to work. This is my body. I got myself back, my health. So once I was able to get that together, I said I'm ready to go back to work.*

General health and wellness behaviors

Not only do individuals with SCI have to relearn their body, they have to perform health behaviors on a regular basis or be able to engage and instruct caregivers to perform the activities for them. When asked about the factors involved in regularly maintaining health, Louis responded, “Water, exercise. I had a bunch of stomach pains, and they couldn't figure out what was going on. So I changed the way I eat and, before I exercise to get that under

control.” Yukami explained how such factors could impact working:

Yukami: Health. I think you have to have good health. You have to do your weight shifts so you don’t have secondary complication after spinal cord injury. Sometimes people have a tendency to forget weight shift and stuff. The fact we can’t feel our body, we may not know the skin is breaking down and it will become something much, much bigger, which we will take you off the working loop a long, long time. And as anybody who knows anything about skin care, it could take years to retain its balance again.

She summed it up with, “So doing just doing basic maintenance is key.”

As noted by one participant, maintaining health can take significant time and effort:

No major medical issues luckily. Not a pressure sore. I owe most of that of course to my PCA [personal care assistant] who keeps an eye on me. Also I bike at [the rehab center] 3 times a week. But you’ve got to have time for that. It’s a hard balance. I tried working full time at first, and almost immediately things didn’t feel right, so I had to make a choice.

Employment can negatively impact wellness activities if individuals are not able to achieve a healthy balance:

Facilitator: Did your health take a hit because of working?

Frank: Mine has. My first 10 years at the hospital, I worked most second shift but some days. Then since I worked every other weekend, I had days off during the week; and I took care of myself much better. Now I work straight days, and I’m constantly fighting the feeling that I need to stay past my appointed hours to keep on top of things. I’ve been talked to about that. I don’t have a bowel program anymore. It’s out of control because I can’t maintain it like I used to, so my wife and I deal with that. I would prefer (but my position is not needed on the weekend) a different schedule to live day to day better. But now I guess I’m resolved to deal with it, hope it doesn’t get too bad until I can retire.

A key behavior for general wellness for individuals with higher level injuries was learning how to interact and deal with caregivers and assistants. As articulated by Frank and Benjamin, work is often dependent on having reliable and qualified attendant care.

Frank: I try to keep that separate, work and attendant care. It overlaps a lot. You get a good person (a good attendant), all of a sudden you’re work seems to be going good too because you don’t have bladder infections. You’re being taken care of. It goes in cycles. But yeah, attendant care business is a whole other ballgame isn’t it?

Benjamin: All your work is dependent on it.

Participants seemed to agree that finding personal care attendants and aides was a process they had to be actively engaged in – not one that could be handled by others.

Vernon: I’ve had reliable aides. With home health care nurses, I screen my own health care service. I ask them questions. I interviewed them. Even though they’re hired through a company, they send out about three aides, I choose who I like. I have my questions, and I make sure that they can comply to my needs. I make sure they got to be here at a certain time. And even at the home health-care service that I use, they know “You’re going to see Mr. [Smith]. He’s very straight, so you got to behave.” And it’s a good thing because they know I don’t play. That’s because you’re dealing with my life, and if I get a job and I’m late, I get fired because of you. That’s not going to set well with me.

Participants also brought up the importance of knowing how to communicate with strangers and becoming comfortable in doing so. As articulated by several of the women in the group in Minnesota, individuals with SCI who use public transportation have to ask strangers to assist them and, especially for women, doing so can result in feelings of vulnerability or having privacy invaded.

Sabrina: Asking a stranger to help you. I said to my therapist I ride Metro Mobility for the last 21 years. I would have to say there have been over a thousand plus men who have been driver who have come close enough putting belts over me and touching my chair. I would never as an able-bodied person run into a thousand men that I would have allow that interaction. And now I have to allow that to get from one place to the other. Have their comments, and can I get away from someone who has just belted me down with five belts. As a single, able-bodied woman, would you ever have had to ask a stranger to help you that way?

Joanne: And then trust them.

Sabrina: And have to trust them and be that close to be vulnerable.

Communication, educating others, and advocacy

The ability to communicate and self-advocate appears to be important for managing physical health after SCI. However, while these skills are helpful for participating in the community, they appear to be critical to maintaining employment, especially when it comes to asking for accommodations at your job. What distinguishes this theme is the focus on not just engaging and

instructing a single individual but interacting with confidence and assertiveness to ensure the environment and accommodations needed to maintain health.

Yukami articulated the importance of advocating for oneself and not expecting employers to know what you may need:

One thing that's important for all of us who are looking for employment is to be a self-advocate because my needs are going to be different than someone else's. Even though we are all categorized as somebody with a spinal cord injury, self-advocacy is one of the most important things. You can do it in a nice way where people will want to help you. It depends on your tone and body language. It's one of those things we have to be conscientious [sic] of.

A statement from Stanley summarized this same view, *"That brings the point too that if you don't ask, you don't get. Depending on how you ask, a lot of companies, if they're not told, it will continue."*

Others provided examples of times they had to advocate for themselves at work.

Alton: *I remember when I was doing this last job I had, I worked in a lobby area, and the cold air comes in. Especially downtown, it's real cold when the air whips around the building. But I always wore a hat. ... My supervisor came in one day and said, "Listen, you can't wear a hat." I'd been wearing a hat for 6 months. All of a sudden I can't wear a hat, so I asked him why. It's not in uniform. I had to wear a suit every day. So I told him I have to have a hat so I don't get too cold and get a spasm. So I asked him, "Look at this suit I have on. It's two size big." So pulled my collar open, and he see I have two layers of thermal. I said, "I've been wearing this all year long because, in this building, it's very cold. I have to take care of my body." So I was educating him that you have to take care of your body. ... And you don't really want to see me spasm, because my spasm be so bad, it can lift me up."*

Allen and others continued this line of conversation, reinforcing why communication is important:

Allen: *There's a lot of times it's education for that person. That job or HR department or supervisor, even co-workers, you're an educational experience for them. So everybody doesn't have to know your business, but there are people you have to communicate with to let them know what's going on about you.*

As noted by Victoria, the way in which you communicate and advocate for yourself should be considered.

Victoria: *You've got to be prepared that if you need assistance or you want to participate, that you are advocating. It's all about self-advocacy and realizing that sometimes you may*

not get your way and accepting that. I don't usually go into it thinking that, but there are always times when something doesn't work out perfectly, and the way you deal with that is important, especially in the workplace. You can get mad and threaten to call the EEOC [Equal Employment Opportunity Commission], or you can say, "Maybe I should talk to HR about this." I'm not saying I don't go to rage in other areas, but I definitely don't go into rage at work. That's important to maintain your temper if you're disabled or not.

Developing relationships with other people within the work environment was one way to facilitate accommodations that would support health and maintain employment.

Jeffrey: *Yeah, human resource people are good, especially ones at my company. They've asked if I needed anything. They're based out of Texas. I actually had the vice president of the company fly up to meet me, and she was real nice and supportive and asked if I need accommodations or help. So once you get your foot in the door and talk to them and explain it, everything ...*

Facilitator: *So form relationships with people in your company.*

Jeffrey: *Right. The people on top.*

Several of the participants in the Minnesota women's group suggested that classes or training in communication would be particularly helpful to those with SCI. Sabrina explained, *"You now have to use a whole new set of terminologies applied to yourself or the description of who you are."* She went on to discuss how that impacts communication:

Part of it is education, communication. People with disabilities should take communication training because in the tone of your voice and how you come over, they tend to look at disabilities as uneducated. It's "do you have the skills to communicate what you want in their language?" That gets you in the door because you sound like you know something. Again, how we talk about ourselves or how you see and talk about yourself with a disability with the ease of it's okay for me to roll into the room so they know that's not an obstacle for you.

Secondary conditions and aging with SCI

For many of the participants, secondary conditions resulted in the end of their work life. Health problems may have resulted from their failure to perform the behaviors needed to maintain health or additional health challenges that arose. Frequently though, it was just aging and associated physical decline, including fatigue, that led them to end their work life. The problems

identified by the participants appear to be common late complications of SCI (eg, osteoporosis with fractures and related complications; shoulder degeneration correlated with higher wheelchair propulsion activity) that are exacerbated over time and with age, rather than being a direct function of age itself. Most of the narratives in this theme reflect the participants' inability to maintain employment while managing the changing impairments and health demands they face as they age with SCI.

In about 2003 when I was putting in applications with my chair . . . ended up breaking my leg, having pulmonary arteries that gave me pulmonary hypertension, went on medication and everything else, and said maybe that's it for a while.

A participant in another group shared:

Eloise: . . . The surgeries affected me going back to work, but it also affected my whole life. That being said, anytime you have anything like that, it's going to be harder to maintain a job.

Often, though, participants talked about age impacting functioning.

Kevin: Somebody mentioned that as we age, the stamina lessens. That goes without saying; but toward the end, I used to roll out of bed at seven and get to work at eight and work until whenever. But my God, toward the end I had to get up at ten to five to get there.

Chester: Because it took longer to get ready?

Kevin: Absolutely! Everything took longer. My shoulders are shot and a myriad of other things. It got more difficult. That's why I hung it up. Plus I wanted to work until 66 just because I wanted to do that to fulfill my work life because that's where I came from. But anyway, it just became difficult. Life is very hard. Now everything takes longer.

A variation of this was age-related declines that resulted in an unwillingness to continue working due to the impact on other areas of their life. Kevin continued to explain his retirement:

I figured if there is something I want to do like travel or whatever, I'd better do it now because I can see, physically, I'm on the downside. The slide is pretty slippery. I can feel a decline.

Other participants who had left work after experiencing secondary conditions or injuries were interested in returning to employment but were cautious about doing so for fear of once again experiencing problems or because of loss of compensation and benefits.

Joanne: It's also frightening because if you're waiting, when you go from Social Security back to the workforce, you better know you're going to do that job and get back and forth to

work because most employers are not going to wait for you. The money you make is withdrawn from Social Security benefits slower and slower. Eventually you've lost benefits. It's hard if not impossible to get back to it because you need three or four . . . The last year and a half I was missing a lot of work (unexcused absences) to prove I might have to go back on disability again because of pain management.

Only a few participants talked about their decision to continue to work despite numerous health challenges. Peggy, a White female in her 40s with paraplegia since birth, explains the decisions that she made that allowed her to continue with work:

I had that dilemma this year. I had some major surgery. Before I was driving and used to pull my wheelchair in the passenger seat. It's a lot of physical work. Now I don't see myself doing that like I was able to because I can't bend and not as flexible. I was worried about that. I work from home now, but I was like "Am I going to be happy with that" because I had always gone to a workplace and traveled. I actually miss people, but I recently decided to get a van with a lift. That has opened some doors for me and possibly some decisions. I don't think I could be happy out of work.

Another individual who maintained work despite significant health challenges was Edmund, an African American male with tetraplegia in his 50s. In the narrative below, he shares both his motivation for continuing employment and how he worked with employers to be able to do it:

Actually, this year since I've been going through all the things the first five months, this was going to be my last year. I was going to give it up because everything's jumping on me at one time (the injury that kept me in rehab for five months). But the job, they wouldn't let me quit. They kept calling me, and "Ah, you know I got to quit," and "You know we need you." And this sort of job encourage me not to quit. . . . With my two jobs that I have, I have not switched many jobs, I had only two jobs in 28 years, so the jobs have been really good working with me. Like you said, I would tell them the type of situation I have because, when I first got hurt, I had a lot of urinary tract infections. That would take me off work some days and take medication. Sometimes when you take medication, sometimes it makes you have bowel movements, sometimes sweats and chill fever. So I would have to leave and go home while I'm working. So instead of them getting rid of me for having to leave so much, they work with me at both jobs and the job I'm working with now. See I work overnight now.

Discussion

Results from this qualitative study highlight the importance of addressing health-related issues and teaching health management skills to

enhance individuals' employment outcomes across their work lifecycle. Immediately after the SCI, individuals need to relearn their body and how it functions and then condition it to meet the demands of employment. Once on the job, they must balance the demands of their employment with the regular performance of health management and wellness activities; for those with high-level injuries, this includes engaging and effectively managing personal care attendants who assist with the activities of daily living that must occur before individuals can get to work. Individuals with SCI who work must also learn how to communicate effectively with supervisors, co-workers, and others in the work environment to educate them and advocate for appropriate accommodations to maintain employment. Finally, a strong connection appears to exist between poor health (whether associated with secondary conditions or aging) and the decision to leave employment and end the work lifecycle. For this group, health management may be associated with encouraging flexible approaches and problem solving, altering environmental factors, and reducing anxiety and fear of losing benefits.

Findings from this study appear to extend the TRPM¹⁴ and clarify that while employment is a protective factor for mortality, it is also a primary outcome in itself. The themes identified in this study provide information about the specific skills and health behaviors that allow individuals to maintain employment after SCI; these can then be used as the focus of interventions to be provided following injury.

Limitations

Threats to validity may come from several sources, including haphazard processing, analysis, or interpretation of the narratives; failure to demonstrate construct validity, external validity, or generalizability; and reliability. The detailed transcription process and data analytic methods were designed to limit these threats to validity as was the use of 2 group facilitators. We added elements to the plan of evaluation to ensure 90% agreement in coding between the 2 facilitators. Additionally, while participants represented

a variety of backgrounds and employment experiences, the results are not generalizable to the SCI population as a whole but provide a framework for further study of qualitative employment outcomes.

Future research

Until research and practice focus on a wider array of predictors and outcomes, people with disabling conditions, even when employed, will lag behind the general population in quality of employment, quality of life, and longevity. The data from this qualitative study should be used to inform the types of issues that are assessed in research and asked about in clinical practice.

Conclusion and implications

Learning to manage health after SCI can be a long and complicated process that is dependent on numerous personal and environmental factors. Four behaviors associated with the management of SCI appeared to particularly impact employment – relearning one's body and how to do things; general health and wellness behaviors; communication, education, and advocacy; and aging and management of secondary conditions. Participants emphasized how success required taking responsibility for doing these actions themselves. Themes identified through this study may serve as a starting point for the development of interventions to enhance employment outcomes after SCI.

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REFERENCES

1. Lucas RE, Clark AE, Georgellis Y, Diener E. Unemployment alters the set point for life satisfaction. *Psychol Sci*. 2004;15(1):8-13.
2. Lin CC, Rogot E, Johnson NJ, Sorlie PD, Arias E. A further study of life expectancy by socioeconomic factors in the National Longitudinal Mortality Study. *Ethn Dis*. 2003;13(2):240-247.
3. Krause JS, Edles P, Charlifue S. Changes in employment status and earnings after spinal cord injury: A pilot comparison from pre to post injury. *Top Spinal Cord Inj Rehabil*. 2011;16(4):74-79.
4. Krause JS, Saunders LL, Staten D. Race-ethnicity, education, and employment after spinal cord injury. *Rehabil Couns Bull*. 2010;53:78-86.
5. Wise HH, Brotherton SS, Thomas JK, Krause JS. Employment outcomes: Health factors and role of the physical therapist. *Top Spinal Cord Inj Rehabil*. 2004;9(4):11-18.
6. Anderson CJ, Vogel LC. Employment outcomes of adults who sustained spinal cord injuries as children or adolescents. *Arch Phys Med Rehabil*. 2002;83(6):791-801.
7. Lidal IB, Huynh TK, Biering-Sorensen F. Return to work following spinal cord injury: A review. *Disabil Rehabil*. 2007;29:1341-1375.
8. Krause JS. Aging and self-reported barriers to employment after spinal cord injury. *Top Spinal Cord Inj Rehabil*. 2001;6(3):101-115.
9. Liese H, MacLeod L, Drews JR. Barriers to employment experienced by individuals with mobility impairment. *SCI Psychosoc Process*. 2002;15:157-157.
10. Mitchell JM, Adkins RH, Kemp BJ. The effects of aging on employment of people with and without disabilities. *Rehabil Couns Bull*. 2006;49(3):157-165.
11. Krause JS, Terza JV, Dismuke C. Earnings among people with spinal cord injury. *Arch Phys Med Rehabil*. 2008;89(8):1474-1481.
12. Krause JS, Saunders LL, Acuna J. Gainful employment and risk of mortality after spinal cord injury: Effects beyond that of demographic, injury and socioeconomic factors. *Spinal Cord*. 2012;50:784-788.
13. Krause JS. Secondary conditions and spinal cord injury: A model for prediction and prevention. *Top Spinal Cord Inj Rehabil*. 1996;2(2):217-227.
14. Krause JS, Saunders LL, DiPiro ND, Reed KS. Theoretical risk and prevention model for secondary health conditions and mortality: 15 years of research. *Top Spinal Cord Inj Rehabil*. 2013;19(1):15-24.
15. Krause JS, Carter RE, Pickelsimer E. Behavioral risk factors of mortality after spinal cord injury. *Arch Phys Med Rehabil*. 2009;90(1):95-101.
16. Krause JS, Broderick L. Patterns of recurrent pressure ulcers after spinal cord injury: Identification of risk and protective factors 5 or more years after onset. *Arch Phys Med Rehabil*. 2004;85:1257-1264.
17. Krause JS, Bozard JL. Natural course of life changes after spinal cord injury: A 35-year longitudinal study. *Spinal Cord*. 2012;50(3):227-231.
18. Morgan DL. *Focus Groups as Qualitative Research*. Newbury Park, CA: Sage; 1988.