

Constructing Recovery Narratives: Experiences and Expectations Following Spinal Cord Injury

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Abstract

Purpose: This study aimed to explore how married individuals construct narratives following spinal cord injury (SCI).

Design: Prospective qualitative study.

Methods: Eighteen married people with SCI were recruited during inpatient hospitalization. In-depth interviews were conducted at approximately 1, 4, and 7 months post-SCI. Interviews were analyzed using thematic analysis.

Findings: Participants constructed three primary narrative types (optimistic, anxious, and stability) about their trajectories following SCI, focusing on their expectations about recovery and their past and current experiences with their spouse, peers, and health professionals. These narrative types are the foundation for understanding how people make sense of the rehabilitation experience in relation to others.

Conclusions: Findings provide an initial understanding of how expectations of life with SCI as well as social interactions in the healthcare setting influence experiences of injury and recovery.

Clinical Relevance: Findings can inform future interventions during SCI rehabilitation to ease transitions and decrease anxiety following SCI.

Keywords: Married persons; personal narratives; qualitative research; rehabilitation center; spinal cord injury.

Introduction

Approximately 17,000 people of all ages sustain a spinal cord injury (SCI) each year, and almost 300,000 people are currently living with SCI in the United States (National Spinal Cord Injury Statistical Center, 2016). Men account for 80% of new cases, and 64% of new cases occur among non-Hispanic Whites (National Spinal Cord Injury Statistical Center, 2016). SCI primarily affects people during their early adult years with the mean age for all patients of 34.9 years (National Spinal Cord Injury Statistical Center, 2015). This age is when many people are in the first decade of marriage, engaged in full-time employment, and have young children. Although more than half of people with

SCI are single at the time of injury (51%), those who are married (32%; National Spinal Cord Injury Statistical Center, 2015) are at increased risk of marital instability, especially in the early years post-SCI (Kreuter, 2000).

Social scientists have employed varied frameworks when examining sudden or traumatic illness, but two dominant narratives—illness trajectories (Strauss et al., 1984) and biographical disruption (Bury, 1982)—exist in most of the literature surrounding the illness or injury experience and transitions following illness. Strauss et al. (1984) introduced the concept of the illness trajectory, which is useful for examining linkages between individual experiences of illness or injury and the broader social experiences in the medical setting. This has been a useful concept for examining stroke (Becker & Kaufman, 1995), chronic illness (Markle, Attell, & Treiber, 2015), and care transitions (Godfrey & Townsend, 2008). The illness trajectory is inclusive of the entire scope of the illness and includes patients, family members, and health professionals (Wiener & Dodd, 1993). Scholars have identified three dimensions of the illness trajectory: the medical prognosis, the “sickness career” of the individual, and the personal narrative, which emphasizes how individuals make sense of the other two dimensions (Becker & Kaufman, 1995; Corbin & Strauss, 1987). Personal narratives allow patients to interpret their condition through their interactions with

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health professionals and family members and ultimately shape a personal narrative of the future (Becker & Kaufman, 1995).

Although Strauss and colleagues emphasized illness trajectories as occurring over time, Bury (1982) viewed illness as a disruption of everyday life. Illness, such as arthritis, disrupts an individual's future biography and challenges their daily social, physical, and emotional lives (Bury, 1982). Biographical disruption has become the most prevalent perspective for examining the relationship between self and illness (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2004), especially surrounding sudden traumatic injuries resulting in changes in neurological functioning such as brain injury, SCI, or stroke (Bourke, Hay-Smith, Snell, & DeJong, 2015; Dickson, Allan, & O'Carroll, 2008; Lewis, Willis, Yee, & Kilbreath, 2016). Although this body of research relies heavily on the concept of biographical disruption, multiple mitigating factors impact how illness influences an individual's biographical narrative. For example, interactions with health professionals (Hammell, 2007), the physical environment (Nunnerley, Hay-Smith, & Dean, 2013), family members, or others with similar health conditions shape narrative construction. In addition, the injury or illness might not be perceived as a biographical disruption but as just one of many challenges in life (Becker, 1993; Becker & Kaufman, 1995).

The concepts of illness trajectories and biographical disruption are useful for understanding how people make sense of chronic illness or sudden injury. However, both frameworks focus on the individual experience and not the experience in relation to partners or spouses. There is limited research exploring how people, in particular married people, experience and make sense of sudden injury early in the rehabilitation process. Sustaining an SCI at any point in time can be life altering—physically, emotionally, and financially—for all persons affected by SCI. Adapting to SCI can provide unique challenges for younger married people because of their individual and shared life course including less financial and career security and the shorter duration of the relationship (Kreuter, 2000). Both partners involved in the injury face uncertainty about the future and the concern about whether their relationship will “survive” (Kreuter, 2000). The experience of sustaining an SCI might magnify or modify existing problems in a relationship, create a burden for one partner, or impede life satisfaction for both partners (Chan, 2000). Couples experiencing brain injury report having moderately high levels of relationship stability and satisfaction while simultaneously reporting moderate levels of conflict (Agyemang, Marwitz, & Kreutzer, 2017). In a longitudinal study of subjective well-being among people with SCI, Cao, Krause, Saunders, and Clark (2015) overall found a complicated

relationship between marital status and subjective well-being. Specifically, they found that married and cohabiting participants had higher levels of subjective well-being when compared to single participants; however, satisfaction in some domains declined over time, and they had slight increases in social isolation (Cao et al., 2015).

Building on previous research on narrative construction surrounding life events (LaRossa & Sinha, 2006; Zerubavel, 2003), we extend these concepts of illness trajectories and biographical disruption to incorporate social and interactive influences on how individuals make sense of sudden injury or illness. In this article, we examine how married individuals construct narratives following SCI and how their interactions with partners, practitioners, and others influence their experiences in the first months following injury. Through analysis of prospective and retrospective narratives, we explore how married individuals make sense of the transition to injury across the spectrum from inpatient to community settings.

Methods

Design

This prospective qualitative study involved married adults ages 21–55 years with one partner experiencing a traumatic SCI within 1 month of the first interviews. Recruitment occurred in a large spinal rehabilitation center in the southeastern United States. This center is part of the SCI model system, which is identified as providing the highest and most comprehensive level of care (Special Interest Group on SCI Model System Innovation, 2010). The first author conducted individual interviews at three time points with 18 individuals who recently experienced SCI, resulting in 49 completed interviews. We chose the three time points for interviews based on the typical stages of care for patients in this center: approximately 1 month following SCI (Int. 1) during inpatient care, but following acute care; 3 months following the first interview (Int. 2), which typically coincided with intensive outpatient care; and about 6 months following the first interview (Int. 3) following the transition home. The timing of follow-up interviews varied slightly to accommodate the respondent's current health or living situation. The three interviews allowed for a rich understanding of adjustment for people with traumatic SCI over time.

Sample and Setting

In order to be included in the study, respondents had to meet the following two criteria. First, they had to have sustained a new SCI without cognitive impairment and started inpatient acute therapy no less than 1 month before

the first interview. Persons with a previous SCI or brain injury caused by surgery or disease were excluded. Second, they had to be married or cohabiting and under the age of 55 at the time of injury. Although people do not anticipate SCI at any point in their life course plans, people frequently associate disability with onset at birth or in later life. Capturing the experiences of individuals in early and mid-adult years, which typically are characterized by numerous demands of raising children, caring for parents, and full-time employment, allowed us to examine SCI in relation to these potential competing demands. Five rehabilitation counselors served as gatekeepers in this study by identifying eligible participants, introducing the study, and asking for consent for researchers to contact the couple. The counselors then facilitated introductions. Participants were recruited until we reached saturation at the first interview point.

Participants were recruited over a period of 14 months, and we made efforts to pay attention to various sociodemographic and injury characteristics where feasible. We were given consent to contact 24 eligible participants, of which 18 agreed to participate. Overall, 18 patients with SCI participated at the first interview point, 16 at the second interview point, and 15 at the third interview point, for a total of 49 individual interviews. Only one participant gave a reason for leaving the study, stating it was too difficult to schedule with young children and care needs. Others who did not continue did not return calls or messages to schedule follow-up interviews. Data from the 15 respondents (45 interviews) retained through the end of the study are included in this analysis.

Data Collection and Analysis

Existing literature (cf. Becker, 1993; Chan, 2000; Corbin & Strauss, 1987; LaRossa & Sinha, 2006), previous interviews (Bender, 2012), and observations over 14 months in the rehabilitation center informed each semistructured interview. The initial interview guide was pilot tested with an individual living with SCI who provides peer support to newly injured patients. As data collection progressed, interview questions were added or modified to achieve data saturation (Strauss & Corbin, 1998). The interviews began with a broad question about the respondent’s current and recent life events, including details surrounding the SCI and relationship history at Int. 1. Participants were also asked questions about their routine, formal and informal social supports, sexuality and intimacy, and interactions with rehabilitation providers. The three interviews used a combination of retrospective and prospective questions to examine how participants experience this transition over time. Table 1 includes sample interview questions and probes.

The first author conducted in-person, individual interviews in patient rooms, private spaces within the rehabilitation center, or participants’ homes, and the interviews lasted between 40 and 90 minutes. For participants living more than 250 miles from the main study site, the first author conducted follow-up interviews via telephone. Interviews were digitally recorded, transcribed, and analyzed using thematic analysis (Boyatzis, 1998; Braun & Clarke, 2006). The first author initially analyzed data line by line by constantly comparing instances within the data

Table 1 Sample interview questions

Main Question	Topics for Probes (Not Exhaustive)
1. Tell me a little about your relationship with your partner. ^a	Relationship history ^a ; significant milestones or changes; shared/differing interests or upbringing ^a ; satisfaction; conflict; sexuality and intimacy
2. Describe your average day and routines before the injury.	Activity involvement; interest in activities; employment; leisure; decision-making; division of household and paid labor; changes since we last talked
3. Tell me about your friends and family.	Satisfaction; conflict; activities; response to injury
4. Tell me about your injury ^a and where you are today.	Initial thoughts about SCI; expectations of recovery/meeting expectations; support received; fears
5. What kinds of conversations have you had with your partner since your injury/we last talked?	Shared fears; concerns; hopes; avoidance
6. I would like to know about your rehabilitation process.	Positive/negative events and interactions; goals; successes; frustrations; anticipation; ADL/IADL assistance; inclusion of partner/friends
7. What are your expectations going forward?	Short term; long term; various aspects of life; hope; concern
8. Is there anything we haven't covered that you think is important to discuss or to know about you or your relationship with your partner?	

Note. ADL = Activities of Daily Living; IADL = Instrumental Activities of Daily Living.

^aOnly asked at Int. 1.

Table 2 Demographic characteristics at Int. 1

	%	n
Age (years)		
Under 30	13	2
30–39	27	4
40–49	47	7
50+	13	2
Race		
Black	7	1
White	93	14
Gender		
Female	11	2
Male	89	13
Education		
High school	27	4
Some college	33	5
College graduate	40	6
Income		
\$12,501– \$25,000	13	2
\$25,001– \$32,000	20	3
\$32,501– \$50,000	20	3
\$50,001– \$62,500	27	4
\$62,501– \$75,000	7	1
\$75,001	13	2

and applying codes to the text as concepts emerged. Related concepts were combined into categories and grouped into themes to summarize the key ideas and experiences discussed by the participants (Creswell, 1998).

Initially, the first author open-coded each transcript individually and then met regularly with the coauthor to discuss each transcript, the coding structure, and revisions to the interview guide to achieve theoretical saturation. In addition, the first author engaged in member checking (Kuzel & Like, 1991) with all participants during each follow-up interview and with a sample of participants at the end of data collection. The first author presented preliminary findings to confirm interpretation of findings and identify any inconsistencies. On completion, the first author retroactively applied the final coding structure to all 45 transcripts to ensure that early transcripts were coded for concepts that emerged during later data collection and analysis. NVivo qualitative software Versions 9 and 11 were used to facilitate data organization.

All participants were informed about the aims and procedures of the study and gave their informed consent. The institutional review boards at both Georgia State University and the center approved this research. Names and identifying information of participants were kept confidential. Specific level of injury and other identifying characteristics were removed to increase confidentiality among these participants. Participant names reported here are pseudonyms.

Results

Sample Characteristics

The sample of SCI patients was predominately White, middle aged, educated, and male. We aimed to sample based on characteristics similar to the general population of people with SCI, but given the unpredictability of SCI, we were not able to achieve this goal in all areas. There was a range in household income at the time of injury, but most couples were above the U.S. median household income for married couples (\$61,335). Table 2 details participant demographics at the first interview point. Participants' length of marriage varied from 2 weeks to 37 years, with a mean marriage length of 11 years at the time of injury, and it was the second marriage for two participants and the only long-term intimate relationship for four participants. Although the study did not exclude cohabiting couples, we only had married couples who met the eligibility criteria for inclusion in the study and who expressed interest to participate. In this analysis, there were no notable differences in narratives of recovery by length of marriage. Causes of injury included external events (e.g., auto accidents, falls) and health-related events (e.g., spinal stroke, abscess). Table 3 includes these participant characteristics, pseudonyms, and severity/level of SCI for each participant.

Constructing Recovery Expectation and Change Narratives

Following SCI, participants constructed narratives about their trajectories, which focused on their expectations about recovery and their past and current experiences with their spouse, peers, and health professionals in the rehabilitation

Table 3 Participant pseudonyms and characteristics

Pseudonym	Years Married at Time of SCI	Cause of SCI	Severity/Type of SCI
Derek	12	Gunshot	Complete quadriplegia
Steve	10	Spinal stroke	Incomplete paraplegia
Jeff	12	Fall	Incomplete quadriplegia
Brenda	15	Auto accident	Incomplete paraplegia
Timothy	6	Work related	Incomplete paraplegia
John	37	Viral infection	Incomplete quadriplegia
Don	6	Auto accident	Incomplete paraplegia
Chuck	24	Abscess	Incomplete paraplegia
Keith	6	Abscess	Incomplete quadriplegia
Scott	2	Auto accident	Incomplete quadriplegia
Jesse	4	Auto accident	Complete paraplegia
Marcus	12	Work related	Incomplete quadriplegia
Lisa	10	Viral infection	Incomplete paraplegia
Phil	0.1	Fall	Incomplete paraplegia
Jim	10	Auto accident	Incomplete paraplegia

Note. SCI = spinal cord injury.

center. We found three primary themes or narrative types, which varied by direction (i.e., positive, negative, no change), time (i.e., looking forward or based on previous experiences), intensity, and focus (e.g., relationship, health, employment). These components of narrative construction emerged from the data and were not part of an a priori model of narrative construction. The three narrative types were as follows: 1) optimistic narratives, which emphasize hope and positive outcomes and focus on how things will be better as time passes and recovery is realized; (2) anxious narratives, which represent feelings of hopelessness, fear, uncertainty, and resignation, emphasizing negative change or ambiguity following SCI; and (3) stability narratives, which, although rarely used, indicate little to no change following the event. These narrative types reflect how married individuals make sense of their experiences at any point following SCI (i.e., inpatient hospitalization, transition home, community settings). The use of these distinct narrative types varied depending on the area of focus or timing of the interview in relation to other life events. One or more narratives could exist simultaneously across different domains (e.g., optimistic about recovery while anxious about relationships).

Optimistic Narratives

At the first interview, the injury experience was overwhelming for most participants, and their days were dictated by the needs of the rehabilitation center schedules and routines. For many, the primary focus was on positive and tangible recovery goals and outcomes. Rehabilitation goals set by and with therapists frequently included walking. At the center, walking can be laborious and require extensive assistance, yet respondents found hope in the possibility that recovery would entail walking and narratives at Int. 1 reflected this hope. For example, Lisa (incomplete paraplegia resulting from a viral infection) said, "I hope to be walking...my plan is to walk out of [the center]." As people transitioned away from the support of the center, goals of independence, such as showering alone or driving, replaced the emphasis on walking. At Int. 2, Jim (incomplete paraplegia from an auto accident) said,

I'm in a chair...I'm much more independent than I was last time we spoke. I can almost do everything myself, in other words, dress, eat, cook, get in the bed, get out of the bed, use the rest room. When we first spoke, I couldn't do any of that...and I've just gradually made some changes. The body has just, for lack of a better word, I guess, just evolved to this point...But I've been workin' out very hard...I'm just tryin' to get as strong as I possibly can, so I can do transfers, so I can sit up without, you know, leaning on something, uh, and just trying to get really as strong as I can.

At Int. 1, Jim was hopeful he would be able to walk and make a full recovery. He realized over time that his paralysis was likely permanent yet he remained optimistic by shifting his focus and working to build strength to maintain independence.

After injury, many participants reflected on their life and priorities before their injury. At Int. 1, participants frequently stated how much the injury drew them closer to their spouse and resulted in "learning to love each other more." In addition, participants described the injury as a "wake-up call" that will "help put things in perspective." This included a desire to shift their focus to their relationship or spirituality, rather than allowing work and external obligations to overwhelm them. This perception decreased in frequency and intensity in later interviews as people transitioned home and other obligations such as work and children reentered their lives.

Optimistic narratives about recovery and relationships were also constructed through a combination of looking back to early rehabilitation experiences and looking forward to future goals. As Chuck (incomplete paraplegia from a spinal abscess) at Int. 2 said,

So much stuff happened over the five weeks that I was in-patient...so everything was a step forward and then after awhile [progress] stopped and then you talk to your doctor about it and he goes, well, those things normally 6 months to a year...so, I was fortunate to start feeling what I was feeling, [at] the 3-4 week part...I just keep hoping that...as...we go on and keep working that we're not hitting the wall anymore...things are gonna start going ahead for us, and for me and the way I'm feeling, so, we'll see.

Anxious Narratives

Anxious narratives were complicated and focused on challenges, fears, or uncertainty related to recovery, finances, and relationships with friends and children. Anxious narratives were the most frequently used narrative type. Of the 15 participants who we followed for all three time points, the five who were experiencing limited recovery had the most consistently bleak narratives. Moreover, respondents who had perceived lower levels of social support and higher levels of uncertainty about future employment tended to be more pessimistic about their situation. Many participants focused on how their injury would affect their ability to provide for their family. Derek (complete quadriplegia from a gunshot) at Int. 3 said,

It scares me going back to work and just because I'm going to be so slow. Again, I just don't want to screw anything up. I don't want to disappoint

Amanda, and I don't want to screw the family up as far as money. Yeah, I just don't want it to get messed up anymore than it has been.

Participants also expressed concerns about returning home and not being able to share in cherished traditions with their partners:

I just [wish] that I could get out of this chair... um, for instance, we enjoy just walkin' around the yard together, lookin' at the trees, lookin' at the grass, lookin' for ant hills to get rid of and you know, I'm not able to do that...and that's frustrating. (Lisa, incomplete paraplegia from a viral infection, Int. 2)

Anxious narratives also included a high level of uncertainty about multiple facets of life following injury. Respondents in this study frequently spoke of life “in transition” or “in limbo,” the inability to focus on the future, and the difficulty in making decisions because of waiting for information from others.

Social interactions and limited guidance from professionals within the rehabilitation setting further shaped the uncertainty and anxiety for participants. The center, in general, and staff members' messaging, in particular, influenced how people construct the transition to injury. This was especially clear among respondents with incomplete injuries. As Steve (incomplete paraplegia from a spinal stroke) at Int. 3 said,

They don't have...hardly any research or documentation what the outcome can be, so they really don't know what to tell ya. So it's one of those things that, you know, they can't guarantee.... They don't know enough about it to tell ya that might not happen or will happen kind of thing. So you know, at this point, I'm kinda frustrated. I'm in that limbo space that I've got to either try to walk or its not gonna be possible then I've got to look forward to making the best I can with bein' in the wheelchair.

Practitioners were frequently unwilling to provide concrete outcomes because SCI varies, but respondents wanted at least some short-term guidance. These interactions further intensified the feelings of frustration and uncertainty for respondents in this study. For example, Jim (incomplete paraplegia from an auto accident) at Int. 2 said,

I've spoken to voc[ational] rehab about goin' back to work and I was told 'wait'...wait 'til all the Medicaid and disability goes through, which is still a couple of months, couple, three months away from that goin' through, so, I'm kinda just bidin' my time....

Anxious narratives focused on loss, frustration, and uncertainty. In these narratives, respondents had difficulty in constructing a positive future with SCI particularly on dimensions that they defined essential to adult identity, such as the role of provider, spouse, and parent.

Stability Narratives

In contrast to optimistic and anxious narratives, the stability narrative represents consistency, real or desired, across time. This narrative was more common among participants with high rates of recovery, and stability narratives frequently relied on recovery as an anchor point across time. Jack (incomplete paraplegia from a fall) at Int. 2 highlighted this return to normalcy when talking about his return to work:

It's almost like I was gone, and there I am. Within a week, I was back to normal from that [work] standpoint. Even though there is some times it still it just, you know, hurts me and you know, cooped up sitting there. I'll get up and walk around and stuff, but really, there's—nothing really changed. It's great.

Because the first 6 months following SCI was a period of adjustment, it was difficult for people to find and focus on stability in their lives. However, despite the event of SCI, some participants were able to focus on continuity, particularly if they felt that important dynamics in their relationships had not changed such as humor, shared activities, or shared beliefs. Brenda (incomplete paraplegia from an auto accident) at Int. 2 said,

That's the part that has never changed, even though we went through all kinds of whirlwinds. The basics haven't changed, that we want our kids to believe in God and do the right things and make the right choices and look the right ways.

Tim (incomplete paraplegia from a work related accident) at Int. 2 describes his time in the residential outpatient therapy program as the thing that will return his life to how it was before the injury. He said,

Every day's been well worth it, you know, for the help I'm gettin' and we know it's not gonna be forever if we just tough it out for a little bit longer, it'll be back to where we'll be together every night, everything'll be back to normal...so it's, it's nothin' that we can't handle.

Discussion

The goal of this study was to explore how married individuals with SCI create meaning and construct narratives by focusing on life before injury at the current point in

time and hopes and fears of the future. Everyone constructs a story of their lives by selectively focusing on some events and ignoring others (Zerubavel, 2003). Interactions with other people serve as reference points and influence narratives of the future or narratives of change. Building on previous research about narrative construction surrounding life events (LaRossa & Sinha, 2006; Zerubavel, 2003), this study examines how married people construct narratives during an unexpected event and how these narratives are filtered through the context of rehabilitation.

Participants' previous life experiences influenced how they constructed narratives about their past, present, and future after the transition of SCI. In addition, the level and severity of the patient's injury shaped narratives. Although existing frameworks such as illness trajectories (Strauss et al., 1984) or biographical disruption (Bury, 1982) are useful for understanding the individual transition to injury, we found that the narratives constructed by the married participants in this study are complicated by interpersonal interactions and social context. This conceptualization of narrative construction addresses a critique that the presentation of illness narratives overemphasizes the individual experience and they need to include the social context and different levels of experience (Bury, 2001). In addition, our perspective allows for the interactive nature of trajectories in ways that will allow for addressing dyadic narratives. People do not experience life or illness in clean, discrete phases (Papadimitriou & Stone, 2011; Zerubavel, 2003). Similarly, experiences and expectations following SCI do not follow a linear story line. The narrative types presented here are the building blocks for understanding how people make sense of the rehabilitation experience, which they do by focusing on both internal (e.g., strength) and external (e.g., family) needs with varying intensity. Married individuals construct narratives in relation to their spouse, which can complicate experiences and expectations following SCI. Because the SCI experience is dynamic and encompasses several dimensions and trajectories, individuals employ multiple narratives over time.

In addition to past experiences and relationships, interactions and expectations in the rehabilitation center also influenced narrative construction. For people experiencing traumatic SCI, the intense nature of an inpatient specialty hospital setting puts them in close contact with others experiencing the same event, as well as ongoing contact with counselors and staff in the center. The mission of the center is to "help people...rebuild their lives with hope, independence and dignity," which is prominently displayed in hallways and throughout the building. The emphasis on hope and independence is clear in respondents' narratives and has been examined in previous literature (Soundy, Stubbs, Freeman, Coffee, & Roskell, 2014; Van Lit & Kayes,

2014). Although nurses, therapists, and counselors explain that independence does not have to mean walking, participants in this study perceived walking as an important element of recovery during our early interviews. Participants who did not experience high levels of functional improvement—especially walking—had the least hopeful narratives, partially because their outcomes were not congruent with their expectations. Transition points, such as the return home, were difficult for some, especially for participants with limited social support or those who realized in hindsight how much they or their spouse relied on the center for encouragement.

Furthermore, the challenge for individuals in the face of a catastrophic injury or illness is not merely the experience of loss (Dickson et al., 2008) or burden as the result of illness but the uncertainty about the illness and potential recovery (Becker & Kaufman, 1995; Giovannetti et al., 2017), which can result in anxious narratives. In the immediate months following SCI, individuals may experience ambiguous loss or lack of clarity on what exactly has been lost. Boss (1987, 2007) explains ambiguous loss in both physical and psychological terms. Although the person with injury is still physically present, they are present in a different form than before injury, and it is not clear what recovery will look like for that individual. Uncertainty and worry are common during transition points, and interactions in the rehabilitation setting can increase or decrease worry about care transitions (Sawin et al., 2015).

This study had some limitations. This research was conducted in one specialty hospital that is recognized as a SCI Model Systems Center. Approximately 20% of the 17,000 new cases of SCI each year receive inpatient treatment at a model systems center (National Spinal Cord Injury Statistical Center, 2016), and of those, 25% are treated at our focal center. Therefore, the participants in this study were likely different from others with SCI because of their exposure to the model system of care, which included clinical research and cutting edge treatments likely unavailable in local or regional hospitals. Recruiting and retaining participants with various experiences were limited. It also is possible that people facing multiple stressors were less likely to agree to participate in the study and those who had difficult transitions home were less likely to return follow-up calls. As such, these narratives of participants with less stress before and after the transition may be overrepresented in our sample. Finally, because of the unpredictability of SCI, it was difficult to achieve variability on a number of demographic characteristics, in particular race and gender. Our sample was mostly White and middle class, which mirrored the patient demographic of the center during recruitment; however, this does not reflect the larger SCI population.

Key Practice Points

- Following spinal cord injury, people construct complex narratives based on their life experiences, relationships with spouses and peers, and expectations of recovery.
- Acknowledging the multiple narratives that people construct following SCI allows for an understanding of the multiple dimensions and perspectives that are in play during the recovery and rehabilitation process.
- Within the rehabilitation setting, emphasis on walking and recovery can shape people's narratives about their future and impact mental health outcomes, especially among people with limited recovery. Providing tools for managing a variety of outcomes could help support people following the transition home.
- Healthcare professionals in the rehabilitation setting (e.g., nurses, counselors, physical therapists) can help alleviate anxiety for individuals before transitioning home by providing specific guidance about home care and home modifications as early and often as possible.

We utilized gatekeepers for assistance with recruitment, and it is possible they did not mention the study to all eligible participants. Although this might have reduced the variability in the project, it was important to the research team to rely on professionals who had rapport and knowledge of their patients in order to reduce patient burden and discomfort. Regardless, this article's contribution is unique in that it sheds light on the experiences of an understudied yet important segment of the population, married, middle-aged adults managing unexpected traumatic injury.

Conclusions and Implications for Practice

Our research has implications for practitioners working with people experiencing SCI. First, acknowledging the multiple narratives that people construct following SCI allows for an understanding of the multiple dimensions and perspectives that are in play during the recovery and rehabilitation process. Rehabilitation is part physical and part social, and focusing on both during the recovery process can help newly injured patients align their experiences with their expectations. In addition, it is important to recognize and acknowledge the rehabilitation setting, especially specialty rehabilitation, is an ideal setting. Life beyond rehabilitation is complicated and not easily controlled. Second, the emphasis on walking and recovery can shape people's narratives about their future and impact mental health outcomes for people with limited recovery because of the level or severity of their injury. Providing tools and recognition of multiple recovery paths can help patients adjust if their trajectory does not align with expectations. Third, the reluctance to share possible outcomes or provide guidance about things such as the realistic need for home

modifications can create ambiguity and anxiety for individuals and their families in this process. Therefore, rehabilitation professionals can provide specific strategies (e.g., offering two variations of modification rather than avoiding the discussion) to manage ambiguity and minimize anxiety for people as they transition home. This turning point, for many, results in a reexamination of relationship dynamics and, subsequently, hope the injury will bring them closer to their spouse or family members. However, the process of going home can be stressful on the individual and their families. Therefore, it is important for rehabilitation professionals to recognize the connections patients have within and beyond the rehabilitation setting that impact their expectations and experiences and to provide guidance and support beyond the patient, especially as people prepare to leave the supportive environment of the rehabilitation setting.

Conflict of Interest

The authors declare no conflict of interest.

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