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Experience of sleep in individuals with spinal cord injury

Donald J. Fogelberg, PhD, OTR/L¹, Natalie E. Leland, PhD, OTR/L, FAOTA², Jeanine Blanchard, PhD, OTR/L², Timothy J. Rich, OTR/L¹, and Florence A. Clark, PhD, OTR/L, FAOTA²

¹University of Washington

²University of Southern California

Abstract

Background—Poor sleep contributes to adverse health outcomes making it important to understand sleep in medically vulnerable populations, including those with spinal cord injury (SCI). However, little attention has been paid to circumstances specific to SCI that may negatively impact sleep, or to consequences of poor sleep in this population.

Objectives—To examine the experience of sleep among individuals with SCI.

Methodology—Secondary analysis using thematic coding of qualitative data from an ethnographic study of community-dwelling adults with SCI.

Results—Sleep-related data were found in transcripts for 90% of the sample. Participants described diminished sleep duration and irregular sleep patterns. Several factors contributing to poor sleep were identified, including SCI-related circumstances and sleep environment. Participants also discussed how poor sleep affected occupational engagement.

Conclusion—This study highlights the extent of sleep disturbance experienced after SCI, the subsequent impact on occupational performance, and provides direction for clinical practice.

Keywords

complications of spinal cord injury; occupational engagement; qualitative research; sleep

In 2006, the Institute of Medicine published an overview of the extensive body of research that has documented the pivotal role that the occupation of sleep plays in maintaining health, function, and quality of life (Colten & Altevogt, 2006). Failure to achieve healthy sleep has been associated with a variety of poor health outcomes, including cardiovascular disease, hypertension, and weight gain (Knutson & Van Cauter, 2008; Smith, Edwards, & McCann, 2007). Poor sleep strongly correlates with increased pain, low mood, and impaired cognition (Smith & Haythornthwaite, 2004). Individuals who chronically experience either very short or long nighttime sleep durations are at greater risk of mortality (Watson et al., 2015). Given

The corresponding author for this manuscript will be: Donald Fogelberg, PhD, Assistant Professor, Department of Rehabilitation Medicine, University of Washington, Box 356490, Seattle, WA 98195-6490, Tel: (206) 598-0005, fogelber@uw.edu.

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the extent and severity of health difficulties that can stem from poor sleep, it is important to develop a clear understanding of sleep in medically vulnerable populations, including individuals with spinal cord injury (SCI).

More specifically, those with SCI are at increased risk of secondary conditions that may further impact functional ability and quality of life, including pain, depression, obesity, and pressure ulcers, all of which can be exacerbated by poor sleep. Alternatively, these secondary conditions can impact sleep quality creating a cyclical relationship that perpetuates the secondary conditions and further perpetuates poor sleep. For example, pain often interferes with sleep, which then can further exacerbate the pain due to disturbed sleep (Smith & Haythornthwaite, 2004). Insomnia is both a symptom of major depressive disorder and a risk factor for its development (Harvey, 2001). Poor or restricted sleep predisposes a person to weight gain, and obesity is a major risk factor for both sleep-related breathing disorders and pressure ulcers (Grunstein, Wilcox, Yang, Gould, & Hedner, 1993; Knutson & Van Cauter, 2008; VanGilder, MacFarlane, Meyer, & Lachenbruch, 2009; Young, Peppard, & Taheri, 2005). Therefore, because sleep is complexly related to multiple conditions commonly occurring in this population, it is critical that we better understand sleep in the context of SCI.

Although the existing literature describing sleep in the context of SCI is limited, studies of sleep in other neurologic populations, including traumatic brain injury (Fogelberg, 2012), multiple sclerosis (Bamer, 2010; Fleming, 2005), stroke (Cherkassky, 2003) and Alzheimer's disease (Vitiello, 1989) consistently find that sleep is significantly compromised by neurologic disorders. Studies that have focused specifically on sleep following SCI suggest that those with SCI experience sleep that is worse in almost all aspects than that of the non-SCI population. Individuals with SCI describe sleep that is subjectively worse and less restorative than that of the general population (Biering-Sørensen & Biering-Sørensen, 2001; Fogelberg, Vitiello, Hoffman, Bamer, & Amtmann, 2015). More specifically, those with SCI report shorter sleep duration, more daytime sleepiness, and greater difficulty falling and staying asleep, (Fogelberg et al., 2015), more frequent naps, and are prescribed more sleeping pills than those without SCI (Biering-Sørensen & Biering-Sørensen, 2001). Studies of sleep disordered breathing in individuals with SCI have consistently found prevalence rates exceeding those in the general population (Biering-Sørensen, Jennum, & Laub, 2009; Fuller, Lee, & Tester, 2013; Sankari, Bascom, Oomman, & Badr, 2014). Although these studies address specific sleep dysfunctions among the SCI population, none examines factors that may causally contribute to such outcomes, nor the impact of disturbed sleep on their daily lives. Given the complexity of both sleep and sleep disturbances, a better understanding of the types and severity of sleep disturbances would be critical in designing effective sleep interventions tailored for those with SCI.

Despite the growing recognition of sleep's critical role in maintaining health, function, and quality of life, and that clear implications for sleep's impact on occupation, very little attention has been paid to the subject in the occupational therapy literature. Green (2008) provides a comprehensive overview of the question of whether or not sleep should be considered an occupation, and suggests that this uncertainty may be one reason for the relative neglect of the sleep by the profession. Contemporaneous with Green's article, the

second edition of the AOTA Practice Framework (2008) included rest and sleep as a distinct area of occupation, providing institutional support to those arguing for sleep's status as an occupation. Although there have been a few articles focused on sleep in the OT literature in recent years, including a scoping review (Leland, 2014) and reports from two clinical trials (Gutman 2017; Leland 2016), the topic remains poorly represented within the literature.

Therefore, given the paucity of evidence in the focusing on sleep among this population there is a need to understand the lived experiences of individuals whom have had a SCI. Toward this end, much can be learned from examining the subjective experience of individuals living with SCI, especially pertaining to lifestyle and behavioral factors that contribute to secondary complications of SCI. Indeed, qualitative studies involving individuals with SCI complement the epidemiologic, diagnostic, and medical literature in areas such as bladder management (Engkasan, Ng, & Low, 2014), fatigue (Hammell, Miller, Forwell, Forman, & Jacobsen, 2009), and pressure ulcers (Clark et al., 2006). Yet, to our knowledge, there is no qualitative study examining sleep disturbance in adults with SCI. This study is an initial step in addressing that gap.

Methods

This study aims to further our understanding of the subjective experience of sleep among individuals with SCI by performing a qualitative, secondary analysis of data that were derived from an ethnographic study of community-dwelling adults with SCI (Clark et al., 2006). All research activities were approved by the University Institutional Review Board.

Participants

The total sample of participants (n=20) in the parent study from which this analysis was drawn consisted of 14 men and six women who were recruited from a medical rehabilitation facility that specializes in treating individuals with SCI. Eligible participants were individuals age 18 years or older who were fluent in English or Spanish, had been living with paraplegia or tetraplegia secondary to spinal cord damage for greater than one year, and had completed acute inpatient rehabilitation. As the primary focus of the parent study was the development of pressure ulcers, almost all participants had a history of at least one documented stage III or stage IV pressure ulcer. Purposive sampling was conducted in the parent study to maximize demographic heterogeneity (e.g., ethnicity, age, gender, socioeconomic status, level of injury, social support). In the present secondary analysis, transcripts were reviewed for all 20 participants from the parent study described above.

Data Collection

In the parent study, medical records were used to extract demographic and injury-related data. Qualitative data were collected over an average of 18 months through a series of unstructured interviews ($\bar{x}$ 11.5 sessions) and naturalistic behavioral observation sessions ($\bar{x}$ 2–3 observations). During data collection, researchers inquired about the structure of participants' days, with the goal of capturing detailed circumstances surrounding the development of pressure ulcers. Participants were not asked specifically about sleep-related issues. Interviews were audio recorded and transcribed by graduate student research

assistants. The researchers who conducted the interviews also kept field notes regarding their observations and impressions, which augmented the data contained in the audio recordings.

Data Analysis

The first author of the current manuscript reviewed all transcripts and field notes and extracted sections relating to sleep or sleep-related difficulties, totaling 130 double-spaced pages. Each participant's transcript extracts were reviewed and independently coded by at least two researchers. Transcripts were reviewed as Microsoft Word documents and codes were noted using the "comments" feature of that software. Coding was carried out in two stages: *open* and *focused* coding (Charmaz, 2006; Emerson, Fretz, & Shaw, 2011; Padgett, 2012). Open coding is an emergent and iterative process in which data are analyzed to identify categories of data without regard for the relationships between these categories. The research team then discussed the list of categories and organized them into overarching topics. This higher level organization of the categories constituted the focused coding stage of data analysis (Emerson et al., 2011). After the coding scheme was finalized, each transcript was reviewed and re-coded as needed. All participants were assigned a pseudonym, and any potentially identifying details were omitted.

Results

Demographic and injury characteristics for the 20 participants in the parent study are presented in Table 1. Eighteen of these participants (90%) discussed sleep-related issues. Two participants did not mention sleep in any significant way. Three major categories were identified: sleep difficulties following SCI, barriers to achieving sufficient amounts of high-quality sleep, and impacts of sleep disturbance on daily function. (See Figure 1). Each of these categories will be explored in depth.

Sleep difficulties

Sleep disturbance and quality—Participants frequently referenced difficulties in initiating sleep, maintaining sleep, or achieving a deep, restorative sleep. Rachel, for example, said "...I don't sleep at all. I'm just... up all night.... Even in the hospital, I cannot go to sleep. It's just like I'm usually up 24 hours.... I lay here, I'll close my eyes, I keep them closed – nothing."

Poor quality, non-restorative sleep also was described by several participants. Dave summarized his sleep problems by saying: "I don't sleep well at all. I just don't [pause], I don't sleep. I mean, I fall asleep, but it's just not a good sleep." He contrasted this with his quality of sleep prior to his SCI:

"I used to sleep like you wouldn't believe, and I can't do that anymore. I am up all night long, and then all of a sudden I will fall asleep for a few hours, and then I'll be awake for a few hours, then I fall asleep for a few hours...."

For Mitch, one of the main problems with his sleep was the lack of deep sleep: "I'm a light sleeper. When I'm asleep, I'm not even sure I'm asleep because I can hear stuff.... If I'm sleeping, and you're talking, I can hear you. So I'm not even sure if I'm sleep sometimes."

Sleep patterns and quantity—Multiple participants reported irregular and unpredictable sleep patterns, some including episodes in which they stayed awake for prolonged periods. Brenda said that after sustaining her SCI, she became: “such an insomniac... Unless I’m really, really dead-beat tired, I can basically function for two to three days on hardly any sleep at all. As long as I get a couple of naps or whatever, I’m ok.” Another participant, Steve, told the researcher that he might “fall asleep” during his interview because he hadn’t slept for over two days. In addition to prolonged periods of sleeplessness (*sleep deprivation*), participants also described habitually short nighttime sleep (*sleep restriction*). Five of the participants, for example, said that they typically slept for between two and four hours each night.

Several participants described irregular sleep patterns, including frequent daytime naps and being awake during the night. Steve’s preference for sleeping during the day and being active at night was so pronounced that he described himself as a “vampire.” Although Steve’s preference for a nocturnal lifestyle pre-existed his SCI, he stated that the stigma he experienced following his injury reinforced his tendency to avoid going out during the day. Mitch’s sleep schedule was so unpredictable that he found it difficult to answer questions about his typical daily routine:

I can’t give you a specific amount [of sleep] because it changes, and... if you just pick a week... I could tell you, but you’re saying ‘on the average’, or whatever, I can’t give you one because it changes.... I mean I go to bed different times. [If] nothing’s on TV then I go bed early. [If] I want to stay up and watch television [I might] stay up to midnight. But then again I might wake back up at two or three o’clock in the morning.

In addition to having no set schedule for going to sleep or waking, Mitch also indicated that if he was particularly tired he would take short naps during the day.

Barriers to high quality sleep

In addition to describing their overall sleep patterns, participants also shared their views on what factors hindered their attempts to get sufficient good quality, appropriately timed sleep.

SCI-related dysfunction and care—Several participants described SCI-related motor and sensory dysfunction and medical conditions associated with SCI as factors that were detrimental to achieving good quality sleep. The treatment and management of SCI-related dysfunction and medical conditions were also cited as factors influencing sleep.

Bed positioning: Multiple participants reported limited ability to position themselves comfortably for sleep, either due to paralysis or muscle weakness caused by SCI, or because of pressure ulcer prevention or healing regimens. Following a visit to Chris, a participant who had a high-level SCI, a researcher’s field note indicated:

“He talked about [how] at night, having to lie straight, with his legs [straight] out, because whatever position he gets laid in is the position he’s going to stay in for the next twelve hours. And sometimes it can just be... very hard to get himself

comfortable in bed.... He has to be comfortable when his attendant leaves because he [can't] move after that."

Many participants recounted episodes in which they had to adopt modified sleeping positions in order to avoid exacerbating pressure ulcers. After Mitch developed a pressure ulcer on his buttock, he spent most of his time (both awake and asleep) in a prone position. The resultant pressure on his elbow, however, quickly led to a new ulcer in that location which forced him to sleep on his side, a posture he found very uncomfortable:

"Mainly because of my arm, I couldn't really raise myself up and I would lie [down] and my face would be buried in the mattress, so it wasn't too comfortable. And I couldn't turn my head too much, because [the vertebrae in] my neck [had] been fused, so my head was pretty much like that on the mattress."

The difficulty participants experienced in positioning themselves for comfortable sleep and adjusting position during the night also increased their risk of developing pressure ulcers. Some participants addressed this risk by having nurses or care attendants reposition them at intervals while in bed. Other participants had beds that automatically redistributed weight by turning in space or alternating air pressure. Participants described both pressure-shifting approaches as being chronically disruptive to sleep. Chris, whose inability to reposition himself at night was discussed above, experienced significant difficulties with his automatic bed:

"Sometimes it's annoying, when you're trying to take a nap and then my head will start sliding across the pillow.... I'm lying [there] and then I will go that way and my head will start [sliding] this way, and I'm like, oh, man! And then sometimes when I sleep with my elbows out like this I'll feel my arms all of a sudden get mashed into the side.... And when it tilts, I can feel my head slowly slipping on the pillow... and it feels like I am about to fall over."

Bladder management: Bowel and bladder routines might take place early in the morning and/or late at night, often dependent on the schedules of nurses or care attendants. Two participants reported frequently waking up during the night to ensure that a catheter was working properly or had not been disconnected during sleep.

Medications and substance use: Many participants said they were prescribed medications that impacted their sleep. In some cases, the medications were prescribed to aid with sleep, however, participants indicated that some medications intended to treat pain, spasms, or depression also affected their sleep. Tom described his recent switch from prescription sleeping pills to over-the-counter melatonin because he had become addicted to the prescription medication after many years of use:

I'm sleeping maybe 2–3 hours a night, which is about as much as I was sleeping before [switching medication]. But I'm feeling more tired now [that] I'm just doing the Melatonin. I'm sleeping a couple of hours but it's not a restful sleep. It's not a good sleep, a deep sleep, nothing like that. It's just a relaxed mind, state of mind or something. I'm not really sure what it is I just know that I feel a lot more tired now and exhausted than I did before.

Sometimes medications for pain or muscle spasms led participants to sleep during the day, which hampered their ability to participate in desired activities and often interfered with their nighttime sleep. Chris noted said that “[my doctor was] keeping me on medication – sedatives, muscle relaxants – as much as I can tolerate [and] still function during the day.” Despite his doctor’s attempts to optimize the dose, he reported that the side effects of his medications sometimes prevented him from working and would cause him to fall asleep during the day. Participants also discussed self-medicating with substances ranging from caffeine and methamphetamine to increase arousal, to marijuana, alcohol, and benzodiazepines to help with relaxation and sleep inducement. Gary used caffeinated soda to keep himself awake:

“I watch TV, and then I fall asleep again. Then it’s dinner time. And then after dinner, I start dozing off and that’s why I keep all those sodas up there, because the soda... has more caffeine than the coffee does. I can drink like two cups of coffee and then fall asleep. But I drink the soda and that keeps me going.”

Some participants cited marijuana’s effectiveness in inducing sleep by reducing pain, spasms, and anxiety. Tom disclosed that he smoked marijuana, and described it as “probably the best medicine [he had] ever had.”

When I smoke marijuana ... it helps me sleep, because I don’t sleep for crap, at all.... I have really bad, dumb sleeping problems, and the marijuana seems to help with that. Due to my injury, I have some real bad pains. The pains don’t go away because of the marijuana; it just helps me deal with it.

Sleep environment and surfaces—Analysis of the transcripts revealed that the physical and social environment in which participants slept, as well as their sleeping surface, often negatively impacted their sleep patterns and quality.

Sleep environments: Several participants in this study described episodes in which they had to sleep in institutions, such as hospitals, care homes, or jails, where they had limited opportunities to modify their environment to make it more conducive to sleep. Brenda, for example, said that her sleep problems were particularly bad when she was in the hospital:

“Well, it’s not home, you know. It’s a foreign place. You know, something’s always going on and you have to follow a schedule.... It’s just a routine of the way things are done [in hospital] as opposed to being at home.”

Aaron recounted how he developed a pressure ulcer while he was in the county jail. “I slept on the floor, under the benches. It was three or four days before they moved me to a room, with a bed.” Steve explained that while he was in jail, the lights were on all the time. “When you’re on the top bunk, you got the lights right on your face... and they’re bright lights.” In these environments, the participants reported that they had little to no control over their sleep environment and thus were subject to unwanted light and noise and uncomfortable temperatures. Chris spoke at length about how the ambient temperature would affect his ability to sleep, saying that if it was too hot, it would “slam” him: “I don’t sleep good (sic) [when it’s hot]. I like the heat when I’m up but when I’m [lying] down, I don’t like it at all. I like it cold.”

Sleep surfaces: Uncomfortable sleep surfaces were one of the factors most frequently cited by participants as hindering their ability to sleep. Mitch described a rubber-based mattress that he had received after developing a pressure ulcer that was “a lot harder” than he was used to, saying “it was almost like sleeping on concrete.” When he complained about the mattress, he received an inflatable mattress pad that he complained was “little to no help.... It was like sleeping on little bubble things – bubble wrap – the mattress [pad] just sort of like deflated.” Rachel was similarly unhappy with the air pad she had been given to put on top of her mattress. Like Mitch, she compared it to sleeping on bubble wrap, but commented that:

“Bubble wrap would probably work better, because if one little cell busted, the whole thing would be left unaffected. But the air pad, the little bubbles run from one to the other to the other, and if one busts, the whole thing would deflate. And it’s plastic.... If you put too much pressure on one spot you bust one of the bubbles and there goes your air pad.”

Brenda described the bed she slept on in the hospital as “so weird – I’m trying to get used to it. The floor is more comfortable than this bed.”

Pain, anxiety, and avoidance—Pain was frequently cited as a significant barrier to sleep. Participants experienced pain directly from the neurologic damage of the SCI and from remaining positioned in their wheelchair for several hours or being confined to bed for weeks after a flap surgery. Chris, for example, described how his difficulty with resuming a sitting position following an extended period of post-surgical bed rest ultimately impacted his ability to sleep. Specifically, he noted that he would experience soreness in his back when reclining after sitting for a while, which made it difficult to sleep at night. “It’s hard for me to sleep with so much pain. It’s weird; my body is like freaking out on me...” Gary also linked sleeping problems with his pain:

“This week, it’s been so horrible because of the pain in my shoulder.... I haven’t been sleeping that much; if I’m lucky I get like maybe three or four hours of sleep. And that’s kind of irritating, because I need at least like four, five hours of sleep.”

Brenda spoke about how the anxiety she experienced while adjusting to SCI interfered with her sleep:

“... I guess [my sleeplessness is] from being paralyzed, the anxiety of being paralyzed... from being able to walk and then not being able to walk anymore and then you have to get it through your head that you’ve got to have assistance in whatever you are doing. So, it’s just adjustments really. Mental adjustments and all that kind of stuff.”

For Rachel, sleep was a welcome escape from her severe chronic pain. “The type of medicine I need is [one that would] put me to sleep. And that is what I like when I’ve got pain. I don’t want to feel it; I’d rather be asleep” Rachel’s preference to sleep rather than to experience pain was echoed in other participants’ stories, as they related instances in which they used sleep to avoid unpleasant situations. When faced with the emotional stress of the holidays, Steve opted to sleep:

“I was here [at home] for Christmas. I was here... I came in Christmas Eve and I slept almost all Christmas [day].... I didn’t want to – I didn’t want to be awake. I was just, ‘I’m going to sleep. I don’t want to be thinking.’ So I just fell asleep.”

For Steve, this was part of a pattern of using sleep to avoid unwanted activities (such as going to church) or unwanted emotions such as boredom, stress or depression:

“[This caused] big-time stress, which is leading to depression, because every morning, or whenever I go to sleep, I wake up... and I don’t want to see tomorrow”.

Implications of poor sleep on daily lives

Occupational disengagement—Participants discussed the many ways in which poor sleep negatively influenced their participation in meaningful life tasks and roles. When participants slept poorly, it compounded the effects of the time and energy expenditures of daily living tasks associated with chronic SCI care. Missed healthcare appointments, social activities, and work obligations were frequently attributed to fatigue or sleepiness resulting from poor nighttime sleep. Steve shared that he frequently fell asleep during the day while watching his children, which he contends resulted in his ex-wife taking full custody of them:

“I have to take her [his ex-wife] to court if I want to see my kids.... I called her up, I said, ‘how come you didn’t bring my kids? I was supposed to have my kids’. Then she says, ‘you know I’m not gonna take them over there no more... every time I call you, they tell me you’re not home or you’re sleeping’.”

For these participants, the social isolation of life after SCI seemed to be both cause and result from irregular and disjointed sleep patterns.

Daytime fatigue—Many participants spoke of feeling tired or fatigued during the day, which they frequently attributed to a lack of nighttime sleep. Tom reflected on the fact that he had routinely slept only three to four hours each night in the 10 years since he incurred his SCI, and commented that it left his body feeling “tired... real tired.... Even if I sleep, I feel exhausted the following day. When I wake up, I feel exhausted.” Bill described difficulties he faced staying in touch with one of his friends, because he was “tired, all the time, tired.... I told [his friend] I’d call him back, but I never called him back – I would fall asleep.” Brenda spoke of needing to take a nap in the early afternoon to recover from the effort of her morning routine, saying she “got pretty tired after going through all this stuff and being awake at night. So this part of the day I do get sleepy.”

In some instances, this sense of fatigue impacted the participant’s cognitive functioning. Alma described the clouded mind that resulted from sleep deprivation: “You know, I just... as a result of not sleeping I couldn’t think right... I just, I just wasn’t functioning right at all now that I look back.” In many instances, participants responded to daytime fatigue by disengaging from valued activities. In other cases, they attempted to maintain engagement despite the fatigue, which often created safety concerns. Helen, for example, mentioned that she had fallen asleep while driving her power chair, waking only after she crashed into an obstacle.

Discussion

Individuals with SCI often face an overwhelming degree of occupational dysfunction, both in the acute and chronic phases of their injury and recovery. Much attention in the rehabilitation sciences has been given to maximizing function and minimizing the risk of secondary health conditions characteristic of SCI, such as pressure ulcers, bladder infections, and weight gain. However, sleep dysfunction is often overlooked by rehabilitation clinicians, despite the robust interdisciplinary literature linking sleep disturbances with a range of poor health outcomes. The narratives included in this study provide an important phenomenological contribution to the literature on sleep dysfunction after SCI and highlight the need for rehabilitation professionals to effectively integrate the assessment and treatment of sleep disturbances into their post-SCI rehabilitation protocols. In particular, this study highlights individuals' perspectives on sleep, barriers to high-quality sleep, and the impact of poor sleep on daily occupations. These findings complement existing survey based research documenting the prevalence of sleep disturbances in SCI (Biering-Sørensen & Biering-Sørensen, 2001; Fogelberg et al., 2015).

In order to fully understand sleep's impact on health, it is important to consider multiple sleep parameters, including duration, quality, and timing of sleep. It is noteworthy that several participants described having habitual sleep duration that falls significantly below the amount recommended for maintaining optimal health (Watson et al., 2015). There is a compelling body of research demonstrating that chronic sleep restriction such as that described by our participants can have widespread and significant negative effects on health (Colten & Altevogt, 2006). Sleep depth, identified as different stages of sleep, is also important for health (Van Cauter, Spiegel, Tasali, & Leproult, 2008). Although sleep stages cannot accurately be judged by self-report, the number of participants who reported feeling that their sleep was not deep enough to be restorative suggests a need to better understand how SCI and its complications impact sleep architecture. Finally, the timing of sleep within the circadian cycle is important to consider. Studies have shown that excessive daytime sleep, such as that reported by multiple participants, is associated with poorer overall sleep quality and diminished nighttime sleep (Burszty, Ginsberg, Hammerman-Rozenberg, & Stessman, 1999; McDevitt, Alaynick, & Mednick, 2012). One noteworthy finding of the current study was the use of daytime sleep to avoid particular experiences such as pain or boredom. This finding highlights the importance of finding constructive, engaging daytime activities that could fulfil the same function of distracting from or avoiding the unpleasant experience without negatively impacting nighttime sleep. Indeed, findings from research examining the impact of daytime activity levels on sleep parameters in older adults (e.g., Morgan, 2003; Ohayon et al., 2001) suggests that such interventions would improve nighttime sleep for those with SCI.

The factors impacting sleep that were described by participants in this study suggest possible intervention strategies for occupational therapists to help individuals improve their sleep. The number of our participants who reported erratic or disturbed sleep patterns suggest that sleep scheduling, a core component of cognitive behavioral therapy for insomnia (Mitchell, Gehrman, Perlis, & Umscheid, 2012) could be an important treatment approach for this client group. Occupational therapists' expertise in environmental modification and provision

of equipment to support task performance could be used to remediate factors such as lighting, ambient temperature and sleep surfaces that participants described as disruptive. Occupational therapists are also well positioned to help clients with SCI develop strategies to mitigate some of the effects of poor sleep that participants described. For example, energy conservation techniques can compensate for fatigue resulting from poor sleep, and may minimize disengagement from valued occupations and roles.

Limitations

The analysis presented in this paper is based on secondary analysis of data collected from a non-random sample that is not representative of the general SCI population in terms of pressure ulcer history, ethnicity, cause of injury, or socioeconomic status. The overwhelming majority (95%) of participants had experienced one or more medically serious pressure ulcers. Although lifetime incidence of pressure ulcers has been estimated to be approximately 85% (Byrne & Salzberg, 1996), this number includes medically serious Stage III and IV ulcers as well as less serious Stage I and II ulcers. This suggests that more participants in our study would report needing to alter their sleeping positions to allow wound healing, relative to the general SCI population. Such adaptive behaviors are recommended during rehabilitation following SCI as pressure ulcer prevention strategies, which are a key component of SCI self-management. However, these prevention strategies were described as interfering with this study sample's ability to sleep. The secondary use of qualitative data from a study which had completed data collection also prevented us from member-checking our interpretations of the data, a limitation which lead the research team to adopt a conservative approach to data interpretation. For example, self-report of fatigue or tiredness is difficult to definitively attribute to sleep problems, as fatigue following neurological trauma is a highly complex phenomenon with a number of contributing factors (Hammell et al., 2009). For this reason, we limited the use of this code to those instances in which the participants themselves explicitly linked fatigue and sleep.

Conclusion

Individuals who sustain a SCI typically experience an array of adverse health outcomes beyond paralysis and impaired sensation. Sleep problems, such as those described by participants in this study, have the potential to exacerbate several conditions that commonly occur after SCI and to significantly impact health-related quality of life. Rehabilitation protocols following SCI should routinely include a detailed assessment of sleep and appropriate interventions to address any difficulties that are identified.

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References

- American Occupational Therapy Association. Occupational therapy practice framework: Domain & process (2nd ed.). American Journal of Occupational Therapy. 2008; 62(6):625–683. DOI: 10.5014/ajot.62.6.625 [PubMed: 19024744]
- Bamer AM, Johnson KL, Amtmann DA, Kraft GH. Beyond fatigue: Assessing variables associated with sleep problems and use of sleep medications in multiple sclerosis. Clinical Epidemiology. 2010; 2010(2):99–106. DOI: 10.2147/CLEP.S10425 [PubMed: 20838467]
- Biering-Sørensen F, Biering-Sørensen M. Sleep disturbances in the spinal cord injured: An epidemiological questionnaire investigation, including a normal population. Spinal Cord. 2001; 39(10):505–513. [PubMed: 11641793]
- Biering-Sørensen F, Jennum P, Laub M. Sleep disordered breathing following spinal cord injury. Respiratory Physiology & Neurobiology. 2009; 169(2):165–170. S1569-9048(09)00260-2 [pii]. DOI: 10.1016/j.resp.2009.08.014
- Bursztyn M, Ginsberg G, Hammerman-Rozenberg R, Stessman J. The siesta in the elderly: Risk factor for mortality? Archives of Internal Medicine. 1999; 159(14):1582–1586. [PubMed: 10421281]
- Byrne DW, Salzberg CA. Major risk factors for pressure ulcers in the spinal cord disabled: A literature review. Spinal Cord. 1996; 34(5):255–263. [PubMed: 8963971]
- Charmaz, K. Constructing grounded theory: A practical guide through qualitative analysis. Thousand Oaks, CA: Sage; 2006. (Introducing Qualitative Methods Series)
- Cherkassky T, Oksenberg A, Froom P, Ring H. Sleep-related breathing disorders and rehabilitation outcome of stroke patients: A prospective study. American Journal of Physical Medicine & Rehabilitation. 2003; 82(6):452–455. DOI: 10.1097/01.PHM.0000069194.61078.6E [PubMed: 12820788]
- Clark FA, Jackson JM, Scott MD, Carlson ME, Atkins MS, Uhles-Tanaka D, Rubayi S. Data-based models of how pressure ulcers develop in daily-living contexts of adults with spinal cord injury. Archives of Physical Medicine and Rehabilitation. 2006; 87(11):1516–1525. DOI: 10.1016/j.apmr.2006.08.329 [PubMed: 17084129]
- Colten, HR., Altevogt, BM., editors. Sleep disorders and sleep deprivation : An unmet public health problem. Washington, DC: National Academies Press; 2006.
- Emerson, RM., Fretz, RI., Shaw, LL. Writing ethnographic fieldnotes. Chicago, IL: University of Chicago Press; 2011.
- Engkasan JP, Ng CJ, Low WY. Factors influencing bladder management in male patients with spinal cord injury: A qualitative study. Spinal Cord. 2014; 52(2):157–162. DOI: 10.1038/sc.2013.145 [PubMed: 24276416]
- Fleming WE, Pollak CP. Sleep disorders in multiple sclerosis. Seminars in neurology. 2005; 25(1):64–68. [PubMed: 15798938]
- Fogelberg DJ, Hoffman JM, Dikmen S, Temkin NR, Bell KR. Association of sleep and co-occurring psychological conditions at 1 year after traumatic brain injury. Archives of physical medicine and rehabilitation. 2012; 93(8):1313–1318. [PubMed: 22840828]
- Fogelberg DJ, Vitiello MV, Hoffman JM, Bamer AM, Amtmann D. Comparison of self-report sleep measures for individuals with multiple sclerosis and spinal cord injury. Archives of Physical Medicine and Rehabilitation. 2015; 96(3):478–483. DOI: 10.1016/j.apmr.2014.10.001 [PubMed: 25450136]
- Fuller DD, Lee KZ, Tester NJ. The impact of spinal cord injury on breathing during sleep. Respiratory Physiology & Neurobiology. 2013; 188(3):344–354. DOI: 10.1016/j.resp.2013.06.009 [PubMed: 23791824]
- Green A. Sleep, occupation and the passage of time. British Journal of Occupational Therapy. 2008; 71(8):339–347.
- Grunstein R, Wilcox I, Yang TS, Gould Y, Hedner J. Snoring and sleep apnoea in men: Association with central obesity and hypertension. International Journal of Obesity and Related Metabolic Disorders. 1993; 17(9):533–540. [PubMed: 8220656]
- Gutman SA, Gregory KA, Sadlier-Brown MM, Schlissel MA, Schubert AM, Westover LA, Miller RC. Comparative effectiveness of three occupational therapy sleep interventions: A randomized

controlled study. OTJR: Occupation, Participation, and Health. 2017; 37(1):5–13. DOI: 10.1177/1539449216673045

Hammell KW, Miller WC, Forwell SJ, Forman BE, Jacobsen BA. Fatigue and spinal cord injury: A qualitative analysis. Spinal Cord. 2009; 47(1):44–49. DOI: 10.1038/sc.2008.68 [PubMed: 18542089]

Harvey AG. Insomnia: Symptom or diagnosis? Clinical Psychology Review. 2001; 21(7):1037–1059. [PubMed: 11584515]

Knutson KL, Van Cauter E. Associations between sleep loss and increased risk of obesity and diabetes. Annals of the New York Academy of Sciences. 2008; 1129:287–304. DOI: 10.1196/annals.1417.033 [PubMed: 18591489]

Leland NE, Fogelberg D, Sleight A, Mallinson T, Vigen C, Blanchard J, Carlson M, Clark F. Napping and nighttime sleep: Findings from an occupation-based intervention. American Journal of Occupational Therapy. 2016; 70(4):7004270010. p1-7004270010p7.

Leland NE, Marcione N, Niemiec SLS, Kelkar K, Fogelberg D. What is occupational therapy's role in addressing sleep problems among older adults? OTJR: Occupation, Participation and Health. 2014; 34(3):141–149. DOI: 10.3928/15394492-20140513-01

McDevitt EA, Alaynick WA, Mednick SC. The effect of nap frequency on daytime sleep architecture. Physiology & Behavior. 2012; 107(1):40–44. DOI: 10.1016/j.physbeh.2012.05.021 [PubMed: 22659474]

Mitchell MD, Gehrman P, Perlis M, Umscheid CA. Comparative effectiveness of cognitive behavioral therapy for insomnia: A systematic review. BMC Family Practice. 2012; 13(40)doi: 10.1186/1471-2296-13-40

Morgan K. Daytime activity and risk factors for late-life insomnia. Journal of Sleep Research. 2003; 12(3):231–238. [PubMed: 12941062]

Ohayon MM, Zulley J, Guilleminault C, Smirne S, Priest RG. How age and daytime activities are related to insomnia in the general population: consequences for older people. Journal of the American Geriatrics Society. 2001; 49(4):360–366. [PubMed: 11347777]

Padgett, D. Qualitative and mixed methods in public health. Thousand Oaks, CA: SAGE Publications Ltd; 2012.

Sankari A, Bascom A, Oomman S, Badr MS. Sleep disordered breathing in chronic spinal cord injury. Journal of Clinical Sleep Medicine. 2014; 10(1):65–72. DOI: 10.5664/jcsm.3362 [PubMed: 24426822]

Smith M, Edwards R, McCann U. The effects of sleep deprivation on pain inhibition and spontaneous pain in women. Sleep. 2007; 30(4):494–505. [PubMed: 17520794]

Smith M, Haythornthwaite J. How do sleep disturbance and chronic pain inter-relate? Insights from the longitudinal and cognitive-behavioral clinical trials literature. Sleep Medicine Reviews. 2004; 8(2): 119–132. DOI: 10.1016/s1087-0792(03)00044-3 [PubMed: 15033151]

Van Cauter E, Spiegel K, Tasali E, Leproult R. Metabolic consequences of sleep and sleep loss. Sleep Medicine. 2008; 9(Suppl 1):S23–28. DOI: 10.1016/S1389-9457(08)70013-3 [PubMed: 18929315]

VanGilder C, MacFarlane G, Meyer S, Lachenbruch C. Body mass index, weight, and pressure ulcer prevalence: An analysis of the 2006–2007 International Pressure Ulcer Prevalence Surveys. Journal of Nursing Care Quality. 2009; 24(2):127–135. DOI: 10.1097/01.NCQ.0000347449.83052.1a [PubMed: 19287251]

Vitiello MV, Prinz PN. Alzheimer's disease. Sleep and sleep/wake patterns. Clinics in Geriatric Medicine. 1989; 5(2):289–299. [PubMed: 2665912]

Watson N, Badr M, Belenky G, Bliwise D, Buxton O, Buysse D, ... Tasali E. Joint Consensus Statement of the American Academy of Sleep Medicine and Sleep Research Society on the recommended amount of sleep for a healthy adult: Methodology and discussion. Journal of Clinical Sleep Medicine. 2015; 11(8):931–952. DOI: 10.5664/jcsm.4950 [PubMed: 26235159]

Young T, Peppard PE, Taheri S. Excess weight and sleep-disordered breathing. Journal of Applied Physiology. 2005; 99(4):1592–1599. DOI: 10.1152/jappphysiol.00587.2005 [PubMed: 16160020]

Categories Related to Sleep among Individuals with SCI		
Sleep Difficulties	Barriers to high quality sleep	Implications of poor sleep on daily lives
<ul style="list-style-type: none"> • Sleep disturbance and quality • Sleep patterns and quantity 	<ul style="list-style-type: none"> • SCI-related dysfunction and care <ul style="list-style-type: none"> ▪ Bed positioning ▪ Bladder management ▪ Medications and substance use • Sleep environment and surfaces <ul style="list-style-type: none"> ▪ Sleep environments ▪ Sleep surfaces • Pain, anxiety, and avoidance 	<ul style="list-style-type: none"> • Occupational disengagement • Daytime fatigue

Figure 1.

Table 1

Demographics and injury characteristics

Variable	Frequency (%)	
Sex		
Male		14 (70)
Female		6 (30)
Education		
High School Graduate or Less		8 (40)
Some College/College Graduate		11 (55)
Graduate School or Higher		1 (5)
Race/Ethnicity		
White		6 (30)
Black/African American		8 (40)
Asian		1 (5)
Hispanic		5 (25)
SCI Level		
C1-C4		3 (15)
C5-C8		8 (40)
T1-S5		9 (45)
SCI Completeness		
Complete		16 (80)
Incomplete		3 (15)
Not applicable		1 (5)
	Mean	SD (Range)
Age at study commencement (Years)	43.6	±12.52 (28–78)
Time Since Diagnosis/Injury (Years)	14.9	±11.76 (1–37)
Age at Time of Injury (Years)	27.5	±12.65 (5–60)

Note: M=mean SD= standard deviation n=number