Loneliness and Perceived Social Isolation in Individuals Living with Spinal Cord Injuries and Disorders:

Educational Curriculum for Health Care Professionals

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Overview

This educational curriculum was created to help health care providers and others involved in the care and well-being of individuals with spinal cord injuries and disorders (SCI/D) to understand how to help individuals with SCI/D manage loneliness and perceived social isolation. The educational curriculum provides content and guidance for learners (providers) based on stakeholder (provider, patient) feedback, literature, existing resources, and expert consensus.

All or some of the components of the educational curriculum can be used or adapted for in-services, workshops, webinars, and other delivery formats that offer a focused curriculum to educate and inform health care providers across disciplines.

Several components are included:

- **5 topic areas** that are intended to improve comprehension of the curriculum content and encourage active learning. Each topic area includes:
  - learning objectives
  - learning activities
  - assignment
  - learning materials

- **Other resources/additional reading** are listed for each topic that supplement the learning materials provided in the educational curriculum.

***Note:* Learners may choose to review topics independently, as the curriculum does not require a cumulative review in consecutive order by topic.**

Using the Educational Curriculum

The components of the educational curriculum are intended to be used by health care professionals who provide care to persons with SCI/D. This is intentionally a broad professional audience, as all types of providers may encounter an individual with a spinal cord injury or disorder who is experiencing loneliness and/or perceived social isolation.

It may be helpful to those who wish to improve general understanding of and skills around current knowledge of loneliness and perceived social isolation in persons with SCI/D.

It may benefit those who wish to understand:

- Common subjective and objective definitions of loneliness and social isolation
- The scope (magnitude) of loneliness and social isolation as a problem in general and in persons living with SCI/D
- The consequences, risks, and factors associated with loneliness, perceived social isolation, and social isolation
- Cues to loneliness exhibited by individuals living with SCI/D who may be experiencing loneliness or social isolation
- How to quantitatively measure loneliness and perceived social isolation using validated instruments
- Facilitators to alleviate loneliness and social isolation among individuals with SCI/D

As noted, each component, activity, and other resources can be used alone or in combination with other components.

Topic 1: Defining Loneliness and Social Isolation

Learning Objectives

- Describe the subjective measure of loneliness/perceived social isolation
- Describe objective measure of social isolation

Learning Activities

- Review the 'Summary of definitions of loneliness, perceived social isolation, and social isolation'
- Read the 'National Academies of Sciences Perspectives on Defining Social Isolation, Loneliness, and Related Aspects of Social Relationships'
- Watch/listen to "Loneliness explained" by Harvard University
    - https://www.youtube.com/watch?v=TvSRZpiSN-U

Assignment

List key factors that distinguish subjective vs. objective isolation definitions

Learning Materials for Topic 1

Summary of definitions of loneliness, perceived social isolation, and social isolation.

Throughout the literature, the construct of isolation is separated into a subjective and objective component. *Loneliness*, often interchanged with perceived social isolation, is a subjective measure of feeling isolated, left out, and lacking companionship (Cimino et al., 2022). Loneliness can occur when an individual feels dissatisfaction with or a difference between desired and actual social interaction and relationships (Holt - Lunstad et al., 2015; Hughes et al., 2004). *Social isolation* is an objective state of having limited or lack of social interactions and is often measured by small social network size, infrequent contact with others, lack of engagement in activities, and living alone (Cimino et al., 2022).

Individuals may experience a combination of loneliness and social isolation. An individual may be surrounded by people and have many social contacts but still experience loneliness. Whereas social isolation reflects actual time alone or without social interaction and may not elicit feelings of loneliness (LaVela et al., 2024). Although these definitions have not achieved wide-scale consensus (Fried et al., 2020), it is generally agreed that loneliness and social isolation are independent constructs, due to their often non-significant correlation (Coyle et al., 2012).

National Academies of Sciences Perspectives on Defining Social Isolation, Loneliness, and Related Aspects of Social Relationships

Excerpt below adapted from:
Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System. National Academies of Sciences, Engineering, and Medicine; Division of Behavioral and Social Sciences and Education; Health and Medicine Division; Board on Behavioral, Cognitive, and Sensory Sciences; Board on Health Sciences Policy; Committee on the Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults. Washington (DC): National Academies Press (US); 2020 Feb 27. Chapter 1.

The broad, interdisciplinary scientific fields that together form the modern science of social relationships have used a variety of terms (e.g., social isolation, social connection, social networks, social integration, social support, social exclusion, social deprivation, social relationships, loneliness) to refer to empirical phenomena related to social relationships. Although there are important distinctions among these terms concerning what they describe or measure, they are often, incorrectly, used interchangeably. Some of the key terms that will be used throughout this report are presented in Box 1.

Social Isolation and Loneliness

Box 1. Key Definitions

Loneliness: the perception of social isolation or the subjective feeling of being lonely.

Mediators: also known as mechanisms or pathways; the factors that help explain how social isolation or loneliness affects health outcomes.

Moderators: the factors that can influence the magnitude or direction of the effect of social isolation or loneliness on health.

Social connection: an umbrella term that encompasses the structural, functional, and quality aspects of how individuals connect to each other.

Social isolation: the objective lack of (or limited) social contact with others.

Social support: the actual or perceived availability of resources (e.g., informational, tangible, emotional) from others, typically one's social network.

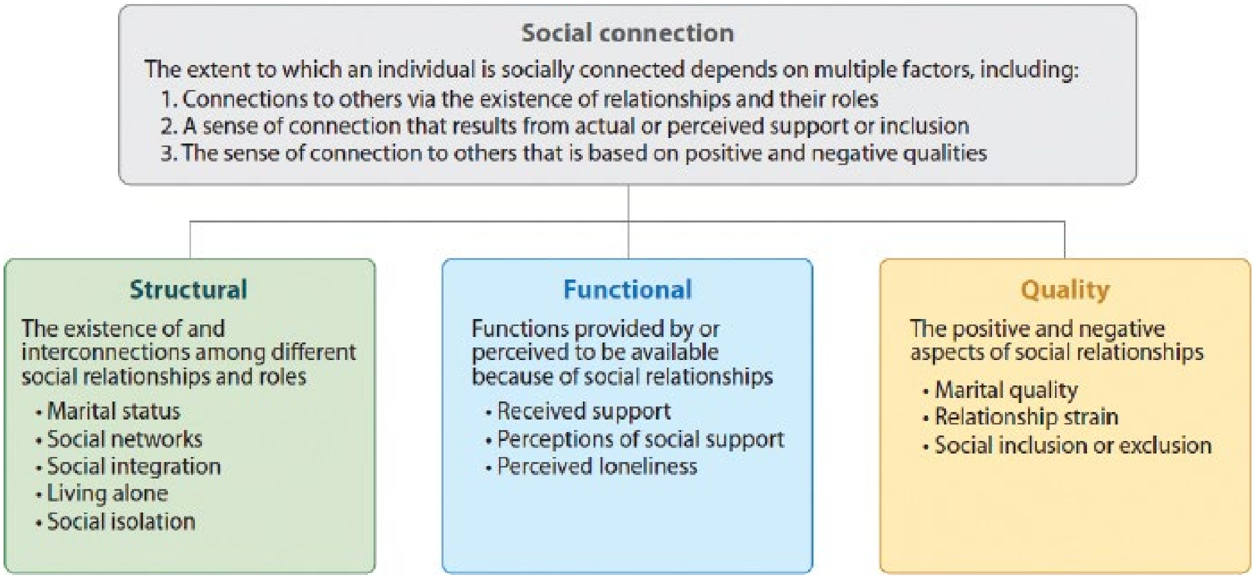
Social isolation and loneliness represent distinct phenomena. *Social isolation* typically refers to the objective lack of (or limited) social contact with others, and it is marked by an individual having few social network ties, having infrequent social contact, or, potentially, living alone. Markers of social isolation objectively and quantitatively establish a dearth of social contact and network size. *Loneliness* refers to the perception of social isolation or the subjective feeling of being lonely that "occurs when there is a significant mismatch or discrepancy between a person's actual social relations and his or her needed or desired social relations" (Perlman and Peplau, 1998). While loneliness is subjective, there are measurement tools that can help to quantify the degree of loneliness. Although those who lack social contact may feel lonely (Yildirim and Kocabiyik, 2010), social isolation and loneliness are often not highly correlated (Coyle and Dugan, 2012; Perissinotto and Covinsky, 2014). Thus, it is important to distinguish between social isolation and loneliness.

Related Aspects of Social Relationships

"Social relationships" is arguably the most common term for the connections and intersections among human beings, and it derives from and is employed in broader common usage. The term "social networks" has been used for some time as a similarly broad rubric for the connections among human beings, but it is also used more specifically to refer to the structure and way of analyzing relationship data (Scott, 1988). Berkman and Syme (1979) documented the powerful impact of social relationships on all-cause mortality and hence life expectancy, using the terms "social networks" and also "social integration" to denote the broad pattern of social relationships that they were examining; these terms are now part of the concept of social isolation. Beginning before the Berkman and Syme study and continuing over the succeeding four decades, the study of social relationships and health came to focus on social support. *Social support* is defined as the actual or perceived availability of resources (e.g., informational, tangible, emotional) from others, typically one's social network (Cohen and Wills, 1985). While each of these terms used to describe social relationships have been linked to important health outcomes, they are not highly correlated, suggesting that each may influence health through different pathways (Cohen et al., 2000). Thus, the literature often refers to organizing themes—the structure, functions, and quality of our social relationships—that categorize the broader class of terms that have been termed social relationships by sociologists and epidemiologists or social connection by psychologists (Berkman et al., 2000; Holt-Lunstad, 2018b; Holt-Lunstad et al., 2017; House et al., 1988). "Social connection" is an umbrella term that some have proposed using to encompass the different conceptual and measurement approaches represented in the scientific literature. (Holt-Lunstad, 2018a). According to Holt-Lunstad et al. (2017), social connection encompasses the variety of ways one can connect to others socially—through physical, behavioral, social–cognitive, and emotional channels. The extent to which an individual is socially connected takes a multifactorial approach, including (1) [*structural aspects*] connections to others via the existence of relationships and their roles; (2) [*functional aspects*] a sense of connection that results from actual or perceived support or inclusion;

and (3) [*qualitative aspects*] the sense of connection to others that is based on positive and negative qualities. Figure 1 below shows the three categories of indicators of social connection (i.e., structural, functional, and quality indicators) and provides examples of such indicators.

Figure 1. Social connection as a multifactorial construct including structural, functional, and quality components



Social connection

The extent to which an individual is socially connected depends on multiple factors, including:
1. Connections to others via the existence of relationships and their roles
2. A sense of connection that results from actual or perceived support or inclusion
3. The sense of connection to others that is based on positive and negative qualities

Structural

The existence of and interconnections among different social relationships and roles

- Marital status
- Social networks
- Social integration
- Living alone
- Social isolation

Functional

Functions provided by or perceived to be available because of social relationships

- Received support
- Perceptions of social support
- Perceived loneliness

Quality

The positive and negative aspects of social relationships

- Marital quality
- Relationship strain
- Social inclusion or exclusion

SOURCE: Holt-Lunstad, 2018a. Reproduced with permission from the *Annual Review of Psychology*, Volume 69 © 2018 by Annual Reviews, http://www.annualreviews.org.

When considering risk factors and protective factors for social isolation and loneliness, having indicators of high social connection is typically considered protective while having indicators of low social connection is typically considered detrimental. Social isolation and loneliness are examples of low social connection, with social isolation being a structural aspect and loneliness a functional aspect. Some indicators of social connection are more stable than others, and the acute or chronic nature of these indicators will influence the degree of risk or protection.

References Cited for Topic 1

Berkman LF, Glass T, Brissette I, Seeman TE. From social integration to health: Durkheim in the new millennium. Social Science & Medicine. 2000;51(6):843–857.

Berkman LF, Syme SL. Social networks, host resistance, and mortality: A nine-year follow-up study of Alameda county residents. American Journal of Epidemiology. 1979;109(2):186–204.

Cimino SR, Cadel L, Guilcher SJT, Wasilewski M, Hitzig SL. Social disconnectedness and perceived social isolation in persons with spinal cord injury/dysfunction living in the community: A scoping review. J Spinal Cord Med. J Spinal Cord Med. 2023;46(3):367-389.

Cohen S, Gottlieb BH, Underwood LG. Social relationships and health. In: Cohen S, Underwood LG, Gottlieb BH, editors. Social support measurement and intervention: A guide for health and social scientists. New York: Oxford University Press; 2000. pp. 3–25.

Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. Psychological Bulletin. 1985;98(2):310–357.

Coyle CE, Dugan E. Social isolation, loneliness, and health among older adults. Journal of Aging and Health. 2012;24(8):1346–1363.

Harvard University. Loneliness Explained. YouTube; 2021. Accessed January 17, 2024. https://www.youtube.com/watch?v=TvSRZpiSN-U

Holt-Lunstad J. The potential public health relevance of social isolation and loneliness: Prevalence, epidemiology, and risk factors. Public Policy & Aging Report. 2018b;27(4):127–130.

Holt-Lunstad J. Why social relationships are important for physical health: A systems approach to understanding and modifying risk and protection. Annual Review of Psychology. 2018a;69:437–458.

Holt-Lunstad J, Robles TF, Sbarra DA. Advancing social connection as a public health priority in the United States. American Psychologist. 2017;72(6):517–530.

Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspectives on Psychological Science. 2015;10(2):227-237.

House JS, Landis KR, Umberson D. Social relationships and health. Science. 1988;241(4865):540–545.

Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A Short scale for Measuring loneliness in large surveys: results from two population-based studies. Research on Aging. 2004, 26(6), 655–672.

LaVela SL, Motl RW, Berryman K, Wirth M, Bartle B, Aguina K, Solanki P, Bombardier CH. Facilitators to alleviate loneliness and social isolation as identified by individuals with spinal cord injuries and disorders: A qualitative study. Rehabilitation Psychology. 2024. doi: 10.1037/rep0000540.

National Academies of Sciences, Engineering, and Medicine. Social isolation and loneliness in older adults: Opportunities for the health care system. Washington DC: National Academies Press; 2020.

Perissinotto CM, Covinsky KE. Living alone, socially isolated or lonely—What are we measuring? Journal of General Internal Medicine. 2014;29(11):1429–1431.

Perlman, D. and Peplau, L. Loneliness. In: Friedman, H.S., Ed., Encyclopedia of Mental Health, Vol. 2. San Diego, CA: Academic Press; 1998: 571-581.

Scott J. Trend report: Social network analysis. Sociology. 1988;22(1):109–127.

Yildirim Y, Kocabiyik S. The relationship between social support and loneliness in Turkish patients with cancer. Journal of Clinical Nursing. 2010;19(5-6): 832–839.

Other Resources/Additional Readings for Topic 1

Fried L, Prohaska T, Burholt V, et al. A unified approach to loneliness. Lancet. 2020;395(10218):114. doi:10.1016/S0140-6736(19)32533-4.

Topic 1 Assignment

List key factors that distinguish subjective vs. objective isolation definitions

Topic 2: Scope and Consequences/Risks associated with Loneliness/Social Isolation

Learning Objectives

- Describe the scope/magnitude of loneliness and social isolation in the general population and in persons with SCI/D
- Identify associated health consequences/risks of loneliness and social isolation

Learning Activities

- Review the ‘Summary of the scope/magnitude and consequences/risks associated with loneliness and social isolation’
- Read the articles by Wirth et al. (2024), Berryman et al. (2024), and Guilcher et al. (2021)
- Watch/listen to “Are we in a loneliness epidemic?” by Public Broadcasting Service (PBS):
    - https://www.pbs.org/video/are-we-in-a-loneliness-epidemic-dcgfpk/

Assignment

List 3 associated health consequences/risks of loneliness and social isolation in individuals with SCI/D

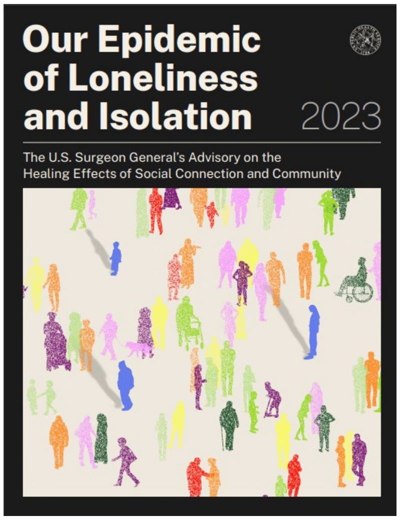
Learning Materials for Topic 2

Summary of the scope/magnitude and consequences/risks associated with loneliness and social isolation

Scope. Loneliness is a common and growing issue with 46% of United States adults reporting feeling alone or isolated (Nemecek 2018). In 2023, the World Health Organization made loneliness and social isolation a global health priority (World Health Organization) and that same year the United States Surgeon General identified loneliness and social isolation as a current US ‘epidemic’ that requires immediate action (US Surgeon General 2023).

In the United States, 35% of adults 45 years of age and older reported feeling lonely (Anderson & Thayer, 2018). Another study found that 30% of the general population reported loneliness (Hawkley & Kocherginsky, 2018). Additionally, 24% of adults 65 and older are considered to be socially isolated (Cudjoe et al., 2020).

Furthermore, larger proportions of individuals with SCI/D may be impacted. In one study of individuals with SCI/D, 55% reported loneliness (Tough et al., 2018). Likewise, Berryman et al. (2024) found that 66% of Veterans with SCI/D experienced moderate to high loneliness. Additionally, Wirth et al. (2024) found that 56% of individuals with SCI/D had perceived social isolation scores that were higher than the general population.


Our Epidemic of Loneliness and Isolation 2023

The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community

Consequences and risks to the general population. Loneliness and social isolation pose a significant health risk. Loneliness and social isolation are associated with increased risk of all-cause mortality by 22% and 26% respectfully (Kanbay et al., 2023), which is as much as smoking up to 15 cigarettes a day (Holt-Lunstad et al., 2017). Loneliness and social isolation have been associated with an increased risk for a variety of health concerns such as type 2 diabetes (Henriksen et al., 2023; Brinkhues et al., 2018), metabolic syndrome (Henriksen 2019), physiological responses such as heightened inflammatory reactivity to stress (Menec et al., 2020), and a weaker immune response when exposed to infectious diseases (Cimino et al., 2023). Furthermore, they are associated with coronary heart disease, stroke (Valtorta et al., 2016), and hypertension (Yang et al., 2016), and in late 2022, the American Heart Association published study findings indicating that social isolation increases risk of heart attack or stroke by 30% (Cene et al., 2022). Loneliness and social isolation are also associated with negative health behaviors such as reduced physical activity (Menec et al., 2020), sleep issues (Cimino et al., 2023), and unmet health care needs (Chamberlain et al., 2023). Additionally, they are also linked to vast negative impacts on mental health such as depression (Menec et al., 2020, Richard et al., 2017), anxiety (Domenech-Abella et al., 2019), and suicide or hospitalization for self-harm (Shaw et al., 2021), and reduced cognitive function (Menec et al., 2020, Richard et al., 2017) including dementia (Huang et al., 2023).

Consequences and risks to individuals with SCI/D. Varying degrees of disability due to SCI/D may modify the dynamics of the individual's life roles, social well-being, and feelings of connection to others (Cimino et al., 2023; Guilcher et al., 2012) and make them more susceptible to loneliness and social isolation. Increased loneliness and social isolation in individuals with SCI/D could be due to varying degrees of disability attributed to comorbidities or SCI/D secondary health conditions (e.g. neurogenic bladder and bowel, urinary tract infections) (Müller et al.,2012), environmental barriers (e.g. lack of accessibility of surroundings) (Barclay et al., 2016), and social inequities associated with being in marginalized or vulnerable groups (LaVela et al., 2024). In addition, in persons with SCI/D, Berryman et al. (2024) reported that having paraplegia, a shorter duration of injury, being unmarried, being in fair/poor general health, having dysfunctional sleep, and experiencing bowel dysfunction were each independently associated with greater odds of moderate/high loneliness. Wirth et al. (2024) noted greater risk of high perceived social isolation for individuals with SCI/D who had a smaller social network size was associated with increased odds of high perceived social isolation (OR 3.59, P<.0001). Additionally, they found other factors associated with perceived social isolation among individuals with SCI/D included having depression, anxiety, and post-traumatic stress in the previous 6 months, and having 4 or more chronically occurring SCI/D secondary conditions.

61% of individuals reported that simply having a spinal cord injury or disorder impacts feeling lonely and socially isolated.

Research Article

Factors associated with perceived social isolation among veterans with spinal cord injury and disorders: Cross sectional survey

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Context/Objective: Examine demographics, injury characteristics, objective measures of social isolation and health factors that are associated with perceived social isolation (PSI) among Veterans with spinal cord injury and disorders (SCI/D).
Design: Cross-sectional survey.
Setting: The Veterans Health Administrations (VHA) SCI/D system of care.
Participants: Veterans with SCI/D who have used the VHA health care system.
Intervention: Not applicable.
Outcomes Measures: We assessed unadjusted associations of high PSI (above population mean) vs low (normative/below population mean), and multivariable logistic regression for independent associations with PSI.
Results: Out of 1942 Veterans with SCI/D, 421 completed the survey (22% response rate). Over half (56%) had PSI mean scores higher than the general population. Among the objective measures, having a smaller social network size was associated with increased odds of high PSI (OR 3.59, $P < .0001$); additionally, for health factors, having depression (OR 3.98, $P < 0.0001$), anxiety (OR 2.29, $P = 0.009$), and post-traumatic stress (OR 2.56, $P = 0.003$) in the previous 6 months, and having 4 or more chronically occurring secondary conditions (OR 1.78, $P = 0.045$) was associated with increased odds of high PSI. The most commonly identified contributors to feelings of PSI included mobility concerns (63%), having a SCI/D (61%), and concerns about being a burden on others (57%).
Conclusions: Factors such as social network size may be used to identify individuals with SCI/D at risk for PSI. Additionally, by identifying mental health problems, presence of multiple chronically occurring secondary conditions, and Veteran-identified contributors of PSI, we can target these factors in a patient-centered interventions to identify and reduce PSI.

Keywords: Spinal cord injury and disorder, Perceived social isolation, Loneliness, Veteran

Introduction

The quantity and quality of social relationships play a key role in mental, behavioral, and physical health, and inadequacies in these social relationships can affect overall well-being (1–6). Throughout the literature, the construct of isolation is separated into a subjective and objective component. Perceived social isolation (PSI), often referred to as loneliness, is typically defined as a subjective measure of feeling isolated (1). Whereas objective social isolation, often referred to as social isolation, is the quantity of social interactions and relationships and is often measured by the quantity and quality of social contact and network size (3, 7, 8).

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Color versions of one or more of the figures in the article can be found online at www.tandfonline.com/yscm.

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Although these definitions have not achieved wide-scale consensus (9), it is generally agreed that loneliness and social isolation are independent constructs, due to their often non-significant correlation (10).

PSI is a common and growing issue with 46% of United States (U.S.) adults reporting feeling alone or isolated (11). Individuals with any mental or physical disabilities have been shown to experience significantly higher rates of PSI compared to people without a disability (12). One population that may be at risk is individuals with spinal cord injuries and disorders (SCI/D). In surveys of individuals with SCI/D, up to 55% (13) reported loneliness. People living with SCI/D may have greater risk of experiencing PSI due to varying degrees of disability attributed to comorbidities or SCI/D secondary health conditions (e.g. neurogenic bladder and bowel, urinary tract infections) (14) and environmental barriers (e.g. lack of accessibility of surroundings) (15). Additionally, 57% of Veterans reported some of the time or often feeling lonely (16). Approximately 302,000 individuals in the U.S. are living with traumatic SCI/D (17) and over 15% of traumatic and nontraumatic individuals are receiving care from the Veterans Health Administration (VHA) (18), the largest integrated healthcare system in the United States, this allows VHA a unique opportunity to provide research-based knowledge, such as factors associated with PSI, to the Veteran SCI/D community.

Feelings of PSI can influence a person's biological pathways by heightening inflammatory response, which in turn can increase the risk of dementia (19), sleep issues (20), depression, and other cognitive, mental, and physical health outcomes (21, 22). In 2022 the American Heart Association published a statement indicating PSI is associated with a 30% increased risk of heart attacks and a 32% increased risk of stroke among the general public (23). PSI has even been shown to increase the risk of premature mortality, with a hazard ratio up to 1.22 (95% confidence interval (CI): 1.10–1.35) (24). Due to the widespread and profound threat on individuals' health and well-being, in 2023 the U.S. Surgeon General put an advisory on loneliness and social isolation (25).

Given the association of PSI and an individual's health and wellbeing, especially those with SCI/D, it is important to identify factors associated with PSI. Identifying associated factors with PSI can help healthcare professionals and other stakeholders identify those at risk for PSI and understand the self-reported contributors of PSI; furthermore, it can highlight areas that can be targeted for interventions to help people manage PSI, which aligns with the call to action the U.S. Surgeon General indicated in his advisory on the epidemic of loneliness and social isolation in the U.S. The aim of this study was to examine factors that are independently associated with PSI, considering demographics, injury characteristics, health factors, and objective measures of social isolation among Veterans with SCI/D.

Methods

Design/Setting/Sample. A cross-sectional, national survey was conducted with a sample of Veterans with SCI/D between October 2022 and January 2023. The sampling frame included 16,672 Veterans with SCI/D who had a recent encounter within the VHA healthcare system, and a valid residential mailing address documented. Our goal was to invite 2,000 individuals to participate, which is 12% of the sampling pool. Our power calculation determined that 376 Veterans with SCI/D were needed with a 5% margin of error at 95% confidence level. A response rate of 20–25% was assumed in the sample size calculation (26, 27), and the population of eligible Veterans with SCI/D was 16,672. The sample was identified using VHA medical record databases, including the Corporate Data Warehouse (CDW), a national repository for VHA clinical and administrative data, and the SCI/D registry, a national data registry for Veterans with SCI/D who received care within the VHA SCI/D system of care. The sample was comprised of individuals with both traumatic and non-traumatic SCI/D and could include those diagnosed with nonmalignant neoplasms resulting in neurologic deficit; vascular insults of a thromboembolic, hemorrhagic, or ischemic nature; cauda equina syndrome producing neurologic deficit; inflammatory disease of the spine, spinal cord or cauda equina resulting in non-progressive neurologic deficit; and demyelinating disease of the spinal cord. The Institutional Review Board at Edward Hines, Jr. VA Hospital approved this study and approved waived written informed consent for participants.

Eligible Veterans were mailed an introductory letter providing a brief overview of the study and invitation to participate in the survey, copy of the survey, and a postage-paid envelope. To increase response rate, we conducted a follow-up mailing approximately 6 weeks after the first mailing with non-respondents.

Survey Instrument and Variables. The survey collected data on the dependent variable, *PSI*, which was measured using the validated Patient-Reported Outcomes Measurement Information System short form for social isolation (PROMIS-SI) (28). The survey also collected *demographics, objective social* *isolation measures, and health factors. A stand-alone question asked individuals to identify what contributes to their feelings of PSI.*

PSI. We defined PSI as subjectively feeling left out, avoided, and detached from others and isolated even when not alone. We measured PSI using the PROMIS-SI which consists of 8 questions on a 5-point Likert scale coded from 1 (never) to 5 (always). Raw scores were converted to T-scores, with higher scores indicating greater PSI. To determine above average PSI, a score of 50, which is the U.S. general population average PSI score, was used (26). PSI was dichotomized into scores above the population mean (> 50) indicating *high PSI* and at/below the normative population mean (< = 50) indicating *low PSI*.

Demographics characteristics included sex (male/female), race (white/black/other), ethnicity (Hispanic or Latino/not Hispanic or Latino), marital status (married/never married, separated, or widowed), age, and injury characteristics (including injury level, completeness, etiology, duration, and age at onset). We supplemented missing survey data on demographics and injury characteristics with data from the CDW.

Based on previous surveys conducted by the authors, *objective social isolation* included self-reported presence/absence of an informal caregiver (question asked if they have an informal caregiver that helps with their care) and current living arrangement (lives alone/does not live alone) (26, 27). We also asked about social network size (response options: 1 person, 2–3 people, and 4 or more, responses were dichotomized to <4 or 4+ people); modeled from Guilcher *et al.* (2). Frequency of meaningful contacts (question asked how often they can open up to someone to talk about their worries; response options: never/hardly ever vs. some of the time/often), and frequency of reliable contacts (question asked how often they can rely on someone to help if they have a problem; response options: never/hardly ever vs. some of the time/often) were modeled on items from the psychosocial core module on the Health and Retirement study surveys (29).

Health factors included the presence of health complications in the last 6 months (depression, anxiety, dysfunctional sleep, and post-traumatic stress). We also collected presence of SCI/D secondary health conditions (chronic pain, joint/muscle pain, sexual function, bladder dysfunction, muscle spasms/spasticity, bowel dysfunction, circulatory problems, loss of sensation, urinary tract infection, respiratory problems, contractures, autonomic dysreflexia, postural hypertension, pressure injuries, and heterotopic ossification) utilizing the validated spinal cord injury-secondary conditions scale (30). Participants rated secondary conditions as none, infrequent, occasional, or chronically occurring problems. We dichotomized responses as none/infrequently/occasionally vs. chronically occurring problem. In addition, we created a count variable for the number of SCI/D secondary conditions (< 4 vs. 4+ SCI/D secondary conditions as a chronically occurring problem), for inclusion in the multivariable regression model.

Contributors to feelings of PSI were collected by an independent question asking Veterans to identify factors that contributed to their feelings of PSI at least some of the time. Participants were asked to select all that apply, the items were derived from qualitative themes identified through interviews with 33 Veterans with SCI/D focused on the most common factors that contributed to PSI in persons with SCI/D (LaVela 2022), options included: concerns about mobility, having a SCI/D, concerns about being a burden on others, environmental barriers, transportation issues/limitations, care needs due to injury (such as bowel care), limited social network, and concerns about people staring (31).

Analyses. Descriptive statistics were used to summarize demographics, injury characteristics, objective measures of social isolation, health factors, and contributors to feelings of PSI. Bivariate comparisons including chi-square and t tests, were used to assess unadjusted associations of high vs. low PSI for demographics, injury characteristics, objective measures of social isolation, and health factors.

Multivariable analysis. Multivariable logistic regression modeling was used to generate odds ratios (OR) and 95% confidence interval (CI) to determine variables independently associated with high PSI. Variables statistically significant in the bivariate analysis were considered for inclusion in the model. An alpha level of 0.05 was used to determine statistical significance.

Contributors to feelings of PSI. The independent question asking Veterans to identify contributors of PSI was only included in the descriptive analysis and not included in the bivariate or multivariable logistic regression, due to the dependent variable being measured in the question. We present percentages of endorsed responses.

Bias assessment. To assess non-response bias, we conducted bivariate comparisons of demographic and injury characteristics to determine if respondents ($n = 421$) differed from non-respondents ($n = 1521$). To assess self-selection bias, we conducted bivariate comparisons of demographic and injury characteristics to determine if our final model sample (*n* = 383) differed from those not in the model (*n* = 38) due to missing data. Statistical analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC) and Stata version 17 software (StataCorp, College Station, TX).

Results

We invited 2000 Veterans to complete the survey, of those 58 Veterans were removed from the denominator for the following reasons: 54 undeliverable surveys, 2 deceased, 1 did not have a SCI/D, and 1 was in the intensive care unit. A total of 421 Veterans completed the survey (response rate of 22%, 421/1942). Analysis was conducted on data from 410 Veterans; 11 Veterans were excluded due to missing PSI data.

Demographics, injury characteristics, objective measures of social isolation, and health factors that could impact PSI are provided in Table 1. Over half (56%) had PSI mean scores higher than the general population. Most respondents were male (71%), white (76%) non-Hispanic (93%), married (56%), had paraplegia (50%), and had an incomplete (73%) traumatic SCI/D (60%). On average participants were 65 years old (range: 25–95), had injury duration of 18 years (range: 1–62), and experienced injury onset at 47 years old (range: 19–91). Bivariate findings show that participant characteristics associated with high vs low PSI included younger mean age (63 vs. 68 years $P < 0.0001$) and younger mean age at injury onset (45 vs. 49 years $P = 0.0367$). No differences were seen for sex, race, marital status, injury level, injury completeness, etiology, or duration of injury. Objective social isolation measures associated with high vs low PSI include those with no informal caregiver (39% vs. 29%, $P = 0.036$), fewer than 4 people in their social network (71% vs. 26%, $P < 0.0001$), infrequently or never having meaningful contacts (38% vs. 17%, $P < 0.0001$), and infrequently or never having reliable contacts (14% vs. 3%, $P = 0.0003$). There were no significant differences in high vs low PSI for living alone.

The most reported complication in the last 6 months was dysfunctional sleep (60%). Complications in the last 6 months associated with high vs low PSI include having depression (74% vs. 20%, $P < 0.0001$), anxiety (70% vs. 21%, $P < 0.0001$), dysfunctional sleep (71% vs 45%, $P < 0.0001$), and post-traumatic stress (52% vs 15%, $P < 0.0001$) in the last 6 months. Most reported secondary conditions were chronic pain (72%), joint/muscle pain (65%), and sexual dysfunction (55%), and bladder dysfunction (50%). Bivariate comparisons showed statistically significant high PSI vs low PSI for all SCI/D secondary conditions except sexual dysfunction, loss of sensation, postural hypertension, pressure injuries, and heterotopic ossification. In addition, a greater proportion of individuals had 4 or more SCI/D secondary conditions that were chronically occurring problems (high PSI (54%) vs. low PSI (31%), $P < 0.0001$).

The final multivariable logistic regression model for variables associated with PSI is presented in Table 2. Among the objective measures, having a smaller social network size was associated with increased odds of high PSI (OR 3.59, $P < .0001$). Among health factors, having depression (OR 3.98, $P < .0001$), anxiety (OR 2.29, $P = 0.009$), and post-traumatic stress (OR 2.56, $P = 0.003$) in the previous 6 months and having 4 or more SCI/D secondary conditions be chronically occurring problems (OR 1.78, $P = 0.045$) was associated with increased odds of high PSI.

Contributors to feelings of PSI. Self-identified contributors to PSI are shown in Fig. 1. Almost two thirds of Veterans identified mobility (63%), and over half indicated having SCI/D (61%) and concerns about being a burden on others (57%) as contributing to feelings of PSI.

Non-response bias. There were no statistically significant differences for respondents (*n* = 421) vs non-respondents (*n* = 1521) for race, ethnicity, duration of injury, and level of injury. There were statistically significant differences between respondents andnon-respondents for age [mean age 65 years for respondents vs 59 years for non-respondents, $P < 0.0001$], age at injury [mean age 47 for respondents vs 43 for non-respondents, $P < 0.0001$] and sex [26% of respondents where female vs 21% of non-respondents, $P = 0.045$].

Selection bias. There were no differences in most variables, including PSI, demographics, and injury characteristics. The only exceptions of persons included in the regression model (*n* = 383) vs. those not in the model (*n* = 38) were marital status [61% in the model indicated married vs 37% not in the model, $P = 0.004$] and level of injury [52% in the model indicated paraplegia vs 38% not in the model; 28% in the model indicated tetraplegia vs 24% not in the model; and 21% in the model indicated AIS D vs 38% not in the model, $P = 0.05$].

Discussion

Our analysis aimed to describe PSI among Veterans living with SCI/D, specifically, and identify which demographic, injury characteristics, objective social isolation measures, and health factors were significantly associated with high PSI. Overall, PSI was prevalent in over half of the sample of Veterans living with SCI/

Table 1 Demographic, injury characteristics, objective measures of social isolation, and health factors of Veterans with spinal cord injury and disorders by normal/low vs high perceived social isolation (PSI).

	n (*N* = 410)	Overall *n* (%)	Low PSI: at or below population mean (≤ 50) *n* = 182 *n* (%)	High PSI: above population mean (>50) *n* = 228 *n* (%)	P value*
Demographic characteristics					
Sex					
Male	410	305 (74)	143 (79)	162 (71)	0.0886
Female		105 (26)	39 (21)	66 (29)	
Race					
White	409	305 (75)	133 (73)	172 (76)	0.7946
Black		86 (21)	40 (22)	46 (20)	
Other		18 (4)	9 (5)	9 (4)	
Ethnicity					
Hispanic or Latino	407	30 (7)	14 (8)	16 (7)	0.8494
Not Hispanic or Latino		377 (93)	166 (92)	211 (93)	
Marital Status					
Married	410	243 (59)	115 (63)	128 (56)	0.1578
Never married, separated, widowed		167 (41)	67 (37)	100 (44)	
Age mean (sd) [range]	410	65 (12) [25–95]	68 (11) [34–95]	63 (12) [25–93]	<0.0001
Level of Injury					
Paraplegia	397	203 (51)	93 (53)	110 (50)	0.384
Tetraplegia		109 (27)	42 (24)	67 (30)	
AIS D		85 (21)	40 (23)	45 (20)	
Completeness					
Complete	280	71 (25)	30 (23)	41 (27)	0.4925
Incomplete		209 (75)	99 (77)	110 (73)	
Etiology					
Traumatic	410	232 (69)	114 (63)	137 (60)	0.599
Non-traumatic		105 (31)	68 (37)	91 (40)	
Duration of injury mean (sd) [range]	410	19 (15) [1–62]	19 (16) [1–62]	18 (15) [1–58]	0.4892
Age at injury mean (sd) [range]	410	47 (17) [19–91]	49 (18) [19–83]	45 (16) [19–91]	0.0367
Objective measures of social isolation					
Informal Caregiver					
Informal Caregiver	410	268 (65)	129 (71)	139 (61)	0.036
No informal caregiver		142 (35)	53 (29)	89 (39)	
Living arrangement					
Live alone	406	110 (27)	41 (23)	69 (31)	0.0735
Does not live alone		296 (73)	140 (77)	156 (69)	
Social network size					
<4 people	400	204 (51)	46 (26)	158 (71)	<0.0001
4+ people		196 (49)	133 (74)	63 (29)	
Frequency of meaningful contacts					
Hardly ever/never	399	115 (29)	30 (17)	85 (38)	<0.0001
Some of the time/Often		284 (71)	148 (83)	136 (62)	
Frequency of reliable contacts					
Hardly ever/never	401	36 (9)	6 (3)	30 (14)	0.0003
Some of the time/Often		365 (91)	173 (97)	192 (86)	
Health Factors					
Complications last 6 months					
Depression	410	206 (50)	37 (20)	169 (74)	<0.0001
Anxiety	410	197 (48)	38 (21)	159 (70)	<0.0001
Dysfunctional sleep	410	245 (60)	82 (45)	163 (71)	<0.0001
Post-traumatic stress	410	146 (36)	27 (15)	119 (52)	<0.0001
Number of secondary conditions identified as a chronic problem**					
<4 Chronic	401	226 (56)	123 (69)	103 (46)	<0.0001
≥4 Chronic		175 (44)	54 (31)	121 (54)	
Individual secondary conditions***					
Chronic pain					
None/Infrequent/Occasional	388	155 (40)	93 (55)	62 (28)	<0.0001
Chronic		233 (60)	76 (45)	157 (72)	
Joint and muscle pain					
None/Infrequent/Occasional	391	185 (47)	107 (63)	78 (35)	<0.0001
Chronic		206 (53)	63 (37)	143 (65)	

Continued

Table 1 ***Continued***

	n (*N* = 410)	Overall *n* (%)	Low PSI: at or below population mean (≤ 50) *n* = 182 *n* (%)	High PSI: above population mean (>50) *n* = 228 *n* (%)	P value*
Sexual dysfunction					
None/Infrequent/Occasional	380	185 (49)	89 (54)	96 (45)	0.0904
Chronic		195 (51)	77 (46)	118 (55)	
Bladder dysfunction					
None/Infrequent/Occasional	385	217 (56)	108 (65)	109 (50)	0.0040
Chronic		168 (44)	59 (35)	109 (50)	
Muscle spasms/spasticity					
None/Infrequent/Occasional	376	234 (62)	116 (71)	118 (55)	0.0018
Chronic		142 (38)	47 (29)	95 (45)	
Bowel dysfunction					
None/Infrequent/Occasional	381	246 (65)	122 (74)	124 (58)	0.0014
Chronic		135 (35)	44 (27)	91 (42)	
Circulatory problems					
None/Infrequent/Occasional	361	283 (78)	130 (84)	153 (74)	0.0283
Chronic		78 (22)	25 (16)	53 (26)	
Loss of sensation					
None/Infrequent/Occasional	359	306 (85)	135 (85)	171 (86)	0.8747
Chronic		53 (15)	24 (15)	29 (15)	
Urinary tract infection(s)					
None/Infrequent/Occasional	378	327 (87)	149 (91)	178 (83)	0.0304
Chronic		51 (13)	15 (9)	36 (17)	
Respiratory problems					
None/Infrequent/Occasional	368	332 (90)	152 (94)	180 (87)	0.0387
Chronic		36 (10)	10 (6)	26 (13)	
Contractures					
None/Infrequent/Occasional	322	290 (90)	135 (94)	155 (87)	0.0466
Chronic		32 (10)	9 (6)	23 (13)	
Autonomic dysreflexia					
None/Infrequent/Occasional	323	294 (91)	140 (95)	154 (88)	0.0154
Chronic		29 (9)	7 (5)	22 (13)	
Postural hypertension					
None/Infrequent/Occasional	315	294 (93)	134 (96)	160 (91)	0.1297
Chronic		21 (7)	6 (4)	15 (9)	
Pressure injuries					
None/Infrequent/Occasional	354	334 (94)	146 (94)	188 (95)	0.5822
Chronic		20 (6)	10 (6)	10 (5)	
Heterotopic ossification					
None/Infrequent/Occasional	312	296 (95)	133 (94)	163 (95)	0.6916
Chronic		16 (5)	8 (6)	8 (5)	

*chi-square tests were performed on all variables except for the continuous variables age, duration of injury, and age at injury for which t tests were conducted.

**≥4 SCI secondary conditions that were a chronic problem vs. <4 secondary conditions that were a chronic problem (vs. none, infrequent, or mild).

*** Presented in order of overall column highest to lowest percentage of secondary conditions reported as chronic problems.

D. Our findings further indicated that objective social isolation measures including social network size, health factors including depression, anxiety, and post-traumatic stress, and multiple chronically occurring SCI/D secondary conditions were statistically associated with high PSI.

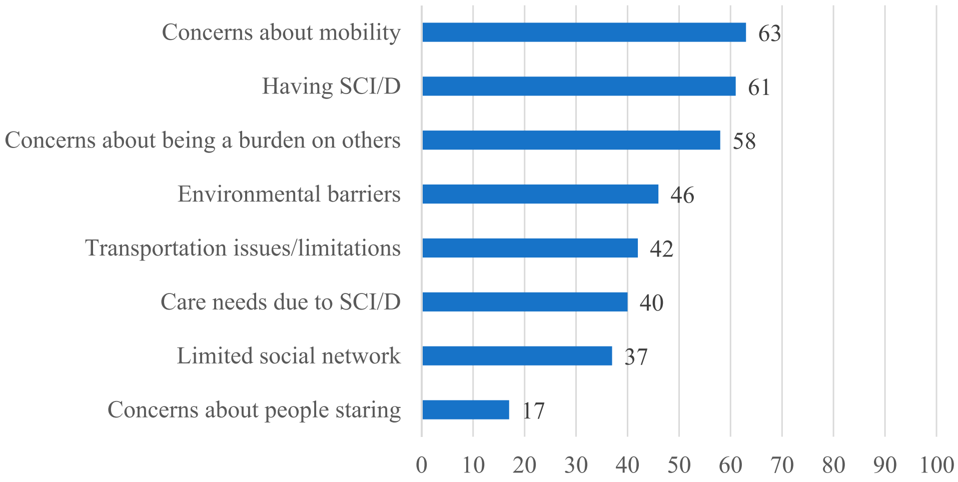
We found high PSI in Veterans with SCI/D who had less than 4 people in their social network. Although network size and quality of interactions are reduced following a SCI/D (2), there is an association between small social network and PSI in this population (1). However, other cross-sectional surveys of individuals living with SCI/D did not find an association with PSI and smaller network size but found associations with fewer number of contacts and lower levels of intimacy with contact (2, 32). In our survey we measured a similar concept, the frequency of reliable contacts (e.g. how often can you rely on others if you have a problem?) and we found that hardly ever/never having someone to rely on was statistically related to high PSI in the bivariate analysis and the multivariable analysis showed a trend for 3 times higher odds of high PSI (P = 0.06). In addition, we measured the composition of social network by analyzing the presence or

Table 2 Multivariable logistic regression: Variables independently associated with high perceived social isolation [reference: normative/low perceived social isolation] (*n* = 383).

Variables	Odds Ratio	95% Confidence interval	P value
Age (years)	0.991	0.964–1.02	0.546
Age at injury (years)	0.999	0.971–1.01	0.225
Objective measures of social isolation			
Informal caregiver			
Informal Caregiver [ref: no informal caregiver]	0.570	0.317–1.03	0.061
Social network size			
<4 people [ref: 4+]	3.59	2.07–6.21	<0.0001
Frequency of meaningful contacts			
Hardly ever/never [ref: some of the time/often]	1.58	0.828–3.00	0.166
Frequency of reliable contacts			
Hardly ever/never [ref: some of the time/often]	3.08	0.953–9.92	0.060
Health factors			
Depression	3.98	2.13–7.40	<0.0001
Anxiety	2.29	1.23–4.30	0.009
Dysfunctional sleep	0.969	0.532–1.76	0.918
Post traumatic stress	2.56	1.38–4.77	0.003
Secondary conditions identified as a chronic problem			
≥4 secondary conditions [ref: <4]	1.78	1.01–3.11	0.045

absence of an informal caregiver. The presence of an informal caregiver was found to have lower odds, or a protective effect (P = 0.06) of having high PSI in the multivariable analysis and the bivariate analysis showed those with an informal caregiver reported greater frequency of low PSI (P = 0.036). There are mixed findings on how having an informal caregiver can affect PSI. Some studies looking at informal caregivers of individuals with SCI/D share similar findings as our study that informal caregivers help decrease PSI, by giving individuals higher perceived social support (15, 33). However, other studies have found that once the role of a family member, spouse/partner, or friend change to that of an informal caregiver the relationship/intimacy dynamic changes and negatively impacts PSI (34). Our findings suggest that measuring social network size represents an important indicator of PSI. Additionally, social support which is a construct that may be related to one's social network is associated with better health outcomes in individuals with SCI/D (14). These findings suggest that social network size and level of support may be beneficial to target in an intervention to lower PSI. However, more research in Veterans living with SCI/D is warranted to understand the types of social network needed, such as family, friends, Veterans living with SCI/D acting as peer support or role models, caregivers, and other type of social connections that are the most beneficial to lowering PSI. Future research is needed to examine what kinds of social support (*i.e.* emotional support, instrumental support, or information support) are related to PSI and health outcomes in Veterans living with SCI/D.

Our findings showed that higher PSI was associated with three distinct mental health problems, depression, anxiety, and post-traumatic stress. Our results align with literature indicating that PSI is associated with developing, having, or worsening of depression and anxiety (22, 32, 35). In a systematic review of the general population, adults who reported feeling lonely



*Questions were select all that apply; n=410

Figure 1 Percent of veterans with spinal cord injury/disorders (SCI/D) identified contributors of perceived social isolation*. *Questions were select all that apply; *n* = 410.

more often had more than double the odds of developing depression compared to those who rarely/never feel lonely (36). Our results indicate those with depression having almost 4 times greater odds of higher *P*SI vs those without depression is consistent with the general population findings (36). Additionally, a study focusing on individuals with SCI/D found that increasing PSI, also increased depression ($r = .29$, $P < .001$; reflecting a medium effect size) (37). Our study also found high PSI was associated with post-traumatic stress, which is similar to other studies such as a systemic review of loneliness among Veterans found loneliness to be related to symptoms of post-traumatic stress disorder (38) and a longitudinal cohort study found greater hazard for post-traumatic stress disorder among individuals with SCI/D compared to those without a SCI/D. Further research is needed to better understand the relationship between PSI and mental health conditions such as depression, anxiety, and post-traumatic stress, the underlying mechanisms, and what potential interventions addressing these mental health conditions would be on PSI.

In addition, having four or more chronically occurring SCI/D secondary conditions was associated with nearly 2 times greater odds of high PSI. A scoping review of individuals living with SCI/D found associations between loneliness and loss of sexual function, bladder disorders, and symptoms of SCI/D (1). This is similar to our findings, with some of the most common significant SCI/D secondary conditions identified in our study being pain, bladder dysfunction, and muscle spasms/spasticity, although sexual dysfunction was shown to be higher in those with high PSI it was not significant. It would be beneficial to identify the ways in which secondary conditions in Veterans living with SCI/D contribute to PSI in order to develop interventions to improve SCI/D secondary condition management in ways that would alleviate PSI.

Respondents identified concerns they felt most commonly impacted their PSI were related to their SCI/D diagnosis. In other words, they felt that simply having a SCI/D influenced their feelings of PSI. Participants identified mobility as a common concern impacting their PSI. Robinson-Whelen *et al.* (39) similarly found mobility to be associated with loneliness in individuals living with SCI/D. A qualitative study looking at factors associated with PSI (40) also found that mobility was a bigger issue due to environmental barriers, such as when a building lacked accessibility and during winter months due to weather conditions making it more difficult for social interactions. In the same study, individuals also described feeling like they were a burden due to their SCI/D care and needs, which is similar to our study's findings of having concerns about being a burden on others as a contributor of PSI. Both mobility impairments and the feeling of being a burden could cause individuals to feel disconnected from individuals socially, which can affect factors of PSI such as engagement with social relationships or maladaptive social cognition, *i.e.* negative thoughts about self-worth (41). Interventions, such as cognitive behavioral therapy, addressing maladaptive ways of thinking been reported to be effective in reducing PSI (41, 42). It is important to statistically identify what is associated with high PSI, but it is also essential to identify what the individual feels in contributory (42), such as impaired mobility and feeling like a burden.

Limitations: The analysis was limited by potential selection bias given the 22% survey response rate. A cross-sectional survey design with self-reported responses could have recall bias affecting responses. While there were no differences in the majority of variables, our assessments of potential sources of bias indicated that there was a respondent bias towards older persons and women and a model selection bias towards those who were married, people with paraplegia, and those with AIS D injury severity. These biases may impact the generalizability of the findings. Finally, Veterans with SCI/D may differ from other SCI/D cohorts which may limit generalizability.

Conclusion

Objective social isolation measures such as social network size may be used to identify Veterans with SCI/D at risk for PSI, and more research for future interventions needs to be conducted on the type and quantity of social network interactions are most beneficial in reducing PSI in this population. A better understanding of the co-occurrence of mental health conditions such as such as depression, anxiety, and post-traumatic stress is needed to understand if one precedes the other or if addressing one improves the other. In addition, research is warranted on the impact of having chronically occurring SCI/D secondary conditions and how care needs can impact social health, e.g. bowel care programs may stifle social plans. In addition, contributors identified by Veterans with SCI/D such as "feeling like a burden to others" may benefit from different interventions such as targeting maladaptive social cognition. These findings reinforce the complexity of PSI and the need for more research to develop patient-centered interventions aimed at reducing PSI. These findings help in identifying what variables are associated with high PSI in Veterans with SCI/D, which will aid in the creation of evidence-based interventions for PSI as requested in the Surgeon General's advisory on the epidemic of loneliness and social isolation in the U.S.

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Conflicts of interest Authors have no conflict of interests to declare.

References

1 Cimino SR, Cadel L, Guilcher SJT, Wasilewski M, Hitzig SL. Social disconnectedness and perceived social isolation in persons with spinal cord injury/dysfunction living in the community: a scoping review. J Spinal Cord Med. 2023;46(3):367–389. doi:10.1080/10790268.2022.2129170. Epub ahead of print. PMID: 36269865.
2 Guilcher SJ, Craven B, Bassett-Gunter RL, Cimino SR, Hitzig SL. An examination of objective social disconnectedness and perceived social isolation among persons with spinal cord injury/dysfunction: a descriptive cross-sectional study. Disabil Rehabil. 2021;43(1):69–75.
3 Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci. 2015;10(2):227–237.
4 Newman SD, Li C, Krause JS. Social isolation after spinal cord injury: indicators from the longitudinal aging study. Rehabil Psychol. 2016;61(4):408–416.
5 Tate DG, Forchheimer M, Reber L, Meade M, Tan N, Clarke P. Factors enabling comorbidities and secondary conditions in older adults with spinal cord injury. J Spinal Cord Med. 2023;46(6):929–940. doi:10.1080/10790268.2022.2108662. Epub ahead of print. PMID: 35993788.
6 Umberson D, Karas Montez J. Social relationships and health: a flashpoint for health policy. J Health Soc Behav. 2010;51(1_suppl):S54–S66.
7 Havens B, Hall M, Sylvestre G, Jivan T. Social isolation and loneliness: differences between older rural and urban Manitobans. Can J Aging. 2004;23(2):129–140.
8 Nicholson NR Jr. Social isolation in older adults: an evolutionary concept analysis. J Adv Nurs. 2009;65:1342–1352.
9 Fried L, Prohaska T, Burholt V, Burns A, Golden J, Hawkley L, Lawlor B, Leavey G, Lubben J, O'Sullivan R, *et al.* A unified approach to loneliness. Lancet. 2020;395(10218):114. https://doi.org/10.1016/S0140-6736(19)32533-4
10 Coyle CE, Dugane E. Social isolation, loneliness and health among older adults. J Aging Health. 2012;24(8):1346–1363.
11 Nemecek D. Cigna US Loneliness Index: survey of 20,000 Americans examining behaviors driving loneliness in the United States. Bloomfield (CT): Cigna; 2018.
12 Emerson E, Fortune N, Llewellyn G, Stancliffe R. Loneliness, social support, social isolation and wellbeing among working age adults with and without disability: cross-sectional study. Disabil Health J. 2021;14(1):100965.
13 Tough H, Brinkhof MW, Siegrist J, Fekete C. The impact of loneliness and relationship quality on life satisfaction: a longitudinal dyadic analysis in persons with physical disabilities and their partners. J Psychosom Res. 2018;110:61–67.
14 Müller R, Peter C, Cieza A, Geyh S. The role of social support and social skills in people with spinal cord injury—a systematic review of the literature. Spinal Cord. 2012;50(2):94–106.
15 Barclay L, McDonald R, Lentin P, Bourke-Taylor H. Facilitators and barriers to social and community participation following spinal cord injury. Aust Occup Ther J. 2016;63(1):19–28.
16 Straus E, Norman SB, Tripp JC, Tsai J, Sippel LM, Jeste DV, Pietrzak RH. Behavioral epidemic of loneliness in older US military veterans: results from the 2019–2020 national health and resilience in veterans study. Am J Geriatr Psychiatry. 2022;30(3):297–310.
17 National Spinal Cord Injury Statistical Center. Traumatic Spinal Cord Injury Facts and Figures at a Glance. Birmingham (AL). Available from: https://www.nscisc.uab.edu/public/Facts%20and%20Figures%202023%20-%20Final.pdf 2023.
18 Sippel JL, Daly JE, Poggensee L, Ristau KD, Eberhart AC, Tam K, Smith BM. Modernization of a large spinal cord injuries and disorders registry: the veterans administration experience. Arch Rehabil Res Clin Transl. 2022;4(4):100237.
19 Shen C, Rolls ET, Cheng W, Kang J, Dong G, Xie C, Zhao XM, Sahakian BJ, *et al.* Associations of social isolation and loneliness with later dementia. Neurology. 2022;99(2):e164–e175.
20 Jiang HX, Liu Y, Jiang JJ, Wei JH, Niu CC, Yu J. Community support, social isolation and older adults' life satisfaction: evidence from a national survey in China. Aging Ment Health. 2023: 1–9. Epub ahead of print. PMID: 37395111.
21 Furman D, Campisi J, Verdin E, Carrera-Bastos P, Targ S, Franceschi C, Slavich GM. Chronic inflammation in the etiology of disease across the life span. Nat Med. 2019;25(12):1822–1832.
22 Smith BJ, Lim MH. How the COVID-19 pandemic is focusing attention on loneliness and social isolation. Public Health Res Pract. 2020;30:3022008. doi:10.17061/phrp3022008.
23 Cene CW, Beckie TM, Sims M, Suglia SF, Aggarwal B, Moise N, McCullough LD. American Heart Association Social Determinants of Health Committee of the Council on Epidemiology and Prevention and Council on Quality of Care and Outcomes Research; *et al.* Effects of Objective and Perceived Social Isolation on Cardiovascular and Brain Health: A Scientific Statement From the American Heart Association. J Am Heart Assoc. 2022;11:e026493.
24 Kanbay M, Tanriover C, Copur S, Peltek IB, Mutlu A, Mallamaci F, Zoccali C. Social isolation and loneliness: undervalued risk factors for disease states and mortality. Eur J Clin Investig. 2023: e14032.
25 United States. Public Health Service. Office of the surgeon general. Our epidemic of loneliness and isolation: A report of the surgeon general. U.S. Department of Health and Human Services, Public Health Service, Office of the Surgeon General 2023.
26 LaVela SL, Etingen B, Miskevics S, Heinemann AW. What determines low satisfaction with life in individuals with spinal cord injury? J Spinal Cord Med. 2019;42(2):236–244.
27 LaVela SL, Heinemann AW, Etingen B, Miskovic A, Locatelli SM, Chen D. Relational empathy and holistic care in persons with spinal cord injuries. J Spinal Cord Med. 2017;40(1):30–42.
28 Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, Hays R. The patient-reported outcomes measurement information system (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. J Clin Epidemiol. 2010;63(11):1179.
29 Questionnaires | Health and Retirement Study [Internet]. hrs.isr.umich.edu. Available from: https://hrs.isr.umich.edu/documentation/questionnaires.
30 Jørgensen V, Von Rosen P, Butler Forslund E. Considerations on the psychometric properties and validity of the spinal cord injury secondary conditions scale. Spinal Cord. 2021;59(8):894–901. https://doi.org/10.1038/s41393-021-00655-z.
31 LaVela SL, *et al.* Academy of spinal cord injury professionals 2022 ASCIP hybrid educational conference & expo September 7–10 Kansas City, MO, platform abstracts 1–23. J Spinal Cord Med. 2022;45(5):773–788.

32 Hitzig SL, Cimino SR, Alavinia M, Bassett-Gunter RL, Craven BC, Guilcher SJ. Examination of the relationships among social networks and loneliness on health and life satisfaction in people with spinal cord injury/dysfunction. Arch Phys Med Rehabil. 2021;102(11):2109–2116.e1.

33 Jensen MP, Smith AE, Bombardier CH, Yorkston KM, Miró J, Molton IR. Social support, depression, and physical disability: age and diagnostic group effects. Disabil Health J. 2014;7(2):164–172.

34 Quinn C, Clare L, Woods B. The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review. Aging Ment Health. 2009;13(2):143–154.

35 Domènech-Abella J, Mundó J, Haro JM, Rubio-Valera M. Anxiety, depression, loneliness and social network in the elderly: longitudinal associations from The Irish Longitudinal Study on Ageing (TILDA). J Affect Disord. 2019;246:82–88.

36 Mann F, Wang J, Pearce E, Ma R, Schlief M, Lloyd-Evans B. Loneliness and the onset of new mental health problems in the general population: a systematic review. medRxiv. [Preprint]. 2021.

37 Robinson-Whelen S, Hughes RB, Taylor HB, Holmes SA, Rodriquez J, Manohar S. Impacts of the COVID-19 pandemic on people with spinal cord injury. Rehabil Psychol. 2023;68(1):1.

38 Wilson G, Hill M, Kiernan MD. Loneliness and social isolation of military veterans: systematic narrative review. Occup Med (Chic Ill). 2018;68(9):600–609.

39 Robinson-Whelen S, Taylor HB, Feltz M, Whelen M. Loneliness among people with spinal cord injury: exploring the psychometric properties of the 3-item loneliness scale. Arch Phys Med Rehabil. 2016;97(10):1728–1734.

40 Cimino SR, Hitzig SL, Craven BC, Bassett-Gunter RL, Li J, Guilcher SJ. An exploration of perceived social isolation among persons with spinal cord injury in Ontario, Canada: a qualitative study. Disabil Rehabil. 2022;44(14):3400–3409.

41 Mann F, Bone JK, Lloyd-Evans B, Frerichs J, Pinfold V, Ma R, Johnson S. A life less lonely: the state of the art in interventions to reduce loneliness in people with mental health problems. Soc Psychiatry Psychiatr Epidemiol. 2017;52:627–638.

42 Masi CM, Chen HY, Hawkley LC, Cacioppo JT. A meta-analysis of interventions to reduce loneliness. Pers Soc Psychol Rev. 2011;15(3):219–266.

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ORIGINAL RESEARCH

Variables Associated With Moderate to High Loneliness Among Individuals Living With Spinal Cord Injuries and Disorders

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Abstract

Objective: To identify variables independently associated with moderate to high loneliness in individuals living with Spinal Cord Injuries or Disorders (SCI/D).

Design: A cross-sectional, national survey of a random sample of community-dwelling Veterans with SCI/D in the United States. Survey methodology was used to collect data on demographic and injury characteristics, general health, chronic and SCI-secondary conditions, and loneliness.

Setting: The VHA SCI/D System of Care including 25 regional SCI/D Centers (or Hubs).

Participants: Among 2466 Veterans with SCI/D, 592 completed surveys (24%). Most participants were men (91%), white (81%), not currently married (42%), had tetraplegia (33%), and on average injured for 18 years at the time of data collection (N=562).

Interventions: Not applicable.

Main Outcome Measure: The dependent variable, loneliness, was collected using the UCLA-3 instrument. Loneliness was dichotomized into never/low loneliness and moderate/high loneliness (UCLA score ≥ 4).

Results: Bivariate analyses assessed unadjusted associations in demographics, injury characteristics, chronic disease, and SCI-secondary conditions. Multivariable logistic regression was used to identify factors independently associated with moderate/high loneliness. Participants had a mean loneliness score of 5.04, SD=1.99. The point prevalence of moderate to high loneliness was 66%. Lower duration of injury, paraplegia, being unmarried, being in fair/poor general health, having dysfunctional sleep, and having a diagnosis of bowel dysfunction were each independently associated with greater odds of moderate/high loneliness.

Conclusions: Findings suggest that interventions to reduce/manage loneliness in the Veteran SCI/D population should focus on those who are more newly injured, have paraplegia, currently unmarried, have bowel problems, and experience dysfunctional sleep.

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Loneliness is a subjective emotional state that occurs when one feels isolated, left out, and lacking companionship.[1,2] In May 2023, the US Surgeon General released an advisory about the "epidemic" or "public health crisis of loneliness, isolation, and lack of connection in our country."[3] Loneliness and social isolation have been associated with an increased risk for a variety of health concerns and diseases type 2 diabetes,[4] metabolic syndrome,[5] coronary heart disease and stroke,[6] and dementia.[7] Additionally, loneliness has a vast negative effect on physical and mental health,[8,9] health behaviors,[10] and health care utilization.[11,12] Therefore, it is important to identify populations

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with high risk of loneliness and understand characteristics of those who are most affected to deliver interventions to curb this phenomenon.

Populations with spinal cord injury or disorder (SCI/D) are seemingly vulnerable to loneliness. For instance, SCI/D can drastically change an individual's physical mobility and social environment.[13] As SCI/D changes the physical and social aspects of a person's life, those with SCI/D may encounter newfound barriers to social interaction, which could elicit feelings of separation and increase the risk of loneliness.[14] Having an SCI/D radically changes an individual's life, often affecting their closest relationships.[15] This change can result in a recategorization of relationships, as those with SCI/D may require informal caregiving and help with daily needs from those around them.[16] Furthermore, transitioning from recovery to post-hospital discharge life can result in a loss of community and connection that was initially present during the acute care phase.[17] Changes in both relationships and loss of community support can contribute to loneliness among those with SCI/D that may occur alone or along with other consequences, such as poor quality of life.[18] Using data from Swiss residents with and without SCI, researchers found that individuals with SCI reported significantly less social support.[19]

In addition to potential role and relationship changes, chronic and secondary health conditions can have a significant adverse effect on postinjury social health and participation.[20] Across a sample of over 11,000 participants with SCI, Strøm et al[20] found that 95% reported experiencing at least 1 or more secondary health problems due to their SCI. These secondary conditions greatly vary, with pain, bladder, and bowel dysfunction often cited as some of the most common.[20] Furthermore, secondary disorders like bladder and bowel dysfunction can be stigmatizing and require management routines that can make social situations more difficult.[21] If the individual with SCI/D is a Veteran, this may compound feelings of loneliness. Veteran populations may have unique experiences of military-related trauma and post-traumatic stress that are associated with loneliness.[22] Using data from the National Health and Resilience in Veterans Study conducted from 2019 to 2020, Straus et al[23] reported that over half their sample of older Veterans (n=4069) felt lonely either sometimes or often. This is particularly alarming as Veterans experiencing loneliness have higher rates of suicidal ideation.[23,24] Furthermore, the Veteran population is aging.[25] With older age, the risk of loneliness may increase,[26] making Veterans with SCI/D vulnerable to loneliness and its negative consequences. Veterans also have a higher proportion of nontraumatic injuries compared with the general population; however, it remains unclear if etiology affects loneliness.[27,28]

Veterans with SCI/D face many challenges to social interaction and participation, and their unique experiences may put them at higher risk of loneliness than the general population.[22] Despite the high prevalence of secondary conditions and dramatic social life changes that accompany SCI/D, little is known about factors associated with loneliness among Veterans with SCI/D. The objective of the current study is to identify factors associated with moderate to high levels of loneliness among Veterans with SCI/D. Findings will inform future trials of loneliness interventions among Veterans with SCI/D who may be most at risk for loneliness and who may benefit from an intervention.

List of abbreviations:

SCI/D spinal cord injuries or disorders

Methods

Design

A cross-sectional, national survey focused explicitly on individuals' experiences with loneliness was conducted with a random sample of community-dwelling Veterans with SCI/D. This study was approved by the Institutional Review Board at Edward Hines, Jr VA Hospital.

Setting

The VHA SCI/D System of Care includes 25 regional SCI/D Centers (or Hubs). These provide comprehensive, coordinated, lifelong care delivered by interdisciplinary teams. The SCI/D Hubs are linked with 123 SCI/D Spoke sites at other VHA medical centers and outpatient clinics located across the country. The VHA cares for over 15% of individuals with SCI/D in the US.[28]

Sample and recruitment

The sample included Veterans with SCI/D who had used VHA health care services between March 2017 and March 2022. The sample was derived from a sampling frame of 12,464 Veterans who had a diagnosis of paraplegia or tetraplegia in the VHA medical record database and were injured for at least 1 year. The sample was inclusive of both traumatic and nontraumatic SCI/D and included those diagnosed with nonmalignant neoplasms resulting in neurologic deficit; vascular insults of a thromboembolic, hemorrhagic, or ischemic nature; cauda equina syndrome producing neurologic deficit; inflammatory disease of the spine, spinal cord, or cauda equina resulting in nonprogressive neurologic deficit; and demyelinating disease of the spinal cord. SAS 9.4 (SAS Institute Inc, Cary, NC) Proc SurveySelect was used to perform random sampling. We chose a 20% random sample from the sampling frame for our survey sample. Because the prevalence of SCI/D is much lower in women than men, at around 5%,[29] we oversampled women with the goal of enrolling approximately 10% women. The final sample to invite for participation included 2700 individuals (91% men and 9% women).

Data collection

Invitation letters were mailed along with a previously field-tested survey (incorporating feedback from 5 individuals with SCI/D to ensure understandability) and a business reply envelope between April 2022 and July 2022. This included 2 follow-up mailings to nonrespondents of the initial survey to facilitate response. Participants were given the option to participate by telephone if needed. Responses were accepted until December 2022, and respondents did not receive financial remuneration.

Variables

The dependent variable, loneliness, was measured using the UCLA 3-item loneliness scale.[2] Each item was rated on a 3-point scale from 1 (*Hardly ever or never*) to 3 (*Often*). The 3 items asked “How often do you feel that you lack companionship? Feel left out? and Feel isolated?” Possible scores range from 3 to 9, with a score of 9 indicating the highest level of loneliness.

The survey also included items to collect demographic characteristics, injury details, and health conditions. Demographic variables included sex, age, race/ethnicity, education (*level completed*), employment status (*work full time, work part time, or retired*), relationship status (*married, member of an unmarried couple, separated/divorced, widowed, never married*), and living arrangement (*live alone, live with family, spouse, or friend, or live with formal (hired) caregiver*). Injury characteristics included injury type/level (*paraplegia* vs *tetraplegia*), complete vs incomplete, duration of injury (*number of years*), age at injury onset, and etiology (*traumatic* vs *nontraumatic*). Health characteristics included general health, chronic conditions, and SCI-secondary conditions. General health was rated on a scale from 1 (*poor*) to 5 (*excellent*) and was dichotomized as excellent/very good/good vs fair/poor.[30] Presence of chronic conditions during the past 6 months included high blood pressure, high cholesterol, heart problems, respiratory problems, diabetes, and dysfunctional sleep. SCI-secondary conditions assessed included pain, spasms, bladder issues, bowel issues, and pressure injuries.

Data analyses

The dependent variable was examined descriptively, including mean, standard deviation (SD), and range. Scores were dichotomized as no/low loneliness and moderate/high loneliness (UCLA score≥4) for bivariate analyses to assess unadjusted associations with demographics, injury characteristics, and health variables. This cut-off was based on past research using the UCLA 3-item scale.[2,31,32] Multivariable logistic regression was used to identify factors independently associated with moderate/high loneliness. Variables were considered for model inclusion based on associations reported in the literature as well as statistically significant bivariate associations comparing no/low vs moderate/high loneliness. In addition, to assess selection bias, we conducted bivariate analyses to examine any differences in demographic and injury characteristics between those excluded from the model due to missing data (n=30) compared with those included in the model (n=562). An alpha level of 0.05 was used to determine statistical significance. Statistical analyses were performed with SAS 9.4 (SAS Institute Inc, Cary, NC).

Results

Sample characteristics/responses

Surveys were distributed to 2700 individuals. Of these, 162 mailings were returned as undeliverable, 16 were to recently deceased Veterans, and 3 were ineligible (eg, back injury, not SCI/D); leaving a valid denominator of 2519 for recruitment. A total of 592 (24%) Veterans with SCI/D responded. Nonrespondents (n=1927) and respondents (n=592) were compared on available demographic and injury variables for both groups. Respondents and nonrespondents did not differ on sex (*P*<.900) or duration of injury (*P*<.200) in years. However, respondents were significantly younger (*P*<.001), more were White (*P*<.001), had paraplegia (*P*<.001), and were older at injury onset (*P*<.001).

Of the 592 respondents, 562 had complete data available on all variables for inclusion in the multivariable regression models. Participants were overwhelmingly men (91%) and White (81%). Most were currently married or a member of an unmarried couple (59%) compared with not currently married (41%). Sixty-seven percent had paraplegia and 33% had tetraplegia. On average, participants had been injured for 18.39 years (SD=16.69). Participants reported a variety of health complications, the most prevalent of which included pain (59%), spasms (54%), and bladder issues (40%). For the full list of demographics, injury details, and health complications, see table 1. Overall, the sample had a mean loneliness score of 5.04 (SD=1.99). Among the 562 respondents, 370 (66%) had moderate to high loneliness.

Bivariate associations

Bivariate analyses compared participants with no/low loneliness with moderate/high loneliness scores on the UCLA 3-item scale. Differences in the distribution of demographic or injury characteristics by loneliness status were not statistically significant (table 1). However, compared with those with no/low loneliness, participants with moderate/high loneliness were significantly younger (*P*=.034), more lived alone (*P*=.008), less likely to be married (*P*<.001), more had paraplegia (*P*=.047), and had their injury for significantly less amount of time (*P*=.001).

For health variables, no statistically significant differences were found for heart problems, high cholesterol, diabetes, breathing/lung issues, or pressure injuries. However, compared with those with no/low loneliness, significantly more participants with moderate/high loneliness reported fair/poor health (*P*<.001), high blood pressure (*P*=.046), dysfunctional sleep (*P*<.001), pain (*P*<.001), bladder issues (*P*<.001), bowel issues (*P*<.001), and spasms (*P*<.001). See table 2 for bivariate analyses.

Multivariable logistic regression

A multivariable logistic regression was performed to determine variables independently associated with moderate/high loneliness compared with no/low loneliness. After controlling for covariates in the model, lower duration of injury (OR=0.99, *P*=.01), paraplegia (OR=1.73, *P*=.01), being unmarried (OR=1.95, *P*=.006), self-reporting fair/poor general health (OR=2.29, *P*<.001), dysfunctional sleep (OR=1.79, *P*=.006), and bowel dysfunction (OR=1.87, *P*=.010) were each independently associated with greater odds of moderate/high loneliness compared with low loneliness. Age, living arrangement, high blood pressure, spasticity, pain, and bladder issues were not significantly associated with moderate/high loneliness (table 2).

In our comparisons of those included in the model vs not in the model based on missing data, there were no statistically significant differences in loneliness measures, demographics, injury characteristics, or any of the chronic or SCI-secondary conditions. Living arrangement differed between groups, with 20% of modeled observations living alone vs 33% of those not in the model (*P*=.01).

Discussion

This study identified characteristics of those with SCI/D at risk for moderate to high levels of loneliness. Overall, we identified several injury-related and health-related factors associated with

Table 1 Bivariate associations: no/low loneliness vs moderate/high loneliness among individuals with SCI/D (n=562)

Variable	Overall (n=562, Unless Otherwise Noted)	No/Low Loneliness (n=192)	Moderate/High Loneliness (n=370)	*P* Value
Demographics				
Sex				.20
Men	91%	93%	90%	
Women	9%	7%	10%	
Age mean ± SD	63.03 (13.14), 21.10-93.64	64.83 (13.00), 21.10-91.73	62.85 (12.97), 24.55-93.64	**.034**
Race (n=560)				.70
White (non-Hispanic)	81%	82%	80%	
Non-White	19%	18%	20%	
Ethnicity:				.60
Hispanic or Latino	6%	6%	7%	
Not Hispanic or Latino	94%	94%	93%	
Education completed (n=557)				.60
College graduate	36%	37%	35%	
Some college	43%	41%	45%	
High school graduate or less	21%	22%	20%	
Marital status				**<.001**
Married/member of unmarried couple	59%	69%	53%	
Not married	41%	31%	47%	
Living arrangement				**.008**
Living alone	20%	14%	23%	
Living with family/friend, spouse	71%	79%	67%	
Living with formal caregiver	9%	7%	10%	
Injury characteristics				
Injury level				**.047**
Tetraplegia	33%	38%	30%	
Paraplegia	67%	62%	70%	
Completeness (n=511)				.10
Complete	52%	47%	55%	
Incomplete	48%	53%	24%	
Age at injury onset mean ± SD	44.69 (18.89), 17.75-88.41	43.16 (19.63), 18.32- 87.15	46.10 (18.02), 17.75-88.41	.058
Duration of injury, y. Mean ± SD	18.39 (16.69), 1.00-72.26	21.67 (17.51), 1.00-64.00	16.49 (15.33), 1.00-72.26	**.001**
Etiology				.50
Traumatic	80%	82%	79%	
Nontraumatic	20%	18%	21%	
Health characteristics				
General health				**<.001**
Good/very good/excellent	69%	82%	61%	
Fair/poor	31%	18%	39%	
Health conditions				
Heart problems	7%	5%	8%	.13
High blood pressure	33%	28%	36%	**.046**
High cholesterol	16%	17%	15%	.50
Diabetes	19%	17%	20%	.40
Breathing/lung issues	15%	11%	18%	.081
Dysfunctional sleep	43%	29%	50%	**<.001**
Pain	59%	48%	65%	**<.001**
Bladder issues	46%	36%	51%	**<.001**
Bowel issues	40%	25%	47%	**<.001**
Spasms	54%	45%	58%	**.004**
Pressure injuries	26%	21%	28%	.095

*Percentages provided unless otherwise indicated.

higher loneliness. A greater odds of moderate/high loneliness was found among those with paraplegia vs tetraplegia. This finding contrasts with other research that has suggested greater severity of injury is associated with worse quality of life and life satisfaction,[33,34] which may be related to less loneliness perhaps due to greater social connections experienced by greater social participation.[35] It is also possible that severity is not as important in determining emotional well-being as other sociodemographic and injury variables.[36,37] While these studies look at certain aspects of quality of life and emotional well-being, none of these

Table 2 Multivariable logistic regression: variables independently associated with moderate to high loneliness (vs no/low loneliness) among individuals with SCI (n=562)

Variable	OR	95% CI	*P* Value
Demographics			
Age	0.99	0.97, 1.01	.20
Marital status			
Married/member of unmarried couple	-	-	-
Not married	1.95	1.22, 3.17	**.006**
Living arrangement			
Living alone			
Living with family, spouse, friend, or formal caregiver	0.85	0.46, 1.55	.60
Injury characteristics			
Injury level			
Tetraplegia	-	-	-
Paraplegia	1.73	1.13, 2.63	**.011**
Duration of injury (years)	0.99	0.97, 1.00	**.014**
General health characteristics			
General health			
Good/very good/excellent	-	-	-
Fair/poor	2.29	1.44, 3.70	**<.001**
Health conditions [reference: not having the condition]			
High blood pressure	1.21	0.78, 1.89	.40
Dysfunctional sleep	1.79	1.18, 2.73	**.006**
Pain	1.24	0.82, 1.89	.30
Bladder issues	0.89	0.56, 1.40	.60
Bowel issues	1.87	1.17, 3.03	**.010**
Spasms	1.23	0.81, 1.87	.030

examined the differences in loneliness among those with paraplegia vs those with tetraplegia. It is possible that related, but distinct, concepts such as objective social isolation or perceived social isolation (PSI) or could be affected differently by injury severity. Notably PSI and/or objective social isolation has been shown to lack correlation with loneliness.[38] Therefore, it's possible that this finding is unique to loneliness, which could help explain the current findings. One study reported higher levels of optimism among those with tetraplegia compared with paraplegia, a mindset that is associated with effective coping strategies in times of stress.[39] It's possible that greater optimism was experienced by those with tetraplegia in our sample, leading them to be less likely to perceive their situation as isolated. However, optimism was not measured among our sample, and so it is unknown whether this could be contributing to the differences in loneliness. More research is needed to better understand this phenomenon.

Shorter duration of injury was another injury characteristic associated with higher levels of loneliness compared with no/low levels of loneliness. This finding aligns with past research on the adjustment period experienced post-injury.[17,40] Barclay et al[40] identified a period of withdrawal from society early after injury. As individuals with SCI/D are adjusting to their new way of life, they are at risk for feelings of loneliness. SCI/D may result in a loss of independence and acceptance of needing help. This can require a revamping of social relationships, as significant others or other family members may change to more caregiver roles. Such changes may strain relationships and social connections.[15,16] Therefore, as all of these changes are occurring post-injury, a lower duration of time since injury or diagnosis may be a time when individuals are particularly at risk for greater loneliness, as evident in the current study.

While the changing in status of social relationships can be a source of stress, these very same relationships may serve to alleviate stress and be a support system for those with SCI/D. Higher odds of expressing moderate/high loneliness was found among nonmarried participants. Unlike being married or in a nonmarried couple, nonmarried participants may not have as consistent or intimate social interactions. However, whether this means that married or those in a domestic partnership are less lonely is not a consistent finding within the literature, particularly for those with physical disabilities.[15,18] Those in a partnership can experience more stress due to the strain their physical disability puts on the relationship.[41] However, the quality of close personal relationships may alleviate some of these strains. In our study, being in a relationship was positive and was associated with lower loneliness. As high-quality marriages can be protective against negative mental health effects,[15] it's possible that our particular sample had higher quality relationships, thereby buffering against feelings of loneliness. One study found that among individuals with SCI, functional social relationships, not partnership status, was associated with better mental health and well-being outcomes.[42] As we did not measure relationship quality, it is difficult to establish if this explains our results. Nevertheless, a connection between relationship status and loneliness was a factor in the current study.

Besides the lifestyle and relationship changes post-injury, the experience of secondary health conditions is quite common for those with SCI.[20,43] In the current study, a high proportion of participants experienced health complications, such as pain, spasms, bladder issues, and bowel dysfunction. In our sample, bowel dysfunction was associated with 1.87 times higher odds of moderate/high loneliness. The experience of neurogenic bowel disorders can result in avoidance of leaving home or engaging in social activities due to fear of bowel issues or accidents.[21] Bowel accidents can be a newfound reality and can elicit negative reactions from others.[21] The fear of such events can prevent social interaction, leading to increased feelings of loneliness. While some studies have found an association between moderate/severe bowel dysfunction and quality of life,[44] none, to our knowledge, have directly looked at the relationship between bowel dysfunction and loneliness. The findings from the current study suggest that among those with SCI/D, bowel dysfunction is associated with moderate to high loneliness and is a factor to consider when planning efforts and interventions to reduce loneliness.

In addition to bowel dysfunction, sleep disturbances were another important health complication associated with loneliness. The current study linked moderate/high loneliness to dysfunctional sleep, which is a consistent finding within the loneliness literature in other populations.[45,46] Sleep is a critical aspect of physical and mental health. Poor sleep has been linked as a mediator for loneliness and adverse health conditions.[47] In 1 study, high loneliness contributed to poor sleep quality, which then contributed to migraines, diabetes, and cardiovascular disease in older adults.[47] The presence of dysfunctional sleep illustrates how loneliness and the experience of secondary health condition can be additive. Therefore, sleep may be an important catalyst for the effect of loneliness on health conditions and should be considered when identifying those with higher levels of loneliness.

Limitations

A limitation of this study is the low response rate. It is possible that nonrespondents may have differed on levels of loneliness. Nonrespondents could have lower or higher rates of loneliness compared with the participants. Furthermore, only a third of our sample included those with tetraplegia. The effect of moderate/high loneliness being more prevalent among those with paraplegia compared with tetraplegia could have been the result of an underrepresentation of people with tetraplegia. One possibility for the lower response rate from people with tetraplegia could be due the written response method. Those who did choose to reply may have had more functional hand dexterity. Beyond the physical requirements of the survey, it is hard to conjecture why there was a smaller proportion of people with tetraplegia compared with those with paraplegia in our study. Nevertheless, more research is needed to better understand loneliness differences based on injury level and severity.

In addition, our sample focused exclusively on US Veterans with SCI/D. It is possible that our population of Veterans may not be representative of all individuals with SCI/D, including civilians with SCI/D and Veterans who receive their care outside of the VHA. Veterans tend to be older, and a higher proportion are men,[25] which was also reflected in our sample. Likewise, more veterans have nontraumatic compared with other SCI samples.[27,28] Therefore, our findings may not be generalizable to women, younger individuals with SCI, and those with traumatic injuries. In addition, self-reported findings such as with health conditions, may be subject to recall bias.

Further directions and conclusions

This study documented that 66% of Veterans with SCI/D experienced moderate to high levels of loneliness, which is markedly higher than rates reported for the general population. The current study highlights the characteristics that may be associated with increased loneliness in this population. This may be helpful in intervention development and health care delivery efforts to decrease loneliness among Veterans with SCI/D. The current study highlights how taking into consideration demographics (including social relationships), injury characteristics, and health conditions, can provide a better picture of loneliness among Veterans with SCI/D in the hopes of targeting the appropriate sample of individuals for an intervention.

Keywords

Chronic conditions; Loneliness; Psychosocial outcomes; Rehabilitation; Secondary conditions; Spinal cord injury

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References

1. Holt-Lunstad J, Smith TB, Baker M, et al. Loneliness and social isolation as risk factors for mortality: a meta-analytic review. Perspect Psychol Sci 2015;10:227–37.
2. Hughes ME, Waite LJ, Hawkley LC, et al. A short scale for measuring loneliness in large surveys: results from two population-based studies. Res Aging 2004;26:655–72.
3. Office of the Surgeon General. Our epidemic of loneliness and isolation: the U.S. Surgeon General’s advisory on the healing effects of social connection and community. 2023. Available at: https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf. Accessed June 2, 2023.
4. Henriksen RE, Nilsen RM, Strandberg RB. Loneliness increases the risk of type 2 diabetes: a 20 year follow-up - results from the HUNT study. Diabetologia 2023;66:82–92.
5. Henriksen RE, Nilsen RM, Strandberg RB. Loneliness as a risk factor for metabolic syndrome: results from the HUNT study. J Epidemiol Community Health 2019;73:941–6.
6. Valtorta NK, Kanaan M, Gilbody S, Ronzi S, Hanratty B. Loneliness and social isolation as risk factors for coronary heart disease and stroke: systematic review and meta-analysis of longitudinal observational studies. Heart 2016;102:1009–16.
7. Huang AR, Roth DL, Cidav T, et al. Social isolation and 9-year dementia risk in community-dwelling Medicare beneficiaries in the United States. J Am Geriatr Soc 2023;71:765–73.
8. Menec VH, Newall NE, Mackenzie CS, Shooshtari S, Nowicki S. Examining social isolation and loneliness in combination in relation to social support and psychological distress using Canadian Longitudinal Study of Aging (CLSA) data. PLoS One 2020;15:e0230673.
9. Richard A, Rohrmann S, Vandeleur CL, Schmid M, Barth J, Eichholzer M. Loneliness is adversely associated with physical and mental health and lifestyle factors: results from a Swiss national survey. PLoS One 2017;12:e0181442.
10. Gutkind S, Gorfinkel LR, Hasin DS. Prospective effects of loneliness on frequency of alcohol and marijuana use. Addict Behav 2022;124:107115.
11. Christiansen J, Pedersen SS, Andersen CM, Qualter P, Lund R, Lasgaard M. Loneliness, social isolation, and healthcare utilization in the general population. Health Psychol 2023;42:63–72.
12. Chamberlain S, Savage RD, Bronskill SE, et al. Retrospective cross-sectional study examining the association between loneliness and

unmet healthcare needs among middle-aged and older adults using the Canadian Longitudinal Study of Aging (CLSA). BMJ Open 2023;13: e068769.

13. Budd MA, Gater Jr DR, Channell I. Psychosocial consequences of spinal cord injury: a narrative review. J Pers Med 2022;12:1178.
14. Macdonald SJ, Deacon L, Nixon J, et al. 'The invisible enemy': disability, loneliness and isolation. Disabil Soc 2018;33:1138–59.
15. Tough H, Fekete C, Brinkhof MWG, Siegrist J. Vitality and mental health in disability: associations with social relationships in persons with spinal cord injury and their partners. Disabil Health J 2017; 10:294–302.
16. Jeyathevan G, Cameron JI, Craven BC, Munce SEP, Jaglal SB. Re-building relationships after a spinal cord injury: experiences of family caregivers and care recipients. BMC Neurol 2019;19:117.
17. Dickson A, Ward R, O'Brien G, Allan D, O'Carroll R. Difficulties adjusting to post-discharge life following a spinal cord injury: an interpretative phenomenological analysis. Psychol Health Med 2011; 16:463–74.
18. Shin JC, Goo HR, Yu SJ, Kim DH, Yoon SY. Depression and quality of life in patients within the first 6 months after the spinal cord injury. Ann Rehabil Med 2012;36:119–25.
19. Geyh S, Nick E, Stirnimann D, et al. Biopsychosocial outcomes in individuals with and without spinal cord injury: a Swiss comparative study. Spinal Cord 2012;50:614–22.
20. Strøm V, Månum G, Arora M, et al. Physical health conditions in persons with spinal cord injury across 21 countries worldwide. J Rehabil Med 2022;54:jrm00302.
21. Nevedal A, Kratz AL, Tate DG. Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel. Disabil Rehabil 2016;38:573–81.
22. Wilson G, Hill M, Kiernan MD. Loneliness and social isolation of military veterans: systematic narrative review. Occup Med (Lond) 2018;68:600–9.
23. Straus E, Norman SB, Tripp JC, et al. Behavioral epidemic of loneliness in older U.S. military veterans: results from the 2019-2020 National Health and Resilience in Veterans Study. Am J Geriatr Psychiatry 2022;30:297–310.
24. Teo AR, Marsh HE, Forsberg CW, et al. Loneliness is closely associated with depression outcomes and suicidal ideation among military veterans in primary care. J Affect Disord 2018;230: 42–9.
25. Vespa J. Aging veterans: American's veteran population in later life. US Census Bureau; July 2023. p. 1–9. https://www.census.gov/library/publications/2023/acs/acs-54.html. Accessed November 1, 2023.
26. Franssen T, Stijnen M, Hamers F, Schneider F. Age differences in demographic, social and health-related factors associated with loneliness across the adult life span (19-65 years): a cross-sectional study in the Netherlands. BMC Public Health 2020;20:1118.
27. Molinares DM, Gater DR, Daniel S, Pontee NL. Nontraumatic spinal cord injury: epidemiology, etiology and management. J Pers Med 2022;12:1872.
28. Sippel JL, Daly JE, Poggensee L, et al. Modernization of a large spinal cord injuries and disorders registry: the veterans administration experience. Arch Rehabil Res Clin Transl 2022;4:100237.
29. LaVela SL, Heinemann AW, Etingen B, Miskovic A, Locatelli SM, Chen D. Relational empathy and holistic care in persons with spinal cord injuries. J Spinal Cord Med 2017;40:30–42.
30. Ware Jr J, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care 1996;34:220–33.
31. LaVela SL, Motl RW, Gonzalez B, Tarlov E, Aguina K, Bombardier CH. Randomised controlled trial of the Caring Connections intervention to reduce loneliness and perceived social isolation in persons with spinal cord injuries and disorders: study protocol. BMJ Open 2022;12:e063246.
32. Basu A, Kim HH, Basaldua R, et al. A cross-national study of factors associated with women's perinatal mental health and wellbeing during the COVID-19 pandemic. PLoS One 2021;16:e0249780.
33. Jain NB, Sullivan M, Kazis LE, Tun CG, Garshick E. Factors associated with health-related quality of life in chronic spinal cord injury. Am J Phys Med Rehabil 2007;86:387–96.
34. van Koppenhagen CF, Post MW, van der Woude LH, et al. Changes and determinants of life satisfaction after spinal cord injury: a cohort study in the Netherlands. Arch Phys Med Rehabil 2008;89:1733–40.
35. Savic G, Frankel HL, Jamous MA, Soni BM, Charlifue S. Participation restriction and assistance needs in people with spinal cord injuries of more than 40 year duration. Spinal Cord Ser Cases 2018;4:28.
36. Ebrahimzadeh MH, Soltani-Moghaddas SH, Birjandinejad A, Omidi-Kashani F, Bozorgnia S. Quality of life among veterans with chronic spinal cord injury and related variables. Arch Trauma Res 2014;3:e17917.
37. Halvorsen A, Pape K, Post MWM, et al. Participation and quality of life in persons living with spinal cord injury in Norway. J Rehabil Med 2021;53:jrm00217.
38. Wirth W, Motl RW, Bombardier CH, et al. Factors associated with perceived social isolation among individuals with spinal cord injury and disorders: Cross sectional survey. J Spinal Cord Med. 2024. https://doi.org/10.1080/10790268.2023.2299500.
39. Rostowska T, Kossak D. Strategies for coping with stress in patients with tetraplegia and paraplegia. Acta Neuropsychol 2011;9:31–48.
40. Barclay L, Lentin P, Bourke-Taylor H, McDonald R. The experiences of social and community participation of people with non-traumatic spinal cord injury. Aust Occup Ther J 2019;66:61–7.
41. Warner DF, Adams SA. Physical disability and increased loneliness among married older adults: the role of changing social relations. Soc Ment Health 2016;6:106–28.
42. Fekete C, Tough H, Arora M, et al. Are social relationships an underestimated resource for mental health in persons experiencing physical disability? Observational evidence from 22 countries. Int J Public Health 2021;66:619823.
43. Tallqvist S, Kauppila AM, Vainionpää A, et al. Prevalence of comorbidities and secondary health conditions among the Finnish population with spinal cord injury. Spinal Cord 2022;60:618–27.
44. Ture SD, Ozkaya G, Sivrioglu K. Relationship between neurogenic bowel dysfunction severity and functional status, depression, and quality of life in individuals with spinal cord injury. J Spinal Cord Med 2023;46:424–32.
45. Hom MA, Chu C, Rogers ML, Joiner TE. A meta-analysis of the relationship between sleep problems and loneliness. Clin Psychol Sci 2020;8:799–824.
46. Griffin SC, Williams AB, Ravyts SG, Mladen SN, Rybarczyk BD. Loneliness and sleep: a systematic review and meta-analysis. Health Psychol Open 2020;7:2055102920913235.
47. Christiansen J, Larsen FB, Lasgaard M. Do stress, health behavior, and sleep mediate the association between loneliness and adverse health conditions among older people? Soc Sci Med 2016;152:80–6.

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RESEARCH PAPER

An examination of objective social disconnectedness and perceived social isolation among persons with spinal cord injury/dysfunction: a descriptive cross-sectional study

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ABSTRACT

Purpose: To describe objective social disconnectedness and perceived social isolation post-spinal cord injury/dysfunction (SCI/D), and to examine associations among social disconnectedness and social isolation by sociodemographic and clinical characteristics.

Materials and Methods: A telephone-based questionnaire was administered to 170 community dwelling individuals with a SCI/D. Social disconnectedness was measured by social network size, composition, and frequency of contact. Social isolation was measured using the revised three item UCLA Loneliness Scale.

Results: Of the 170 participants, the majority were men ($n = 136$, 80%), had a traumatic injury ($n = 149$, 87.6%), and had incomplete tetraplegia ($n = 58$, 34%). The mean network size was 3.86 (SD = 2.0) of a maximum seven. The mean loneliness score for the sample was 4.93 (SD = 1.87). Factors associated with lower feelings of loneliness included being married, living with a higher proportion of network members, and being employed. Size of networks was not significantly associated with feelings of loneliness.

Conclusions: This study highlights the vulnerability for perceived social isolation among persons with SCI/D. The size of network does not seem to matter as much as the frequency and quality of social interactions. Findings reinforce the complexity of social disconnectedness and the importance in understanding the various indicators of social disconnectedness as they relate to social isolation.

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Spinal cord injury; social networks; social disconnectedness; social isolation; loneliness; network intimacy

➤ IMPLICATIONS FOR REHABILITATION

- Social relationships have been shown to be a vital component of optimal health and well-being.
- Individuals with a spinal cord injury/dysfunction are faced with a number of challenges in developing and maintaining social relationships and community participation.
- Rehabilitation professionals should encourage opportunities for social inclusion, employment and community participation to optimize health and well-being for this population.

Introduction

Social relationships are essential components of optimal health and well-being [1]. Adults who have more social relationships are healthier with a longer life expectancy than those in the general population with less social relationships [1,2]. The lack of social relationships impacts health behavior, physical and mental health [1,2]. For persons with disabilities, such as those with spinal cord injury or disease/dysfunction (SCI/D), social relationships may be negatively impacted due to the challenges of living with neurological impairments (e.g., impaired mobility, neurogenic bowel and bladder) and the associated secondary health conditions (e.g., urinary tract infection, tissue injury) [3,4], as well as the environmental barriers to social participation [4–7].

Poor social relationships are in this study characterized by two key constructs, which are social disconnectedness and perceived social isolation. *Social disconnectedness* is an objective lack of contact with others, lack of participation in social activities, and small social network [8]. *Perceived social isolation* is the subjective reaction to being socially disconnected, which may be expressed as a sense of not belonging or feelings of loneliness [9]. Although both constructs have underlying commonalities, the relationship between the two constructs is not entirely clear [10] and in some

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Supplemental data for this article can be accessed here.

instances, they are mutually exclusive [11]. As an example, adults may not subjectively report feeling lonely, despite being objectively socially disconnected (e.g., living alone, smaller networks); thus, placing more emphasis on the quality of relationships within smaller social networks [12].

Despite the considerable literature in the field of SCI/D regarding quality of life, social participation, as well as coping/social skills and social support [4,5,13,14], there is a paucity of research specifically examining social disconnectedness and perceived social isolation. To date, there have only been few studies that have examined social disconnectedness and perceived isolation following a SCI/D [15–18]. Tzonichaki and Kleftaras assessed associations among self-esteem (positive or negative attitude toward oneself), loneliness and life satisfaction among 44 community-dwelling persons with paraplegia in Athens, Greece [15]. Greater feelings of loneliness were associated with lower life satisfaction and self-esteem. Moreover, persons living alone had higher scores on loneliness compared to those living with a spouse or with others (e.g., parents or a roommate). Further, those living with a spouse had lower feelings of loneliness compared to those living with others (non-spouse). Unfortunately, this prior study did not consider the quality of the social relationships or social disconnectedness (e.g. network size), which may have provided additional insights on factors contributing to perceived social isolation.

More recently, Newman et al. conducted a cross-sectional study using secondary data analyses to test a conceptual model of social isolation that included *both social disconnectedness and perceived social isolation* [17]. In a large sample of 768 participants with traumatic injury (71.9% men), the results showed that perceived social isolation (loneliness) was positively associated with social disconnectedness. Factors associated with social disconnectedness included marital status, number of persons in household, and frequency of social activities. However, both social disconnectedness and social isolation were inversely associated with years post injury and age. Interestingly, these results differ from other studies examining these concepts among older adults without SCI/D, which have identified no significant association between social disconnectedness and social isolation [2,19].

Overall, there is a paucity of research that has examined these important concepts of social disconnectedness and social isolation among persons living with chronic SCI/D. The limited literature on social isolation post-SCI/D has focused only on a single dimension of this complex phenomena [15], has had a small sample size [16], or has adapted measures of other psychosocial constructs to examine social isolation [17]. To further advance our understanding, the objective of this study was to describe social disconnectedness and social isolation post- SCI/D, and to examine the associations among social disconnectedness and social isolation by sociodemographic and clinical characteristics.

Methods

Design and participants

A cross-sectional study was conducted with survey data collected between November 2016 to December 2017. Participants were adults with SCI/D who were current or former patients of a tertiary SCI/D rehabilitation center in Toronto Ontario. Participants were identified from two sources: 1) the Jousse Long-term Follow-up database (hereafter Jousse database); and 2) the Rick Hansen Institute Spinal Cord Injury Registry. The Jousse database is a research platform that tracks the long-term health and quality of life outcomes of an aging cohort of Ontarians with SCI/D [20–22]. Participants enrolled in the Jousse database provided written and/or verbal consent for study participation and their consent for ongoing monitoring of their health status over time. For the present study, 360 persons were identified from the Jousse database as potential participants. The Rick Hansen Institute Spinal Cord Injury Registry is a national Canadian registry of persons who have sustained a traumatic SCI/D, with 31 participating sites in nine provinces, including Ontario [23,24]. The system collects data on sociodemographic factors, medical history, injury details, diagnoses and interventions, neurologic impairment, complications and patient-reported outcomes. A total of 199 participants from the Rick Hansen Institute Spinal Cord Injury Registry local Toronto site had provided consent for future research contact and were identified from the database as potential participants. Thus, a total of 559 potential participants were identified and invited to participate.

The inclusion criteria for participation were English-speaking adults (18 years and older) with traumatic or non-traumatic SCI/D (Neurological Level of Impairment C2-L4, American Spinal Injury Association Impairment Scale A-D [25]), who were at least two years post-injury and who were living in the community. Persons with significant hearing and/or speech impairments that prevented clear communication over the telephone, or self-reported significant cognitive impairments, were excluded from the study at the time of screening ($n = 13$). Of the 559 potential participants, 51 were deceased, 229 were lost-to-follow-up (invalid contact information, did not return calls after initial contact), 13 were not eligible, and 96 declined. The final sample consisted of 170 adults with traumatic and non-traumatic SCI/D.

This study was approved by the Research Ethics Board of the various investigators' institutions (University Health Network - Toronto Rehabilitation Institute and York University). All the applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed.

Measures

Sociodemographic and clinical characteristics

The A.T. Jousse Long-term Follow-up Questionnaire is a non-standardized survey and was used to gather sociodemographic data, impairment and health status post- SCI/D [14]. Age, sex, marital status, employment, net income per month, level of education, the number of years post-injury, neurologic level of injury, and the American Spinal Injury Association Impairment Scale [26] were collected. The first three digits of the postal code were collected to identify whether participants were living in a rural or urban environment and smartphone/internet ownership was assessed.

Social disconnectedness. Several measures were used to determine social disconnectedness: social network size, composition and frequency of contact. Social networks were assessed following a similar approach used by the National Social Life, Health and Aging Project [11,27,28]. Participants were asked to provide an initial list of five people from the past 12 months with whom they most often discussed important matters [11]. If there were additional persons the respondent wished to add (who they deemed as very important or especially close), they were allowed to add up to two persons. Thus, the maximum network size was seven. Follow-up questions assessed the respondent's frequency of interaction (volume of contact), and likelihood of discussing health matters with network members. These data provided the basis for assessing network size, volume of contact with network members, network intimacy, network composition, and network proximity (see Supporting Information file for description of social network variables).

Social network range or diversity captures the extent to which a respondent's network comprises different types of relationships. Different types of ranges were examined, which included the proportion of network members who were family (kin), the proportion of members who were female, and the proportion of members who had a disability. These distinctions were made because there is evidence that family members often serve as the most important sources of support in both routine and crisis situations [29,30] and that women typically provide more informal caregiving support than men [30–32]. The proportion of social network members who live in the household provides an estimate of the physical proximity (distance) of one's network members. Finally, frequency of contact with network members indicates an individual's exposure to network members.

Perceived social isolation (i.e., loneliness)

Loneliness was measured using the revised three-item UCLA Loneliness Scale [33,34]. Respondents are asked to rate how often they felt a "lack of companionship, left out, or isolated" from others ranging from hardly ever, some of the time to often. Responses to each question are summed, with higher scores indicating greater loneliness (max score of 9). The revised shorter version was created to be better suited for a telephone survey, and has demonstrated good internal reliability in an older adult (57 to 85 years) sample, with a Cronbach's α of 0.81 [33]. Further, the UCLA Loneliness Scale has been previously used and validated in community-dwelling persons with SCI/D [35].

Procedures

Letters of introduction to the study were mailed to potential participants ($N = 559$), who were then contacted by telephone by trained interviewers to obtain informed consent. Individuals who consented to participation underwent the telephone cross-sectional survey, which lasted approximately 45 min. Once completed, participants were sent a $10.00 gift card.

Analysis

Descriptive statistics and frequencies were calculated for the demographic, social disconnectedness and social isolation variables. There were no outliers, missing data, or non-normal distributions. Pearson correlation coefficients were used to examine relationships among variables and independent *t*-tests were utilized to examine differences in social network structures and loneliness between different sociodemographic (e.g., sex; marital status, living situation, education, geography) and impairment characteristics (e.g., tetraplegia vs. paraplegia). A one-way analysis of variance was conducted to determine differences in social network variables and loneliness across income groups (persons earning less than $2,500 CAD per month vs. those earning between $2,501 and $4,000 CAD per month vs. those earning $4,100 CAD or more per month). Data were analyzed using SPSS (v25; IBM SPSS Statistics c/o IBM Corp., Armonk, NY).

Results

Sociodemographic and clinical characteristics

Of the 170 participants, the majority were men ($n = 136$, 80%), had a traumatic injury ($n = 149$, 87.6%), and had incomplete tetraplegia ($n = 58$, 34%; see Table 1). The mean age at the time of the survey was 58.9 years (range 25–95) with mean 21.9 years post injury (SD = 13; range 3–51). The majority of participants were: married/common-law ($n = 102$, 60%), living with others ($n = 129$, 75.9%), living in an urban setting ($n = 136$, 80%), able to access the internet ($n = 165$, 97%), had at least post-secondary education ($n = 129$, 75.9%) and not working at the time of the interview ($n = 125$, 73.5%).

Table 1. Sociodemographic and clinical characteristics of participants ($N = 170$).

Variable	Value ($N = 170$)	Percent (%)
Sex		
Men	136	80.0
Women	34	20.0
Etiology		
Traumatic	149	87.6
Non-traumatic	21	12.4
Impairment (Severity)		
Incomplete tetraplegia	58	34.0
Complete tetraplegia	30	18.0
Incomplete paraplegia	40	24.0
Complete paraplegia	40	24.0
Missing	2	0.0
Mean age (range) years	58.9 (25-92)	
Mean years post-injury/onset (range) years	21.9 (3-51)	
Marital status		
Married/common-law	102	60.0
Single/divorced/separated/widowed	68	40.0
Education		
< Post-secondary	41	24.1
≥ Post-secondary	129	75.9
Employment status		
Working (full-/part-time/student/etc.)	45	26.5
Not working (unemployed/retired)	125	73.5
Net Income per Month		
< $2500 per month	38	22.4
$2501–$4000 per month	37	21.8
$4001 or more per month	68	40.0
No response	27	15.8
Living situation		
Living alone	41	24.1
Living with others	129	75.9
Geographic region		
Urban	136	80.0
Rural	34	20.0

Values expressed as *n* (%), mean (range), or mean ± SD.

Social disconnectedness and perceived social isolation

Table 2 provides a summary of the participants' social network characteristics and UCLA Loneliness Scale scores. The mean network size was 3.86 (SD = 2.0) of a maximum 7. Forty-three percent ($n = 73$) had a network size of one to three persons, and 39.4% had a network of four to six persons, and only 14% had a network of seven individuals. There were six individuals who reported having no one in their networks to whom they felt they could discuss important things and these individuals were excluded for subsequent network analyses which were not applicable. The average number of days per year respondents ($N = 164$) interacted with persons identified in their networks was 190.2 (SD = 97.8), which translates to several times per week. The mean general network intimacy was 3.10 (SD = 3.63), with a mean health-related network intimacy of 1.62 (SD = 0.57). Persons who scored higher on network intimacy, also scored higher on health-related network intimacy ($r = 0.30$, $p < 0.01$). There were slightly higher proportions of network members who were kin (0.59; SD = 0.35), female (0.56; SD = 0.30) and a lower proportion who also had a disability (0.34, SD = 0.12).

Table 2. Social network characteristics and UCLA loneliness scores.

Social network variable	Mean (SD)
Network size[a]- Average number of individuals in the past 12 months with whom the respondent most often discussed important matters	3.86 (2.0)
Network distance[b]– Proportion of listed network members who live with the respondent.	0.28 (0.31)
Network frequency[b]– Average number of days across network members that the respondent interacts with over the past year.	190.20 (97.84)
Network intimacy[b]– Average score of how close the respondent feels to their network.	3.1 (0.63)
Network intimacy (health)[b]– Average score of how comfortable a respondent is in asking for health advice from their network members.	1.62 (0.57)
Network range (kin)[b]– The proportion of network members who are kin.	0.59 (0.35)
Network range (sex)[b]– The proportion of network members who are female.	0.56 (0.30)
Network range (disabled)[b]– The proportion of network members with a disability.	0.34 (0.12)

UCLA Loneliness Scale[a]

Response item	Lack companionship	Feel left out	Feel isolated from others
Hardly ever	91 (53.5%)	95 (55.9%)	83 (48.8%)
Some of the time	46 (27.1%)	48 (28.2%)	60 (35.3%)
Often	33 (19.4%)	27 (15.9%)	27 (15.9%)

[a] Data on full sample ($N = 170$).

[b] Data excluding persons with no social networks ($N = 164$).

Table 3. Associations among social network variables ($N = 164$).

	1	2	3	4	5	6	7
1. Proportion In House	1.00	**0.63****	**0.21****	–0.13	**0.74****	**.22****	**0.17***
2. Proportion Kin		1.00	**0.25****	**–0.27****	**0.56****	**.31****	**0.17***
3. Proportion Women			1.00	**–0.21****	0.15	0.13	0.09
4. Proportion Disability				1.00	**–0.17***	0.03	0.06
5. Average Days Interact					1.00	**0.21****	**0.23****
6. Intimacy						1.00	**0.30****
7. Health Advice							1.00

$^{*}p < 0.05$.

$^{**}p < 0.01$.

The mean score on the UCLA Loneliness Scale for the sample ($N = 170$) was 4.93 (SD = 1.87). Further, 53 persons (31%) had a score of 6 or higher on the UCLA Loneliness Scale, which indicates that approximately one third of the sample felt lonely at least "some of the time" to all three items on the scale. Lower feelings of loneliness were associated having a greater number of average days interacting with one's network ($r = –0.18$, $p < 0.05$) and greater levels of intimacy ($r = –0.27$, $p < 0.01$). Size of the network was not significantly associated with loneliness.

Associations between sociodemographics, clinical characteristics, social disconnectedness, and perceived social isolation

Sex

There were no significant differences between network size for women (t [52.6] = –1.59, *ns*; $M = 4.44$, SD = 1.68) compared to men ($M = 3.89$, SD = 1.93). Those with a higher proportion of women in their networks had a higher proportion of network members living in the household ($r = 0.21$, $p < 0.01$; see Table 3). Women were more comfortable asking for health advice from their network members (t [73.39] = –3.34, $p < 0.01$; $M = 0.68$, SD = 0.27) than men ($M = 0.53$, SD = 0.31). There were no significant sex differences on the UCLA Loneliness Scale.

Marital status and living arrangement

Persons who were married ($n = 101$) had a higher proportion of network members living in the household (t [162] = –5.60, $p < 0.01$; $M = 0.38$, SD = 0.30) than those who were not married ($n = 63$; $M = 0.12$, SD = 0.27), and had a higher average number of days interacting with network members (t [162] = –3.38, $p < 0.01$; $M = 210.00$, SD = 97.51) than those who were not ($M = 158.48$, SD = 90.39). Persons who were married had a higher proportion of network members who were kin (t [162] = –5.94, $p < 0.01$; $M = 0.70$, SD = 0.32) than those who were not married ($M = 0.40$, SD = 0.30). Persons who were married ($n = 102$) had a significantly lower score on the UCLA Loneliness Scale (t [168] = 2.36, $p < 0.01$; $M = 4.56$, SD = 1.82) than those who were not married ($n = 68$; $M = 5.49$, SD = 1.82).

Persons who lived alone ($n = 37$) had a lower proportion of network members who were kin (t [162] = –5.66, $p < 0.01$; $M = 0.33$, SD = 0.31) than those who lived with others ($n = 127$; $M = 0.66$, SD = 0.32) and had a lower average number of days interacting with their network members (t [79.58] = –5.71, $p < 0.01$; $M = 126.30$, SD = 70.62) than those who lived with others ($M = 208.81$, SD = 97.00). Those who lived alone had lower levels of network intimacy (t [162] = –2.76, $p < 0.05$; $M = 2.86$, SD = 0.59 vs. $M = 3.18$, SD = 0.62) but had no differences in network size (t [162] = 0.69, ns; $M = 4.19$, SD = 1.96 vs. $M = 3.94$, SD = 1.88). Lower feelings of loneliness were associated with having a higher proportion of network members living in the household ($r = –0.24$, $p < 0.01$) and who were kin ($r = –0.25$, $p < 0.01$).

Impairment

Participants with tetraplegia ($n = 85$) had a lower average number of days interacting with their social networks (t [146.33] = –2.36, $p < 0.05$; $M = 173.48$, SD = 84.94) compared to persons with paraplegia ($n = 78$; $M = 209.60$; SD = 107.65). Having a greater proportion of persons with a disability in one's network was associated with having a lower proportion of women in the network ($r = –0.21$, $p < 0.05$), as well as a lower proportion of kin ($r = –0.27$, $p < 0.01$). Having a higher proportion of persons with disabilities in one's network was associated with a lower average of days of interacting with one's network ($r = –0.17$, $p < 0.05$). There were no significant differences in network size or loneliness scores by level of impairment.

Education, employment, and income

Persons with higher levels of education ($n = 124$) had a lower number of average days of interacting with network members (t [162] = 2.54, $p < 0.05$; $M = 179.35$, SD = 95.87) than those with lower levels of education ($M = 223.80$, SD = 97.39). They also had a lower proportion of network members who were kin (t [162] = 2.12, $p < 0.05$; $M = 0.56$, SD = 0.35) than those with lower levels of education ($M = 0.68$, SD = 0.33). Persons who were employed ($n = 45$) were significantly less lonely (t [168] = 2.54, $p < 0.05$; $M = 4.33$, SD = 1.64) than those who were not employed ($M = 5.14$, SD = 1.90). However, there were no significant differences in loneliness or network size by level of education, geographic location, and income.

Discussion

This descriptive cross-sectional study aimed to describe the objective social disconnectedness and perceived social isolation post-SCI/D, and to examine associations among social disconnectedness and perceived social isolation by sociodemographic and clinical characteristics. Findings suggest that participants had relatively small networks and approximately one third of the sample felt lonely at least "some of the time" to all three-items on the UCLA Loneliness Scale. Interestingly, there was no significant association between network size and feelings of loneliness. However, having a greater number of average days interacting with one's network and greater levels of intimacy were associated with lower feelings of loneliness. Therefore, the size of network does not seem to matter as much as the frequency and quality of social interactions. These findings reinforce the complexity of social disconnectedness and the importance of understanding the various indicators of social disconnectedness as they relate to perceived social isolation.

The present study's finding of smaller and stronger ties within networks aligns with previous work on SCI/D [16]. Guilcher et al. [16] found social networks of persons with SCI/D tended to be robust and of quality, yet smaller than social networks observed in the general population. The average size of the intimate network was 3.10 in the present study which is similar to that of Guilcher et al. [16] (median network size 2.5). Intimate network size for persons with disabilities have been previously shown to be smaller [36–38] especially when compared to the general population [39–41]. Further, previous work has shown that network size following a SCI/D changes, both in size and quality. In a qualitative study by Isaksson et al., female participants with SCI/D described losing connections with colleagues and friends following their injury but strengthening their connections with family. Further, Isaksson et al. found that new relationships were established among persons with disabilities, which were helpful for peer support [42]. The present study found that the majority of persons within a network did not have a disability; however, of those that did, they were more likely to be male which likely reflects more persons in the sample being male. More research is required to better understand the composition characteristics of social networks, and how they might influence outcomes for the SCI/D population.

Interestingly, the smaller but quality networks align with age-related changes identified in aging adults [43]. Older adults tend to shift priorities and time towards interactions with smaller and closer personal network members who provide meaningful interactions and sense of belonging [43,44]. The socioemotional selectivity theory suggests that as people age, time remaining in life is perceived to be shorter, and their goals change to be more focused on emotional meaning and closer connections [45]. Aligned with this theory, older adults gain more positive emotional and health-related benefits interacting with close members of their social network compared with acquaintances [43,46]. Participants in the present study may demonstrate similar socioemotional selectivity in the composition of their networks and the allocation to whom their time is allocated. Further research is needed to explore this theory among persons with SCI/D as well as other populations with disability and the intersection of aging with a disability.

Another key finding from this study was that employment status was found to be protective against feelings of loneliness. Employment has been shown to provide a sense of purpose, belongingness, social inclusion, and increase social networks [47]. Engaging in meaningful employment has also been associated with physical health, mental health, and overall well-being [1,48–53]. Unfortunately, employment rates after SCI/D are low, ranging from 35 to 40% [54,55], despite social policies intended to be more inclusive for persons with disabilities [56,57]. These findings reinforce the importance of developing and evaluating interventions targeted to increase return to meaningful vocation for persons with SCI/D. A recent systematic review has highlighted significant benefits to employers as well as persons with disabilities, including improvements in profitability, inclusive work culture, and improved quality of life for persons with disabilities, enhanced self-confidence, increased social networks, and stronger sense of community [58]. More explicit effort is needed from health and social sectors to help transitions persons with SCI/D back to employment following their injury.

Another key finding in the present study is that not all of the social disconnectedness variables were significantly associated with feelings of loneliness. While there was no significant association between network size and feelings of loneliness, the greater number of average days interacting with one's network and greater levels of intimacy were associated with lower feelings of loneliness. These results are supported by Newman et al.'s recent work [17]. In their secondary data analysis of cross-sectional data, these researchers used structural equation modeling to examine the relationships between social disconnectedness and social isolation. Similar to the present study's findings, Newman et al. identified frequency of contact, number of days getting out, frequency of social activities, and marital status to be significant predictors of a latent variable "social disconnectedness." This latent variable of social disconnectedness was constructed from seven-items from the Life Situation Questionnaire (LSQ), and several items from the Mobility, Occupation, and Social Integration sub-scales of the Craig Handicap Assessment and Reporting Technique (CHART). Social disconnectedness was also found to be significantly associated with perceived social isolation. However, the authors did not measure size of social networks and examine the extent to which size of networks influences social isolation.

Given the differential associations between frequency of contact and size of social networks, the present study's findings suggest the importance of understanding the relationship of these indicators of social disconnectedness separately. Importantly, size may not be as critical as to the composition of networks (e.g., spouse, kin, close friends) and their respective characteristics and supporting roles. For example, marital status was found to be significantly negatively associated with feelings of loneliness, that is persons who were married were less likely to be lonely. Barclay et al. [5] in a qualitative study found that persons within one's network, especially their attitudes, influences the extent to which people with SCI/D are engaged in the community. These findings reinforce the importance of supporting caregivers of persons with SCI/D in their supportive roles, as higher perceived support has been shown to be associated with better health and well-being outcomes [5,59]. Further, given social networks are relatively small, persons with SCI/D may be especially vulnerable if they were to lose member(s) of their caregiving network.

Limitations

This study has a few limitations worth noting. While the findings did not show an association between years post injury and social disconnectedness and perceived social isolation, the sample of participants were older, and the majority had sustained their injury greater than 10 years. It is possible that factors associated with social disconnectedness and social isolation may vary by age and years post injury, but the present study's cohort did not have enough variation in participant demographics to fully examine these relationships. In a larger cohort, Newman et al. found age and years post injury to be negatively associated with social disconnectedness and social isolation. Of note, the participants in this study were at least three years post injury. Future longitudinal research would be useful in examining social disconnectedness and social isolation following injury among a cohort of participants over time and unpacking how aging with a SCI/D impacts social disconnectedness and perceived social isolation. The present study's sample was also primarily comprised of men and persons with a traumatic injury living in an urban setting. Given the difference in etiology of injury between non-traumatic and traumatic, it would be of value to examine these associations by type of injury with a larger sample. Despite these limitations, this descriptive study was purposefully designed using validated measures of social disconnectedness and social isolation.

Conclusions

This study highlights the vulnerability for perceived social isolation among persons with SCI/D, as approximately a third of our sample reported feelings of loneliness. Participants had smaller networks; however, size of networks does not seem to matter as much as the frequency and quality of social interactions. These results suggest the need to enhance support of caregivers due to their importance on feelings of loneliness. Further, these findings reinforce the complexity of social disconnectedness and the importance of future research to understand the various indicators of social disconnectedness as they relate to social isolation.

Disclosure statement

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References

[1] Umberson D, Montez JK. Social relationships and health: a flashpoint for health policy. J Health Soc Behav. 2010; 51(Suppl):S54–S66.

[2] Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. PLoS Med. 2010; 7:e1000316.

[3] Kreuter M. Spinal cord injury and partner relationships. Spinal Cord. 2000;38:2–6.

[4] Muller R, Peter C, Cieza A, et al. The role of social support and social skills in people with spinal cord injury-a systematic review of the literature. Spinal Cord. 2012;50:94–106.

[5] Barclay L, McDonald R, Lentin P, et al. Facilitators and barriers to social and community participation following spinal cord injury. Aust Occup Ther J. 2016;63:19–28.

[6] Tsai IH, Graves DE, Chan W, et al. Environmental barriers and social participation in individuals with spinal cord injury. Rehabil Psychol. 2017;62:36–44.

[7] Reinhardt JD, Ballert C, Brinkhof MW, et al. Perceived impact of environmental barriers on participation among people living with spinal cord injury in Switzerland. J Rehabil Med. 2016;48:210–218.

[8] De Jong Gierveld J, Kamphuls F. The development of a rasch-type loneliness scale. App Psychol Measure. 1985;9: 289–299.

[9] van Baarsen B, Snijders TAB, Smit JH, et al. Lonely but not alone: emotional isolation and social isolation as two distinct dimensions of loneliness in older people. Educ Psychol Measure. 2001;61:119–135.

[10] Victor CR, Scambler SJ, Bowling A, et al. The prevalence of, and risk factors for, loneliness in later life: a survery of older people in Great Britain. Ageing Soc. 2005;25:357–375.

[11] Cornwell EY, Waite LJ. Social disconnectedness, perceived isolation, and health among older adults. J Health Soc Behav. 2009;50:31–48.

[12] Schnittker J. Look (closely) at all the lonely people: age and the social psychology of social support. J Aging Health. 2007;19:659–682.

[13] Kennedy P, Lude P, Taylor N. Quality of life, social participation, appraisals and coping post spinal cord injury: a review of four community samples. Spinal Cord. 2006;44:95–105.

[14] Tonack M, Hitzig SL, Craven BC, et al. Predicting life satisfaction after spinal cord injury in a Canadian sample. Spinal Cord. 2008;46:380–385.

[15] Tzonichaki I, Kleftaras G. Paraplegia from spinal cord injury: self-esteem, loneliness, and life satisfaction. Occup Participation Health. 2002;22:96–103.

[16] Guilcher SJ, Casciaro T, Lemieux-Charles L, et al. Social networks and secondary health conditions: the critical secondary team for individuals with spinal cord injury. J Spinal Cord Med. 2012;35:330–342.

[17] Newman SD, Li C, Krause JS. Social isolation after spinal cord injury: indicators from the Longitudinal Aging Study. Rehabil Psychol. 2016;61:408–416.

[18] Tough H, Fekete C, Brinkhof MWG, et al. Vitality and mental health in disability: associations with social relationships in persons with spinal cord injury and their partners. Disabil Health J. 2017;10:294–302.

[19] Coyle CE, Dugan E. Social isolation, loneliness and health among older adults. J Aging Health 2012;24:1346–1363.

[20] Craven C, Hitzig SL, Mittmann N. Impact of impairment and secondary health conditions on health preference among Canadians with chronic spinal cord injury. J Spinal Cord Med. 2012;35:361–370.

[21] Hitzig SL, Campbell KA, McGillivray CF, et al. Understanding age effects associated with changes in secondary health conditions in a Canadian spinal cord injury cohort. Spinal Cord 2010;48:330–335.

[22] Hitzig SL, Tonack M, Campbell KA, et al. Secondary health complications in an aging Canadian spinal cord injury sample. Am J Phys Med Rehabil. 2008;87:545–555.

[23] Noonan VK, Kwon BK, Soril L, et al. The Rick Hansen Spinal Cord Injury Registry (RHSCIR): a national patient-registry. Spinal Cord. 2012;50:22–27.

[24] Noonan VK, Thorogood NP, Joshi PB, et al. Meeting the privacy requirements for the development of a multi-centre patient registry in Canada: the Rick Hansen Spinal Cord Injury Registry. Healthc Policy 2013;8:87–99.

[25] American Spinal Injury Association. International standards for neurological classifications of spinal cord injury (rev). Chicago (IL): American Spinal Injury Association; 2000.

[26] Kirshblum SC, Burns SP, Biering-Sorensen F, et al. International standards for neurological classification of spinal cord injury (revised 2011). J Spinal Cord Med. 2011;34: 535–546.

[27] Cornwell EY, Waite LJ. Social network resources and management of hypertension. J Health Soc Behav. 2012;53: 215–231.

[28] O'Muircheartaigh C, Eckman S, Smith S. Statistical design and estimation for the national social life, health, and aging project. J Gerontol B Psychol Sci Soc Sci. 2009;64: i12–i19.

[29] Haines VA, Hurlbert JS. Network range and health. J Health Soc Behav. 1992;33:254–266.

[30] Haines VA, Hurlbert JS, Beggs JJ. Exploring the determinants of support provision: provider characteristics, personal networks, community contexts, and support following life events. J Health Soc Behav. 1996;37:252–264.

[31] Sharma N, Chakrabarti S, Grover S. Gender differences in caregiving among family - caregivers of people with mental illnesses. World J Psychiatry. 2016;6:7–17.

[32] Umberson D, Chen MD, House JS, et al. The effect of social relationships on psychological well-being: are men and women really so different? Am Socio Rev. 1996; 61:837–857.

[33] Hughes ME, Waite LJ, Hawkley LC, et al. A short scale for measuring loneliness in large surveys: results from two population-based studies. Res Aging. 2004;26:655–672.

[34] Russell D, Peplau LA, Cutrona CE. The revised UCLA Loneliness Scale: concurrent and discriminant validity evidence. J Pers Soc Psychol. 1980;39:472–480.

[35] Robinson-Whelen S, Taylor HB, Feltz M, et al. Loneliness among people with spinal cord injury: exploring the psychometric properties of the 3-item loneliness scale. Arch Phys Med Rehabil. 2016;97:1728–1734.

[36] Fyrand L, Moum T, Wichstrom L, et al. Social network size of female patients with rheumatoid arthritis compared to healthy controls. Scand J Rheumatol. 2000;29:38–43.

[37] Goering P, Durbin J, Foster R, et al. Social networks of residents in supportive housing. Community Ment Health J. 1992;28:199–214.

[38] Mohr DC, Classen C, Barrera M. Jr. The relationship between social support, depression and treatment for depression in people with multiple sclerosis. Psychol Med. 2004;34:533–541.

[39] Steptoe A, Shankar A, Demakakos P, et al. Social isolation, loneliness, and all-cause mortality in older men and women. Proc Natl Acad Sci USA. 2013;110:5797–5801.

[40] Wellman B, Gulia M. A network is more than the sum of its ties: the network basis of social support. In: Wellman, B, editor. Networks in the global village. Boulder (CO): Westview Press; 1999. p. 83–118.

[41] Wellman B, Hogan B, Berg K, et al. Connected lives: the project. In Patrick P, editor. Networked neighborhoods. Guilford (UK): Springer; 2006. p. 157–211.

[42] Isaksson G, Skar L, Lexell J. Women's perception of changes in the social network after a spinal cord injury. Disabil Rehabil. 2005;27:1013–1021.

[43] Rook KS, Charles ST. Close social ties and health in later life: strengths and vulnerabilities. Am Psychol. 2017;72: 567–577.

[44] Charles ST, Carstensen LL. Social and emotional aging. Annu Rev Psychol. 2010;61:383–409.

[45] Carstensen LL, Isaacowitz DM, Charles ST. Taking time seriously. A theory of socioemotional selectivity. Am Psychol. 1999;54:165–181.

[46] Charles ST, Piazza JR. Memories of social interactions: age differences in emotional intensity. Psychol Aging. 2007;22: 300–309.

[47] Evans J, Repper J. Employment, social inclusion and mental health. J Psychiatr Ment Health Nurs. 2000;7:15–24.

[48] Clifton S. Spinal cord injury and the joy of work. Scand J Disabil Res. 2014;16:377–390.

[49] Cacioppo JT, Hawkley LC, Thisted RA. Perceived social isolation makes me sad: 5-year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago Health, Aging, and Social Relations Study. Psychol Aging. 2010;25:453–463.

[50] Cohen S, Doyle WJ, Skoner DP, et al. Social ties and susceptibility to the common cold. JAMA. 1997;277:1940–1944.

[51] Hawkley LC, Thisted RA, Masi CM, et al. Loneliness predicts increased blood pressure: 5-year cross-lagged analyses in middle-aged and older adults. Psychol Aging. 2010;25: 132–141.

[52] Penninx BW, van Tilburg T, Kriegsman DM, et al. Effects of social support and personal coping resources on mortality in older age: the Longitudinal Aging Study Amsterdam. Am J Epidemiol. 1997;146:510–519.

[53] Leiulfsrud AS, Ruoranen K, Ostermann A, et al. The meaning of employment from the perspective of persons with spinal cord injuries in six European countries. Work. 2016; 55:133–144.

[54] Lidal IB, Huynh TK, Biering SF. Return to work following spinal cord injury: a review. Disabil Rehabil. 2007;29:1341–1375.

[55] Ottomanelli L, Lind L. Review of critical factors related to employment after spinal cord injury: implications for research and vocational services. J Spinal Cord Med. 2009; 32:503–531.

[56] Toldra RC, Santos MC. People with disabilities in the labor market: facilitators and barriers. Work. 2013;45:553–563.

[57] Vlachou A, Stavroussi P, Roka O, et al. Policy guidelines for effective inclusion and reintegration of people with chronic diseases in the workplace: national and European perspectives. Int J Environ Res Public Health. 2018;15:E493.

[58] Lindsay S, Cagliostro E, Albarico M, et al. A systematic review of the benefits of hiring people with disabilities. J Occup Rehabil. 2018;28:634–655.

[59] Jensen MP, Smith AE, Bombardier CH, et al. Social support, depression, and physical disability: age and diagnostic group effects. Disabil Health J. 2014;7:164–172.

References Cited for Topic 2

Anderson, G.O. & Thayer. C. (2018). Social Isolation: Myths vs. Realities Among Adults Age 40 and Older. Washington, DC: AARP Research.

Barclay L, McDonald R, Lentin P, Bourke-Taylor H. Facilitators and barriers to social and community participation following spinal cord injury. Australian Occupational Therapy Journal. 2016; 63(1), 19-28.

Berryman, K., Wirth, M., Bombardier, C.H., Motl, R.W., Bartle, B., Jacob L., Aguina, K. LaVela, S.L. Variables associated with moderate to high loneliness among individual living with spinal cord injuries and disorders. Archives of Physical Medicine and Rehabilitation. 2024. doi: 10.1016/j.apmr.2024.01.010.

Brinkhues S, Dukers-Muijrers N, Hoebe C, et al. Social Network Characteristics Are Associated With Type 2 Diabetes Complications: The Maastricht Study. Diabetes Care. 2018;41(8):1654-1662

Cene CW, Beckie TM, Sims M, Suglia SF, Aggarwal B, Moise N, McCullough LD. American Heart Association Social Determinants of Health Committee of the Council on Epidemiology and Prevention and Council on Quality of Care and Outcomes Research; et al. Effects of Objective and Perceived Social Isolation on Cardiovascular and Brain Health: A Scientific Statement From the American Heart Association. J. Am. Heart Assoc. 2022; 11, e026493.

Chamberlain S, Savage RD, Bronskill SE, et al. Retrospective cross-sectional study examining the association between loneliness and unmet healthcare needs among middle-aged and older adults using the Canadian Longitudinal Study of Aging (CLSA). BMJ Open. 2023;13(3):e068769.

Cimino SR, Cadel L, Guilcher SJT, Wasilewski M, Hitzig SL. Social disconnectedness and perceived social isolation in persons with spinal cord injury/dysfunction living in the community: A scoping review. J Spinal Cord Med. J Spinal Cord Med. 2023;46(3):367-389.

Cudjoe TKM, Roth DL, Szanton SL, Wolff JL, Boyd CM, Thorpe RJ. The Epidemiology of Social Isolation: National Health and Aging Trends Study. J Gerontol B Psychol Sci Soc Sci. 2020;75(1):107-113.

Domènech-Abella J, Mundó J, Haro JM, Rubio-Valera M. Anxiety, depression, loneliness and social network in the elderly: Longitudinal associations from The Irish Longitudinal Study on Ageing (TILDA). J Affect Disord. 2019;246:82-88

Guilcher, S. J., Casciaro, T., Lemieux-Charles, L., Craven, C., McColl, M. A., & Jaglal, S. B. Social networks and secondary health conditions: the critical secondary team for individuals with spinal cord injury. The Journal of Spinal Cord Medicine. 2012;35(5):330–342.

Guilcher SJ, Catharine Craven B, Bassett-Gunter RL, Cimino SR, Hitzig SL. An examination of objective social disconnectedness and perceived social isolation among persons with spinal cord injury/dysfunction: a descriptive cross-sectional study. Disability and rehabilitation. 2021;43(1):69-75.

Hawkley, L. C., & Kocherginsky, M. Transitions in loneliness among older adults: A 5-year follow-up in the National Social Life, Health, and Aging Project. Research on Aging. 2018;40(4):365-387.

Henriksen RE, Nilsen RM, Strandberg RB. Loneliness increases the risk of type 2 diabetes: a 20 year follow-up - results from the HUNT study. Diabetologia. 2023;66(1):82-92. doi:10.1007/s00125-022-05791-6

Henriksen RE, Nilsen RM, Strandberg RB. Loneliness as a risk factor for metabolic syndrome: results from the HUNT study. J Epidemiol Community Health. 2019;73(10):941-946. doi:10.1136/jech-2019-212335

Holt-Lunstad J, Smith TB, Baker M, Harris T, Stephenson D. Loneliness and social isolation as risk factors for mortality: a meta analytic review. Perspect Psychol Sci. 2015;10(2):227-237.

Holt-Lunstad J, Robles TF, Sbarra DA. Advancing social connection as a public health priority in the United States. Am Psychol. 2017;72(6):517-530.

Huang, AR, Roth, DL, Cidav, T, et al. Social isolation and 9-year dementia risk in community-dwelling Medicare beneficiaries in the United States. J Am Geriatr Soc. 2023; 1- 9. doi:10.1111/jgs.18140

Kanbay, M., Tanriover, C., Copur, S., Peltek, I. B., Mutlu, A., Mallamaci, F., & Zoccali, C. Social isolation and loneliness: Undervalued risk factors for disease states and mortality. European Journal of Clinical Investigation. 2023;e14032.

LaVela SL, Motl RW, Berryman K, Wirth M, Bartle B, Aguina K, Solanki P, Bombardier CH. Facilitators to alleviate loneliness and social isolation as identified by individuals with spinal cord injuries and disorders: A qualitative study. Rehabilitation Psychology. 2024.

Menec VH, Newall NE, Mackenzie CS, Shooshtari S, Nowicki S. Examining social isolation and loneliness in combination in relation to social support and psychological distress using Canadian Longitudinal Study of Aging (CLSA) data. PLoS One. 2020;15(3):e0230673. doi:10.1371/journal.pone.0230673

Müller R, Peter C, Cieza A, Geyh S. The role of social support and social skills in people with spinal cord injury—a systematic review of the literature. Spinal Cord. 2012; 50(2), 94-106.

Nemecek D. Cigna US Loneliness Index: survey of 20,000 Americans examining behaviors driving loneliness in the United States. Bloomfield, CT: Cigna 2018.

Richard A, Rohrmann S, Vandeleur CL, Schmid M, Barth J, Eichholzer M. Loneliness is adversely associated with physical and mental health and lifestyle factors: Results from a Swiss national survey. PLoS One. 2017;12(7):e0181442. doi:10.1371/journal.pone.0181442

Shaw RJ, Cullen B, Graham N, et al. Living alone, loneliness and lack of emotional support as predictors of suicide and self harm: A nine-year follow up of the UK Biobank cohort. J Affect Disord. 2021;279:316-323

Tough H, Brinkhof MW, Siegrist J, Fekete C. The impact of loneliness and relationship quality on life satisfaction: A longitudinal dyadic analysis in persons with physical disabilities and their partners. Journal of Psychosomatic Research. 2018; 110, 61-67.

US Surgeon General. (2023) Our Epidemic of Loneliness and Isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community. https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf

Valtorta NK, Kanaan M, Gilbody S, Ronzi S, Hanratty B. Loneliness and social isolation as risk factors for coronary heart disease and stroke: systematic review and meta-analysis of longitudinal observational studies. Heart. 2016 Jul 1;102(13):1009-16.

Wirth M, Motl RW, Bombardier CH, Bartle B, Wong AWK, Aguina K, LaVela SL. Factors associated with perceived social isolation among individuals with spinal cord injury and disorders: Cross sectional survey. J of Spinal Cord Med. 2024. doi: 10.1080/10790268.2023.2299500.

World Health Organization. Social Isolation and Loneliness. https://www.who.int/teams/social-determinants-of-health/demographic-change-and-healthy-ageing/social-isolation-and-loneliness

Yang YC, Boen C, Gerken K, Li T, Schorpp K, Harris KM. Social relationships and physiological determinants of longevity across the human life span. Proc Natl Acad Sci U S A. 2016;113(3):578-583.

Other Resources/Additional Readings for Topic 2

Hitzig SL, Cimino SR, Alavinia M, Bassett-Gunter RL, Craven BC, Guilcher SJT. Examination of the relationships among social networks and loneliness on health and life satisfaction in people with spinal cord injury/dysfunction. Arch Phys Med Rehabil. 2021;102(11):2109-2116.

Tough H, Gross-Hemmi M, Stringhini S, Eriks-Hoogland I, Fekete C. Who is at risk of loneliness? a cross-sectional recursive partitioning approach in a population-based cohort of persons with spinal cord injury. Arch Phys Med Rehabil. 2022;103(2):305-312. doi:10.1016/j.apmr.2021.08.018

Topic 2 Assignment

List 3 associated health consequences/risks of loneliness and social isolation in individuals with SCI/D.

(1) ____

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(2) ____

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(3) ____

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Topic 3: Loneliness Cues Exhibited by Persons With SCI/D

Learning Objectives

- Describe potential cues to loneliness exhibited by individuals with SCI/D
- Discuss factors that may influence health care provider's reaction to patient cues

Learning Activities

- Read the 'Summary of loneliness cues exhibited by persons with SCI/D' below, including Box 1 which lists loneliness cues
- Review the excerpt and Box 2 from Lussier et al. (2009) below that describes reasons health providers may not explore cues

Assignment

Answer three quiz questions

Learning Materials for Topic 3

Summary of loneliness cues exhibited by persons with SCI/D

- Individuals with spinal cord injuries and disorders (SCI/D) are at increased risk of experiencing loneliness. There are often numerous cues from patients that may tell a story about their social health, including loneliness. Verbal cues may be direct or indirect suggesting they have more to say than what has been said outright. Cues may also be non-verbal and observed by the health care provider. Health care providers must recognize loneliness cues in order to take steps to explore them.

- Our VA research team conducted in-depth interviews with 14 interdisciplinary health providers (psychologists, social workers, physicians, nurses, therapists, and one chaplain) who interact regularly with Veterans with SCI/D in the health care setting.

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*Important note: Because there is overlap in many psychosocial and mental health indicators, it is difficult to attribute cues specifically to loneliness. For example, these expressions may also be signs of depression, grief, social anxiety, or other conditions (Bombardier et al. 2021). Upon recognizing potential cues, next steps might include screening/measuring or differential diagnosis (including the above conditions) to determine what the source(s) of the distress are. When loneliness is severe or persistent or it is unclear if depression is involved, referrals to mental health providers should be considered. How to measure loneliness and perceived social isolation is described in Topic 4. Other mental health indicators and their measurements are discussed in Bombardier et al. (2021); these should be reviewed, as well, in order to guide next steps.

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- SCI/D health care providers identified several loneliness cues commonly exhibited by individuals with SCI/D. These cues, whether verbal or nonverbal, may indicate a signal used by a patient to alert the health care provider of a concern around loneliness (or a related mental health concern). The value of such cues depends on the health provider's ability to identify them in order to decide next steps, e.g., formal screening or validated measurement to learn more about the concern, followed by collaborative patient engagement to identify potential sources contributing to loneliness and areas patient's wish to address. See Box 1 below for the list of cues.

Box 1. Common loneliness cues exhibited by persons with SCI/D

1. **Verbal expression**, including directly stating loneliness or indirectly verbally expressing negative talk, or humor, to elicit a response or follow-up.

2. **Mental health indicators**, such as poor mood, depression, hopelessness, irritability, and anger.

3. **Avoiding health care and neglecting self-health care management**, including missed medical appointments, not letting home health in, no longer attending hospital wellness programs. This category also includes lack of self-management of health care needs, such as not taking medications, and neglecting wound care, bowel care, and bladder management.

4. **Neglecting personal self-care**, this includes being dirty, unkempt, and having poor hygiene and appearance (looking disheveled). Individuals exhibiting these cues are often wearing dirty clothes and not bathing.

5. **Withdrawal and lack of engagement**, such as reclusing themselves and cutting family/friends off (not communicating with or engaging with). Individuals in this category, if they do make it out of the house, they are described as reserved, quiet, and standoffish.

6. **'Severe' voluntary seclusion**, such as not leaving the house, not getting out of bed, keeping the lights off, blinds closed, and just sitting in the dark.

7. **Physical symptoms/chronic conditions**, this includes exacerbated chronic conditions such as diabetes, heart problems, and high blood pressure. Other physical symptoms, such as fatigue and pain may be present or worse due to loneliness.

8. **Extending time in clinic/hospital** or avoiding going home just to socialize with health care providers, such as noticeably prolonging a health care encounter for the purpose of social interaction.

9. **Poor lifestyle behaviors**, including poor nutrition, lack of motivation to exercise, and poor sleep habits, e.g., sleeping too much or not enough. Individuals in this category may be engaged in substance use, e.g., "smoking a lot of pot" and/or drinking a lot of alcohol.

10. **Neglecting one's internal environment**, including visual cues in their environment, such as a messy house, "cockroaches coming out of wheelchair", and hoarding.

Source: Interviews with SCI/D health care providers, 2023, PVA study #876

Text excerpt below and Box 2 adapted from Lussier et al. (2009)

Whether or not to react:

There are several ways to avoid dealing with the cues a patient gives: ignore them, put the discussion off until later, offer premature reassurance, interrupt, change the subject, normalize the conversation, etc. Unfortunately, the decision not to follow up on a cue has more to do with pressures outside the consultation that have nothing to do with the patient's health. See Box 2 below for some reasons health providers do not explore patient cues in the health care setting.

Box 2. Reasons health providers may not explore patient cues

- Overwork
- Personal feelings toward the patient (dislike or irritation)
- Time constraints
- Assumption that the patient's problem is known (or the responsibility of others)
- Lack of standard protocol on how to address the cue, especially psychosocial cues
- Patient's demeanor contradicts the cues
- Professional experience contradicts patient cues
- Patient cues do not fit in with the providers' hypothesis

References Cited for Topic 3

Bombardier, C. H., Azuero, C. B., Fann, J. R., Kautz, D. D., Richards, J. S., & Sabharwal, S. (2021). Management of Mental Health Disorders, Substance Use Disorders, and Suicide in Adults with Spinal Cord Injury: Clinical Practice Guideline for Healthcare Providers. Topics in spinal cord injury rehabilitation, 27(2), 152–224. https://doi.org/10.46292/sci2702-152

Lussier MT, Richard C. Handling cues from patients. Can Fam Physician. 2009;55(12):1213-4.

Other Resources/Additional Readings for Topic 3

Back AL, Arnold RM. "Yes it's sad, but what should I do?" Moving from empathy to action in discussing goals of care. J Palliat Med. 2014;17(2):141-144.

Cocksedge S, May C. The listening loop: a model of choice about cues within primary care consultations. Med Educ. 2005;39(10):999–1005.

Topic 3 Assignment

Answer three quiz questions.

1. **Using humor, such as in a serious but joking manner saying “well, nobody visits me anyway” is which of the following types of cues?**
   Please select one.

a. A direct verbal loneliness cue
b. A non-verbal loneliness cue
c. An indirect verbal loneliness cue

2. **Which of the following may be a cue indicative of feelings of loneliness in an individual with a spinal cord injury or disorder?**
   Please select all that apply

a. Poor nutrition
b. Substance use
c. Skipping needed health care visits
d. Exhibiting depression, irritability, and/or hopelessness

3. **Clinical time constraints and lack of a standard protocol on how to address a loneliness cue exhibited by an individual living with a spinal cord injury or disorder may each be a reason a health care provider does not address the cue.**
   Please select true or false

☐ True
☐ False

Correct response key:

(1) c; (2) a, b, c, d; (3) True

Topic 4: Measuring Loneliness and Perceived Social Isolation

Learning Objectives

- Describe examples of instruments used to measure loneliness and perceived social isolation, in the general population, and in persons with SCI/D
- Describe scoring and interpretation of instruments

Learning Activities

- Review the 'Summary of selected instruments to measure loneliness and perceived social isolation'
- Review two instruments that have been validated in the SCI/D population to assess loneliness and perceived social isolation
    - 3-item UCLA Loneliness Scale
    - PROMIS-Social Isolation Short Form-8

Assignment

Practice using loneliness and perceived social isolation instruments.

- 3-item UCLA Loneliness Scale
- PROMIS-Social Isolation Short Form-8

Learning Materials for Topic 4

Summary of selected instruments to measure loneliness and perceived social isolation. There are several options to measure loneliness and perceived social isolation. Examples of two validated quantitative instruments are described below.

The **3-item UCLA Loneliness Scale** (Hughes 2004) is an abbreviated version of the 20-item Revised UCLA Loneliness Scale, with satisfactory reliability (Russell 1996; Hughes 2004) internal consistency (α =0.84-.094) (Vassar 2008; Russell 1996; Britton 2007; Lee 2017) as well as concurrent and discriminant validity in a large U.S. population (Hughes 2004), and internal consistency (α =0.74) and convergent and divergent validity in individuals with SCI/D (Robinson-Whelen 2016). In addition, the scale has demonstrated high test-retest reliability (r=0.77 - 0.85) (Britton 2007; Hartshorne 1993) up to over a 1-year period (r = 0.73) (Russell 1996). The UCLA-3 has been validated in the SCI/D population (Robinson-Whelen 2016), shows higher reliability in a direct comparison with the R-UCLA (0.92 vs. 0.87, respectively) (Vassar 2008), and has demonstrated high correlation with the UCLA-R, 0.82 (p < .001) (Hughes 2004). In addition, the 3-item UCLA Loneliness Scale is less burdensome than the 20-item version and is robust across different interview modalities, e.g., self-administered and telephone (Hughes 2004). The 3-item loneliness scale has demonstrated sensitivity to change in a randomized clinical trial of an intervention to address loneliness (Kahlon 2021).

THE 3-ITEM UCLA SCALE ASKS HOW OFTEN THE RESPONDENT FEELS THEY LACK COMPANIONSHIP, FEELS LEFT OUT, AND FEELS ISOLATED FROM OTHERS.

Scoring of UCLA-3 Loneliness Scale. Rated from 1 (*never/hardly ever*) to 3 (*often*), items are summed to create a score ranging from 3 to 9 with higher scores reflecting greater loneliness. A score of 4-5 indicates moderate loneliness and a score of 6 or more indicates high levels of loneliness (LaVela et al. 2022; Basu et al. 2021, Berryman et al. 2024).

Consider intervening and/or taking steps to probe and learn more when the 3-item UCLA score is 4 or greater.

The PROMIS **Social Isolation Short Form-8**, available under the domain “Social Health,” is a measure of perceived social isolation. The instrument has shown good construct and criterion validity (Hahn 2014), high internal consistency reliability (α= 0.86- 0.97) (Carlozzi 2019; PROMIS Scoring Manual 2021), and satisfactory test-retest reliability (r= 0.71 - 0.83) in individuals with traumatic injuries (Carlozzi 2019).

The PROMIS Social Isolation item bank assesses perceptions of being avoided, excluded, detached, disconnected from, or unknown by others (Health Measures 2021).

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Scoring of PROMIS SI instrument. All items have five response options ranging in value from 1 (*never*) to 5 (*always*). Item banks are scored using the total raw score by summing the values of the response to each question. A standardized T-score metric is used in which 50 is the mean of a relevant reference population and 10 is the standard deviation (SD) of that population. Published tables are used for scoring (PROMIS Scoring Manual 2021). Higher scores indicate worse self-reported social isolation.

Consider intervening and/or taking steps to probe and learn more when the PROMIS-SI score is above the population mean of 50.

3-item UCLA Loneliness Scale

How often do you feel that you lack companionship? *(Please select one)*

☐ Hardly ever (or never) ☐ Some of the time ☐ Often

How often do you feel left out? *(Please select one)*

☐ Hardly ever (or never) ☐ Some of the time ☐ Often

How often do you feel isolated? *(Please select one)*

☐ Hardly ever (or never) ☐ Some of the time ☐ Often

Source: Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A short scale for measuring loneliness in large surveys: results from two population-based studies. Research on Aging. 2004;26(6):655-72.

PROMIS-Social Isolation Short Form-8

Please respond to each item by selecting one choice.

	Never	**Rarely**	**Sometimes**	**Usually**	**Always**
I feel left out	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I feel that people barely know me.	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I feel isolated from others	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I feel that people are around me but not with me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I feel isolated even when I am not alone	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I feel that people avoid talking to me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I feel detached from other people	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
I feel like a stranger to those around me	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Source: Health Measures. Social Isolation Item Bank. Short Form-8. PROMIS. https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures

References Cited for Topic 4

Basu A, Kim HH, Basaldua R, et al. A cross-national study of factors associated with women's perinatal mental health and wellbeing during the COVID-19 pandemic. PLoS One. 2021;16(4):e0249780.

Berryman, K., Wirth, M., Bombardier, C.H., Motl, R.W., Bartle, B., Jacob L., Aguina, K. LaVela, S.L. Variables associated with moderate to high loneliness among individual living with spinal cord injuries and disorders. Archives of Physical Medicine and Rehabilitation. 2024. doi: 10.1016/j.apmr.2024.01.010.

Britton PC, Conner KR. Reliability of the UCLA Loneliness Scale in opiate dependent individuals. J Pers Assess. 2007;88(3):368-71.

Carlozzi NE, Ianni PA, Lange RT, Brickell TA, Kallen MA, Hahn EA, French LM, Cella D, Miner JA, Tulsky DS. Understanding health-related quality of life of caregivers of civilians and service members/veterans with traumatic brain injury: establishing the reliability and validity of PROMIS Social Health measures. Arch Phys Med Rehabil. 2019;100(4S):S110-S118.

Hahn EA, DeWalt DA, Bode RK, et al. New English and Spanish social health measures will facilitate evaluating health determinants. Health Psychol. 2014;33(5):490-499. doi:10.1037/hea0000055

Hartshorne TS. Psychometric properties and confirmatory factor analysis of the UCLA loneliness scale. J Pers Assess. 1993;61(1):182-95.

Health Measures. Social Isolation Item Bank. PROMIS. https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures

Hughes ME, Waite LJ, Hawkley LC, Cacioppo JT. A short scale for measuring loneliness in large surveys: results from two population-based studies. Research on Aging. 2004;26(6):655-72.

Kahlon MK, Aksan N, Aubrey R, Clark N, Cowley-Morillo M, Jacobs EA, Mundhenk R, Sebastian KR, Tomlinson S. Effect of layperson-delivered, empathy-focused program of telephone calls on loneliness, depression, and anxiety among adults during the COVID-19 pandemic: a randomized clinical trial. JAMA Psychiatry. 2021;78(6):616-622.

LaVela SL, Motl RW, Gonzalez B, Tarlov E, Aguina K, Bombardier CH. Randomised controlled trial of the Caring Connections intervention to reduce loneliness and perceived social isolation in persons with spinal cord injuries and disorders: study protocol. BMJ Open. 2022 Nov 18;12(11):e063246. doi: 10.1136/bmjopen-2022-063246.

Lee J, Cagle JG. Validating the 11-Item Revised University of California Los Angeles scale to assess loneliness among older adults: an evaluation of factor structure and other measurement properties. Am J Geriatr Psychiatry. 2017;25(11):1173-1183.

PROMIS Social Isolation Scoring Manual. http://www.healthmeasures.net/images/promis/manuals/PROMIS_Social_Isolation_Scoring_Manual.pdf

Robinson-Whelen S, Taylor HB, Feltz M, Whelen M. Loneliness among people with spinal cord injury: exploring the psychometric properties of the 3-Item Loneliness Scale. Arch Phys Med Rehabil. 2016;97(10):1728-1734.

Russell DW. UCLA Loneliness Scale (Version 3): reliability, validity, and factor structure. J Pers Assess. 1996;66(1):20-40.Vassar 2008

Vassar M, Crosby JW. A reliability generalization study of coefficient alpha for the UCLA loneliness scale. J Pers Assess. 2008;90(6):601-7.

Other Resources/Additional Readings for Topic 4

Cornwell EY, Waite LJ. Social disconnectedness, perceived isolation, and health among older adults. Journal of Health and Social Behavior. 2009;50(1):31–48.

de Jong Gierveld J, Kamphuis F. The development of a Rasch-type loneliness scale. Applied Psychological Measurement. 1985;9(3):289–299

de Jong Gierveld J, Van Tilburg T. A 6-item scale for overall, emotional, and social loneliness: Confirmatory tests on survey data. Research on Aging. 2006;28(5):582–598.

Deol ES, Yamashita K, Elliott S, Malmstorm TK, Morley JE. Validation of the ALONE Scale: A Clinical Measure of Loneliness. J Nutr Health Aging. 2022;26(5):421-424. doi: 10.1007/s12603-022-1794-8. PMID: 35587752; PMCID: PMC9098380.

Topic 4 Assignment

Test each instrument on 2 individuals with SCI/D, score, and record your scores.

Patient 1. 3-item UCLA score ________________

Actions you might take based on this score: ___________________________________

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Patient 2. PROMIS-SI score _________________

Actions you might take based on this score: ___________________________________

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Topic 5: Facilitators to Alleviate Loneliness in Persons with SCI/D

Learning Objectives

- Describe strategies to alleviate loneliness as identified by individuals with SCI/D

Learning Activities

- Review the brief ‘Summary of facilitators to alleviate loneliness’ and the articles by LaVela et al. (2024) and Cimino et al. (2022) in Learning Materials below

- Visit https://facingdisability.com/ for resources on recreation, adaptive sports, employment, education, and more for individuals with SCI/D

facingdisability.com
for families facing spinal cord injuries

Assignment

- Identify three strategies that may alleviate loneliness in persons with SCI/D
- Imagine patient scenarios and reflect on which of the strategies would be most helpful to your patients living with SCI/D

Learning Materials for Topic 5

Summary of facilitators to alleviate loneliness.
A variety of approaches have been suggested by individuals with SCI/D to alleviate feelings of loneliness and perceived social isolation.

- LaVela, Motl, Berryman et al. (2024) presented 8 strategies to alleviate loneliness and perceived social isolation identified through interviews with individuals living with SCI/D in the United States (n=23). These included:

Facilitators/Strategies	Recommended Actions for Veterans with SCI/D
Engage in/pursue interests	-become involved in pre-injury interests and begin new interests (from gardening to adaptive sports to electronics) -interests may occur in the company of other people or may be done independently -join interest specific groups or clubs (e.g., church, canning group) -make adaptations/adjustments to accommodate wheelchair
Interact with/spend time with others	-make a concerted effort to interact with positive people that are part of your network, e.g., family, friends, and health providers (where appropriate), as well as meeting new people, to communicate with regularly, including by way of social media
Embrace acceptance	- accept yourself and your post-SCI/D 'normal' so that you can allow others to accept you and become close to you -Acceptance allows you to not let things bother you, including sometimes being alone
Take part in reciprocity	- give back and volunteer -help or mentor those in need, especially other individuals with SCI/D – it benefits all involved
Find a purpose/accomplish goals	- find a new purpose and work to accomplish goals, including large and small achievements -relish in seeing progress on something -look forward to what you can achieve
Get out of residence, get outside	- find places that are accessible -learn to navigate your injury to the best degree possible to limit dependence on others to get outside
Connect with SCI/D community/SCI/D peers	- connect with SCI/D community of peers because they are relatable and have shared experiences to learn from
Seek help from [mental] health care professionals	- when loneliness becomes serious, gets progressively worse, or leads to severe depression or suicidal thoughts, seek help from a mental health care provider

The facilitators identified by individuals with SCI/D lived experience encompass **changes in ways of thinking** (e.g., embrace acceptance, find a purpose), **actions to expand participation in life** (e.g., engage in/pursue interests, get out of residence-get outside), and **efforts focused on involving others** (interact with others, connect with peers with SCI/D and the SCI/D community, engage in reciprocity; involving health care professionals when loneliness is severe).

- Similar findings were provided by Cimino et al. (2022) from interviews with individuals with SCI/D living in Canada (n=30).

Strategies (based on experiences and factors that contribute to perceived social isolation)	**Recommended Actions for Individuals with SCI/D**
Accept new reality, adjust	-redefine life roles post-injury -maintain an optimistic and proactive outlook on life
Adapt to changes in social network after SCI/D	- replace preinjury social network with a different network, if needed, and interact with network regularly -although network size may decrease, acquire new and different acquaintances
Seek peer-to-peer support	-turn to peers with disabilities for support and understanding -value peer relationships for problem-solving solutions related to having a SCI/D
Engage in activities, such as hobbies and sports	-participate in meaningful activities such as hobbies and sports -replace previous activities (that they are unable to participate in) with new opportunities related to your injury
Be aware of the need for improvements in physical accessibility and built environment	-be aware of accessibility within environmental, social, and functional contexts -be mindful of unintentional exclusion (invited someplace that is not accessible)
Participate in SCI/D specific employment or leisure programs	-if able, continue working in pre-injury employment (get needed accommodations and overcome social stigmas) or find new meaningful work

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Facilitators to Alleviate Loneliness and Social Isolation as Identified by Individuals With Spinal Cord Injuries and Disorders: A Qualitative Study

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Purpose/Objective: Individuals with spinal cord injuries and disorders (SCI/D) are at increased risk for experiencing loneliness and social isolation. The aim is to describe facilitators identified by individuals living with SCI/D to alleviate loneliness and perceived social isolation. ***Research Method/Design:*** Descriptive qualitative design using in-depth interviews with veterans with SCI/D ($n = 23$). Descriptive statistics was used to calculate demographic and injury characteristics. Audio-recorded and transcribed verbatim transcripts were coded and analyzed using Braun and Clarke's (2006) six thematic analysis phases. ***Results:*** Participants were male (70%), white (78%), and not currently married (35%), with an average age of 66 years (42–88). Participants had paraplegia (61%), with traumatic etiology (65%) and were injured 14 years (1–45) on average. Eight themes were identified by participants living with SCI/D that described facilitators to alleviate loneliness and perceived social isolation. (a) Engage in/pursue interests; (b) Interact with/spend time with others; (c) Embrace acceptance; (d) Take part in reciprocity; (e) Find a purpose/accomplish goals; (f) Get out of residence, get outside; (g) Connect with SCI/D community/SCI/D peers; and (h) Seek help from (mental) healthcare professionals. ***Conclusions/Implications:*** Individuals with SCI/D identified facilitators to alleviate loneliness that encompasses changes in ways of thinking, actions to expand participation in life, and efforts focused on involving others. Findings can be used to guide healthcare delivery and develop interventions to target feelings of loneliness and social isolation in persons with SCI/D, which may be particularly impactful if they involve reciprocal interactions with peers with SCI/D.

Impact and Implications

Due to the many consequential health impacts, loneliness and social isolation have been deemed an epidemic. Individuals with spinal cord injuries and disorders (SCI/D) are at increased risk for feelings of loneliness and social isolation because of barriers they face after injury, such as mobility issues and smaller social networks. Efforts are needed to help individuals with SCI/D manage loneliness/isolation; the current study findings offer actionable facilitators that can be used in rehabilitation settings. Individuals with lived experiences provide a rich source for understanding multiple strategies that can be used to address psychosocial outcomes. Individuals with SCI/D offered personal insights on ways to alleviate feelings of loneliness and social isolation, which are directly applicable to guide patient-centered treatment planning. Lack of published interventions to reduce loneliness/isolation among persons with SCI/D makes these findings an invaluable source of information to develop novel interventions.

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Sherri L. LaVela served as lead for conceptualization, data curation, formal analysis, funding acquisition, supervision, and writing–original draft. Robert W. Motl served in a supporting role for conceptualization. Kelsey Berryman served in a supporting role for data curation and project administration. Marissa Wirth served in a supporting role for data curation, project administration, and writing–original draft. Brian Bartle served in a supporting role for data curation, formal analysis, and writing–original draft. Keith Aguina served in a supporting role for conceptualization, writing–original draft, and consumer review–data interpretation. Pooja Solanki contributed equally to data curation and formal analysis and served in a supporting role for writing–original draft. Charles H. Bombardier served in a supporting role for conceptualization. Sherri L. LaVela and Charles H. Bombardier contributed equally to methodology. Robert W. Motl, Kelsey Berryman and Charles H. Bombardier contributed equally to writing–original draft.

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Understanding the full scope of meeting an individual's social needs, considering social relationships and social interactions, is complex. In addition to the absolute number or quantity of social relationships or contacts, the quality and meaningfulness of such relationships are also important, as both have an impact on health. Several distinct, but related, constructs have been described, including loneliness, perceived social isolation, and social isolation. Loneliness is a subjective emotional state marked by feeling left out, lacking companionship, and isolated; it often arises when there is dissatisfaction with or a discrepancy between desired and actual social interactions and relationships (Holt-Lunstad et al., 2015; Hughes et al., 2004). Perceived social isolation, often used interchangeably with loneliness, is a similar subjective measure that also includes feeling like a stranger to others, barely known, avoided, detached from others, and isolated even when not alone (Cimino et al., 2023; PROMIS-SI, 2021; Santini et al., 2020). Social isolation (sometimes referred to as social disconnectedness) is an objective state of having lack of (or limited) social contact and is assessed through measures such as, small social network size, infrequent contact with others, and living alone (Cimino et al., 2023; National Academies of Sciences, Engineering, and Medicine [NASEM], 2020; Santini et al., 2020). It is worth noting that an individual may be surrounded by people and have many social contacts but still experience loneliness, whereas objective social isolation, which reflects actual time alone or without social company may not elicit feelings of loneliness. Although the definitions and measurement components have not yet achieved wide-scale consensus (Fried et al., 2020), there is agreement that loneliness as well as both subjective and objective social isolation affects health and well-being throughout the life course among persons with and without disabilities such as spinal cord injuries and disorders (SCI/D; Cimino et al., 2023; Guilcher et al., 2021; NASEM, 2020; US Surgeon General, 2023). As such, these conditions require treatment and intervention efforts.

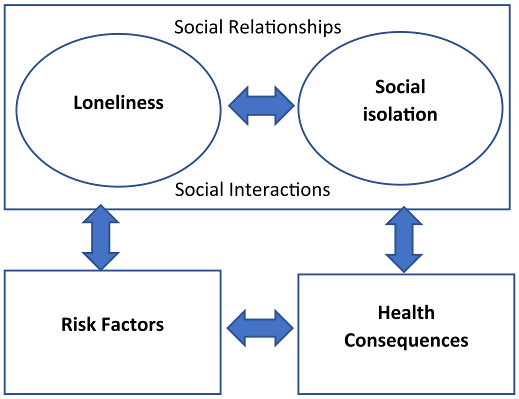
In fact, in 2023, the Surgeon General (2023) identified loneliness and social isolation as a current U.S. "epidemic" that requires immediate action. In late 2022, the American Heart Association published study findings indicating that social isolation increases the risk of heart attack or stroke by 30% (Cené et al., 2022). A recent meta-analysis of 90 studies showed that both loneliness and objective social isolation were significantly associated with an increased risk of all-cause mortality in the general population (Wang et al., 2023). In the United States, 35% of adults 45 years of age and older reported feeling lonely (Anderson & Thayer, 2018). Another study found that 30% of the general population reported loneliness based on a three-item University of California Los Angeles score of ≥5 (scale scores can range from 3 to 9; Hawkley & Kocherginsky, 2018). It is plausible that individuals with SCI/D are at particular risk for loneliness and social isolation due to social inequities associated with being in marginalized or vulnerable groups. Indeed, in a sample of 592 individuals with SCI/D, 66% had a three-item loneliness score ≥5 (LaVela, Motl, et al., 2022), a score indicative of moderate to high loneliness (Basu et al., 2021; Perissinotto et al., 2012).

In persons with SCI/D, several barriers may prevent opportunities for social interaction and participation, disruptions in social relationships, as well as perceptions of no longer belonging and feeling left out, giving rise to an increased risk of loneliness, social isolation, and other poor social health outcomes (Barclay et al., 2016; Cimino et al., 2023; Locatelli et al., 2017). Varying degrees of disability due to SCI/D may modify the dynamics of the individual's life roles, social well-being, and feelings of connection to others (Cimino et al., 2023; Guilcher et al., 2012). Factors such as reduced social network size and quality have been reported among individuals following SCI/D (Cimino et al., 2022, 2023; Guilcher et al., 2012, 2021; Isaksson et al., 2005). Additionally, secondary health conditions common in persons with SCI/D, such as pain, bowel and bladder issues, and excess weight have a significant adverse effect on postinjury social health and participation (Battalio et al., 2019; LaVela et al., 2019, LaVela, Wu, et al., 2022; Piatt et al., 2016).

The current study applies a loneliness and social isolation framework to further understand these concepts in individuals with SCI/D. An adapted version of the NASEM (2020) guiding framework of loneliness and social isolation is depicted in Figure 1. Overall, the framework demonstrates the dynamic relationships between risk factors, loneliness and social isolation, and health consequences. It focuses on the collective impact of loneliness and social isolation and emphasizes the need for efforts to reduce negative health consequences impacted by loneliness and social isolation. Many individuals with SCI/D experience loneliness and social isolation, and growing evidence suggests that this puts them at increased risk for health consequences (Cimino et al., 2023); this emphasizes the

Figure 1

Framework Showing the Dynamic Relationships Involved in Loneliness and Social Isolation



Note. Adapted from *Social Isolation and Loneliness in Older Adults: Opportunities for the Health Care System*, by National Academies of Sciences, Engineering, and Medicine [NASEM]; Division of Behavioral and Social Sciences and Education; Health and Medicine Division; Board on Behavioral, Cognitive, and Sensory Sciences; Board on Health Sciences Policy; Committee on the Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults, 2020 (https://pubmed.ncbi.nlm.nih.gov/32510896/). Copyright 2020 by National Academies Press. See the online article for the color version of this figure.

need for efforts to reduce loneliness/isolation in this population. Patients offer unique and important perspectives about their own needs and what they think will be most helpful to improve their outcomes (Bombard et al., 2018). The objective of this study was to describe facilitators identified by individuals living with SCI/D to alleviate loneliness and perceived social isolation.

Method

Transparency and Openness

We reported how we determined our sample size, all data exclusions, all manipulations, and all measures in the study, and we followed Journal Article Reporting Standards for qualitative reporting (Levitt et al., 2018). Interview guide items as described in the methods section are provided as a figure. There were no relationships or interactions between the participants and the researchers prior to the research. NVivo software, designed to support layered qualitative analysis and concept building, was used to organize the data (QSR International, Version 12 NVivo, 2018, Doncaster, Victoria, Australia). This study adhered to ethical and privacy processes and was approved by the Hines VA Institutional Review Board. Deidentified data will be made available upon reasonable request to the primary author (study PI) pending approval of the organization's institutional review board.

Design and Framework

We implemented a descriptive qualitative design using in-depth semistructured interviews to answer the research question: What do individuals with SCI/D identify as facilitators to alleviate loneliness and social isolation? To guide this work, we used an adapted version of the loneliness and social isolation framework (Figure 1; NASEM, 2020). The framework shows the dynamic relationship between risk factors (health factors, e.g., SCI/D secondary conditions, emotional, social, environmental, and demographic factors) and loneliness and social isolation (which may occur independently and in relation to one another, sometimes one leading to the other) and health consequences (physical, mental, emotional, social health, and well-being). Each construct can impact the others, creating cyclical associations and multidirectional relationships. Although many risk factors are pre-existing (e.g., age, duration of injury), other risk factors (e.g., marital status, living alone) may be both caused by and a result of loneliness/social isolation, for example, not only can marital status and living alone lead to loneliness/isolation but also loneliness/isolation may lead to a change in marital status and living arrangement.

Setting

The Veterans Health Administration (VHA) SCI/D System of Care includes 24 SCI/D Centers and over 130 outpatient clinics that deliver comprehensive, coordinated, lifelong care to veterans with SCI/D. The facilities are geographically dispersed throughout the United States.

Sample/Recruitment

Sample/Recruitment

Our target sample included 23 community-dwelling veterans with SCI/D. We followed established guidelines suggesting the inclusion of 20–30 qualitative interviews in order to unfold a rich understanding while enabling in-depth analysis (Adler & Adler, 2012; Warren, 2002).

The sample was obtained from VHA medical records to identify veterans who utilized the SCI/D System of Care nationwide within a 5-year time period (2018–2022), were 18 years of age or older, were injured for 1 year or more, resided in urban or rural areas in the community (nonnursing home or residential care facility), and had a valid mailing address documented. We stratified by sex, injury type (paraplegia vs. tetraplegia), and duration of injury ($<$5 years vs. 5 years or more) to obtain a diverse sampling pool. These inclusion criteria resulted in a sampling pool of 5,436 individuals from which we extracted a ($\sim$10%) random sample of 500 participants to mail letters inviting them to contact the research team if interested in participating. Letters were sent in batches of 40 until the target sample was reached (a total of 280 invitation letters were mailed). At initial contact, potential participants were screened for inclusion criteria to ensure they had a SCI/D, had experienced loneliness and/or social isolation since their injury, and spoke fluent English. Participants were offered $50 for one-time participation.

Data Collection

Surveys

We conducted a brief preinterview survey by telephone with participants to collect self-reported demographic, injury, and general health information.

Interviews

In-depth interviews were conducted by the first author using an interview guide and included items asking, for example, what makes you feel connected to others and what interventions to manage loneliness/isolation would be desirable to you. The interview guide was developed based on the framework of loneliness and social isolation (adapted from NASEM, 2020), social health literature, and the experience of the research team. The study team was comprised of health professionals knowledgeable across disciplines, including SCI/D medicine, rehabilitation psychology, physical medicine and rehabilitation, mental health, social health, public health, and research. We field-tested the interview guide draft with three individuals with SCI/D and incorporated their feedback to refine and improve interview questions to ensure understandability and relevance (Kallio et al., 2016). Interview questions are shown in Figure S1 in the online supplemental materials.

Individual interviews were conducted by telephone during March–July 2022. Interviews lasted 45–60 min and were audio-recorded. The audio recordings were transcribed verbatim. To ensure the accuracy of each transcript, a two-step quality control process was used that included initial transcription by one person followed by a full audio-review verification by another person.

Analysis

We used descriptive statistics, including mean, range, and standard deviation for continuous variables and frequencies for categorical variables, to analyze demographic and injury characteristics. We coded and analyzed transcripts using Braun and Clarke's (2006) six-step thematic analysis methodology. We chose thematic analysis because research on this topic was limited, and patient viewpoints on the subject were unknown (Braun & Clarke, 2006). The thematic analysis approach supported a focus on the data, while recognizing pragmatic limitations provided adequate flexibility to permit an understanding of how individuals make meaning of experiences (Braun & Clarke, 2006) within the framework of loneliness and social isolation (Figure 1; NASEM, 2020). The philosophical assumptions of the authors were ontological (driven by qualitative data that signified individuals' perspectives and experiences and reflected realities from a variety of participants and researchers) and methodological (shaped by the individuals' experiences in collecting and analyzing the data; Creswell, 2018).

Two experienced qualitative researchers (Sherri L. LaVela, Pooja Solanki) with collective backgrounds in social psychology, public health, physical medicine and rehabilitation, disability studies, and SCI/D research conducted a thematic analysis based on interview narratives. While the authors/research team members have personal experiences of loneliness and social isolation, most of us do not belong to the group of participants with SCI/D with whom our findings represent, and we acknowledge that this may have created preconceptions and a lack of deep understanding of lived experiences of persons with SCI/D. In addition, the power differential between researchers and participants along with the authors' perspectives that social health is mutable likely impacted the participant's disclosure of a myriad of facilitators. Therefore, throughout data collection and analytical interpretation, we practiced continual awareness, reflection, and critical self-evaluation in relation to our similarities and differences with participants and our positionality.

As a first step, we familiarized ourselves with the data by listening to audio-recorded interviews as well as reading the narrative text from the transcripts to gather a broad sense of data meaning. Using a blended deductive-inductive approach, we began with preestablished codes from our theoretical framework and applied them to the data and then identified constructs driven directly by the data to generate initial codes and an initial codebook. We used in vivo and descriptive open coding to identify codes based on meaningful interpretation of the data. In this approach, we deliberately emphasized content meaning and quality rather than quantity (Frost et al., 2011; Miles et al., 2014). Our next step was to review coded data to discover themes that represented patterns of meaning and to examine relationships among themes. Next, we checked themes against groups of data excerpts and against all transcripts. Throughout this step, we assessed fit and made modifications by either discarding or relocating codes. We then fine-tuned themes until saturation was reached (Bradley et al., 2007; Braun & Clarke, 2006; Miles et al., 2014). Saturation was defined as the point when no additional novel information on higher-level concepts or characterizations of concepts was identified in the data (Ando et al., 2014). Theoretical saturation was embedded in an iterative process of concurrent sampling, conducting interviews, and thematic analysis of data, as such data continuously informed sampling until the point of saturation. We maintained an audit trail of the themes and rationale for decisions using field notes, a codebook, and coding rules to support dependability and confirmability (Guest et al., 2012; Nowell et al., 2017; Stenfors et al., 2020). The final step included forming, naming, and defining the final themes, followed by convening to compare and resolve discrepancies until full agreement was reached (Kurasaki, 2000; Miles et al., 2014).

Results

Sample Characteristics

Participants were mostly male (70%) and white (78%). On average they were 66 years of age (range: 42–88) and 35% were not currently married (35%). Participants had paraplegia (61%), with traumatic etiology (65%), and were injured 14 years (range: 1–45) on average. Individuals resided in urban (70%) and rural (30%) areas. See Table 1 for participant characteristics.

Themes

Eight themes were identified that reflect facilitators to alleviate loneliness and social isolation as identified by individuals with SCI/D, each of which may serve as a catalyst to ease the multidirectional impact of loneliness and social isolation as suggested by the

Table 1

SCI/D Interview Participant Demographic, Injury, and Health Characteristics (n = 23)

Participant characteristics	*N* (%) or *M* (*SD*) range
Demographic characteristics	
Sex	
Male	16 (69.6%)
Female	7 (30.4%)
Age (years) *M*, *SD* (range)	65.5 (11.4) 42.0–88.2
Race	
White	18 (78.3%)
Black/African American	3 (13.0%)
Other: Asian; American Indian/Alaska Native; Native Hawaiian/Other Pacific Islander	2 (8.6%)
Ethnicity	
Hispanic or Latino	3 (13.0%)
Not Hispanic/Latino	20 (87.0%)
Education completed	
Did not complete high school	1 (4.3%)
High school graduate	3 (13.0%)
Some college/technical school	12 (52.2%)
College graduate	7 (30.4%)
Relationship status	
Currently married/member of unmarried couple	15 (65.2%)
Not currently married: never married, separated, divorced, widowed	8 (34.8%)
Living arrangement	
Lives alone	5 (21.7%)
Lives with other (informal or formal)	18 (78.3%)
Informal caregiver status	
Does not have an informal caregiver	4 (17.4%)
Has 1 informal caregiver	16 (69.6%)
Has more than 1 informal caregivers	3 (13.0%)
Residence	
Urban	16 (69.6%)
Rural	7 (30.4%)
Injury characteristics	
Injury level	
Paraplegia	14 (60.9%)
Tetraplegia	9 (39.1%)
Age at injury onset *M*, *SD*, range	51.4 (18.6) 20.1–82.2
Duration of injury *M*, *SD*, range	14.1 (14.5) 1.0–45.0
Etiology: traumatic (vs. nontraumatic)	
Traumatic	15 (65.2%)
Nontraumatic	8 (34.8%)

Note. SCI/D = spinal cord injuries and disorders.

NASEM (2020) framework. Themes included (a) engage in/pursue interests (make adaptations to accommodate injury, if needed); (b) interact with and spend time with others; (c) embrace acceptance; (d) Engage in reciprocity; (e) find a purpose/accomplish goals; (f) get out of residence/get outside; (g) connect with the SCI/D community and SCI/D peers; and (h) seek help from (mental) healthcare professionals. Each theme is described below, followed by representative quotations identified by participant identification (ID). Participants characteristics by ID are displayed in Table 2.

Theme 1. Engage in/Pursue Interests (Made Adaptations, If Needed)

One facilitator to alleviate loneliness identified by participants was to pursue interests and hobbies. This included becoming involved in pre-injury interests and beginning new interests. Participants identified a range of interests they pursued, from gardening, landscaping, enjoying nature, music, art, writing, traveling, adaptive sports, yoga, and reiki, to crocheting and occupying time with puzzles and electronic gadgets. These interests might occur in the company of other people, but may also be done independently, either way they were described as dissuading loneliness. Some participants pursued interests through groups or clubs based on area of interest, such as a motorcycle group, church group, and online canning group, which often provided them with social interaction opportunities. Participants emphasized that "you can do anything you want in a chair (P05)" even if it requires adaptions or adjustments. Individuals also described their interest in pets as a way to stave loneliness, for example, whether it was learning about breeds of dogs, watching dogs, or having a dog to spend time with. One person felt that if he had a dog (which he did not because he felt he could not properly care for it due to his SCI/D), it would resolve most of his loneliness. Individuals with SCI/D identified a variety of interests that they engaged in alone or with others as ways to reduce loneliness.

Table 2

Demographic and Injury Characteristics of Individuals With SCI by ID (n = 23)

ID	Sex	Age (years)	Injury duration (years)	Injury level	Etiology
P01	Female	61	29	Paraplegia	Traumatic
P02	Male	72	11	Tetraplegia	Traumatic
P03	Male	83	1	Paraplegia	Nontraumatic
P04	Male	88	6	Paraplegia	Traumatic
P05	Female	64	31	Paraplegia	Traumatic
P06	Male	58	3	Paraplegia	Traumatic
P07	Male	72	5	Tetraplegia	Traumatic
P08	Male	74	4	Tetraplegia	Traumatic
P09	Male	82	12	Paraplegia	Nontraumatic
P10	Male	65	4	Paraplegia	Nontraumatic
P11	Male	65	45	Tetraplegia	Traumatic
P12	Female	81	7	Paraplegia	Traumatic
P13	Male	73	45	Tetraplegia	Traumatic
P14	Male	61	3	Paraplegia	Nontraumatic
P15	Male	63	33	Paraplegia	Nontraumatic
P16	Male	51	9	Paraplegia	Traumatic
P17	Female	53	11	Paraplegia	Traumatic
P18	Male	42	3	Paraplegia	Traumatic
P19	Female	62	37	Paraplegia	Traumatic
P20	Male	63	5	Tetraplegia	Nontraumatic
P21	Male	65	3	Tetraplegia	Nontraumatic
P22	Female	57	4	Tetraplegia	Nontraumatic
P23	Female	51	13	Tetraplegia	Traumatic

Note. SCI = spinal cord injuries; ID = identification.

> I was in the hospital and had rehab for 5 months, the thing I wanted to do when I got out was to find a way that I could ride a motorcycle again. That is what I did as soon as I got home. I have a motorcycle which has—it is a trike; it has a ramp on the back so that I can get up into the interior of the trike and drive it with hand controls. I do that with my son, and I also do it with a motor trikes group. We sometimes take rides on the weekend if the weather is nice. I also belong to the Motorcycle Owners of [city], and we have a breakfast once a month. Anybody that has a hobby or an interest that they can find a way to still participate in after their injury—it would be great to stop loneliness. (P04)

> I do reiki energy healing, so I am a practitioner. I believe in like spiritual healing and all that. It helps me cope with feeling isolated. (P16)

> To combat loneliness, get involved. I had to be able to do artwork again after [my SCI/D] and with that I had to be around my store even if I needed help- and that was the few things that kept me motivated. I have an assistant to help me. He picks me up, takes me down to my store, brings me back home. So, I'm interacting with people there and I'm involved with that. So, I'm out there and I never feel isolated as much. And also, just because you're in a wheelchair doesn't mean you can't go to the museum, or you can't go to an art show, or you can't go to the mall, or you can't go shopping for something you enjoy. You know, handicap parking and everything is all over the place. (P21)

> I am a dog lover, if I had one that would clear up for me 80% of my loneliness. Yeah, such joy. (P22)

Theme 2. Interact With/Spend Time With Others

Participants suggested making a concerted effort to interact with or spend time with others to help with loneliness. They commonly noted spending time at family events, with friends, and grandchildren. They stressed the need to spend meaningful time with spouses or partners, outside of help they provide with a care routine. Individuals emphasized the importance of interacting with people who look at life positively. Participants also used social media to chat with acquaintances to break the cycle of loneliness. They highlighted the importance of meeting new people to interact with and communicating with other people on a regular basis. Healthcare professionals at VA hospitals and those providing home care were identified as another group of people to interact with to facilitate reducing loneliness, especially since some of the health workers have long-term relationships with the individuals with SCI/D. In summary, individuals with SCI/D suggested interacting with positive people that are part of their network, for example, family, friends, and health providers (where appropriate), as well as meeting new people to communicate with regularly, including by way of social media.

> My aide is here today that we pay for, [health care aide name] she is like a friend. I've known her over the years. She is part of my social group and I just love talking to someone a little different than my people I know. I also really like to kind of be around people that understand what I am going through and the people at the VA hospital, they really help me out and make me feel [pause]….they make you feel like you are wanted. (P02)

> There's always somebody out there that you can get acquainted with. Communicating with others helps with loneliness. I like to get the girlfriends out and play games and checkers. (P12)

> I interact with people on social media, I'm on Instagram and Facebook. It would like, if I saw a message on there from someone, if there was

> something that was affecting me that day, it would help me feel better, it would help me feel less lonely. (P19)

Theme 3. Embrace Acceptance

Participants identified acceptance of a new normal as a facilitator to help with loneliness. They stressed that early after injury, acceptance is difficult, but even as time passed new changes occur that require ongoing willingness to embrace acceptance. Individuals with SCI/D expressed that you need to figure out that this is the way it is now and make up your mind to mentally accept the situation, including that you will inevitably be alone or left out more often. They stressed that once you accept this, then you learn to be okay with being alone, left out, or "in the corner (P06)" and rather than dwelling on it, try to be positive and learn to appreciate new qualities of life (including quiet time). Participants indicated that acceptance includes knowing that people won't understand what you are going through but not avoiding them because of that. Some participants highlighted the need to accept that you are "stuck in a chair (P18)" and that even though your social situation and relationships may look different, you are the same person inside. Individuals emphasized the importance of accepting yourself so that you can allow others to accept you. In summary, individuals with SCI/D struggled with acceptance early on and throughout their injury but stressed that once you embrace acceptance, you can begin to not let things bother you, including sometimes being alone. In addition, to let others become close to you, you must accept yourself and your new normal.

> After the injury when looking at seeing where I could have wound up since it was such a high break, it could have been a fatality. You know. So, I've always felt fortunate. Now, how I see it, I say it all the time as far as being lucky, even when I'm unlucky, I'm lucky. It sounds silly but it's the way I feel, because holy cow it could have been so much worse. It's a simplification. But you can't just sit there and complain about stuff and never do anything to help yourself and then stay from people and socializing because you sit and dwell on it. I just accept it [SCI/D] and I try to stay positive. (P08)

> Being alone doesn't bother me much since my injury because I never minded being alone before. Having a mental state of accepting my injury and being alone helps me not feel lonely. Like I said, I just switched my mind over. (P09)

> Yeah, like I've always said, there's worse things than being in a wheelchair. The whole idea is to accept it and get to some kind of normalcy and to be part of the world. You need to accept it and get interested in living to have a more viable life than just to be isolated. (P20)

Theme 4. Engage in Reciprocity

Participants described that giving back, volunteering, and being of service helps them with loneliness. Individuals with SCI/D indicated that not being able to help others makes them feel lonely. They described that being able to help others provides a sense of connection. Participants said that especially helping others with SCI/D is genuine and real, which makes them feel empowered. Individuals who volunteered in SCI/D hospitals or provided mentorship to help their peers with SCI/D indicated that it "helps me to help them (P03)" and that they "get twice as much back as what I am giving (P01)." Helping or mentoring those in need, especially other veterans with SCI/D, can provide strong social connections as well as reduced loneliness and benefits both involved.

> You feel seriously lonely when you're not able to help anyone. Yeah. Being of service, especially giving back to my spinal cord [injury] peers puts a lot of positive feelings, you know, in me. (P05)

> When I can help. When they look at me and still say, that even though I have a spinal cord injury and am in a wheelchair, I still can help them. In whatever way that I can. That is what makes me feel connected and less lonely. Helping others, I love it. So, to me, that's important. Being able to help, being a part of a network…um… where people seek out, you know, my help, whether it's an opinion or just whatever it is. That's, that's a big one. (P06)

> I feel socially connected if I reach out to another Veteran and help them. I can motivate people. Because I'm going to contact those people to see if I can help them, and helping others is what has been my purpose for 30 years. (P15)

> Trying to help out people if they need it would make me feel less alone, like giving someone [another person with SCI/D] ideas of stuff I had done or know about that can help them. (P17)

Theme 5. Find a Purpose/Accomplish Goals

Participants described seeking a purpose and working toward goals as facilitators to reduce loneliness. They suggested involving yourself in project(s), something you finish that gives you a purpose. Others said that small achievements help you forget about being lonely. Participants described feeling that everything is taken from them after spinal cord injury and that they "no longer have a path and everyone is doing everything for you, so you have to redefine yourself and find a new purpose because avoiding loneliness is all attitude and perception (P11)." Participants explained that positive moments, such as seeing progress on something of interest and finding a way to be useful help with loneliness and depression. One individual indicated that not feeling lonely is only possible by looking ahead because "disability is tough and makes life too hard without a purpose (P15)." Participants expressed a strong tie to alleviating loneliness with creating positive moments by finding a new purpose and working to accomplish goals, including large and small achievements.

> Doing something like… when you follow instructions and complete a task according to the instructions, you know, you feel positively. Once you put your mind into something, you don't think about the time or the situation. You just get lost in whatever you're doing, you know, and you feel accomplished rather than lonely. (P07)

> [To see] something through regarding the outcome of it, well, you know, and afterwards, I feel better about it or the next day I would see progress regarding that. It can help you with loneliness and depression, uh, to feel good from seeing outcomes that make you realize that you've made some sort of progress on something important to you. (P10)

> Those are the encouraging things that bring a smile to my face and joy to my heart is those small achievements, you know, encouraging things that people with spinal injury have been able to do, ways we have overcome some injury-related things, and just generally goals that are achieved. You forget about being lonely during very positive moments. (P20)

Theme 6. Get Out of Residence/Get Outside

Individuals with SCI/D stressed the importance of getting out of their place of residence, even if it is just to go outside to feel happier, raise spirits, feel positive emotions, and alleviate loneliness. If able, they discussed finding places that are accessible. Participants also emphasized learning to navigate their SCI/D to the best degree possible because it helps to "get around outside of the house independently (P07)" and "be able to go places (P17)" and that getting out on your own (without depending on others) is the best thing to reduce loneliness. Others described not getting "cooped up inside (P18)" and not being "pigeonholed (P21)" in your residence. Participants collectively believed that getting outside of their residence or outside in general improved their moods and reduced loneliness.

> You know, just get out people, just get out. Don't stay in bed. Don't isolate yourself. That's the best thing to get out of that loneliness on your own without depending on family members, and yeah. Just do it yourself. I get in my electric chair, and I'll go off and go to Target. (P12)

> You feel isolated if you are all cooped up inside especially because of this injury or whatever you may have going on. You [need] to get out and get in the sun and it brings your spirit high. It changes your whole mood. It changes your attitude. It helps you to not be lonely. (P18)

> Be part of the world…not just be pigeonholed in an apartment. (P21)

Theme 7. Connect With the SCI/D Community and SCI/D Peers

Individuals with SCI/D emphasized the importance of connecting with the SCI/D community, and some benefitted from being involved with members of advocacy groups such as the Paralyzed Veterans of American and events such as wheelchair games. Others described how helpful it is to have friend(s) with a spinal cord injury because they are relatable and "like me (P03)." Participants described how being part of the SCI/D community has allowed them to meet many people and that staying in contact with them helps to reduce their loneliness and social isolation. Some described both opportunities for interaction and having someone who can listen as advantages of being part of a network of peers with SCI/D. In summary, participants described the importance of the SCI/D community of peers as a facilitator, in part because peers with SCI/D are relatable and have shared experiences that may help with overcoming loneliness.

> I used to be extremely active with PVA. Um and I used to go to the wheelchair games. Oh, I did it like 5 years in a row. It was fun but also it gave me a chance to meet more people like me. A more diverse group. Some of them I keep in touch with. It may be on Facebook or Instagram, but we are still in touch, it absolutely has helped reduce my social isolation and loneliness. (P01)

> My friend and I do a lot of talking about different things. You know. About the war and about our spinal cord injuries and all that kind of stuff. And it is kind of nice and helps to have someone like me to relate to and kind of talk with. (P03)

> So wonderful…the spinal cord injury community of people I've met, hundreds, and hundreds that people that I would have never been able to get to meet on my travels. And, once I was divorced, I just started traveling and meeting people and became [part of] a network of female spinal cord injury vets and we, we had clubs and, and whatever. Yeah, a lot of interaction. The wounded warrior peer Veterans are good ears, good ears that we can lean on with each other. (P05)

Theme 8. Seek Help From (Mental) Healthcare Professionals

Some participants recommended seeking help or guidance from mental healthcare providers, citing psychiatrists, psychologists, counselors, and therapists. Some specified working through loneliness and accompanying suicidal thoughts with a therapist and getting counseling. Participants generally discussed talking to a mental health care provider when loneliness became serious, got progressively worse, or led to severe depression or suicidal thoughts.

> Um. My healthcare [providers] might of asked me about loneliness or isolation a couple of times or something. But I blew it off. No recommendations were given. I was on my own there. It wasn't until a couple years later or something and I went and had it set-up where I did a one-on-one with a guy [health provider] in [location] VA. The place 50 miles away from us. And uh that is the only time I had help. It got me out of my funky ass blues I had. I was just not happy. I am better. (P02)

> I've been able to work through that [loneliness and suicidal thoughts] with my therapist and talking. Um, but yeah. It's tough. (P06)

> I wear a suicide awareness bracelet 24/7 and I will get counseling today and I will get counseling on Wednesday. I just have to… I've been getting counseling over feeling lonely for the past 3 days. (P15)

Discussion

This article describes facilitators to alleviate loneliness/social isolation, which provides a substantial contribution to the limited qualitative literature on loneliness and social isolation among individuals living with SCI/D. Eight themes were identified by our interview participants that are described below in four broad categories of ways to address loneliness, including changes in ways of thinking; actions to expand participation in life; efforts focused on involving others, and involvement of health professionals. Individuals with SCI/D in our study offered a wide range of strategies that may influence the magnitude and/or direction of the multidirectional impacts of loneliness and social isolation, for example, risks and health consequences, as depicted in the NASEM (2020) framework.

A facilitator to mitigate loneliness identified by individuals with SCI/D was focused on changes in ways of thinking, which included "embracing acceptance" and "finding a purpose and goals to accomplish." This idea of accepting a new normal or a new life after SCI/D was also identified by individuals with SCI/D as a coping strategy to deal with injury-related grief (Burkhart et al., 2021). Acceptance-based coping has been found to predict emotional well-being and higher quality of life in persons with SCI/D (Aaby et al., 2020; Elfström et al., 2002). Furthermore, two constructs of acceptance in individuals with SCI/D have previously been classified as "accepting reality" and "value change" (Aaby et al., 2021).' Accepting reality is an acknowledgement of reality as it is (rather than denial), which describes how the individuals with SCI/D in this study portrayed embracing acceptance. Value change is focused on acceptance as a process of changing your perspective and learning to appreciate new aspects of life. Thus, value change may encompass learning to appreciate a new life purpose and new goals as described in the "finding a purpose and goals to accomplish" theme expressed by individuals in the current study. Furthermore, in rehabilitation populations, setting goals has a therapeutic effect beyond the goal itself, such as better awareness of and adaption to disability (Rosewilliam et al., 2011). According to Maribo et al. (2020) individuals with SCI/D are most interested in relevant goals that address the psychosocial components of daily life, such as their new post-injury purpose and roles. Aaby et al. (2022) found both accepting reality and value change to be facets of acceptance that were moderately to strongly correlated with greater psychological quality of life. It is reasonable therefore that reduction of loneliness may be facilitated by acceptance and appreciation of redefined life purposes and new goals.

The participants in our study elucidated that actions to expand participation in life were important ways to reduce loneliness. In short, this was described as living beyond the walls of your residence and included themes on "engaging in/pursuing interests" and "getting out of residence/getting outside." Similarly, a sample of individuals with mental health disorders disclosed that just being able to get outside of their residence including being outside in nature, was enough to reduce loneliness, as was participation in hobbies that could be enjoyed independently or with others (Birken et al., 2023). Literature has reported that "nature" experiences and outdoor pursuits can have positive outcomes on quality of life in persons living with SCI/D (Beringer, 2004).

Research has shown that individuals with SCI/D often change their pre-to-post injury leisure activities (defined as "activities in which people participate, in order to socialize, relax, or to pursue interests and hobbies," Lundström et al., 2014). The changes are often due to personal and/or environmental factors associated with the difficulties performing leisure activities, disruptions in living patterns, and accessibility and can affect well-being and result in negative attitudes toward life after the injury (Lundström et al., 2014). As with the current study participants, individuals with SCI/D from Canada also identified the importance of hobbies and interests on feelings of perceived social isolation. In that study, some felt excluded from social networks because they were not able to participate in former activities, and others replaced former activities with new ones, which sometimes involved new people and created a sense of belonging (Cimino et al., 2022). The latter approach was suggested by the individuals with SCI/D in our study, who highlighted the importance of pursuing interests, engaging in former interests by making adaptations, or taking up new interests.

Individuals with SCI/D identified efforts focused on involving others as facilitators to alleviate loneliness, including "interacting with and spending time with familiar and new people," "connecting with SCI/D peers and community," and "engaging in reciprocity." A central theme in a recent systematic review was that loneliness is centered around meaningful social connections (McKenna-Plumley et al., 2023). Our findings in persons with SCI/D align with this and another recent systematic review of longitudinal risk factors for loneliness in older adults, which reported that having a limited social network and having a low level of social activity were associated with loneliness (Dahlberg et al., 2022). The need for social connection and social contact is likely the most common finding in the literature on loneliness and is the basis for many loneliness interventions, such as those aimed at increasing social interactions (Paquet et al., 2023); enhancing social support and social contact opportunities (Masi et al., 2011); maintaining social network contact (O'Rourke et al., 2018); and supported socialization (Mann et al., 2017).

In the current study, social connections with peers with SCI/D and the SCI/D community, in particular, were expressed as a desired way to manage loneliness. In other studies, individuals with SCI/D have reported that peers care for and empathize with them and provide them with a sense of social connection (Chemtob et al., 2018, Silverman et al., 2017). Peer-based support has been described as an emotional outlet that provides feelings of belonging, inspiration, and hope, among persons with SCI/D (Sweet et al., 2021). Divanoglou and Georgiou (2017) found that community-based programs involving peers with SCI/D had a high level of relatedness that eased and empowered persons with SCI/D. Barclay and Hilton (2019) reported that interventions involving peer volunteers with SCI/D provide hope for the future and enable individuals with SCI/D living in the community to imagine better lives than they thought possible (Barclay & Hilton, 2019).

Individuals in the current study expressed that helping or mentoring those in need (especially other individuals with SCI/D) helped circumvent loneliness. Likewise, Sweet et al. (2021) noted a collective benefit reported by individuals with SCI/D who were receiving help and those providing help. This study also found that persons with SCI/D who were "giving back" felt personal growth and an increase in self-confidence and pride (Sweet et al., 2021), factors that are associated with reduced loneliness in non-SCI/D populations (Lee et al., 2023; Nguyen et al., 2020; Nieboer et al., 2020). Our participants also noted the importance of being asked for help (being sought out) by others because it made them feel useful and improved their self-esteem, and they felt less lonely when they provided this type of help. This is congruent with a study of forty adults with SCI/D whose higher self-esteem was associated with lower feelings of loneliness (Tzonichaki & Kleftaras, 2002).

Individuals with SCI/D felt that social interaction was an important facilitator to alleviate loneliness and found these interactions especially meaningful and helpful if they involved other individuals with SCI/D, as well as reciprocal exchanges. Individuals with SCI/D may be more accepting and responsive to interventions involving a peer. Capitalizing on the shared military experience and camaraderie of veterans, coupled with the shared experience of having a SCI/D, interventions involving reciprocal peer interaction may be an unrealized opportunity to improve social health and reduce social isolation and loneliness in this population.

In the current study, individuals with SCI/D recommended soliciting help from mental healthcare professionals if loneliness becomes "serious" or results in severe depression or suicidal ideation. Poor psychosocial status is associated with increased suicide risk in the general population (Steele et al., 2018). A recent review reported notable rates of suicidal ideation, attempts, and deaths, among individuals with SCI/D (Betthauser et al., 2023). Healthcare professionals are a vital component in identifying individuals at risk for, or already experiencing, loneliness and social isolation in order to prevent or mitigate health consequences (NASEM, 2020). However, the literature on effective healthcare provider or system-level care delivery or interventions on loneliness and social isolation is scarce (NASEM, 2020). In persons living with SCI/D, mental health concerns in general are underrecognized and undertreated (Bombardier et al., 2021). In our related research, we interviewed SCI/D healthcare providers and found a gap in knowledge about both how to identify and treat loneliness in the healthcare setting (LaVela, 2022–2023). In a new scoping review, Cimino et al. (2023) surmised that further research is needed to understand both subjective and objective measures of social isolation in individuals with SCI/D to "help clinicians identify persons at risk and management options." Research is warranted to develop guidelines to help healthcare professionals with both ID and treatment strategies to support individuals with SCI/D in the management of loneliness, an important standalone outcome but also a potential precursor to other serious outcomes.

Limitations

The study included only veterans with SCI/D receiving care at the VHA; therefore, the findings may be different than what might be reported by veterans receiving care outside of the VHA or civilians with SCI/D. While we invited a random sample to participate, self-selection bias may have been a limitation since participants included only individuals who chose to contact the research team to join the study. It is possible that facilitators to alleviate loneliness identified by the participants in this study, who may be, on average, older than individuals with SCI/D at large, may differ for other persons with SCI/D, including those who are younger. The participants in the study represent only a small proportion of veterans with SCI/D, which may impact the transferability of findings.

Conclusions

Our findings provide the perspectives of individuals with SCI/D on ways to alleviate loneliness. Additional research is warranted to understand the most desirable facilitators to alleviate loneliness for individuals of different sex, age, injury level, and duration. The facilitators they identified encompass changes in ways of thinking (e.g., embrace acceptance, find a purpose), actions to expand participation in life (e.g., engage in/pursue interests, get out of residence-get outside), efforts focused on involving others (interact with others, connect with SCI/D community, engage in reciprocity), and involving health care professionals when loneliness is serious. Individuals living with SCI/D provide a rich source for understanding multiple strategies that can be used to address loneliness and social isolation. This information can be used to guide healthcare delivery and the development of interventions to target feelings of loneliness and social isolation in persons with SCI/D, which may be particularly impactful if they involve reciprocal interactions with peers with SCI/D. It is possible that these findings could be extended to other rehabilitation populations, particularly those with mobility impairments.

References

Aaby, A., Lykkegaard Ravn, S., Kasch, H., & Andersen, T. E. (2021). Structure and conceptualization of acceptance: A split-sample exploratory and confirmatory factor analysis approach to investigate the multidimensionality of acceptance of spinal cord injury. *Journal of Rehabilitation Medicine*, *53*(10), Article jrm00232. https://doi.org/10.2340/16501977-2876

Aaby, A., Ravn, S. L., Kasch, H., & Andersen, T. E. (2020). The associations of acceptance with quality of life and mental health following spinal cord injury: A systematic review. *Spinal Cord*, *58*(2), 130–148. https://doi.org/10.1038/s41393-019-0379-9

Aaby, A., Ravn, S. L., Kasch, H., & Andersen, T. E. (2022). Using the multidimensional model of acceptance to investigate how different facets of acceptance are related to quality of life following spinal cord injury. *Journal of Rehabilitation Medicine*, *54*, Article jrm00285. https://doi.org/10.2340/jrm.v54.1055

Adler, P. & Adler, P. (2012). Expert voices. In S. E. Baker & R. Edwards (Eds.), *How many qualitative interviews is enough? National Centre for Research Methods Review Discussion Paper* (pp. 8–11). Economic and Social Research Council. https://eprints.ncrm.ac.uk/2273

Anderson, G. O. & Thayer, C. (2018). *Social isolation: Myths vs. realities among adults age 40 and older*. AARP Research. https://doi.org/10.26419/res.00234.001

Ando, H., Cousins, C., & Young, C. (2014). Achieving saturation in thematic analysis: Development and refinement of a codebook. *Comprehensive Psychology*, *3*, Article 03.CP.3.4. https://doi.org/10.2466/03.CP.3.4

Barclay, L., & Hilton, G. M. (2019). A scoping review of peer-led interventions following spinal cord injury. *Spinal Cord*, *57*(8), 626–635. https://doi.org/10.1038/s41393-019-0297-x

Barclay, L., McDonald, R., Lentin, P., & Bourke-Taylor, H. (2016). Facilitators and barriers to social and community participation following spinal cord injury. *Australian Occupational Therapy Journal*, *63*(1), 19–28. https://doi.org/10.1111/1440-1630.12241

Basu, A., Kim, H. H., Basaldua, R., Choi, K. W., Charron, L., Kelsall, N., Hernandez-Diaz, S., Wyszynski, D. F., & Koenen, K. C. (2021). A cross-national study of factors associated with women's perinatal mental health and wellbeing during the COVID-19 pandemic. *PLoS ONE*, *16*(4), Article e0249780. https://doi.org/10.1371/journal.pone.0249780

Battalio, S. L., Jensen, M. P., & Molton, I. R. (2019). Secondary health conditions and social role satisfaction in adults with long-term physical disability. *Health Psychology*, *38*(5), 445–454. https://doi.org/10.1037/hea0000671

Beringer, A. (2004). Spinal cord injury and outdoor experiences. *International Journal of Rehabilitation Research*, *27*(1), 7–15. https://doi.org/10.1097/00004356-200403000-00002

Betthauser, L. M., Hoffberg, A. S., Stearns-Yoder, K. A., Harmon, M., Coons, D., & Brenner, L. A. (2023). A systematic review of suicidal ideation and behaviors among adults with spinal cord injury. *The Journal of Spinal Cord Medicine*, *46*(4), 602–613. https://doi.org/10.1080/10790268.2022.2029282

Birken, M., Chipp, B., Shah, P., Olive, R. R., Nyikavaranda, P., Hardy, J., Chhapia, A., Barber, N., Lee, S., Pearce, E., Lloyd-Evans, B., Perkins, R., McDaid, D., Stefanidou, T., Shafran, R., Pitman, A., & Johnson, S. (2023). Exploring the experiences of loneliness in adults with mental health problems: A participatory qualitative interview study. *PLoS ONE*, *18*(3), Article e0280946. https://doi.org/10.1371/journal.pone.0280946

Bombard, Y., Baker, G. R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Denis, J. L., & Pomey, M. P. (2018). Engaging patients to improve quality of care: A systematic review. *Implementation Science*, *13*(1), Article 98. https://doi.org/10.1186/s13012-018-0784-z

Bombardier, C. H., Azuero, C. B., Fann, J. R., Kautz, D. D., Richards, J. S., & Sabharwal, S. (2021). Management of mental health disorders, substance use disorders, and suicide in adults with spinal cord injury: Clinical practice guideline for healthcare providers. *Topics in Spinal Cord Injury Rehabilitation*, *27*(2), 152–224. https://doi.org/10.46292/sci2702-152

Bradley, E. H., Curry, L. A., & Devers, K. J. (2007). Qualitative data analysis for health services research: Developing taxonomy, themes, and theory. *Health Services Research*, *42*(4), 1758–1772. https://doi.org/10.1111/j.1475-6773.2006.00684.x

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Burkhart, L., Kale, I. O., & LaVela, S. L. (2021). Grief and loss among veterans with spinal cord injury: A qualitative study. *Rehabilitation Nursing*, *46*(5), 270–278. https://doi.org/10.1097/RNJ.0000000000000303

Cené, C. W., Beckie, T. M., Sims, M., Suglia, S. F., Aggarwal, B., Moise, N., Jiménez, M. C., Gaye, B., McCullough, L. D., & American Heart Association Social Determinants of Health Committee of the Council on Epidemiology and Prevention and Council on Quality of Care and Outcomes Research; Prevention Science Committee of the Council on Epidemiology and Prevention and Council on Cardiovascular and Stroke Nursing; Council on Arteriosclerosis, Thrombosis and Vascular Biology; and Stroke Council. (2022). Effects of objective and perceived social isolation on cardiovascular and brain health: A scientific statement from the American Heart Association. *Journal of the American Heart Association*, *11*(16), Article e026493. https://doi.org/10.1161/JAHA.122.026493

Chemtob, K., Caron, J. G., Fortier, M. S., Latimer-Cheung, A. E., Zelaya, W., & Sweet, S. N. (2018). Exploring the peer mentorship experiences of adults with spinal cord injury. *Rehabilitation Psychology*, *63*(4), 542–552. https://doi.org/10.1037/rep0000228

Cimino, S. R., Cadel, L., Guilcher, S. J. T., Wasilewski, M., & Hitzig, S. L. (2023). Social disconnectedness and perceived social isolation in persons with spinal cord injury/dysfunction living in the community: A scoping review. *The Journal of Spinal Cord Medicine*, *46*(3), 367–389. https://doi.org/10.1080/10790268.2022.2129170

Cimino, S. R., Hitzig, S. L., Craven, B. C., Bassett-Gunter, R. L., Li, J., & Guilcher, S. J. T. (2022). An exploration of perceived social isolation among persons with spinal cord injury in Ontario, Canada: a qualitative study. *Disability and Rehabilitation*, *44*(14), 3400–3409. https://doi.org/10.1080/09638288.2020.1861485

Creswell, J. W. (2018). Philosophical assumptions and interpretive frameworks. In J. W. Creswell & C. N. Poth (Eds.), *Qualitative inquiry and research design: Choosing among five approaches* (4th ed., pp. 15–34). SAGE Publications.

Dahlberg, L., McKee, K. J., Frank, A., & Naseer, M. (2022). A systematic review of longitudinal risk factors for loneliness in older adults. *Aging & Mental Health*, *26*(2), 225–249. https://doi.org/10.1080/13607863.2021.1876638

Divanoglou, A., & Georgiou, M. (2017). Perceived effectiveness and mechanisms of community peer-based programmes for Spinal Cord Injuries—A systematic review of qualitative findings. *Spinal Cord*, *55*(3), 225–234. https://doi.org/10.1038/sc.2016.147

Elfström, M. L., Rydén, A., Kreuter, M., Persson, L. O., & Sullivan, M. (2002). Linkages between coping and psychological outcome in the spinal cord lesioned: Development of SCL-related measures. *Spinal Cord*, *40*(1), 23–29. https://doi.org/10.1038/sj.sc.3101238

Fried, L., Prohaska, T., Burholt, V., Burns, A., Golden, J., Hawkley, L., Lawlor, B., Leavey, G., Lubben, J., O'Sullivan, R., Perissinotto, C., van Tilburg, T., Tully, M., & Victor, C. (2020). A unified approach to loneliness. *The Lancet*, *395*(10218), Article 114. https://doi.org/10.1016/S0140-6736(19)32533-4

Frost, N., Holt, A., Shinebourne, P., Esin, C., Nolas, S. M., Mehdizadeh, L., & Brooks-Gordon, B. (2011). Collective findings, individual interpretations: An illustration of a pluralistic approach to qualitative data analysis qualitative research in psychology. *Qualitative Research in Psychology*, *8*(1), 93–113. https://doi.org/10.1080/14780887.2010.500351

Guest, G., MacQueen, K. M., & Namey, E. E. (2012). *Validity and reliability (credibility and dependability) in qualitative research and data analysis*. SAGE Publications. https://doi.org/10.4135/9781483384436.n4

Guilcher, S. J. T., Casciaro, T., Lemieux-Charles, L., Craven, C., McColl, M. A., & Jaglal, S. B. (2012). Social networks and secondary health conditions: The critical secondary team for individuals with spinal cord injury. *The Journal of Spinal Cord Medicine*, *35*(5), 330–342. https://doi.org/10.1179/2045772312Y.0000000035

Guilcher, S. J. T., Catharine Craven, B., Bassett-Gunter, R. L., Cimino, S. R., & Hitzig, S. L. (2021). An examination of objective social disconnectedness and perceived social isolation among persons with spinal cord injury/dysfunction: A descriptive cross-sectional study. *Disability and Rehabilitation*, *43*(1), 69–75. https://doi.org/10.1080/09638288.2019.1616328

Hawkley, L. C., & Kocherginsky, M. (2018). Transitions in loneliness among older adults: A 5-year follow-up in the national social life, health, and aging project. *Research on Aging*, *40*(4), 365–387. https://doi.org/10.1177/0164027517698965

Holt-Lunstad, J., Smith, T. B., Baker, M., Harris, T., & Stephenson, D. (2015). Loneliness and social isolation as risk factors for mortality: A meta-analytic review. *Perspectives on Psychological Science*, *10*(2), 227–237. https://doi.org/10.1177/1745691614568352

Hughes, M. E., Waite, L. J., Hawkley, L. C., & Cacioppo, J. T. (2004). A short scale for measuring loneliness in large surveys: Results from two population-based studies. *Research on Aging*, *26*(6), 655–672. https://doi.org/10.1177/0164027504268574

Isaksson, G., Skär, L., & Lexell, J. (2005). Women's perception of changes in the social network after a spinal cord injury. *Disability and Rehabilitation*, *27*(17), 1013–1021. https://doi.org/10.1080/09638280500030431

Kallio, H., Pietilä, A. M., Johnson, M., & Kangasniemi, M. (2016). Systematic methodological review: Developing a framework for a qualitative semi-structured interview guide. *Journal of Advanced Nursing*, *72*(12), 2954–2965. https://doi.org/10.1111/jan.13031

Kurasaki, K. S. (2000). Intercoder reliability for validating conclusions drawn from open-ended interview data. *Field Methods*, *12*(3), 179–194. https://doi.org/10.1177/1525822X0001200301

LaVela, S. L. (2022–2023). *Paralyzed Veterans of America Education Grant #876, "Social Isolation and Loneliness in Persons with SCI/D: Developing an Educational Curriculum for Health Care Professionals."*

LaVela, S. L., Etingen, B., Miskevics, S., & Heinemann, A. W. (2019). What determines low satisfaction with life in individuals with spinal cord injury? *The Journal of Spinal Cord Medicine*, *42*(2), 236–244. https://doi.org/10.1080/10790268.2018.1466480

LaVela, S. L., Motl, R. W., Gonzalez, B., Tarlov, E., Aguina, K., & Bombardier, C. H. (2022). Randomised controlled trial of the Caring Connections intervention to reduce loneliness and perceived social isolation in persons with spinal cord injuries and disorders: Study protocol. *BMJ Open*, *12*(11), e063246. https://doi.org/10.1136/bmjopen-2022-063246

LaVela, S. L., Wu, J., Harris, A. H. S., Frayne, S. M., Nevedal, A. L., Arnow, K. D., Barreto, N. B., Davis, K., & Eisenberg, D. (2022). Physical and emotional consequences of excess weight as experienced by individuals with spinal cord injuries. *The Journal of Spinal Cord Medicine*. Advance online publication. https://doi.org/10.1080/10790268.2022.2097994

Lee, J. W., Nersesian, P. V., Suen, J. J., Mensah Cudjoe, T. K., Gill, J., Szanton, S. L., & Hladek, M. D. (2023). Loneliness is associated with lower coping self-efficacy among older adults. *Journal of Applied Gerontology*, *42*(2), 270–279. https://doi.org/10.1177/07334648221129858

Levitt, H. M., Bamberg, M., Creswell, J. W., Frost, D. M., Josselson, R., & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist*, *73*(1), 26–46. https://doi.org/10.1037/amp0000151

Locatelli, S. M., Etingen, B., Miskevics, S., & LaVela, S. L. (2017). Effect of the environment on participation in spinal cord injuries/disorders: The mediating impact of resilience, grief, and self-efficacy. *Rehabilitation Psychology*, *62*(3), 334–344. https://doi.org/10.1037/rep0000153

Lundström, U., Lilja, M., Petersson, I., Lexell, J., & Isaksson, G. (2014). Leisure repertoire among persons with a spinal cord injury: Interests, performance, and well-being. *The Journal of Spinal Cord Medicine*, *37*(2), 186–192. https://doi.org/10.1179/2045772313Y.0000000103

Mann, F., Bone, J. K., Lloyd-Evans, B., Frerichs, J., Pinfold, V., Ma, R., Wang, J., & Johnson, S. (2017). A life less lonely: The state of the art in interventions to reduce loneliness in people with mental health problems. *Social Psychiatry and Psychiatric Epidemiology*, *52*(6), 627–638. https://doi.org/10.1007/s00127-017-1392-y

Maribo, T., Jensen, C. M., Madsen, L. S., & Handberg, C. (2020). Experiences with and perspectives on goal setting in spinal cord injury rehabilitation: A systematic review of qualitative studies. *Spinal Cord*, *58*(9), 949–958. https://doi.org/10.1038/s41393-020-0485-8

Masi, C. M., Chen, H. Y., Hawkley, L. C., & Cacioppo, J. T. (2011). A meta-analysis of interventions to reduce loneliness. *Personality and Social Psychology Review*, *15*(3), 219–266. https://doi.org/10.1177/1088868310377394

McKenna-Plumley, P. E., Turner, R. N., Yang, K., & Groarke, J. M. (2023). Experiences of loneliness across the lifespan: A systematic review and thematic synthesis of qualitative studies. *International Journal of Qualitative Studies on Health and Well-Being*, *18*(1), Article 2223868. https://doi.org/10.1080/17482631.2023.2223868

Miles, M., Huberman, M., Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). SAGE Publications.

National Academies of Sciences, Engineering, and Medicine [NASEM]; Division of Behavioral and Social Sciences and Education; Health and Medicine Division; Board on Behavioral, Cognitive, and Sensory Sciences; Board on Health Sciences Policy; Committee on the Health and Medical Dimensions of Social Isolation and Loneliness in Older Adults. (2020). *Social isolation and loneliness in older adults: Opportunities for the health care system*. National Academies Press (US). https://pubmed.ncbi.nlm.nih.gov/32510896/

Nguyen, T. T., Lee, E. E., Daly, R. E., Wu, T. C., Tang, Y., Tu, X., Van Patten, R., Jeste, D. V., & Palmer, B. W. (2020). Predictors of loneliness by age decade: Study of psychological and environmental factors in 2,843 community-dwelling Americans aged 20–69 years. *The Journal of Clinical Psychiatry*, *81*(6), Article 20m13378. https://doi.org/10.4088/JCP.20m13378

Nieboer, A. P., Hajema, K., & Cramm, J. M. (2020). Relationships of self-management abilities to loneliness among older people: A cross-sectional study. *BMC Geriatrics*, *20*(1), Article 184. https://doi.org/10.1186/s12877-020-01584-x

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. *International Journal of Qualitative Methods*, *16*(1), Article 160940691773384. https://doi.org/10.1177/1609406917733847

O'Rourke, H. M., Collins, L., & Sidani, S. (2018). Interventions to address social connectedness and loneliness for older adults: A scoping review. *BMC Geriatrics*, *18*(1), Article 214. https://doi.org/10.1186/s12877-018-0897-x

Paquet, C., Whitehead, J., Shah, R., Adams, A. M., Dooley, D., Spreng, R. N., Aunio, A. L., & Dubé, L. (2023). Social prescription interventions addressing social isolation and loneliness in older adults: Meta-review integrating on-the-ground resources. *Journal of Medical Internet Research*, *25*, Article e40213. https://doi.org/10.2196/40213

Perissinotto, C. M., Stijacic Cenzer, I., & Covinsky, K. E. (2012). Loneliness in older persons: A predictor of functional decline and death. *Archives of Internal Medicine*, *172*(14), 1078–1083. https://doi.org/10.1001/archinternmed.2012.1993

Piatt, J. A., Nagata, S., Zahl, M., Li, J., & Rosenbluth, J. P. (2016). Problematic secondary health conditions among adults with spinal cord injury and its impact on social participation and daily life. *The Journal of Spinal Cord Medicine*, *39*(6), 693–698. https://doi.org/10.1080/10790268.2015.1123845

PROMIS-SI. (2021). *Health measures. Social isolation item bank*. https://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis/list-of-adult-measures.

Rosewilliam, S., Roskell, C. A., & Pandyan, A. D. (2011). A systematic review and synthesis of the quantitative and qualitative evidence behind patient-centred goal setting in stroke rehabilitation. *Clinical Rehabilitation*, *25*(6), 501–514. https://doi.org/10.1177/0269215510394467

Santini, Z. I., Jose, P. E., York Cornwell, E., Koyanagi, A., Nielsen, L., Hinrichsen, C., Meilstrup, C., Madsen, K. R., & Koushede, V. (2020). Social disconnectedness, perceived isolation, and symptoms of depression and anxiety among older Americans (NSHAP): A longitudinal mediation analysis. *The Lancet Public Health*, *5*(1), e62–e70. https://doi.org/10.1016/S2468-2667(19)30230-0

Silverman, A. M., Molton, I. R., Smith, A. E., Jensen, M. P., & Cohen, G. L. (2017). Solace in solidarity: Disability friendship networks buffer well-being. *Rehabilitation Psychology*, *62*(4), 525–533. https://doi.org/10.1037/rep0000128

Steele, I. H., Thrower, N., Noroian, P., & Saleh, F. M. (2018). Understanding suicide across the lifespan: A United States perspective of suicide risk factors, assessment & management. *Journal of Forensic Sciences*, *63*(1), 162–171. https://doi.org/10.1111/1556-4029.13519

Stenfors, T., Kajamaa, A., & Bennett, D. (2020). How to … assess the quality of qualitative research. *The Clinical Teacher*, *17*(6), 596–599. https://doi.org/10.1111/tct.13242

Sweet, S. N., Hennig, L., Shi, Z., Clarke, T., Flaro, H., Hawley, S., Schaefer, L., & Gainforth, H. L. (2021). Outcomes of peer mentorship for people living with spinal cord injury: Perspectives from members of Canadian community-based SCI organizations. *Spinal Cord*, *59*(12), 1301–1308. https://doi.org/10.1038/s41393-021-00725-2

Tzonichaki, L., & Kleftaras, G. (2002). Paraplegia from spinal cord injury: Self-esteem, loneliness, and life satisfaction. *OTJR: Occupation, Participation and Health*, *22*(3), 96–103. https://doi.org/10.1177/153944920202200302

US Surgeon General. (2023). *Our epidemic of loneliness and isolation: The U.S. Surgeon General's Advisory on the Healing Effects of Social Connection and Community*. https://www.hhs.gov/sites/default/files/surgeon-general-social-connection-advisory.pdf

Wang, F., Gao, Y., Han, Z., Yu, Y., Long, Z., Jiang, X., Wu, Y., Pei, B., Cao, Y., Ye, J., Wang, M., & Zhao, Y. (2023). A systematic review and meta-analysis of 90 cohort studies of social isolation, loneliness and mortality. *Nature Human Behaviour*, *7*(8), 1307–1319. https://doi.org/10.1038/s41562-023-01617-6

Warren, C. A. B. (2002). Qualitative interviewing. In J. F. Gubrium & J. A. Holstein (Eds.), *Handbook of interview research: Context and method* (pp. 83–103). Sage.

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RESEARCH PAPER

An exploration of perceived social isolation among persons with spinal cord injury in Ontario, Canada: a qualitative study

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ABSTRACT

Purpose: To advance the understanding of perceived social isolation among persons with spinal cord injury (SCI), the objectives of the present study were to explore: (1) experiences of perceived social isolation and (2) factors that contribute to perceived social isolation.

Methods: Interpretive description qualitative methodology was used to conduct semi-structured interviews with 30 individuals with SCI from across Ontario (Canada) from November 2016 to August 2017. Data were analyzed using thematic analysis.

Results: Participants identified disruption to social networks that seemed to impact perceived social isolation. Five major themes were identified: (1) impact on structure and frequency of social network; (2) importance of feeling heard; (3) importance of employment, hobbies, and sports; (4) need to improve physical accessibility and built environment; and (5) individual characteristics. Changes in quality of social networks, rather than size, contributed to greater feelings of perceived social isolation. The built environment, maintenance of employment, hobbies, and sports, social media, and technology use, as well as individual traits, were also found to impact perceived social isolation.

Conclusion: Future research should focus on the development of programs to help maintain or improve social network quality for persons with SCI to minimize the impact of perceived social isolation.

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➤ IMPLICATIONS FOR REHABILITATION

- Perceived social isolation, resulting from physical and environmental barriers, is a challenge that is faced by many individuals who are living in the community with a spinal cord injury (SCI).
- Rehabilitation and community programs should utilize an individualized approach to find solutions to challenges faced by this population to prevent the effects of perceived social isolation.
- Education on how to adapt to changes in social network, together with the provision of access to peer-to-peer support groups, and SCI specific return to work or leisure programs, is recommended as an essential component of rehabilitation.

Introduction

Social relations and community participation are pivotal to human health and wellbeing [1,2]. *Social disconnectedness* is conceptualized as the *objective* lack of contact with others and a small social network [3]. Persons who become socially disconnected face health risks including increased systolic blood pressure [4], infections [5], heightened inflammatory response [6], and depression [7]. Perceived social isolation is characterized as the *subjective* feelings of loneliness and not belonging [8], which has also been associated with adverse health outcomes such as cardiovascular disease [9], sleep issues/disorders [10], and heightened inflammatory responses to stress [11]. Both social disconnectedness and perceived social isolation are associated with higher rates of mortality in the general population [12–14].

Given the impact of perceived social isolation on health and wellbeing in the general population, it is important to better understand how social isolation may impact individuals who may be more vulnerable in society, such as those with a physical disability. Individuals with a physical disability have been shown to be at a higher risk of experiencing social isolation [15], which may arise due to impaired mobility [16], the built environment [16,17], challenges with transportation [16–18], lack of finances [19], and societal attitudes such as discrimination and societal marginalization [17]. It is therefore not surprising that individuals with a

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physical disability experience lower levels of social interaction [19,20].

People with long-term spinal cord injury (SCI) are particularly vulnerable to social isolation [21]. Recent cross-sectional studies suggest that approximately 31–40% [21–23] experience perceived social isolation according to the UCLA 3-item Loneliness Scale [24]. There are several barriers that may contribute to these levels. For example, greater perceived environmental barriers (e.g., design of home/community, support at home/community, and transportation) were associated with lower social participation [25–28]. In a series of qualitative studies, social participation was shown to be impacted by physical and mental health [26–29], societal attitudes [26–29], and changes in social networks [26,27]. These factors have also been shown to influence return to work, which is an important marker of a sense of belonging [30]. With respect to facilitators, qualitative evidence suggests that access to social support can help to foster social participation [28,29]. While a considerable amount of literature exists on the barriers and facilitators to community participation, there is minimal research on whether these factors impact experiences of perceived social isolation.

To date, there are a few studies that highlight the importance of understanding how perceived social isolation impacts overall health and wellbeing among persons with SCI. For instance, Dickson and colleagues conducted a qualitative study in Scotland that identified a feeling of loss of camaraderie (relationships with others) following an SCI, as well as feelings of embarrassment, helplessness, and uselessness [31]. Peer-to-peer relationships (i.e., with other individuals with SCI) and the shared experiences of disability reduced feelings of embarrassment [31]. However, following discharge from inpatient rehabilitation, these connections were lost as individuals adjusted to life at home away from peers [31]. Although this study highlighted important information regarding a loss of camaraderie and the impact on feelings of belonging, the study did not discuss the quality of the other connections in their social network, nor the changes to their networks. These are important facets to consider in order to develop a better understanding of relationships and the impact of these relationships on perceived social isolation among individuals living with SCI.

A more recent quantitative cross-sectional study conducted by Newman et al. [32] aimed to develop a model of social isolation which included objective social disconnectedness and perceived social isolation among individuals aging with SCI. This study highlighted several factors such as age and time since injury, that appeared to mitigate perceived social isolation [32]. For example, older individuals as well as those who had lived longer with injury experienced less perceived social isolation [32]. Furthermore, higher neurological level and severity of injury were associated with higher levels of objective social disconnectedness [32]. Newman and colleagues identified that social connectedness, availability of social supports, and satisfaction with social participation were directly related to the frequency of social interactions [32]. Due to the quantitative nature of this research, Newman et al. [32] were unable to capture the nuances of the lived experiences of those with SCI, such as exploring how these individuals perceived their quality of participation [32]. It is necessary to further explore the lived experience of this population to understand the influence of social isolation on their everyday lives.

A previous review of the literature indicates that there is a lack of qualitative studies describing perceived social isolation and the factors that are associated with mitigating or contributing to experiences of perceived social isolation among people with SCI. Information derived from qualitative studies can inform an in-depth understanding of what it means to experience perceived isolation. In order to further advance our understanding of perceived social isolation in this population, the objectives of the present study are two-fold: (1) to explore experiences of perceived social isolation; and, (2) to explore the factors that contribute to perceived social isolation.

Materials & methods

Study design

This qualitative study utilized an interpretive description methodology [33].

Participants

The target population was community-dwelling adults with either a traumatic or non-traumatic SCI living in Ontario, Canada. We used purposeful sampling to ensure that a wide range of experiences were obtained and to include variation in the type of injury, living situation, and gender. Participants were required to have had their SCI for more than 1 year and have completed inpatient rehabilitation prior to the interview. Those who were younger than 18 years of age, non-English speaking, and those who could not tolerate the interview process (e.g., issues with hearing impairment or speech impediments) were excluded.

Data collection

A total of 30 semi-structured interviews were conducted between November 2016 and August 2017. Individuals were recruited from a previously established cohort who had consented to participate in future research [34–36]. Potential participants were mailed an information letter that included a letter of introduction to the study, highlighting the objective and methods and the informed consent form. Once the potential participant returned the consent form, a member of the study team followed up with the participant to explain the study in further detail and answer any questions. The interviews were completed by two trained members of the research team (SC and SRC). Interviewers were not known to the participants prior to the study. At the time of the interviews, SC was a Ph.D. student and SRC was a research analyst working at a tertiary rehabilitation clinic. Senior members of the research team provided supervision and mentoring to the individuals conducting the interviews.

Semi-structured interviews were primarily conducted over the telephone, with two individuals choosing to complete the interview in person at the study site (see Supplementary Material for interview guide). Only the interviewer and the consenting participant were present during each interview. All interviews were audio-recorded and transcribed for analysis. Each participant was assigned a pseudonym to protect their anonymity. We continued interviews until data saturation was obtained. For the purposes of our study, saturation was defined as no new ideas relevant to our research question and objectives were generated from the interviews. We aimed to collect interviews from participants of varying perspectives based on the type of injury and gender. Informal analyses of the interviews were conducted concurrently with data collection in order to assess saturation. We determined that saturation of participant perspectives occurred after 30 interviews. The formal analyses began once the research team believed that saturation was obtained. This study received institutional approval from the Research Institutions (REB Protocol# 16-5028-DE and 16-5028).

Data analysis

Data analysis consisted of an iterative constant comparative process aligned with interpretive description methodology [33]. An inductive approach was used, and the process involved using open-coding and identifying themes from the data [37]. Four team members (SRC, SJTG, SLH, JL) were initially assigned three transcripts to read. After reviewing the assigned transcripts, the team met to discuss the initial codes identified from the data and to develop a preliminary coding framework (names of preliminary codes and definitions). Interpretations of the codes were discussed among the team members. The preliminary coding framework was then applied to two new transcripts. The team met again following the coding to discuss the process as well as any additional ideas that were identified. Once a finalized coding framework was agreed upon, two team members (SRC, JL) coded two additional transcripts to ensure inter-coder agreement [38]. The software programs NVivo 10 and Microsoft Excel were utilized to facilitate the organization of the data. The trustworthiness of the analysis was promoted by training and mentoring of the research coordinators responsible for the coding, multiple team meetings to review the data as described above, and the use of multiple coders. Furthermore, the team met several times to discuss the interpretation of the findings. The results of this study have been reported following the Consolidated Criteria for Reporting Qualitative Research (COREQ) (see Supplementary Material for completed checklist) [39].

Results

Participant characteristics

Thirty individuals with an SCI participated in the study, most of which had a high-level injury (i.e., cervical). A majority of the participants were men, lived with their spouse/partner, and resided in an urban setting at the time of the interview. Many of the participants received a post-secondary education and were not currently employed. A more detailed description of the participants can be found in Table 1.

With regard to perceived social isolation, just over half of the participants described experiencing this phenomenon following their SCI. Conversely, some individuals expressed that they did not experience perceived social isolation. For these participants, they instead recalled potential reasons on why this was the case, which included feeling as though they had strong, robust networks or being able to return to their previous activities (i.e., work, leisure). Participants who did not experience perceived social isolation and those who did were similar in age but varied with respect to years post-injury (YPI). Those who experienced perceived social isolation were below the mean YPI, while those who did not were slightly above the mean YPI. With respect to the number of individuals in their social network, both groups were slightly below the mean.

Table 1. Participant demographic data ($n = 30$).

Patient characteristics	Total
Gender	
Male	19
Female	11
Geographic location	
Urban	25
Rural	5
Mean age (SD)	61.9 ± 13.9 years, range 24–88
Years post injury (SD)	26 ± 12.9 years, range 2–50
Level of injury	
Tetraplegia	19
Paraplegia	11
ASIA grade†	
A	9
B	3
C	2
D	13
Unknown	2
Living situation	
Independent	7
Spouse/partner with/without children	18
Other	5
Education level	
High school or less	4
More than high school	26
Employment status	
Employed/student	9
Retired	13
Unemployed	8
Income	
Less than $2000	2
$2001–$4000	10
$4001 and above	16
Declined response	2
Mean number of people in social network (SD)	5 ± 1.9, range 2–7
Mean number of network people living with respondent (SD)	1 ± 0.9, range 0–5
Use portable technology	
Yes	26
No	4
Have internet at home	
Yes	29
No	1

†American Spinal Cord Injury Association Grade: A = complete injury with no motor or sensory function at S4–S5; B = incomplete injury with sensory function but no motor function preserved at S4–S5; C = incomplete injury with motor function preserved and more than half of key muscles with muscle grade less than 3 below neurological level; D = incomplete injury with motor function and at least half of key muscles grade of 3 or more below neurological level [49].

Main themes identified

Overall, five main themes were discussed by participants in relation to experiences of perceived social isolation following an SCI: (1) "Just faded off": Impact on the structure and frequency of social networks; (2) "My friends are there as a sounding board": Importance of feeling heard; (3) "I don't want to be a spectator": Importance of employment, hobbies, and sports; (4) "We are excluded": The need to improve physical accessibility and the built environment; (5) "I am what I am": The protective effect of individual characteristics.

"Just faded off": Impact on the structure and frequency of social networks

Many individuals felt that the absolute number of connections in their social network decreased following their SCI. Several participants reflected that the time spent in rehabilitation negatively impacted their pre-injury social networks and commented that members from this network had "moved on" (Matthew, >10 YPI, lives alone), "just faded off" (Molly, 5–10 YPI, lives alone) or "most of my friends dropped away completely" (Laura, >10 YPI, lives with a spouse). Participants described how the lives of the individuals in their pre-injury networks continued, while they were engaged in their rehabilitation; thus, effectively halting their lives.

These experiences seemed to be independent of the age of the participants.

With respect to frequency, participants who had a strong sense of belonging generally interacted with some aspect of their network at least a few times a month, and most had interactions at least once a week. Several had interactions a few times a week or even daily.

> Yes, it does because sometimes, some days when you're here … Also, you have really nothing planned that day, all the sudden they give you a call or you meet somebody and say, "Let's go here." I said, "Okay." It gives you that something extra that you weren't expecting. (Matthew, >10 YPI, lives alone)

Participants also identified a significant change in the composition of their social networks. Despite fewer people in their networks, some participants reflected that they acquired new and different acquaintances while undergoing inpatient rehabilitation. For example, one individual explained that prior to her injury, she did not know any individuals with a disability, but post-injury she felt more inclined to diversify her network.

> I think when I'm in the city it's pretty mixed and I've made an effort to make it that way especially in the last year or two because prior to then I did not have a network of friends or acquaintances who have disabilities. So that's grown to a network of people that have a range of disabilities. (Molly, 5–10 YPI, lives alone)

The individuals who indicated that they replaced their pre-injury network with a different network following their injury felt connected and less socially isolated. Several individuals also found that paid caregivers such as personal support workers became important social connections in place of those they lost. One participant described paying for a personal support worker to provide companionship for mental support, as below:

> I'm a person who needs people, that's why the PSW [personal support worker] comes and we pay for her privately. So I don't feel bad if she's just sitting here in the chair talking to me rather than doing the things that most PSWs would do. Her job to me is to listen to me or to talk to me and that's what keeps me happy. If I had to be by myself all the time I would not make it, I would be very depressed. (Laura, >10 YPI, lives with a spouse)

Being able to replace lost connections with new ones, even if they are paid support workers or other healthcare professionals, was important for several participants. Participants indicated that these connections helped to improve the sense of belongingness in the midst of disruptions to their pre-injury network.

"My friends are there as a sounding board": Importance of feeling heard

Participants identified that their networks were utilized as a support system that provided structure to their day, assisted with activities of daily living, as well as provided encouragement to engage or re-engage in activities. Without their connections, participants stated that they would feel lonely and that their social network greatly improves their sense of belonging to the outside world and helped improve their mental and physical health.

> I guess the quality of life I'd say improved for me … my friends are there as a sounding board, I like to think I am one to them as well. And it's always nice to have a safe space with someone. It's never as often as I'd like it to be but I know people have busy lives. They are probably more for my mental health than my physical health. (Pauline, >10 YPI, lives with family)

However, several participants noted feeling frustrated with the individuals in their network who do not have disabilities, indicating that these individuals did not always understand what they were going through and they would try to focus only on the positives. One male participant, Leo, spoke about how those who did not have disabilities tended to focus on his health, and how he felt annoyed that he could not have a set-back without them immediately jumping to the positives of the situation.

> …I guess depending on who you're around, like some members of your family will be, they're so positive and they just want to see the positive side of everything about your injury. And any set back you have … they immediately jump on the positive … (Leo, 5–10 YPI, lives with family)

For Leo, not being able to express how he was feeling about the challenges he faced created a sense of disconnectedness from his family. The frustration felt in this moment is exemplified in other interviews where several participants spoke about similar encounters. These participants briefly described frustrations of not feeling empathy from family or friends by saying that "the able bodied, usually they want to tell you how to live your life … " (Aileen, >10 YPI, lives with family) or suggesting that "what he was going through goes right over his families head" (Jim, >10 YPI, lives with family). In these instances, participants turned to their peers with disabilities for support and understanding, expressing the value of these relationships for discussing their issues and problem-solving solutions to issues arising from their SCI. Some participants also felt as though they were an inconvenience or a burden on their existing social network.

> … it's almost like it's an inconvenience for a lot of people dealing with me because of my limitations [resulting from SCI]. (Alexander, <5 YPI, lives with a spouse)

Participants described feeling like a burden elicited a sense of disconnectedness from the able-bodied individuals in their network. A lack of understanding about the limitations experienced by individuals in this study exacerbated feelings of perceived social isolation. This is where the value of peer support seemed to be most evident. Peer support allowed the participants to feel heard and understood, which tempered feelings of isolation.

"I don't want to be a spectator": Importance of employment, hobbies, and sports

Participation in meaningful activities such as employment, hobbies and sports was reported to impact perceived social isolation. Individuals reported feeling excluded from the networks they were previously a part of because they were no longer able to participate in those recreational activities, such as sports, to the same extent that they had prior to their injury.

> A lot of my social interaction … was based on my activity and when you don't have the activity, it goes away and you just have to find a different basis to have a friendship with people. (Colleen, >10 YPI, lives alone)

Even when individuals were able to attend events they had gone to prior to their injury, there was still a sense of being excluded. Participants felt as though they were unable to participate to the extent to which they had in the past and had a certain level of expectation for themselves. When these expectations could not be met, this resulted in increased feelings of social isolation and disappointment.

> And I just can't do what I used to be doing. So I don't, I kind of, I don't want to be a spectator, I wanted to be a rider (Molly, 5–10 YPI, lives alone)

Several participants discussed replacing their previous activities with new volunteer opportunities related to their injury that they would have not otherwise become involved in. Replacing old activities with new ones created a new social network and thus increased a sense of belonging.

> It's afforded me the extraordinary opportunity… I would never have had that opportunity if I had not been spinal cord injured, ever… One door closes and another opens. (Tom, >10 YPI, lives with others)

Being unable to work post-SCI also had a negative impact on perceived social isolation. For participants who were suddenly cut off from their previous working life, their social connections became greatly limited. However, those who were able to continue working or found other meaningful work generally indicated a better sense of belonging.

> Very much so because I work for [organization] so having an injury gives me some real lived experience that are quite valuable and that people recognize. And they are important to the knowledge level and the way I do my job. So yeah I would say it has a huge positive influence on my belonging in the workplace. (Peter, >10 YPI, lives with family)

A subset of participants who were able to return to work post-SCI described experiencing some difficulty fitting in and feeling connected upon their return to work. They described physical difficulties upon returning to work, such as accessibility issues. The following individual, Adam, discussed how his workplace failed to make the necessary accommodations to facilitate his return to work:

> Well I had mixed feelings about, I thought you know, at that point, that they should have made more of an effort to make the job site where I was more accessible. But I guess they didn't feel the same way, and they didn't, so I had [to] navigate a whole system and work my way back. (Adam, >10 YPI, lives with spouse)

A second individual, Nancy, discussed the stigma of using a wheelchair in the workplace, describing the difficulties she faced with coworkers once she began needing to use a wheelchair instead of a cane:

> …I think it made an impact because as soon as you're in a wheelchair people think your brain doesn't work. (Nancy, >10 YPI, lives with spouse)

Returning to work was an important part of social participation for several participants. However, participants indicated that inaccessibility and societal attitudes made this process more difficult and resulted in increased feelings of perceived social isolation, despite having access to workplace social connections.

"We are excluded": Improving physical accessibility and the built environment

As identified with challenges to return to employment, the built environment surrounding the participants influenced their sense of perceived social isolation. Many participants indicated that their ability to stay connected with their networks was highly influenced by the weather and stated that they felt more isolated during certain seasons where mobility was a bigger issue (i.e., during the winter months with snow and ice). Transportation availability and accessibility issues led to limitations in participants' ability to get out and impacted the frequency of social interactions, which contributed to these feelings of isolation.

If participants were able to get out, accessibility issues (e.g., lack of ramps, elevators) increased isolation as it put up barriers as to what the individual is able to do and limits their participation.

> I think because it takes a lot more for me to do things and like are buildings accessible? Are restaurants accessible? And stuff like that, it hinders a lot of people like oh sorry you can't come to this party because it's upstairs at somebody's apartment that doesn't have an elevator or something like that. So that's a bit of a bummer but I can only do what I can do so if there's something that's great going on that I can go to then I have a good time. (Natalie, >10 YPI, lives alone)

Participants noted a negative impact on their ability to socialize with friends following SCI caused by the physical limitations imposed by their injury. When interacting with others in the community, their mobility and functional limitations created feelings of social isolation and disappointment. For example, if a participant was able to attend social events or outings, the lack of accessibility of the location made it difficult for the participant to be involved or feel included.

> I never got to get to my grandkids bedrooms… I go to the cottage and I only get into her basement at the cottage because the lift broke. So that isolates you and when they're playing games and … when they're out on the dock I just sit and watch from the land because they're scared I'll run my wheelchair off into the water because I probably would. (Laura, >10 YPI, lives with spouse)

This participant, Laura, discussed challenges with accessibility within the social and functional contexts. The inaccessibility of the dock prevented Laura from joining in social activities due to her family's fear of her falling. Further, Laura highlighted concerns in functional capacity to navigate the inaccessible dock. While Laura adapted to this situation, there is evidence of unintentional exclusion and isolation.

Several individuals mentioned this sentiment of unintentional exclusion, which related to participants receiving invitations to social gatherings in areas that are not accessible to them. This exclusion further accentuated their feelings of isolation and caused tension in their social networks. In several cases, it also caused participants to stop connecting with these individuals if they were going to continue to hold events in inaccessible areas.

> I think its accessibility issues… I think when we are excluded so much we don't have the networking opportunity in our professional environment. And when you are excluded over and over again it affects your sense of self. And so its extra work all the time to be out there and to take up space. You know… the same way that everybody else does. (Molly, 5–10 YPI, lives alone)

A few of the participants who lived in rural areas identified their geographical location as having an influence on their sense of belonging. These participants stated that by living in a smaller community, they were able to establish strong social connections and felt like the community supported them. Conversely, other participants indicated feeling more isolated moving into a small close-knit community following their SCI as they found it difficult to break into existing networks.

> Yeah and also because when I came up here I was at an age where most people… it's a family community so people my age, the women primarily were married with children, and most of my friends were professional women who were married without kids or were single. So it was a completely different cohort up here… so I have the challenge of being in a wheelchair and also the challenge of not really having a circle of people who are available to do things with. So it was very lonely when I got here. (Colleen, >10 YPI, lives alone)

Limited resources in these rural areas also had a negative effect on their sense of belonging. A lack of essential resources such as counselling to help people deal with perceived social isolation or specialist physical or occupational therapy expertise to assist in their physical recovery further perpetuated those feelings.

> I think the limitations, I mean there is no support net as far as a group net or a discussion groups, anything like that up here. Same thing there's no really medical support up here. Most of the physiotherapists I would say majority of PTs [physical therapists] or OTs [occupational therapists] the ones that we've dealt with so far, really don't understand the impact of spinal cord injury up here. They do in the city but therapy and stuff like that is minimal to non-existent. So you don't have that kind of support to help you find different ways to manage your time or manage your life or develop coping skills by a

> professional. So you're really left on your own. (Alexander, <5 YPI, lives with spouse)

This participant, Alexander, described the disconnect between community health care services in rural areas and specialist rehabilitation programs often found in more urban centres. Not having access to SCI knowledgeable health care professionals created feelings of perceived social isolation, as he was left on his own to cope and manage his SCI.

Individuals spoke about using technology and social media as an enabler to overcome built environment barriers. Most participants noted that using social media allowed them to reach out to more people, but they found having access to technology did not change their preference for face-to-face interactions. A majority of participants found that technology was not necessarily a barrier to building strong connections but also was not a facilitator of these types of connections. It was simply a means to reach out to a larger number of individuals and keep track of others.

> It's made it easier for me to reach more people. I use it to reach out to other people with injuries and stuff like that and help them. So it has, it's given me a farther reach and it's easier to connect with people around the world. But as far as building a strong connection it doesn't really help with that. (Leo, 5–10 YPI, lives with family)

Although social media was able to help participants reach out to more people, participants reported that the quality of the connection was more important than the number of connections. Furthermore, the number of connections made *via* technology and social media did not replace the impact of in-person connections with respect to feelings of perceived social isolation.

"I am what I am": The protective effect of individual characteristics

Individual characteristics appeared to play a role in experiences of perceived social isolation. Many participants were faced with an identity disruption following their injury; however, those who accepted their new reality were better able to adjust. These individuals were able to redefine their roles in life following their injury (e.g., as a husband, father, wife, mother) while maintaining an optimistic and proactive outlook on life.

> Absolutely not. I mean, in the first initial year, you do the what if, what if, what if, but then you got to let your sense of humor take over a little bit and then you either like me the way I am or you don't. You can't force it upon them. Relationships, as friends, in terms of actually, fiancée, and stuff like that, I mean, I am what I am. I can't change it, so just move forward. (Jeff, >10 YPI, lives with family)

Participants described becoming more assertive, as they had to become advocates for themselves. The ability to adapt ensured that they continued to be heard and that their needs were met. Actions of engagement in advocacy also provided the opportunity to reach out and connect with people in their social networks to ask for help or participate in leisure activities (e.g., going for coffee or lunch).

> Funny, actually when I was able bod[ied] I was a shy person. Once I had spinal cord injury, I became more … I could be more forward because at the beginning people didn't know what to say to you, so I reached out to them. (Molly, 5–10 YPI, lives alone)

Although not prominent, a few differences between men and women became apparent from the analysis. Women described their overall sense of wellbeing and sense of belonging to be connected with their relationships. These connections included close family members or friends, whom they communicated with on a regular basis and often relied on for access to the outside world as described by this participant:

> But I need those networks, let's put it this way if I lost them then that would be even worse … Well I would be cut off even more from the outside world … So from that I know if I lost some of the connections that I have it would really impact me a lot. (Laura, >10 YPI, lives with spouse)

Conversely, several male participants described themselves as "problem-solvers" or "driven" and therefore, were more comfortable being on their own. Furthermore, most men also tended to not describe their relationships as close or feel that they were dependent on these connections for a sense of belonging in contrast to female participants.

> It's by choice, I've always been like that. I haven't felt any particular need to be surrounded by friends. I've been like that my whole adult life. And so you know the kind of work that I do fits well in with my general inclination. To just be on my own. (Terrance, 5–10 YPI, lives with spouse)

The quotes provided by Terrance and Laura above highlights the contrast in how women and men discuss the importance of their relationships for their sense of belonging. Laura described being "cut off even more from the outside world" while Terrance said that "it's by choice … to just be on my own." Highlighting these two differences provides some insight into how gender may impact the sense of belonging. The female participants reported feeling that the abrupt changes to their social connections were a large contributor to their sense of belonging, while the male participants tended to discuss having fewer connections by choice and generally described coping with being on their own.

Discussion

In this qualitative study, we aimed to explore the perceived social isolation experiences of people with SCI and the factors that contributed to their experiences. Overall, participants in our study highlighted a major disruption of the structure and composition of their social networks and the importance of social support within their networks. Key factors associated with perceived social isolation included physical accessibility, return to employment, hobbies, and other leisure activities, the use of technology and social media, and individual traits (e.g., adaptability). Our study highlighted the importance of social connections for persons with SCI and the need for community efforts to improve opportunities for meaningful connections following injury.

One of the key findings from our study was the disruption in the structure and composition of social networks following SCI. Many of the participants discussed losing individuals from their social networks following their injury. Previous quantitative work by our group suggests that the average social network size for someone with an SCI was approximately four people [21]. This is lower than that of the general population which has been reported to be approximately greater than 10 [12,40]. The decline in the number of people in their social network seemed to align with age-related declines observed in the general population. For example, results of a meta-analysis [35] indicated that network size increases in adolescence and young adulthood, plateaus in the mid-20s to early 30s, followed by a decline in those 65 years and older. These findings have implications for the current study, suggesting that individuals who experience their injury at a younger age also may experience a decline, not normally experienced until later in life, in network size. Decreases in social network size seemed to contribute to some participants experiencing increased levels of perceived social isolation. Not only are these participants now susceptible to health conditions related to increased levels of perceived social isolation, but these negative health effects may be compounded by premature aging of the body systems associated with their SCI [41], leading to further health detriments.

Although disruptions in the structure and function of social networks occurred, participants indicated that they felt the overall quality of their networks did not seem to change. This is consistent with other quantitative literature, which showed that despite having declined in social network size, the connections that did exist were robust and of good quality [21,42]. The participants in the current study also highlighted the quality of their relationships as being important. Several individuals discussed how their social networks were responsible for keeping them connected to the outside world, thus improving their feelings of belonging. However, not all individuals had maintained the quality of their social networks. Those that experienced changes, noted that they became frustrated with those who did not have a disability. These findings highlight the importance of peer-to-peer relationships (e.g., those with disabilities) in maintaining a sense of belonging. Individuals felt that they could discuss their issues and potential solutions to these issues arising from SCI more comfortably. Previous qualitative work identified similar findings, where individuals felt a loss of camaraderie upon discharge from rehabilitation [31]. Increasing access to peer support in the community may help improve the sense of belonging in this population [43].

Maintaining meaningful employment, hobbies, exercise and sports were also key contributors to reduced feelings of perceived social isolation. This is consistent with literature exploring leisure-time physical activity in persons with SCI and perceived social isolation [22]. A recent quantitative study by Santino et al. [22] determined that a negative relationship exists between leisure-time physical activity and feelings of loneliness. Individuals in our study who were able to maintain their pre-injury activities, or replace them with new ones, felt a stronger sense of belonging. Quantitative evidence also suggests that those who were employed following their SCI experienced fewer feelings of perceived social isolation [21]. However, for those who were unable to go back to work, they described losing connections to their social network, thus experiencing higher levels of perceived social isolation. While declines in the social network may be similar to individuals who are of retirement age [44], persons with SCI likely experience declines in social network size sooner than those who retire for age. Interestingly, even for some who returned to work, they did not feel as connected to their co-workers as they did prior to their injury. For those participants who attempted to return to their previous social activities, there was a sentiment of unintended exclusion. This was the result of poor physical access to buildings or homes, where participants who were invited to social events often found that the selected locations were not accessible. Unintended exclusion resulted in increased feelings of perceived social isolation, as participants felt disconnected and left out from individuals in their social network.

The theory of complex embodiment may help to explain some of our results. This theory aims to emphasize the effects of disabling environments while maintaining that there are functions of the body (i.e., secondary health conditions, aging) that impact a person's lived experience, as well as how personal factors impact disability experiences [45]. While not discussed by the participants in the current study per se, other research suggests that secondary health conditions such as bladder control or pain, impact participation in employment and leisure activities [46]. These findings in combination with the results of the current study are evidence that the body and the built environment in which a person resides cannot be separated but must be considered in tandem to fully address the impact of SCI on these activities. Further, the current study highlights how personal characteristics such as a change in social roles or self-advocacy can contribute to experiences with perceived social isolation. It would be pertinent for future work to develop education and awareness programs for the non-SCI community about the impact of unintentional exclusion whether socially or in the workplace to help mitigate the impact of unintentional exclusion on the sense of belonging for this population. It would also be important that rehabilitation programs focus on assisting persons to return to their previous activities or replace them with new ones while considering the limitations of their bodies. Potential areas to promote participation include the development of accessible adapted sports programs or peer-to-peer led activity groups to facilitate the return to- or replacement of activities and thus reduce perceived social isolation. In cases where participants can no longer return to their old activities, rehabilitation programs should aim to provide support while individuals re-establish their social roles. Programs should also incorporate strategies and opportunities for self-advocacy.

Our study also identified differences in levels of perceived social isolation based on the participants' residence (i.e., rural vs urban setting). Participants indicated that there were limited resources in more rural settings, as well as increased physical barriers to participation. A recent quantitative study by Glennie et al. [47] showed similar findings: living in a rural setting had more environmental barriers, which the authors defined as physical/structural barriers and limited access to services or assistance. These limitations led to increased feelings of loneliness. However, what is novel from our study is that some individuals actually felt that a smaller community supported them following their injury. These participants also felt that they would have better quality relationships in their rural setting rather than in an urban setting. These individual variations may account for the discrepancy in the previously mentioned study where the authors determined that only a small number of individuals moved to an urban setting from their rural one [47].

Finally, social media and technology were not identified as important for decreasing levels of perceived social isolation despite using technology at home ($n = 26$) or having Internet access ($n = 29$). Findings from our study suggest that individuals may use it simply as a means to reach more people, rather than using technology to facilitate deeper quality connections. A previous qualitative study found that individuals with SCI perceived technology in a similar manner to our participants [48]. The technology was perceived as a highly valued tool that made things easier and facilitates connections with peers with SCI. Future research might investigate how social media and technology may be used to facilitate better quality of relationships and connections. Also of note is the lack of discussion of these communication technologies from persons with tetraplegia. It is possible that individuals with these higher-level injuries simply chose not to use these communication devices but the reasons for these were not described in our interviews. Additional research is needed in order to better understand the implications of using mobile devices and social media for this subset of the population.

Methodological considerations

Despite our best efforts to ensure that a wide variety of experiences was explored, there was a disproportionate representation of individuals living with someone from their social network (i.e., spouse, other families) compared to those living independently.

Having someone from their social network embedded directly within their home may have resulted in over-representation of participants who highlighted greater relationship quality. Future research should seek to capture the experiences of those individuals living alone, in order to fully understand the nuances of perceived social isolation in persons with SCI. Similarly, our participants were primarily living in urban centres; however, we were able to identify a sense of belonging unique to individuals living within a rural setting which is not discussed in previous research. It would still be pertinent to collect the experiences of those living in a rural setting in more detail, in order to identify areas of improvement with respect to access to services. The individuals included in this study were on average 26 years post-SCI, which likely would have resulted in longer lengths of inpatient rehabilitation. More recent cases of SCI tend to have shorter lengths of stay but have access to peer introduction/mentorship which may not have been the case for most of our cohort. Those who had a shorter-term SCI spoke more so about access to peer support compared to participants with more YPI, which may play a role in the sense of belonging. The development of SCI rehabilitation programs over time may account for this difference as described above. However, those who did not endorse experiencing perceived social isolation were above the mean YPI, indicating that YPI may have a protective effect. More research is needed to describe the differences in adjustment between short-term and long-term injuries. A final consideration involves the temporality of the study design. Due to the cross-sectional nature of this qualitative study, the views and experiences expressed by the participant reflect where they were situated at the time of the interview. Future research should seek to collect more longitudinal data to highlight whether or not these changes are maintained over time.

Conclusions

The current study highlights that disruption in an individual's social network, as well as the quality of the relationships within the network, are important components that impact perceived social isolation in individuals with SCI in the community. Future research might consider developing and implementing programs to help people with SCI maintain the quality of their connections. One option may be increasing access to peer-to-peer support programs, as relationships of this type were highly valued by our participants. A more in-depth understanding with respect to the use of technology and social media is needed in order to understand how they can be leveraged to improve the quality of relationships rather than network size. Improvements to physical accessibility and access to recreational and leisure activities should also be investigated as participation in these activities also contributed to improvements in perceived social isolation. The implications from this work also have relevance to the current Coronavirus-19 pandemic as social distancing measures are put in place. It is plausible to suggest that feelings of perceived social isolation may be further exacerbated during the pandemic. Future research should seek to explore the experiences of perceived social isolation in persons with SCI during the pandemic.

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References

[1] House JS, Landis KR, Umberson D. Social relationships and health. Science. 1988;241(4865):540–545.

[2] Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. PLoS Med. 2010;7(7):e1000316.

[3] De Jong Gierveld J, Kamphuls F. The development of a rasch-type loneliness scale. App Psychol Measure. 1985;9(3):289–299.

[4] Hawkley LC, Thisted RA, Masi CM, et al. Loneliness predicts increased blood pressure: 5-year cross-lagged analyses in middle-aged and older adults. Psychol Aging. 2010;25(1):132–141.

[5] LeRoy AS, Murdock KW, Jaremka LM, et al. Loneliness predicts self-reported cold symptoms after a viral challenge. Health Psychol. 2017;36(5):512–520.

[6] Kiecolt-Glaser JK, Gouin JP, Hantsoo L. Close relationships, inflammation, and health. Neurosci Biobehav Rev. 2010;35(1):33–38.

[7] Cacioppo JT, Hawkley LC, Thisted RA. Perceived social isolation makes me sad: 5-year cross-lagged analyses of loneliness and depressive symptomatology in the Chicago Health, Aging, and Social Relations Study. Psychol Aging. 2010;25(2):453–463.

[8] van Baarsen B, Snijders TAB, Smit JH, et al. Lonely but not alone: emotional isolation and social isolation as two distinct dimensions of loneliness in older people. Educ Psychol Measure. 2001;61(1):119–135.

[9] Valtorta NK, Kanaan M, Gilbody S, et al. Loneliness, social isolation and risk of cardiovascular disease in the English Longitudinal Study of Ageing. Eur J Prev Cardiol. 2018;25(13):1387–1396.

[10] Kurina LM, Knutson KL, Hawkley LC, et al. Loneliness is associated with sleep fragmentation in a communal society. Sleep. 2011;34(11):1519–1526.

[11] Hackett RA, Hamer M, Endrighi R, et al. Loneliness and stress-related inflammatory and neuroendocrine responses in older men and women. Psychoneuroendocrinology. 2012;37(11):1801–1809.

[12] Steptoe A, Shankar A, Demakakos P, et al. Social isolation, loneliness, and all-cause mortality in older men and women. Proc Natl Acad Sci USA. 2013;110(15):5797–5801.

[13] Luo Y, Hawkley LC, Waite LJ, et al. Loneliness, health, and mortality in old age: a national longitudinal study. Soc Sci Med. 2012;74(6):907–914.

[14] Beller J, Wagner A. Loneliness, social isolation, their synergistic interaction, and mortality. Health Psychol. 2018;37(9): 808–813.

[15] Zavaleta D, Samuel K, Mills C. Social isolation: a conceptual and measurement proposal. Oxford (UK): University of Oxford; 2014. (OPHI Working Papers).

[16] Shanouda F, Walsh S, Mathieson MS. Aging with a disability. Toronto (Canada): Access Independent Living Services; 2015.

[17] Hammel J, Magasi S, Heinemann A, et al. Environmental barriers and supports to everyday participation: a qualitative insider perspective from people with disabilities. Arch Phys Med Rehabil. 2015;96(4):578–588.

[18] Bezyak JL, Sabella SA, Gattis RH. Public transportation: an investigation of barriers for people with disabilities. J Disabil Policy Stud. 2017;28(1):52–60.

[19] Frier A, Barnett F, Devine S, et al. Understanding disability and the 'social determinants of health': how does disability affect peoples' social determinants of health? Disabil Rehabil. 2018;40(5):538–547.

[20] Holanda CM, De Andrade FL, Bezerra MA, et al. Support networks and people with physical disabilities: social inclusion and access to health services. Cien Saude Colet. 2015; 20(1):175–184.

[21] Guilcher SJT, Craven BC, Bassett-Gunter RL, et al. An examination of objective social disconnectedness and perceived social isolation among persons with spinal cord injury/dysfunction: a descriptive cross-sectional study. Disabil Rehabil. 2019. DOI:10.1080/09638288.2019.1616328

[22] Santino N, Larocca V, Hitzig SL, et al. Physical activity and life satisfaction among individuals with spinal cord injury: exploring loneliness as a possible mediator. J Spinal Cord Med. 2020;7:1–7.

[23] Whelen-Robinson S, Taylor HB, Feltz M, et al. Loneliness among people with Spinal Cord Injury: exploring the psychometric properties of the 3-Item Loneliness Scale. Arch Phys Med Rehabil. 2016;97(10):1728–1734.

[24] Hughes ME, Waite LJ, Hawkley LC, et al. A Short Scale for measuring loneliness in large surveys: results from two population-based studies. Res Aging. 2004;26(6): 655–672.

[25] Tsai IHG, Chan W, Darkoh C, et al. Environmental barriers and social participation in individuals with spinal cord injury. Rehabil Psychol. 2017;62(1):36–44.

[26] Barclay L, McDonald R, Lentin P, et al. Facilitators and barriers to social and community participation following spinal cord injury. Aust Occup Ther J. 2016;63(1):19–28.

[27] Barclay L, Lentin P, McDonald R, et al. Understanding the factors that influence social and community participation as perceived by people with non-traumatic spinal cord injury. Br J Occupational Ther. 2017;80(10): 577–586.

[28] Braaf S, Lennox A, Nunn A, et al. Social activity and relationship changes experienced by people with bowel and bladder dysfunction following spinal cord injury. Spinal Cord. 2017;55(7):679–686.

[29] Barclay L, Lentin P, Bourke-Taylor H, et al. The experiences of social and community participation of people with non--traumatic spinal cord injury. Aust Occup Ther J. 2019;66(1): 61–67.

[30] Hay-Smith EJ, Dickson B, Nunnerley J, et al. "The final piece of the puzzle to fit in": an interpretative phenomenological analysis of the return to employment in New Zealand after spinal cord injury. Disabil Rehabil. 2013;35(17):1436–1446.

[31] Dickson A, Ward R, O'Brien G, et al. Difficulties adjusting to post-discharge life following a spinal cord injury: an interpretative phenomenological analysis. Psychol Health Med. 2011;16(4):463–474.

[32] Newman SD, Li C, Krause JS. Social isolation after spinal cord injury: indicators from the Longitudinal Aging Study. Rehabil Psychol. 2016;61(4):408–416.

[33] Thorne S, Kirkham SR, MacDonald-Emes J. Interpretive description: a noncategorical qualitative alternative for developing nursing knowledge. Res Nurs Health. 1997; 20(2):169–177.

[34] Craven C, Hitzig SL, Mittmann N. Impact of impairment and secondary health conditions on health preference among Canadians with chronic spinal cord injury. J Spinal Cord Med. 2012;35(5):361–370.

[35] Hitzig SL, Campbell KA, McGillivray CF, et al. Understanding age effects associated with changes in secondary health conditions in a Canadian spinal cord injury cohort. Spinal Cord. 2010;48(4):330–335.

[36] Noonan VK, Kwon BK, Soril L, et al. The Rick Hansen Spinal Cord Injury Registry (RHSCIR): a national patient-registry. Spinal Cord. 2012;50(1):22–27.

[37] Patton MQ. Qualitative research & evalutation. Thousand Oaks (CA): SAGE Publications; 2002.

[38] Barbour RS. Checklists for improving rigour in qualitative research: a case of the tail wagging the dog? BMJ. 2001; 322(7294):1115–1117.

[39] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care. 2007;19(6):349–357.

[40] Wrzus C, Hanel M, Wagner J, et al. Social network changes and life events across the life span: a meta-analysis. Psychol Bull. 2013;139(1):53–80.

[41] Hitzig SL, Eng JJ, Miller WC, et al. An evidence-based review of aging of the body systems following spinal cord injury. Spinal Cord. 2011;49(6):684–701.

[42] Guilcher SJT, Casciaro T, Lemieux-Charles L, et al. Social networks and secondary health conditions: the critical secondary team for individuals with spinal cord injury. J Spinal Cord Med. 2012;35(5):330–342.

[43] Sweet SN, Michalovic E, Latimer-Cheung AE, et al. Spinal cord injury peer mentorship: applying self-determination theory to explain quality of life and participation. Arch Phys Med Rehabil. 2018;99(3):468–476.

[44] Patacchini E, Engelhardt GV. Work, retirement and social networks at older ages. Chestnut Hill (MA): Center for Retirement Research at Boston College; 2016. (Crr WP 2016-15).

[45] Siebers T. Disability and the theory of complex embodiment – for identity politics in a new register. In: Davis LJ,

editor. The disability studies reader. 5th ed. New York (NY): Routledge; 2016.

[46] Piatt JA, Nagata S, Zahl M, et al. Problematic secondary health conditions among adults with spinal cord injury and its impact on social participation and daily life. J Spinal Cord Med. 2016;39(6):693–698.

[47] Glennie RA, Batke J, Fallah N, et al. Rural and urban living in persons with spinal cord injury and comparing environmental barriers, their health, and quality-of-life outcomes. J Neurotrauma. 2017;34(20):2877–2882.

[48] Mattar AA, Hitzig SL, McGillivray CF. A qualitative study on the use of personal information technology by persons with spinal cord injury. Disabil Rehabil. 2015;37(15):1362–1371.

[49] Roberts TT, Leonard GR, Cepela DJ. Classifications in brief: American Spinal Injury Association (ASIA) Impairment Scale. Clin Orthop Relat Res. 2017;475(5):1499–1504.

References Cited for Topic 5

Cimino SR, Hitzig SL, Craven BC, Bassett-Gunter RL, Li J, Guilcher SJT. An exploration of perceived social isolation among persons with spinal cord injury in Ontario, Canada: a qualitative study. Disabil Rehabil. 2022;44(14):3400-3409. doi:10.1080/09638288.2020.1861485

LaVela SL, Motl RW, Berryman K, Wirth M, Bartle B, Aguina K, Solanki P, Bombardier CH. Facilitators to alleviate loneliness and social isolation as identified by individuals with SCI/D: A qualitative study. Rehabilitation Psychology. 2024. doi: 10.1037/rep0000540.

Other Resources/Additional Readings for Topic 5

Shekelle PG, Miake-Lye IM, Begashaw MM, et al. Interventions to reduce loneliness in community-living older adults: a systematic review and meta-analysis. J Gen Intern Med. Published online January 10, 2024. doi:10.1007/s11606-023-08517-5

Fakoya OA, McCorry NK, Donnelly M. How do befriending interventions alleviate loneliness and social isolation among older people? A realist evaluation study. PLoS One. 2021;16(9):e0256900. Published 2021 Sep 9. doi:10.1371/journal.pone.0256900

Santino N, Larocca V, Hitzig SL, Guilcher SJT, Craven BC, Bassett-Gunter RL. Physical activity and life satisfaction among individuals with spinal cord injury: Exploring loneliness as a possible mediator. J Spinal Cord Med. 2022;45(2):173-179. doi:10.1080/10790268.2020.1754651

Wang W, Cole S. Travel and social isolation of people with spinal cord injury. Top Spinal Cord Inj Rehabil. 2023;29(4):86-95. doi:10.46292/sci23-00029

Zinberg S, Merino M. Interventions that work to stem the effects of social isolation and loneliness. Generations Journal. Fall 2020. https://generations.asaging.org/interventions-stem-effects-isolation-loneliness

Topic 5 Assignment

Identify three strategies that may alleviate loneliness in persons with SCI/D.

(1) ____

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(2) ____

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(3) ____

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Imagine patient scenarios in which specific strategies would be most helpful. Reflect on which of the strategies your patients living with SCI/D would relate to most and why. Jot down your thoughts.

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