Problematic secondary health conditions among adults with spinal cord injury and its impact on social participation and daily life

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Objective: This exploratory study describes the problematic secondary health conditions among adults with a spinal cord injury (SCI) and the impact these health concerns have on social participation and daily life.

Design: Cross-sectional survey design.

Setting: A community-based rehabilitation program within the United States.

Participants: Fifty-six adults (33 males and 23 females; age 18 to 73 [M = 39.4, SD = 12.7]) with SCI participating in the community-based rehabilitation program.

Methods: Subjects identified the top five problematic secondary health conditions related to his/her SCI, belief about the impact these conditions have on social participation and daily life, and if they believed the secondary health condition(s) were avoidable.

Results: The top problematic areas identified were bladder control, pain, bowel control, and pressure ulcers, and 73% felt these problems were unavoidable. In addition, more than 66% had each of these problems continuously during the last 12 months. When examining the impact of the problematic secondary health conditions, 75% identified that the primary problem had a significant impact on social participation and 64% identified it significantly impacted daily life.

Conclusion: Although the majority of the participants were actively participating in a community-based rehabilitation wellness program, it appears that they thought engagement in social participation and daily life were negatively impacted by the secondary health conditions and unavoidable. The results suggested unfulfilled goals despite the emphasized efforts of medical providers to help manage the secondary conditions. Future research should examine why individuals with SCI still have a difficult time managing secondary health conditions.

Keywords: Social participation, Spinal cord injury, Activities of daily life

Introduction

Secondary health conditions are highly variable and many times poorly managed conditions often leading to further functional limitations imposed by a spinal cord injury (SCI). Research indicates individuals with SCI experience 8–14 secondary conditions per year with more than one condition typically occurring concurrently.^{1–3} Respiratory infections, urinary tract infections, spasticity, pain, blood pressure, and pressure

sores are common secondary conditions among the SCI population. As the leading causes of re-hospitalization and additional financial burden among individuals with SCI, secondary health conditions can also be disruptive to participation within one's life. This is especially common within the realm of social participation and daily life.^{4,5}

The development and adoption of the International Classification of Functioning, Disability and Health (ICF) within rehabilitation has demonstrated a shift in the focus from merely examining the medical condition (e.g. impairment or functioning level) to the impact environmental and personal factors, as well as

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participation and activity can have on one's health and quality of life.^{6,7} Participation ("a person's involvement in a life situation")⁸ strongly related to quality of life⁹ has emerged as an important clinical outcome with the SCI population.⁶ Furthermore, social participation as a subset of participation is defined as engagement in activities that entail social interactions with others within the community and outside the home environment.¹⁰

In recent years, the influence of the ICF on investigating and treating individuals with SCI from a different perspective has advanced the treatment and management of secondary conditions. The ICF views SCI on "three components of functioning: body functions and structures, activities, and participation, in relation to personal and environmental factors".¹¹ Moving to a more holistic view of disability it is important to not only look at these components and factors separately but more importantly to look at their interrelations.¹² Developing community-based rehabilitative interventions, such as wellness programs, focused on more holistic clinical outcomes may be more successful in managing secondary health conditions while at the same time improve daily life and social participation. Daily life, is the engagement in all activities in one's life including domestic and nondomestic, and whether independently or with others.

The ultimate goal of rehabilitation is to assist the patient manage their secondary health conditions and return to the most functional level by maximizing social participation and daily life. Despite the problematic nature secondary health conditions impose, most are manageable if the appropriate interventions are facilitated.^{2,3} For example, patient education and training programs to promote health promotion and self-care for decreasing the onset of secondary health conditions such as pressure ulcer (PU) and urinary tract infection (UTI) have been shown to be effective.^{3,13-15} It also appears that if individuals are provided with the information necessary during hospital stays and within outpatient services, these secondary health conditions may become less problematic throughout one's lifespan. Yet, it is unclear how the current SCI adult population within the United States perceives his or her secondary health conditions, and the impact this has on his or her overall social participation and daily life.

Advanced research has disclosed negative effects of secondary health conditions for individuals with SCI, and researchers and clinicians place significant effort into controlling and managing these health concerns.^{13,16} Although previous studies have demonstrated that some secondary health conditions can be prevented through wellness interventions others may not be preventable.¹⁷ Yet, these secondary health conditions can

be managed through community-based rehabilitation initiatives, including wellness programs.¹⁸

Such conventional knowledge (i.e. are secondary health conditions preventable or manageable) has been predominantly accumulated through clinicians' perspectives. And, these accounts have ignored the client's perceptions of what secondary health conditions directly impact his or her social participation and daily life after discharge. The current study examines the clients' perception about secondary health conditions in a rehabilitation hospital that promotes secondary health condition management through participation in a community based rehabilitation wellness program that encompasses adapted sport, peer support, educational forum and assistive technology. The idea that incorporating the subjective aspects into patient care may decrease, or better manage, the onset of secondary health conditions.¹ Therefore, the purpose of this study was to identify the most problematic secondary health conditions perceived by individuals with SCI, its impact on social participation and daily life, and to clarify whether they perceive those problematic secondary health conditions were avoidable.

Methods

Participants

This exploratory study employed a cross-sectional survey design. A purposive sample of individuals with SCI currently receiving outpatient services from a rehabilitation hospital in the United States were recruited for this study. All research participants currently identified themselves as a current or past participant in a wellness program designed specifically for individuals with SCI. Individuals with a medical diagnosis of a spinal cord injury over the age of 18 and currently living in the community were eligible to participate in the study. Individuals were excluded if they were under the age of 18 and had a medical diagnosis of a cognitive impairment that precluded them from being able to complete the survey independently. An email was sent to 80 potential participants currently affiliated with the wellness program with an information sheet describing the study along with a link to the consent form and Qualtrics questionnaire. A reminder email was sent in four different increments. Research protocol was approved by the Institutional Review Boards at the respective universities and the rehabilitation hospital.

Questionnaire

The questionnaire included demographics, SCI characteristics, secondary health conditions that the participant experienced in the previous 12 months of

completing the survey, and the extent of which the secondary health conditions impact his or her social participation and daily life. Questions regarding social participation and daily life were adopted from van Loo et al.¹ and the original Dutch version was translated into English.

Secondary health conditions determined from this study were placed into a categorical checklist. This checklist included a list of 29 common secondary health conditions experienced by the SCI population. This list was reviewed and confirmed by a physiatrist and other allied health professionals (i.e. physical therapist, occupational therapist, recreational therapist, nurse practitioner) on the medical team. Research participants were asked to check only those problem areas that related to his or her SCI and those that occurred in the last 12 months. Research participants were also instructed that if anything happened prior to the last 12 months but was still an issue, to also check that item. Immediately following the checklist, research participants were asked to rank the top 5 problem areas associated with secondary health conditions.

Following the identification of the top 5 problem areas research participants were asked to indicate how often they had each problem in the last 12 months. In order to estimate whether the problem was an issue several times, or a continuous concern, the participants were given the following response options: one time; 2–4 times; 5–7 times; 8–10 times; 10–12 times; 13–15 times; and continuously. Subsequently, the participants were asked, for each problem area, if the problem could have been avoided. In order to ensure the participants were fully aware of prevention options, they were given the following options: no; yes, by paying attention to my own health; yes, by attention to my own behavior; yes, by changes in my daily behavior; yes, by better information; yes, by changes in the amount of financial

aid; yes, by changes in the quality of care (more competent, flexible, etc.); and other. Research participants were also asked to rate the extent of the impact of the identified secondary health conditions on social participation first followed by the impact on daily life. Single questions for each (i.e. social participation and daily life) were asked on a Likert scale (1 = not at all, 2 = a little, 3 = moderately, 4 = severely, and 5 = completely).

Data analysis

Analyses were performed using SAS 9.4 (SAS Institute Inc., Cary, NC, USA). Descriptive statistics of the top problematic secondary health conditions, sociodemographic variables, and current participation in the wellness program were inspected to examine the characteristics of the sample. The top problematic secondary health conditions were determined by frequencies of the most important problem area that the research participant identified. Impact of the identified five top problematic secondary health conditions on social participation and daily life were analyzed by inspecting descriptive statistics.

Results

Table 1 shows the summary of participant characteristics. A total of 56 participants (33 males and 23 females between the ages of 18 and 73 [$M = 39.4$, $SD = 12.7$]) completed the online questionnaire. This population was unique in that 35.7% sustained the SCI due to a sport injury (compared to the national statistic of 10.3%).¹⁹ In addition, there were less males (58.9%) than the national average (80%) in previous studies (76–84%).^{19–21} Tetraplegia and paraplegia were represented similarly to other studies.^{20,21} The wellness program associated with community-based rehabilitation was selected because it provided a special focus

Table 1 Participant characteristics (N = 56)

<i>Age (years)</i>		<i>Cause of Injury (%)</i>	
Mean (SD)	39.4 (12.7)	Vehicular Accident	28.6
Range	18–73	Work Accident	8.9
		Sports Injury	35.7
<i>Sex (%)</i>		Falls	5.4
Male	58.9	Violence	3.6
Female	41.1	Medical Treatment	5.4
		Others	12.5
<i>Level and Type of SCI (%)</i>		<i>Education (%)</i>	
Tetraplegia	32.1	Some High School	3.6
Paraplegia	64.3	High School	10.7
Missing data	3.6	Some College	25.0
<i>Current wellness participation (%)</i>		Associate Degree	8.9
Yes	75.0	Bachelor Degree	26.8
No	25.0	Graduate Degree	25.0

on managing secondary health conditions through innovative wellness interventions as well as education and training for clinicians. A total of 42 participants (75%) identified as currently participating in at least one of the wellness programs, including sport and recreation. Although 25% did not identify as currently participating in any component of the wellness programs, they were listed with the rehabilitation hospital as a participant in the wellness program at some point in time and in some capacity. Considering prevalent barriers for physical activity participation and low physical activity participation rate (e.g. Martin-Ginis *et al.* reported that 50% of the participants in a population-base sample of individuals with SCI had zero minute of leisure time physical activity.²⁰ Tasiemski *et al.* reported similar results that over half of the national representative sample with SCI did not participate in sports at all).^{20,21} makes this SCI sample population unique. Although it is unclear what portion of the wellness program the research participants were engaging in (i.e. adapted sport, educational forum, peer support), it does appear that 75% were actively engaged in at least one component of the wellness program and the remaining 25% identified with the wellness program.

Table 2 Most common problematic areas identified from participant responses (N = 56)

Problem area rank	Rank	Secondary health conditions	%
Top 1 problem area	1	Bladder control Issues	30.4
	2	Pain	28.6
	3	Bowel Regulation Issues	10.7
	4	Pressure ulcers	5.4
Top 2 problem area	1	Spasm	17.9
	2	Bladder control Issues	16.1
	3	Pain	12.5
	4	Bowel Regulation Issues	10.7
Top 3 problem area	1	Bladder control Issues	12.5
	1	Spasm	12.5
	3	Pain	10.7
	3	Weight gain	10.7
Top 4 problem area	1	Activities of Daily Living	10.7
	2	Edema	10.7
	3	Spasm	8.9
	4	Bowel Regulation Issues	7.1
Top 5 problem area	1	Disability management [†]	12.5
	2	Assertiveness	7.1
	2	Activity of Daily Living	7.1
	2	Dependency [‡]	7.1

[†] Identified that extended time was needed to do daily activities compared to the situation before the SCI including dependent on personal help from partner, family, or home health care.

Table 3 Frequency in the past 12 months of occurrences of the top secondary health conditions identified by the participants (N = 56)

Frequency of the secondary health condition (%)	
1x	3.6
2–4x	10.7
5–7x	7.1
8–10x	3.6
10–12x	7.1
13–15x	1.8
Continuous	66.1

The results of the top 5 problematic areas are shown in Table 2. The most problematic areas of secondary health conditions identified by these research participants were bladder issues (30.4%), pain (28.6%), bowel issues (10.7%), and pressure ulcers (5.4%). The second most problematic areas include spasm (17.9%), bladder issues (16.1%), pain (12.5%), and bowel issues (10.7%). The third most problematic areas include bladder issues (12.5%), spasm (12.5%), pain (10.7%), and weight gain (10.7%). The fourth most problematic areas include activity of daily living (ADL: 10.7%), edema (10.7%), spasm (8.9%), and bowel issues (7.1%). And the fifth most problematic areas included disability management (12.5%), assertiveness (7.1%), ADL (7.1%), and dependency (7.1%). Disability management was defined as extended time needed to do daily activities compared to before the SCI, including physical care.

Table 3 shows the frequency of occurrences of the most problematic secondary health conditions identified by the research participants. A total of 66.1% of the participants responded that the secondary health conditions were a continuous concern. Table 4 summarizes if the research participants indicated whether they felt the secondary health concern was avoidable or not. A total of 73.2% of the participants responded that their secondary health condition(s) was not avoidable. The remaining 26.8% of the participants responded that it was avoidable, but there was not a consensus on prevention method.

A total of 75.0% of the participants reported that the top secondary health conditions had a notable impact on social participation and 64.3% reported a notable

Table 4 Participants perception of avoidable secondary health conditions (N = 56)

Research participants stating if secondary health conditions were avoidable (%)	
No	73.2
Yes – by paying attention to my own health	3.6
Yes – by paying attention to my own behavior	5.4
Yes – by changes in my daily behavior	7.1
Yes – by changes in the amount of financial aid	1.8
Yes – by changes in the quality of care	3.6
Yes – other	5.4

Figure 1 The influence of the most problematic secondary health conditions on social participation (A) and daily life (B). “Significant influence” was defined as the impact was more severe than moderately [i.e. significant influence (%) = moderately (%) + severely (%) + completely (%)]. Significant influence on social participation = 75.0% and on daily life = 64.3%.

impact on daily life. In addition, more than 66.1% experienced this problem continuously during the last 12 months, and 73.2% of the participants responded that these problems were unavoidable. The remaining 26.8% of the participants indicated that they could have avoided the secondary health condition by paying attention to their own health and behavior, by changing their daily behavior, amount of financial aid, and quality of care (Figure 1).

Discussion

This study investigated the top secondary health conditions among a purposive sample of adults with SCI as well as whether they perceived these conditions impacted social participation and daily life. The results of this study were consistent with previous research on the most common secondary health conditions for individuals with SCI (i.e. Richards *et al.*).²² Of the individuals surveyed in this study, the top secondary health conditions of their SCI were bladder, pain, bowel, and pressure ulcers. It is interesting to note that although the sample population for this study is considered to be unique in that they have participated in a wellness program at some point in time by the rehabilitation professionals, the results are similar to that of the general SCI population who may not be actively engaging in life, such as participation in a wellness program. Although previous research has indicated that active engagement in life can prevent secondary health conditions, this was not the perception of this sample SCI adult population.¹⁷

The results demonstrated that the top secondary health conditions adversely affected social participation and daily life within a population that is affiliated with a wellness program. There may be cases that individuals with SCI refrain from various social and daily activities due to the difficulty of managing secondary health conditions, for example the fear of a bladder/bowel related accident. Similarly, they may refrain from engaging fully

in his or her life because of pain level. Considering that a large majority of the research participants experienced these secondary health conditions continuously throughout the past 12 months, the results imply the secondary health conditions may undermine overall life participation. However, it is unclear with this sample which aspect of bladder, pain, and bowel are most problematic as all problem areas were placed within a category for participants to choose from. Future research should focus more specifically on what aspects of bladder, pain, and bowel are more problematic as well as if there is more than one area that creates limitations within that category.

The majority of the research participants reported that the secondary health conditions were unavoidable even though 3/4 of the participants were currently engaging in a community based rehabilitation wellness program. Although it has been noted in prior research and by rehabilitation professionals that secondary health conditions are manageable, this was not the perception of this sample population.^{14,15,17} The discrepancy between clinicians’ assumptions (i.e. the secondary health conditions are manageable) and clients’ perceptions (i.e. the secondary health conditions are unavoidable) suggests that there are possible implementation issues in practice. One area of possibility is in re-examination of health education (i.e. wellness programs) and community integration. The length of stay in inpatient rehabilitation for the SCI population continues to decrease providing less time for health management education. In accordance to increasing duties and responsibilities of rehabilitation professionals in daily practice,²³ the lack of a total amount of time is critical to the long term health of the SCI population. In addition, a previous study reported that patients in SCI inpatient setting learn the preventive skills when they are ready and relevant.²³ Teaching all knowledge and skills for secondary health conditions while patients are in

inpatient rehabilitation program may not be desirable because of such timing issues (i.e. they may not be ready for overwhelming amount of knowledge and may not realize that these secondary health conditions are relevant to them yet). This may explain why community-based rehabilitation wellness programs are effective health care settings for educating individuals with SCI how to manage the secondary health conditions. Such settings in the community would also create opportunities to meet specialists, for example recreational therapists who specialize in participation as defined by the ICF as well as peers with SCI who can provide real life experiences and information related to secondary health condition prevention.^{23,24}

Conclusion

The majority of the research participants within this study identified with a comprehensive community-based rehabilitation program geared primarily to the SCI adult population. Despite the fact that the majority of the participants were engaging in this program, it appears that the top secondary health conditions were consistent with the general SCI population, and that these secondary health conditions had a significant negative impact on engagement in both social participation and daily life. It is not clear why these individuals with SCI did not perceive the secondary health conditions as avoidable despite research evidence that they were manageable. Further in-depth investigation is needed to clarify the gap between clinician's intention to teach secondary health conditions management and clients' perception of it among the SCI adult population.

References

- van Loo MA, Post MWM, Bloemen JHA, van Asbeck FWA. Care need of person with long-term spinal cord injury living at home in the Netherlands. *Spinal Cord* 2010;48(5):423–8.
- Dunn M, Love L, Ravesloot C. Subjective health in spinal cord injury after outpatient healthcare follow-up. *Spinal Cord* 2000;38(2):84–91.
- Kroll T, Neri MT, Ho P-S. Secondary conditions in spinal cord injury: Results from a prospective survey. *Disab Rehabil* 2007;29(15):1229–37.
- Sezer N, Akkuş S, Uğurlu FG. Chronic complications of spinal cord injury. *World J Orthop* 2015;6(1):24–33.
- Krahn GL, Suzuki R, Horner-Johnson W. Self-rated health in persons with spinal cord injury: relationship of secondary conditions, functions and health status. *Qual Life Res* 2009;18(5):575–84.
- Barclay L, McDonald R, Lentin, P. Social and community participation following spinal cord injury: a critical review. *Int J Rehabil Res* 2015;38(1):1–19.
- Polatajko, JH, Davis, J, Steward D, Cantin N, Amoroso B, Purdie L, Zimmerman D. Specifying the domain of concern: occupation as core. In Townsend EA, Polatajko, JH, editors. *Enabling occupation ii: advancing an occupational therapy vision for health, well-being & justice through occupation*. Ottawa: CAOT Publications. 2007.
- World Health Organization. *International classification of functioning, disability, and health (ICF)*. 2001. Geneva: WHO publishing.
- Dijkers M. Quality of life after spinal cord injury: a meta analysis of the effects of disablement components. *Spinal Cord* 1997;35(12):829–40.
- Levasseur M, Richard L, Gauvin L, Raymond E. Inventory and analysis of definitions of social participation found in the aging literature: proposed taxonomy of social activities. *Soc Sci Med* 2010;71(12):2141–9.
- van Leeuwen CM, Post MW, Westers P, van der Woude LH, de Groot S, Sluis T, et al. Relationships between activities, participation, personal factors, mental health, and life satisfaction in person with spinal cord injury. *Arch Phys Med Rehabil*. 2012;93(1):82–9.
- Geyh S, Nick E, Stirnimann D, Ehrat S, Müller R, Michel F. Biopsychosocial outcomes in individuals with and without spinal cord injury: a Swiss comparative study. *Spinal Cord* 2012;50(8):614–22.
- Vogel L, Backus D, Krause J. Risk and prevention of secondary conditions after adult & pediatric SCI. Presented at the meeting of the American Spinal Injury Association, Charleston, SC. 2013.
- Barber DB, Woodard FL, Rogers SJ, Able AC. The efficacy of nursing education as an intervention in the treatment of recurrent urinary tract infections in individuals with spinal cord injury. *Sci Nurs* 1999;16(2):54–6.
- Garber SL, Rintala DH, Rossi CD, Hart KA, Fuhrer MJ. Reported pressure ulcer prevention and management techniques by persons with spinal cord injury. *Arch Phys Med Rehabil* 1996;77(8):744–9.
- Jensen MP, Molton IR, Groah SL, Campbell ML, Charlifue S, Chiodo A, et al. Secondary health conditions in individuals aging with SCI: terminology, concepts and analytic approaches. *Spinal Cord* 2012;50(5):373–8.
- Martin-Ginis KA, Hicks AL. Considerations for the development of a physical activity guide for Canadians with physical disabilities. *Appl Physiol Nutr Metab* 2007;32:S135–47.
- Rosenberg DE, Bombardier CH, Hoffman JM, Belza, B. Physical activity among aging with mobility disabilities: Shaping a research agenda. *J Aging Res* 2011;2011:708510.
- The 2014 annual statistical report for the Spinal Cord Injury Model Systems [Internet]. Birmingham: National Spinal Cord Injury Statistics Center; 2014. Available from: <https://www.nscisc.uab.edu/PublicDocuments/reports/pdf/2014%20NSCISC%20Annual%20Statistical%20Report%20Complete%20Public%20Version.pdf>
- Martin-Ginis KA, Latimer AE, Arbour-Nicitopoulos KP, Buchholz AC, Bray SR, Craven BC, et al. Leisure time physical activity in a population-based sample of people with spinal cord injury part I: demographic and injury-related correlates. *Arch Phys Med Rehabil* 2010;91(5):722–8.
- Tasiemski T, Kennedy P, Gardner BP, Blaikley RA. Athletic identity and sports participation in people with spinal cord injury. *Adapt Phys Act Q* 2004;21(4):364–78.
- Richards JS, Waites K, Chen YY, Kogos S, Schmitt MM. The epidemiology of secondary conditions following spinal cord injury. *Top Spinal Cord Inj Rehabil*. 2004;10(1):15–29.
- Potter PJ, Wolfe DL, Burkell JA, Hayes, KC. Challenges in educating individuals with SCI to reduce secondary conditions. *Top Spinal Cord Inj Rehabil*. 2004;10(1):30–40.
- Ljungberg I, Kroll T, Libin A, Gordon S. Using peer mentoring for people with spinal cord injury to enhance self-efficacy beliefs and prevent medical complications. *J Clin Nurs* 2011;20(3–4):351–8.