Examining How the Perception of Health Can Impact Participation and Autonomy Among Adults with Spinal Cord Injury

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Background: Studies examining participation as defined by the International Classification of Functioning, Disability and Health (ICF) as well as autonomy among the spinal cord injury population (SCI) are only starting to emerge. Little research has looked at how this population perceives their health status and the role this plays in active participation within their lives.

Objective: This exploratory study was developed to determine whether the perception of health has an impact on participation and autonomy among adults with SCI. **Methods:** A convenience sample of adults with SCI currently receiving outpatient services from a rehabilitation hospital completed the online questionnaire. Forty-two subjects responded and were categorized into 2 groups: Group 1, positive perceived health, and Group 2, negative perceived health. The sample completed the Impact on Autonomy and Participation (IPA) that has 5 subscales (autonomy indoors, family role, autonomy outdoors, social life, and work/education) and demographic questions. **Results:** Multivariate analysis of variance (MANOVA) revealed that perceived health had a significant impact on family roles, autonomy outdoors, social life, and work/education. Perceived health did not have a significant impact on autonomy indoors. **Conclusion:** The perception of health may have an impact on participation and autonomy within the areas of family role, outdoors, work/education, and social life. Implications for rehabilitation are included.

Key words: autonomy, community-based rehabilitation, participation, perceived health, spinal cord injury

Once an individual sustains a spinal cord injury (SCI), a primary goal of rehabilitation is to decrease rehospitalizations and increase participation and autonomy in all life domains.¹ As a biopsychosocial model, the International Classification of Functioning, Disability and Health (ICF)² provides a conceptual framework that explains various components of living with a health condition, in this case SCI.³ The ICF examines the individual's health within a variety of contexts, including personal and environmental factors, body functions, and structure as well as activity and participation.² Participation, as a component of the ICF, refers to engagement in one's life through family, community, work, and involvement in culturally and age appropriate roles and activities.⁴⁻⁶

The social consequences after acquisition of the SCI impact one's life and can be detrimental to participation³; these consequences can change one's ability to participate in life experiences such as social relations, self-care, leisure, family roles, work, and education.⁷ Participation, a continuous process beyond the rehabilitation goals, is when an individual engages in his or her life and community.⁸⁻¹¹ Prior research has identified both autonomy and sense of control as important attributes to participation within the SCI population.^{8,12} In addition, it appears that activity engagement and participation in one's life can have an impact on health throughout the lifespan.¹³

Health, no longer merely defined as the absence of illness or disease, is the overall well-being of an individual including physical, psychological, and

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social components.¹⁴ It is ultimately a combination of genetics, lifestyle choices, and environmental factors over the course of a lifespan.¹⁵ Perceived health, or self-reported health, is frequently gathered from the general population as a measure of health.^{16,17} In previous studies, the question “In general, would you say your health is excellent, very good, good or fair” has been used to predict mortality and health care services in the United States within the general population.^{16,18-20} Collecting data on perceived health is important because how an individual perceives his or her current health status with an SCI may be very different than the health status assessed by the health care professional.

Furthermore, how individuals perceive their health status may have a direct impact on how they independently participate within their life. Previous studies with other health conditions (ie, cerebral palsy,²¹ coronary heart disease²²) have indicated that perceived, or self-reported, health has an impact on health outcomes, including participation. Individuals with an SCI want to be as autonomous as possible while managing their health, including within the context of participation and social roles. Even though this perception of health may be inhibited by the level of disability, it still has an important influence on quality of life (QOL) and active participation.^{16, 23} Further, Chang, Wang, Jang, and Wang²⁴ found that active participation (eg, independence with personal care and transportation), marital status, and activity were predictive of QOL.

Recent changes in health care and the delivery of services have had a direct impact on clinical outcomes with the SCI population. One of the biggest challenges facing rehabilitation is the reduction in reimbursed or covered days in both acute care (from about 24 to 11 days from 1973 to 2010) and inpatient rehabilitation days (from about 98 to 36 days from 1973 to 2010).²⁵ This change in care has reduced the opportunities for clinicians to adequately address outcomes such as participation defined by the ICF as a component of health, which then fails to adequately prepare the individual with an SCI for discharge back into their home environment.²⁶ Examining community-based rehabilitation interventions that focus on

self-perception of health, including participation and autonomy after acquisition of an SCI, may improve clinical outcomes and ultimately reduce health care costs associated with physician visits and long-term health care stays.²⁷

Prior research with the SCI population has indicated that participation in life activities, when included in community-based rehabilitation, has a direct influence on physical and psychosocial clinical outcomes.^{28,29} Yet, it is still unclear what aspects of community and social participation within the realm of the ICF actually have a significant impact on the overall health of this population.²⁹

Although the literature has examined QOL in people with SCI, few studies have examined how perception of health impacts participation and autonomy for this population. These researchers believe that how individuals perceive their health while living with an SCI can influence the independent decisions they make in regard to engaging in various activities throughout their life. Therefore, the purpose of this exploratory study is to examine whether perception of health has an impact on participation and autonomy among a sample of adults with an SCI.

Methods

Data collection procedures

This study employed a cross-sectional web survey design. Research participants were recruited through a rehabilitation hospital in the western portion of the United States that provides community-based rehabilitation programs to people with SCI. The program includes adapted sports and recreation, wellness education, and peer mentorship. The hospital sent an e-mail to 80 potential subjects that contained an information sheet describing the study, a link to the consent form, and the *Qualtrics* questionnaire. A reminder e-mail was sent to potential respondents in 4 increments to increase response rate. A total of 42 participants completed the online survey with a response rate of 52.5%. Research participants were provided with an iTunes gift card at the completion of the questionnaire.

Participants

A convenience sample of 42 adults (26 males and 16 females) between the ages of 18 and 73 years with an SCI were recruited for this study. Research participants were included in the study if they met the following criteria: (a) medical diagnosis of an SCI, (b) 18 years or older, and (c) currently living in the community. Research participants were excluded from the study if they were under the age of 18 years or had a medical diagnosis of a cognitive impairment that precluded them from cognitively being able to understand and complete the survey. The research protocol was approved by the institutional review boards at the respective universities.

Measurement

Demographic variables included gender, age, year of onset of injury, level of injury, and current participation in a community-based rehabilitation program. This study assessed perceived health by asking the following question, "In general, how would you rate your overall health?" on a scale where 1 = *excellent* to 5 = *very poor*. Data were collapsed into a dichotomous variable (group 1 = positive perceived health; group 2 = negative perceived health). There were 18 research participants who identified their health as excellent to very good and 24 who rated their perceived health below this. Thus, we chose to dichotomize into 2 groups to best represent the spread of the data from those who had a higher than average perception of health (positive) to those with good to below average (negative) perception. Demographic questions and the item on perceived health were adopted from van Loo et al.³⁰ Participation and autonomy were assessed using the ICF Measure of Impact of Participation and Autonomy (IPA) scale.⁷ The IPA quantifies limitations in participation and autonomy for individuals receiving rehabilitation services. It contains 32 items, loading onto 5 subscales (autonomy indoors, family participation, autonomy outdoors, social life and relationships, and work and education). Each of the items has identical response options ranging from 0 to 4, with higher scores representing lower participation

and autonomy. Autonomy indoors includes 7 items that examine chances of looking after yourself; getting around the house; and being able to wash, dress, go to bed, eat, and drink how you choose. Family role includes items that measure the family role, tasks, responsibilities, finances, and completing tasks around the house. Autonomy outdoors includes social contacts within outdoor activities, spending leisure time within outdoor settings, and leading the life you choose. Social life and relationship examines the quality of social relationships including communication, respect, and intimacy. It also looks at being able to help others as well as receive support. Finally, work and education examines both volunteer and paid positions, as well as autonomy within education and work-related training.⁷ IPA questionnaire construct and convergent and discriminant validity have been supported in prior research, and the questionnaire has also been found to have good test-retest reliability.^{7,31}

Data analysis

Descriptive statistics (mean, frequency, range, and standard deviation) were run on the demographic data including age, gender, year of onset of injury, level of injury, and type of injury. The perceived health variable was collapsed into 2 categorical variables identifying excellent and very good responses as group 1 (positive perceived health) and good, so-so, and very poor responses as group 2 (negative perceived health). These data were collapsed to demonstrate participants who identified as having a positive perceived health versus those who identified as having a negative perceived health, because self-rated health has been shown to be a good predictor of health care utilization.^{8,16,19} In this case, we wanted to see whether a positive perceived health (higher than average) impacted participation autonomy more than having a negative perception of health. Data analysis was completed using IBMS SPSS version 20 (IBM, Inc., Armonk, NY). A multivariate analysis of variance (MANOVA) was conducted to determine the impact perception of health has on participation within autonomy indoors, family participation, autonomy outdoors,

social life and relationships, and work and education. Prior to running the MANOVA, data were screened for missing data, outliers, and normality. Four research participants did not complete the survey, and these data were not included in the final analysis, leaving the total number of participants as 42. All dependent variables appeared normally distributed through visual inspection of the data.

Results

Table 1 provides an overview of the demographics of the sample. Sixty-two percent of the population were male ($n = 26$), the largest age range represented was 39 to 48 years old (31%), and the majority of injuries were thoracic (52%). The majority of participants (60%) had at least some college education or a bachelor's degree, while 30% had a graduate degree or higher. One unique characteristic of this sample of adults with SCI is that the majority sustained an SCI from a sports injury (38%) or a motor vehicle accident (21%). In addition, 39 out of 42 research subjects were currently participating in a community-based rehabilitation program that provides adapted sports and recreation, wellness education, and peer mentorship specifically for the SCI adult population.

As shown in **Table 2**, results from the MANOVA demonstrated a significant multivariate effects for relationship, Wilks' $\lambda = .173$, $F(5, 36) = 34.43$, $p < .01$. This indicates that there is a relationship between perceived health and participation and autonomy among adults with SCI when examining the total scores of participation and autonomy. When examining the univariate results for each one of the subscales, the relationships demonstrated a significant effect for family participation ($p < .02$), autonomy outdoors ($p < .01$), social life and relationships ($p < .04$), and work/education ($p < .01$), indicating that perceived health did not have a significant effect on autonomy indoors ($p > .05$). The mean differences of each group included family role (.60), autonomy outdoors (.77), social life and relationships (.50), work/education (.74), and autonomy indoors (.09) (see **Table 2**). The mean differences show that perceived health is related to each area of participation and autonomy with the SCI population.

Table 1. Demographic information ($N = 42$)

Demographics	Positive perceived health	Negative perceived health	Total n	Total %
Sex				
Male	12	14	26	62
Female	6	10	14	33
Age, years				
18-28	5	4	9	21
29-38	5	5	10	24
39-48	4	9	13	31
49+	4	6	10	24
Marital status				
Single	6	8	14	33
Married	9	13	22	52
Divorced/Separated	3	3	6	14
Education				
High school	1	3	4	10
College	9	16	25	60
Graduate degree	8	5	13	30
Cause of injury				
Work accident	5	1	6	14
Vehicular	3	6	9	21
Sports injury	7	9	16	38
Fall	1	1	2	5
Violence	1	1	2	5
Illness	0	0	0	0
Medical treatment	0	3	3	7
Other	1	3	4	10
Level of injury				
Cervical	7	6	13	31
Thoracic	9	13	22	52
Lumbar	2	4	6	14
Sacral	0	0	0	0
Unknown	0	1	0	2

Discussion

This exploratory study examined how perceived health can have an impact on participation and autonomy specifically within the areas of family roles, outdoor activities, social life and relationships, and work and education among individuals living with an SCI. Although no relationship was found within the domain of autonomy indoors and perceived

Table 2. Mean and standard deviation of Measure of Impact on Autonomy and Participation scores in 5 domains by perceived health status

Domains	Excellent	health	Poor	health
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Autonomy indoors	.65	.87	.74	.73
Family role	1.10	.79	1.70	.85
Autonomy outdoors	1.10	.78	1.87	.82
Social life	.67	.67	1.17	.83
Work/education	.68	.60	1.42	.90

Note: *N* = 42; positive perceived health, *n* = 18; negative perceived health, *n* = 24. Model statistics, Wilks' λ = .173, $F(5, 36) = 34.43$, $p < .01$.

health, there was a difference in mean scores between the 2 groups, with the positive perceived health group scoring higher than the average to negative perceived health group. The findings from this study support prior research among the general population indicating that the perception of health does impact clinical outcomes.^{16,17,19,32} More specifically, the results from this study also support a small body of previous research with the SCI population demonstrating that perception of health directly influences participation¹² and autonomy,^{8,16,33} often identified as clinical outcomes after acquisition of an SCI. The results indicate that a more positive perceived health is related to most areas of participation identified within the IPA instrument. We believe that the results from this study provide new information on the role that perceived health can play when examining participation and autonomy among adults with SCI receiving outpatient medical services.

All of the research participants in this study, those who perceived their health as positive and those who perceived their health as negative, appeared to be involved in many components within the community-based rehabilitation program, including recreational activities, peer mentoring, support group, yoga, educational forum, handcycling, and other cost-effective forms of rehabilitation. Generally, individuals who are more engaged in participation on a daily basis are more likely to be in better health and identify as having positive health, yet over half of this sample identified with negative perceived health. It is unclear whether the time of year that data

were collected, the types of programs they were participating in, or a health condition impacted the results. Each one of these may have influenced the data and should be examined in future research. It appears that although a higher level of participation may be present, some individuals with SCI still perceive their health as negative and further investigation is warranted.

Rehabilitation implications

The ultimate goal of rehabilitation after discharge from inpatient services is full participation in life activities and community integration.^{8,11,27} Rehabilitation professionals indicate active engagement in life roles, community involvement, and autonomy is reflective of full participation leading to positive clinical outcomes.^{8,11,27} The integration into the community life appears to clearly align with a biopsychosocial model (eg, ICF), which acknowledges an interaction between the biological, social, psychological, and environmental components as part of the limitations and success in the treatment of SCI. The ICF, the foundational model of this study, acknowledges that participation and autonomy have a direct influence on overall health,^{8,9,11} QOL^{16,23} and clinical outcomes¹⁷ with various populations, including adults living with an SCI. Utilizing the framework of the ICF may help rehabilitation professionals develop a better understanding of the importance of perceived health within the realm of participation restrictions and autonomy.^{16,34} This study supports the notion that an individual's perception of health impacts participation as defined by the ICF in multiple life roles, including when the individual is currently engaged in a community rehabilitation program.

Rehabilitation professionals typically focus on working on transfer of skills from the rehabilitation hospital to living successfully within the community.^{1,26,28} Based on results from this study, it may be helpful to incorporate education regarding health, especially as it relates to participation in different life roles and activities to outpatient services. Goals related to health could be incorporated into the outcomes to achieve positive engagement in community-based rehabilitation. For example, patient adherence to treatment, greater facilitated

functional gains, and control in managing injury consequences have been reported when patients are involved in the planning of clinical outcomes.^{8,35} Developing specific clinical outcomes within treatment not only to address participation but also to manage health may assist individuals with SCI to integrate more fully within the community¹² and decrease hospitals re-admissions.²⁸

Strengths and limitations of this study

Although the results of this study suggest that there is a relationship between perceived health, participation, and autonomy among a sample of adults with an SCI who are currently receiving outpatient services from a rehabilitation hospital and data indicated differences between the 2 groups (positive perceived health and negative perceived health) when looking at indoor activity, outdoor activity, family roles, social and relationships, as well as work and education, several limitations of this study exist that should be noted. First, the results from this study were delimited to a convenience sample from one rehabilitation hospital within the Intermountain West and did not afford comparison of a random selection of research participants from a variety of rehabilitation hospitals within the United States. The rehabilitation hospital where data collection occurred has an interactive and progressive community-based rehabilitation program that may not be representative of the typical rehabilitation experience for the SCI population. For example, 39 of the research participants are engaged in a community-based rehabilitation program that provides extensive resources not typical at all hospitals. This may have directly impacted the perception of health scores as well as the IPA scores. Furthermore, the sample was highly educated and active before injury, which also may have biased the data. Results may be reflective of these regional demographics and not just program characteristics. The nature of the cross-sectional survey designs only allows researchers to demonstrate that there is a relationship between

perceived health and participation and autonomy. No causal relationship can be made between the 2 variables. In addition, the small sample size limits generalizations to the SCI population as a whole.

Recommendations for future research

Future research should focus on examination of the impact of perceived health on a larger sample of individuals with SCI within the realm of participation and autonomy. Research can also examine different types of community-based rehabilitation interventions to try and understand what clinical intervention is the most effective when addressing clinical outcomes within the SCI population. Examination of age, gender, living environment, type of health insurance, leisure engagement, and access to community-based rehabilitation would help determine what plays an important role in decreasing health care cost through positive, innovative cost-effective interventions. In addition, including a health economist as part of the research team would allow rehabilitation professionals to have the analysis of cost-benefit ratios. With the current change in the inpatient rehabilitation experience for the SCI population, determining what type of community-based rehabilitation programs lead to positive clinical outcomes will further advance health care for this population. Finally, future research can also focus on identifying which rehabilitation professionals can provide successful cost-effective community-based interventions (eg, recreational therapists, social workers, etc).

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