ORIGINAL ARTICLE

Satisfaction with participation using a manual wheelchair among individuals with spinal cord injury

PW Rushton¹, WC Miller^{1,2,3,4,5}, WB Mortenson¹ and J Garden¹

¹Graduate Program in Rehabilitation Sciences, University of British Columbia, Vancouver, British Columbia, Canada; ²Department of Occupational Science and Occupational Therapy, University of British Columbia, Vancouver, British Columbia, Canada; ³International Collaboration on Repair Discovery, Vancouver, British Columbia, Canada; ⁴Vancouver Coastal Health Research Institute, Centre for Clinical Epidemiology and Evaluation, Vancouver, British Columbia, Canada and ⁵GF Strong Rehabilitation Research Lab, Vancouver, British Columbia, Canada

Study design: Cross-sectional.

Objectives: To describe self-identified indoor and outdoor wheelchair-oriented participation outcomes and to report satisfaction with the identified outcomes by people with spinal cord injury (SCI).

Setting: Vancouver, British Columbia.

Methods: Participation outcomes were identified using the Wheelchair Outcome Measure and classified using the International Classification of Functioning, Disability, and Health (ICF).

Results: The average age of the 51 community-dwelling subjects with SCI was 43.7 (± 10.7) years. Of them, 84% were men, 64% had tetraplegia and 66% used a manual wheelchair. There were 258 indoor and 257 outdoor participation outcomes identified by this sample with most outcomes falling into the 'community, social, and civil life' (36.5%), 'domestic life' (23.7%) and 'mobility' (18%) domains of the ICF. All domains had a mean satisfaction score of 7.1/10 or greater except for the indoor 'mobility' domain that had a mean satisfaction score of 6.1/10. Satisfaction scores with performance of the specific participation outcomes ranged from high (10/10) to low (2/10) with most scores falling above 7/10.

Conclusion: Community-dwelling people with SCI commonly engage in wheelchair-oriented participation outcomes related to 'community, social, and civil life', 'domestic life' and 'mobility' and tend to be satisfied with their performance of these participation outcomes. This information is useful for clinicians and may help to guide assessment and intervention.

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Introduction

Participation is a central goal of rehabilitation among people with spinal cord injury (SCI)¹ but little is known about self-identified participation outcomes of these individuals. Studies using standardized measures of participation have found that people with SCI report significant disruptions in their participation in home maintenance,² recreation and physical activities,² employment,^{3,4} sexual relations,² family role^{3,4} and education.^{3,4} An in-depth analysis of studies using domain-based instruments to measure participation among people with SCI^{2,3} revealed that although domain scores may indicate that participation is satisfactory, participation in specific items within those domains is limited. The gap in our knowledge is the value the individual places on the items that are within these predetermined domains,

or perhaps even the domains themselves. Standardized instruments measure society-perceived participation rather than person-perceived participation.⁵ Measuring participation outcomes that are self-selected ensures measurement of outcomes that are important to the individual.

It has also been suggested that standardized participation measures may not capture the ideographic nature of participation among individuals with disabilities. A recent qualitative study designed to gain an insider perspective from people with disabilities on participation revealed important insight into its measurement.⁶ In this study, participation was viewed as not only involving active engagement in life situations at the societal level, but also includes the personal meaning and satisfaction resulting from that engagement. The authors emphasize that there is no gold standard for ideal or optimal participation, no defined set of societal roles or activities that are appropriate for all individuals or indicative of 'full' participation. Further, participants in this study highlighted the need to be free to define and pursue participation on their own terms

Correspondence: Dr WC Miller, Department of Occupational Science and Occupational Therapy, University of British Columbia, T325-2211 Wesbrook Mall, Vancouver, British Columbia, Canada V6T 2B5.
E-mail: bcmiller@telus.net
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rather than measuring whether they have met predetermined societal norms or standards.

Gathering information on participation outcomes using predetermined domains based on societal norms may be useful for epidemiological studies, but it is possible that the items within these domains are not relevant or meaningful to individuals with SCI. Knowledge of wheelchair-oriented participation outcomes that are self-selected by individuals with SCI is lacking. Moreover, there is also an absence of knowledge regarding how satisfied they are with the performance of their self-selected participation outcomes. The purpose of this study was to describe self-identified wheelchair-oriented indoor and outdoor participation outcomes and to report satisfaction with the identified participation outcomes by a sample of community-dwelling people with SCI.

Materials and methods

Design

A cross-sectional study design was used for this study. Ethical approval was obtained from the local university ethics board.

Sample

A convenience sample consisting of 51 individuals with SCI was recruited. To be included subjects had to: be ≥ 20 years of age, use a wheelchair as their primary means of mobility (at least 4 h each day) and have a complete or incomplete SCI at any level. Individuals were excluded if they scored < 24 on the Cognitive Capacity Screening Evaluation,⁷ could not read or speak English, or if they had received a new or replacement wheelchair in the past 6 months.

Data collection

An occupational therapist who was trained in the data collection methods by one of the authors (WBM) collected all of the data. Demographic data including age, sex, marital status, type of wheelchair, date of injury and length of time using current wheelchair were collected.

Participation outcomes were identified using the Wheelchair Outcome Measure (WhOM). The WhOM is a client-centered wheelchair intervention measurement tool designed to measure participation using client-identified participation outcomes rather than domains. Using a semi-structured interview, this instrument enables clients to identify desired participation outcomes performed using their wheelchair at home and in the community. For all participation outcomes clients rate the importance of the participation outcome and their current level of satisfaction with their performance of the participation outcome on an 11-point scale (0–10).⁸

The WhOM shows good psychometric properties among individuals with SCI.⁹ Interrater and intrarater intraclass correlation coefficients of 0.91 and 0.93, respectively, have been shown. The WhOM correlates with the Quebec User Evaluation of Satisfaction with assistive Technology¹⁰ total score ($r=0.58$) and with the Quebec User Evaluation of Satisfaction with assistive Technology device scale ($r=0.66$) showing construct validity. The WhOM is the only available

instrument that captures participation items that are performed using the wheelchair.¹¹

Analyses

Participation outcomes, identified using the WhOM, were classified by two researchers using the International Classification of Functioning Disability and Health (ICF) 'activities and participation' category according to the process outlined by Cieza *et al.*¹² Classification involved three steps: (1) identification of participation outcomes (in some instances one identified participation outcome actually included two outcomes); (2) selection of the ICF categories that most precisely represent the participation outcomes identified in step 1 and (3) comparison of the identified participation outcomes and selected ICF categories by the two researchers in steps 1 and 2, respectively. In instances where the identified participation outcomes contained more than one outcome, both were linked. Where there was disagreement in step 3 the third author (WBM) acted as an arbiter to make a final decision regarding the classification of the participation outcome.

In the ICF there are nine domains in the 'activities and participation' category: 'learning and applying knowledge', 'general tasks and demands', 'communication', 'mobility', 'self-care', 'domestic life', 'interpersonal interactions and relationships', 'major life areas' and 'community, social, and civil life'.¹³ According to Cieza's linking rules, the domains are referred to as the first level of classification and subsequent categories falling under each of these domains are referred to as second, third and fourth levels of classification. For example, in the 'activities and participation' category there is the 'community, social, and civil life' domain which is the first level of classification, 'recreation and leisure' is the second level of classification and 'sports' is the second level of classification. For the purpose of this paper, we refer to the second- and third-level classifications as 'areas' and 'specific outcomes', respectively. In situations where third-level classification/specific outcomes categorization of the participation outcome was not possible, they were referred to as unclassifiable. This scenario occurred when there was not adequate descriptive detail in the third-level classification of the ICF. For example, 'moving around using equipment', a second level classification of the domain 'mobility', provides insufficient detail for many of the participation outcomes in this study.

We used descriptive statistics to characterize the sample. The number and percentage of participation outcomes and means and standard deviations of satisfaction scores at the assigned classification levels were calculated to present the group level summary statistics for the areas and specific outcomes categories. Indoor and outdoor participation outcomes were analyzed separately and subtotals for both groups were calculated for each of the ICF 'activities and participation' domains.

Results

Sample

The average age of the 51 community-dwelling sample was 43.7 (± 10.7) years and they had a mean of 16.1 (± 10.1) years

of living with SCI. The sample was mostly male (84%) and 64% of the sample had tetraplegia. Of the individuals with paraplegia, 23.5% had a complete and 11.8% had an incomplete injury. Of the individuals with tetraplegia, 35.3% had a complete and 27.5% had an incomplete injury. For two participants we were unable to determine completeness of injury. A total of 66% used a manual wheelchair and 34% used a power wheelchair. The mean time using the current wheelchair was 5.7 ($\pm$ 4.7) years.

Participation outcomes

Most subjects (86%) identified five indoor and five outdoor participation outcomes (the maximum number permitted in

this study) using the WhOM. Eight out of the nine domains of the 'activities and participation' category were represented by the identified participation outcomes (all except for 'general tasks and demands'). Participation outcomes were identified in 36 areas under the domains and 258 indoor and 257 outdoor participation outcomes were classified at the specific outcomes level.

Table 1 shows the classification of the indoor and outdoor participation outcomes according to domains, areas and specific outcomes, as well as the mean satisfaction scores. The table is ordered according to the domains with the most to least indoor and outdoor participation outcomes combined. Participation outcomes were most commonly linked

Table 1 Indoor ($n=258$) and outdoor ($n=257$) participation outcomes and satisfaction scores according to domains, areas and specific outcomes

Domain	Area	Indoor participation outcomes n (%)	Satisfaction Mean (s.d.)	Outdoor participation outcomes n (%)	Satisfaction Mean (s.d.)
	Specific outcome				
Community, social and civil life	Community life				8.7 (1.2)
	Informal associations			1 (0.4)	
	Unclassifiable ^a			2 (0.8)	
188 total participation outcomes (36.5%)	Recreation and leisure		7.6 (2.1)		7.7 (2.4)
	Play			1 (0.4)	
	Sports			4 (1.6)	
	Arts and culture	12 (4.7)		8 (3.1)	
	Crafts	1 (0.4)			
	Hobbies	1 (0.4)		1 (0.4)	
	Socializing	6 (2.3)		40 (15.6)	
	Unclassifiable ^a	47 (18.2)		60 (23.3)	
	Religion and spirituality		10.0 ^b		8.0 (3.5)
	Unclassifiable ^a	1 (0.4)		3 (1.2)	
Subtotals		68 (26.4)	7.2	120 (46.8)	7.1
Domestic life	Acquisition of goods and services		8.3 (2.1)		7.7 (1.7)
	Shopping	1 (0.4)		32 (12.5)	
	Unclassifiable ^a	3 (1.2)		2 (0.8)	
122 total participation outcomes (23.7%)	Preparing meals		7.3 (2.8)		
	Unclassifiable ^a	29 (11.2)			
	Doing housework		7.8 (1.8)		
	Cleaning cooking area and utensils	6 (2.3)			
	Cleaning living area	5 (1.9)			
	Using household appliances	9 (3.5)			
	Unclassifiable ^a	7 (2.7)			
	Caring for household objects		7.5 (2.4)		9.0 (1.2)
	Making and repairing clothes	1 (0.4)			
	Maintaining dwellings and furnishings	3 (1.2)			
	Maintaining domestic appliances	1 (0.4)			
	Maintaining vehicles			1 (0.4)	
	Taking care of plants	4 (1.6)		1 (0.4)	
	Taking care of animals	4 (1.6)		7 (2.7)	
	Unclassifiable ^a	1 (0.4)			
	Assisting others		9.5 (0.7)		9.3 (0.6)
	Assisting others in movement			3 (1.2)	
	Unclassifiable ^a	2 (0.8)			
Subtotals		76 (29.6)	7.6	46 (18.0)	8.5
Mobility	Transferring oneself		8.1 (1.9)		6.3 (2.3)
	Transferring oneself while sitting	21 (8.1)		6 (2.3)	
93 total participation outcomes (18%)	Lifting and carrying objects		5.5 (0.7)		
	Carrying in the hands	1 (0.4)			
	Unclassifiable ^a	1 (0.4)			
	Hand and arm use		3.0 ^b		
	Reaching	1 (0.4)			
	Moving around using equipment		8.4 (1.8)		7.9 (2.2)
	Unclassifiable ^a	33 (12.8)		23 (9.0)	

Table 1 Continued

Domain	Area	Indoor participation outcomes n (%)	Satisfaction Mean (s.d.)	Outdoor participation outcomes n (%)	Satisfaction Mean (s.d.)
	Specific outcome				
	<i>Using transportation</i>				7.2 (3.3)
	Using public motorized transportation			3 (1.2)	
	Using private motorized transportation			2 (0.8)	
	<i>Driving</i>				10.0 (0.0)
	Driving motorized vehicles			2 (0.8)	
Subtotals		57 (22.1)	6.1	36 (14.1)	7.5
Self-care	<i>Washing oneself</i>		10 (0.0)		
	Washing body parts	1 (0.4)			
	Unclassifiable ^a	1 (0.4)			
54 total participation outcomes (10.5%)	<i>Caring for body parts</i>		9.5 (0.8)		
	Caring for teeth	2 (0.8)			
	Caring for hair	2 (0.8)			
	Unclassifiable ^a	2 (0.8)			
	<i>Toileting</i>		7.0 ^b		
	Regulating urination	1 (0.4)			
	<i>Dressing</i>		10.0 ^b		
	Putting on clothes	1 (0.4)			
	<i>Eating</i>		9.0 (1.6)		
	Unclassifiable ^a	12 (4.7)			
	<i>Drinking</i>		7.0 ^b		
	Unclassifiable ^a	1 (0.4)			
	<i>Looking after one's health</i>		7.7 (2.4)		7.9 (1.6)
	Ensuring one's physical comfort	1 (0.4)			
	Managing diet and fitness	6 (2.3)		15 (5.8)	
	Maintaining one's health	1 (0.4)		7 (2.7)	
	Unclassifiable ^a	1 (0.4)			
Subtotals		32 (12.6)	8.9	22 (8.5)	7.9
Major life areas	<i>Higher education</i>		6.4 (2.9)		9.4 (0.8)
	Unclassifiable ^a	5 (1.9)		8 (3.1)	
44 total participation outcomes (8.5%)	<i>Remunerative employment</i>		7.1 (2.9)		7.3 (1.9)
	Unclassifiable ^a	8 (3.1)		9 (3.5)	
	<i>Non-remunerative employment</i>		10.0 ^b		8.1 (2.1)
	Unclassifiable ^a	1 (0.4)		7 (2.7)	
	<i>Complex economic transactions</i>				8.8 (2.2)
	Unclassifiable ^a			5 (1.9)	
	<i>Economic self-sufficiency</i>		10.0 ^b		
	Unclassifiable ^a	1 (0.4)			
Subtotals		15 (5.8)	8.4	29 (11.2)	8.4
Interpersonal interactions and relationships	<i>Informal social relationships</i>		7.7 (0.6)		
	Unclassifiable ^a	3 (1.2)			
	<i>Family relationships</i>		7.5 (2.1)		7.5 (0.6)
10 total participation outcomes (1.9%)	Parent-child relationships	2 (0.8)		4 (1.6)	
	<i>Intimate relationships</i>		10.0 ^b		
	Sexual relationships	1 (0.4)			
Subtotals		6 (1.2)	8.4	4 (1.6)	7.5
Learning and applying knowledge	<i>Writing</i>		10.0 ^b		
	Unclassifiable ^a	1 (0.4)			
2 total participation outcomes (0.4%)	<i>Making decisions</i>		7.0 ^b		
	Unclassifiable ^a	1 (0.4)			
Subtotals		2 (0.8)	8.5	0 (0.0)	
Communication	<i>Conversation</i>		10.0 ^b		
	Conversing with one person	1 (0.4)			
2 total participation outcomes (0.4%)	<i>Using communication devices and techniques</i>		9.0 ^b		
	Using telecommunication devices	1 (0.4)			
Subtotals		2 (0.8)	9.5	0 (0.0)	

^aIf there was not adequate descriptive detail in the third-level classification of the ICF to classify the participation outcome at the 'specific outcomes' level, it was categorized as unclassifiable.

^bActual value, not mean.

to three domains: 'community, social, and civil life' (36.5%), 'domestic life' (23.7%) and 'mobility' (18%).

Over two-thirds of subjects (68.6%) identified indoor 'community, social, and civil life' participation outcomes and almost all (95.1%) subjects identified outdoor 'community, social, and civil life' participation outcomes. Most participation outcomes were classified under the area of 'recreation and leisure'. Specific examples of indoor participation outcomes that were commonly identified included: using the computer, watching TV or videos and reading. Less common indoor participation outcomes, identified by only one or two subjects, included playing the piano, weaving, photography and video recording. Specific examples of outdoor participation outcomes that were commonly identified included socializing, visiting friends and family, going out for dinner and going for a stroll. Less commonly identified outcomes included playing basketball, playing pool, camping, curling, wheelchair archery, wheelchair dancing, attending sporting events and going to the beach.

Approximately two-thirds of subjects identified indoor (68.6%) and outdoor (64.7%) participation outcomes in the 'domestic life' domain. Cooking meals and cleaning the house were by far the most common examples of indoor participation outcomes in this category, whereas taking care of the dog, managing the fish aquarium and taking care of the kids were less commonly identified outcomes. Shopping was the most commonly identified outdoor participation outcome for the 'domestic life' category, whereas walking the dog, fixing the car and taking kids to school were much less commonly identified outcomes.

The majority of subjects identified indoor (61.0%) and outdoor (53.0%) participation outcomes in the area of 'mobility'. For indoor participation outcomes, mobility around the house and transfers (for example, bed, toilet, tub, car) were most commonly identified. Transporting items, such as hot food, reaching items off of high shelves, and entering and exiting the home were identified as outcomes by only one or two subjects. Outdoor participation outcomes in the 'mobility' category were more diverse. Examples of outcomes include accessing personal transportation, taking public transportation, driving, getting to various destinations, including appointments, sporting events and accessing various recreational pursuits, such as sailing, yoga and swimming.

Examples of participation outcomes from the other categories included exercising, changing leg bag, grooming activities and resting in tilt position for pressure relief in the 'self-care' domain; working, volunteering, going to school and banking in the 'major life areas' domain; supervising, sexual relations, playing with son in the parks and attending kids sporting events in the 'interpersonal interactions and relationships' domain; writing down one's schedule and picking a movie in the 'learning and applying knowledge' domain; and ordering food and using the phone in the 'communication' domain. These participation outcomes were much less frequently identified than those in the 'community, social, and civil life', 'domestic life' and 'mobility categories'.

Satisfaction with participation outcomes

Satisfaction scores for the individual participation outcomes identified in this study ranged from high (10.0) to low (2.0). However, most scores fell in the range of 7.0 and above and only a few scores were reported to be in the range of 2.0–4.0. The lower scores fell into the play, hobbies, caring for household objects, reaching and using personal privatized transportation participation outcomes.

The mean satisfaction scores for indoor and outdoor participation outcomes in the 'community, social, and civil life' domain were 7.2 (range: 2.0–10.0) and 7.1 (range: 3.0–9.0), respectively. In the 'domestic life' domain the scores were 7.6 (range: 5.8–10) for indoor and 8.5 (range: 7.0–10.0) for outdoor participation outcomes. Finally, in the 'mobility' domain the scores were 6.1 (range: 3.0–8.4) and 7.5 (range: 4.0–10.0) for indoor and outdoor participation outcomes, respectively.

Discussion

This is the first study to the best of our knowledge that has described self-identified indoor and outdoor participation outcomes in conjunction with satisfaction ratings with performance of the outcomes among community-dwelling people with SCI. In general, our study results were consistent with the literature regarding previous descriptions of the activities in which community-dwelling people with SCI participate,¹⁴ and activities in which participation is lacking.³

The high frequency of identified participation outcomes in the 'community, social, and civil life' domain in this study is in keeping with previous research. Carpenter *et al.*¹⁴ found that the most common social activities for their sample of people with SCI were visiting and going out with friends and family, attending social gatherings and engaging in physical activity. The focus on recreation and leisure pursuits noted in this study is also consistent with results of a time-use study that found that men with SCI spent a mean of 7.3 h of their day in leisure pursuits over a 2-day period.¹⁵

The lack of identified participation outcomes in the 'general tasks and demands' and the low frequency of identified participation outcomes in the 'learning and applying knowledge' and 'communication' domains are not surprising as this sample of subjects was asked to identify participation outcomes related to wheelchair use. Many of the activities and participation in these domains do not require a wheelchair. As well, low frequency of participation outcomes in specific areas is supported by the literature. For example, the low frequency of participation outcomes identified in the 'family relationships', 'remunerative employment' and 'higher education' in this study is supported by Lund *et al.*³ who found participation in 'family role' and 'work and education' to be restricted.

Overall, subjects in this study were satisfied with the performance of their self-identified participation outcomes. In previous studies, satisfaction has been measured in terms of satisfaction with degree of choice over life activities¹⁶ and satisfaction with factors that relate to participation such as transportation and building access.¹⁴ However, satisfaction

with performance of self-identified participation outcomes among community-dwelling people with SCI had yet to be measured. Given the overall high satisfaction scores in this study, we wonder if the subjects were more likely to report participation outcomes with which they were satisfied, rather than those with which they were not.

A strength of this study is the identification of self-selected participation outcomes of people with SCI. Use of the WhOM was effective in that very unique participation outcomes were identified by many of the subjects, including wheelchair archery, photography, playing with one's children, camping, curling, yoga, walking the dog and weaving. Capturing such individual participation outcomes is important for developing relevant intervention programs for people with SCI. Instruments that use predetermined domains would not capture these novel participation outcomes, thereby possibly missing areas of importance to the individual. In addition, use of the ICF proved to be a useful method for classifying the participation outcomes in this study.

Our study has some limitations. The sample size of 51 is small. However, the subject characteristics are similar to those in other studies investigating participation of persons with SCI.^{3,14,15} As such, results of this study may be considered to be generalizable to the community-dwelling SCI population. As well, the data collected in this study is cross-sectional. It does not provide longitudinal information and was collected from only community-dwelling people with SCI. Future studies might consider using the WhOM to determine the participation outcomes of people with SCI from the onset of injury onward to determine if identification of participation outcomes changes over time.

The aim of this study was to describe self-identified participation outcomes and the satisfaction with these participation outcomes by a sample of community-dwelling people with SCI. This information about community-dwelling people with SCI is useful for frontline clinicians, as it provides a description of both common and unique participation outcomes as well as satisfaction levels with performance of these participation outcomes. Such information may help to guide clinical assessments and interventions.

Conflict of interest

The authors declare no conflict of interest.

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