
Factors Influencing Participation in Daily Activities by Persons With Spinal Cord Injury: Lessons Learned From an International Scoping Review

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Background: It is important to develop further understanding regarding the facilitating and constraining factors that influence participation in daily activities, including social and human rights issues faced by persons with spinal cord injury (SCI) that affect their opportunities to lead full social lives. **Objectives:** To identify, describe, and compare factors that influence participation in daily activities by persons with SCI living in high-income countries (HICs) and in low- and middle-income countries (LMICs). **Method:** We performed a scoping review of 2,406 articles published between 2001 and 2016 that were identified from electronic databases. From these, 58 remained after checking inclusion and exclusion criteria. Analyses included (a) identifying factors that facilitate and constrain participation in daily activities; (b) categorizing the identified factors as issues related to medical, social, and human rights models; and (c) comparing determinants between LMICs and HICs. **Results:** The medical model factors pertained to long-term physical health and functional capacities, self-efficacy and adjustment skills, relearning capacities for performing daily activities, and availability of cost-effective adaptive equipment. The social model factors pertained to developing accommodating communities (accessible environments and mutual understanding). The factors of the human rights model pertained to autonomy (empowerment) and development of social justice (application of policies, advocacy, and negotiation). **Conclusion:** Eight lessons are proposed to enhance health and functional abilities, ensure disability friendly environments, develop social justice, and provide empowerment to enhance participation in daily activities among person with SCI living in LMICs. **Key words:** Bangladesh, community, occupational, participation, spinal cord injuries

In what the World Bank calls low- and middle-income countries (LMICs),¹ such as Bangladesh, persons with spinal cord injury (SCI) face challenging barriers when accessing resources related to health care and social factors, in particular, education, employment, housing, and transportation. These barriers are not only caused by the low resource conditions (which the World Bank determines from countries' income and lending status); additional barriers to strained financial resources are limited knowledge, negative social attitudes, risk of violence, prejudice, and stigma further compromising opportunities for persons with SCI to lead quality daily lives and to achieve healthy outcomes.²⁻⁸ In Bangladesh, high levels of comorbidity (particularly pressure

injuries) and mortality have been reported with postdischarge poor survival rates of 50% after 5 years and 15% after 10 years.^{8,9} Lack of supporting resources and accessible wheelchair-friendly environments in the community were also linked to poor long-term survival.¹⁰

These conditions raise the question of how persons with SCI in Bangladesh can be enabled to manage their health and live a quality of life in the community. The Centre for the Rehabilitation of the Paralyzed (CRP) is the main provider of treatment and rehabilitation for persons with SCI in Bangladesh.^{8,11} Persons with SCI reported satisfaction with daily life during institution-based rehabilitation at the CRP,^{12,13} in part due to their participation in ongoing activities (work

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and recreational programs) and access to medical facilities, therapeutic trainers, and peer support.^{14,15} This fact alone provides reason enough to explore how integrating resources into the daily lives of persons with SCI, living in Bangladeshi communities, would assist in promoting stable health and well-being. In addition, an increasing body of literature, in occupational therapy and associated occupational science, highlights how participation in occupations (daily activities) significantly impacts the long-term health and well-being^{16,17} of people living with SCI¹⁸ and enhances the quality of life outcomes¹⁹ and empowerment.²⁰ Moreover, being able to choose freely one's involvement in the community is considered important to health and well-being.²¹⁻²³

Thus, it is important to consider "participation" as meaning the involvement in life situations as described by the International Classification of Functioning, Disability and Health (ICF).⁴ Hemmingsson and Jonsson point out the importance of paying attention to the link between experience of participation and health and well-being.²⁴ In this study, participation in daily activities denotes the ICF domains of self-care (activities of daily living [ADLs]), domestic life (instrumental activities of daily living [IADLs]); interpersonal interaction and relationship (social participation); major life areas (education and work); and community, social, and civic life (play, leisure).¹⁶ However, providers in Bangladesh, and other LMICs, focus predominantly on the individual when understanding disability.^{10,13,25} Using the medical model, they shift their focus to morbidity and mortality; they act, for example, as if people need to be cured or supported by compensatory devices or assistance that enable participation in daily activities. Addressing the social and environmental influences is critically important as many persons with SCI face discrimination and other human rights barriers that directly impact their long-term survival, their ability to participate in a quality social life, and their opportunities to be involved in income-generating activities.^{2,26}

Accordingly, this study addresses several gaps in the literature. First, limited research has attempted to describe factors influencing participation in daily activities based on exploring these across

the spectrum of medical, social, and human rights models of understanding disability. It is, therefore, important to develop knowledge of the participation of persons with SCI that integrates the perspectives from the medical, social, and human right models of understanding disability. The medical model prescribes that people need to be cured or supported by compensatory devices or medical technologies to enable participation in daily activities.² In addition, providers have started to take social models of understanding disability into consideration and to incorporate interpersonal and environmental influences. The view in the human rights model is to promote, protect, and ensure the full and equal enjoyment of all human rights (civil, cultural, political, social, and economic rights) and fundamental freedoms to promote respect for the inherent dignity of persons with disabilities.⁴ Yet, the above review of literature has also shown that many persons with SCI face discrimination and other human rights barriers.²⁷ As the medical model has limitations, it is important for providers to incorporate the social and human rights models of understanding disability into their services.^{4,28} Second, there is knowledge on how rehabilitation follow-up service, accessible transportation, community networks of people with SCI, and disability acts and legislation facilitate participation in high-income countries (HICs),^{29,30} but these are far and few between in LMICs,³¹ where disability acts might exist but remain unenforced.⁴ Also, few studies exist of facilitators and constraints to participation. Third, previous literature reviews have focused on facilitators and barriers to participation among individuals with SCI with a focus on social activities,¹⁸ however there is a need for a more comprehensive understanding of facilitators and constraints to participation across the spectrum of the domains described in the ICF.⁴ In conclusion, this study was undertaken to highlight important lessons for occupational therapists, other health care practitioners, and policy makers to better support the participation in daily activities of persons with SCI in LMICs, particularly in Bangladesh. Also, this study endeavored to go beyond the individual perspective by including social and human rights issues.

Objective

The aim of this study was to identify, describe, and compare factors influencing participation in daily activities by persons with SCI living in HICs and LMICs and then to draw lessons for low resource countries.

Methods

A scoping review was designed following the five stages proposed by Arksey and O'Malley³²: (1) identifying the research question; (2) finding relevant studies; (3) selecting the studies; (4) charting the data; and (5) collating, summarizing, and reporting the results.

Data selection

Relevant research literature was identified by searching a combination of electronic databases: EbscoHost (MEDLINE and CINAHL Plus), PubMed, Scopus, Web of Science, and Google Scholar. No limitations were applied to screen for the type of articles relating to this study or for levels of evidence, but only articles published after 2001 were searched for (so studies would reflect changes following the introduction of the ICF). The search started with the key words *spinal cord injury* and *participation*. As this study is about participation in daily activities, commonly referred to as "occupation" in occupational therapy, we refined our search strategy using alternative search terms for activities and occupation based on database thesauruses and key words drawn from trial literature searches (see **Table 1**). All terms were searched in titles, key words, and abstracts.

The database search yielded 2,406 records/articles, and these were screened following a step-by-step process (see **Figure 1**) for the inclusion and exclusion criteria, resulting in 931 records being excluded in the first step. After transferring all records to a Mendeley database, 1,343 duplicated records were excluded. A further 78 articles were excluded because they were unrelated to participation in daily activities in actual living contexts (eg, physical exercise, hospital or clinic-based living studies) or compared SCI with other diagnoses or disabilities or children. On

Table 1. Article search strategy and search terms used

Title	Topic	Refined by: Topic
spinal cord injur*		occupation*
OR		OR
paraplegi*		ADL
OR		OR
tetraplegi*		activit*
OR		OR
quadriplegi*	AND participation	social
OR	AND	OR
spinal lesion		societ*
OR		OR
spinal cord compression		community
OR		OR
spinal cord damage		leisure
		OR
		recreation
		OR
		work
		OR
		employment
		OR
		economic
		OR
		sport

re-verifying the excluded articles, four articles were included again. Although these studies included control groups with other diagnoses than SCI, the research reported environmental and social facilitators and constraints to participation among persons with SCI. There were no differences of opinion that needed to be resolved by discussion among the researchers. Consequently, a total of 58 articles remained for review.

Data extraction and analysis

Data extraction began with the most recent and most relevant articles to ensure quality of data extraction. The first author (Y.A.A.) started extraction data using an Excel spreadsheet and recorded countries, research methods, facilitators, and constraints to participation in daily activities (see **Table 2**). In this study, facilitators are defined as factors that make participation possible or easier and the constraints are factors that suppress or limit participation in daily activities.³³ In a next step, the identified facilitators and constraints were arranged into medical, social, and human rights models of disability.³⁴ Facilitators and constraints

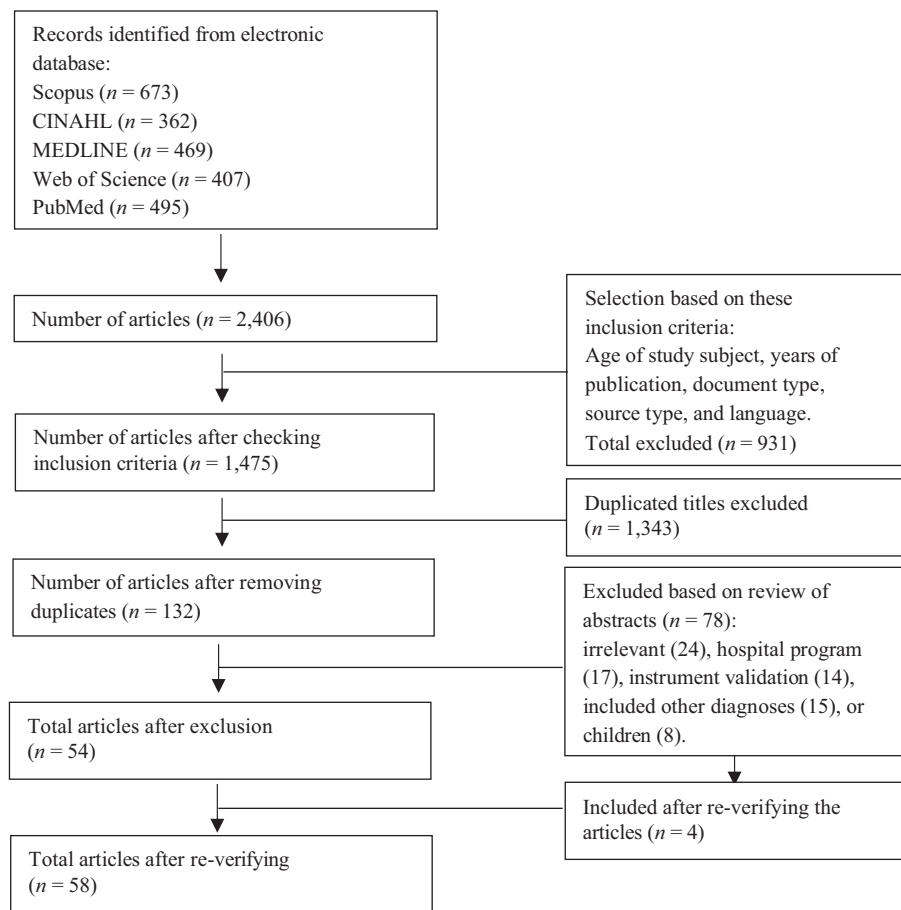


Figure 1. Flow chart of the literature search and article selection.

were categorized and organized as coming from HICs or LMICs. For example, positive/strong social relation, social manners, family supports, negative attitudes, social networks, and others were grouped together under the social model as the category of “social relations based on social skills and mutual understanding.” As another example, under the medical model, the category “self-efficacy and adjustment skills” is a neutral statement that covers facilitators such as psychological treatment and mental strength and constraints such as losing control over emotions, neuroticism, and feelings of grief. Finally, when facilitators or constraints belonged to more than one of the models of disability, these were recorded under each applicable model (see **Table 3**). These activities were performed by the first author (Y.A.A.), and other members of the research team then performed a reverse-

check to verify that facilitators and constraints were indeed reported as such in the analyzed articles. Any disagreements in categorizing were discussed among the researchers (the two authors of this article [Y.A.A., P.B.] and a research assistant [S.B.]) until consensus was reached. Additionally, the emerging analytic results were validated by experts’ opinions in graduate school research seminars and feedback on presentations of resulting categories at an international Spinal Cord conference.

As studies from LMIC were few, we grouped studies from the range of middle-income countries (eg, Iran, Thailand, South Africa, and China) and lower income countries (eg, Nepal, Bangladesh, and India) together.¹ The rationale for this way of comparing data was that the social, political, and economic conditions are considered the most important determinants of health.³⁵

Table 2. Overview of the 58 reviewed articles

Authors	Countries	Methods	Subjects	Sample size	Data analysis	Tools	Medical model	Social model	Human rights model
Price et al, 2011 ⁴⁹	USA	Semi-structured, open-ended	SCI; P,T	11	Inductive approach for analysis	X	✓	✓	✓
Barclay et al, 2016 ¹⁸	Australia	Semi-structured interviews	SCI; P,T	17	Thematic analysis	X	✓	✓	✓
Lundström et al, 2015 ³⁰	Sweden	Narrative method	SCI; T	8	Paradigmatic analysis of narrative	X	✓	✓	✓
Joseph et al, 2016 ³¹	South Africa	Explorative, qualitative study	SCI; P,T	17	Inductive content analysis	X	✓	✓	✓
Scovil et al, 2012 ¹⁰	Nepal	Cohort (1-2 years), semi-structured	SCI; P,T	37	Quantitative measures with description	MBI; P-Scale	✓	✓	✓
Ripat et al, 2012 ⁵¹	Canada	Grounded theory	SCI; P,T	19	Inductive process of constant comparison	X	✓	✓	✓
Reinhardt et al, 2016 ²⁷	Switzerland	Survey design	SCI; P,T	1,549	Multivariable regression modelling applying fractional polynomials	NEFI-SF; SCIM-SR	✓	✓	✓
Hammel et al, 2015 ⁶⁴	USA	Grounded theory	SCI, TBI, stroke	36 focus groups of 201	Constant comparative; qualitative analyses	X	✓	✓	✓
Ruoranan et al, 2015 ⁵⁶	Finland, Germany, Ireland, Switzerland	Semi-structured interviews	SCI & SB	54	Qualitative content analysis	X	✓	✓	✓
Ward et al, 2007 ²¹	USA	Semi-structured, open-ended interview	SCI; P,T	3	Narrative stories	X	✓	✓	✓
Van de Velde et al, 2010 ²²	Belgium	Grounded theory	SCI; P	11	Inductive process of constant comparison	X	✓	✓	✓
Chan et al, 2007 ⁵⁴	Hong Kong, China	Quantitative survey design	SCI; P,T	31	Spearman's rho correlation; bivariate Spearman's rho correlation	C-QUEST; WHOQOL-BREF (HK)	✓	✓	✓

(Continued)

Table 2. Overview of the 58 reviewed articles (CONT.)

Authors	Countries	Methods	Subjects	Sample size	Data analysis	Tools	Medical model	Social model	Human rights model
Piatt et al, 2016 ⁶⁸	USA	Convenience sample with survey questionnaire	SCI; P,T	42	MANOVA	IPAQ	✓	✓	✓
Schönherr et al, 2004 ⁸⁴	Netherlands	Descriptive analysis	SCI; P,T	57	SPSS; logistic regression analyses	Self-developed vocational reintegration questionnaire	✓	✓	✓
Chaves et al, 2004 ⁷⁶	USA	Cross-sectional study	SCI; P,T	70	Chi-square test or Fisher exact test	PARTS/M	✓	✓	✓
Reinhardt et al, 2013 ⁵⁸	Switzerland	Qualitative study	SCI; P,T	14	Iterative coding (by MAXQDA software) based on grounded theory	X	✓	✓	✓
Momin et al, 2004 ⁵⁷	Bangladesh	Mixed	SCI; P,T	48	Stratified random sampling; quota; thematic analysis	X	✓	✓	✓
Müller et al, 2015 ³⁹	Switzerland	Cross-sectional data collection	SCI; P,T	503	Factor analysis and path analysis; chi-square tests	HADS; USER-Participation; WHOQOL-BREF; SSI; SSQ;	✓	✓	✓
Craig et al, 2015 ³⁷	Australia	Prospective longitudinal design	SCI; P,T	88	Logistic regression	IPAQ	✓	✓	✓
Botticello et al, 2016 ³⁷	USA	Secondary analysis of cross-sectional survey	SCI; P,T	6,892	STATA/SE 14.0.b; bivariate tests	CHART	✓	✓	✓
Hosseini et al, 2016 ⁴⁶	Iran	Cross-sectional data collection	SCI; P,T	100	Pearson correlation coefficient; independent <i>t</i> test; one-way ANOVA	Northouse questionnaire of perceived social support; IPAQ	✓	✓	✓
Suttiwong et al, 2015 ⁴⁸	Thailand	Cross-sectional data collection	SCI; P,T	139	Descriptive statistics; F statistic	CHIEF-SF; PRQ (Thai version); FIM	✓	✓	✓
Sekaran et al, 2010 ⁴⁰	India	Cross-sectional data collection	SCI; P,T	35	Descriptive statistic	CHART; CHIEF	✓	✓	✓

Authors	Countries	Methods	Subjects	Sample size	Data analysis	Tools	Medical model	Social model	Human rights model
Kennedy et al, 2006 ⁸³	UK, Germany, Switzerland, Austria	Cross-sectional questionnaire	SCI; P;T	1,000	Descriptive statistics; F statistic	CHART; LSQ; HADS; ALE; SCL-CSQ; FIM	✓	✓	✓
Carpenter et al, 2007 ⁸⁵	Canada	Survey design	SCI; P;T	357	Chi-square tests; <i>t</i> tests; and one-way analysis	SWLS; SHS;	✓	✓	✓
Lindberg et al, 2013 ⁸⁷	Sweden	Qualitative method	SCI; P;T	10	Content analysis	X	✓	✓	✓
Van de Velde et al, 2013 ⁷⁰	Belgium	Phenomenological-hermeneutical method	SCI; P	12	Thematic analysis	X	✓	✓	✓
Rushton et al, 2010 ⁷⁹	Canada	Cross-sectional	SCI; P;T	51	Descriptive statistics	WhOM	✓	✓	✓
Carr et al, 2017 ⁴⁵	Australia	Sequential mixed method design	SCI; P;T	270	Non-parametric Mann-Whitney Wilcoxon tests or Kruskal-Wallis tests	CIM; WHOQOL-BREF	✓	✓	✓
Kuipers et al, 2011 ⁸¹	Australia	Descriptive study	SCI; P;T	269	Thematic analysis	X	✓	✓	✓
Marti et al, 2012 ⁴⁴	Switzerland	Cross-sectional survey	SCI; P;T	559	Bivariate and logistic regression analyses	NIRAL-SCI	✓	✓	✓
Schönherr et al, 2005 ⁸⁵	Netherlands	Survey design	SCI; P;T	57	Descriptive analysis	CHART (Dutch); Fugl-Meyer - LSQ	✓	✓	✓
Newman et al, 2010 ⁵²	USA	Qualitative, photovoice method	SCI; P;T	10	Photovoice participatory analysis (by NVivo 8)	X	✓	✓	✓
Dijkers et al, 2002 ⁸⁹	Turkey	Comparative analysis of survey data	SCI; P;T	66	Analysis of co-variance	FIM motor score; CHIEF; CHART	✓	✓	✓
Geyh et al, 2012 ⁶⁹	Switzerland	Multi-center cross-sectional study	SCI; P;T	102	Bivariate correlations and multivariate linear regression analyses	BPI; HADS; SSQ (Short Form); GSE; RSES; CISS; SOC; RNLI	✓	✓	✓
Sakakibara et al, 2014 ⁴⁶	Canada	Cross-sectional study	SCI; P;T, other disabilities	124	Descriptive statistics	LLFDI; WheelCon; LSA; WST (Questionnaire Version)	✓	✓	✓

(Continued)

Table 2. Overview of the 58 reviewed articles (CONT.)

Authors	Countries	Methods	Subjects	Sample size	Data analysis	Tools	Medical model	Social model	Human rights model
Van Leeuwen et al, 2012 ⁴¹	Netherlands	5 years follow-up cohort study	SCI; P,T	143	Pearson correlations; LSQ; EPQ-RSS statistical program LISREL 8.8; AIC	SF-36; FIM; SIP-68; LSQ; EPQ-RSS	✓		
Papathomas et al, 2015 ⁴²	UK	Semi-structured life-story interview	SCI; P,T	30	Structural narrative analysis; plots; themes	X	✓		
Eriks-Hoogland et al, 2016 ⁴³	Netherlands	Prospective cohort study	SCI; P,T	138	t tests and chi-square tests; basic regression analysis; STROBE	POpeak; WST; FIM (motor score); PASIPD; SIP-68;	✓		
Cooper et al, 2011 ⁷⁴	USA	Correlational study	SCI; P,T, complete	16	Spearman rho correlation test	PARTS/M	✓		
Kilkens et al, 2005 ⁷⁵	Netherlands	Cross-sectional study	SCI; P,T, complete	81	Regression analyses	SIPSOC	✓		
Hastings et al, 2011 ⁷⁷	USA	Descriptive cross-sectional study	SCI; T, complete	30	MANOVA	SCIM III, CHART	✓		
de Groot et al, 2011 ⁷⁸	Netherlands	Cross-sectional study	SCI; P,T	109	Linear regression	D-QUEST (Dutch); PASIPD; UAL; SIPSOC	✓	✓	
Gutierrez et al, 2007 ⁸⁰	USA	Cross-sectional questionnaire study	SCI; P- complete	80	Spearman's rho test	WUSPI; SOOL; PASIPD; VAS; CAC	✓		
Tsai et al, 2014 ⁸²	USA	Cross-sectional study	SCI; P,T	2,986	STATA 10 software; logistic regression analysis; univariate linear	CHART-SF; AIS; FIM	✓	✓	
Bushnik et al, 2002 ⁵⁰	USA	Cross-sectional study	SCI; T, complete	168	ANOVA; post hoc comparisons; paired t tests; Fisher's r to z computation; chi-square analyses; Mann-Whitney U test	HQ; Level of Free Time Activities Scale; RSES; QOL - 2	✓		
Murphy et al, 2005 ⁹⁵	Australia	Cross-sectional study	SCI; P,T	289	Descriptive statistics	Self-report survey; FIM	✓		

Authors	Countries	Methods	Subjects	Sample size	Data analysis	Tools	Medical model	Social model	Human rights model
Blauwet et al, 2013 ⁷¹	USA	Cross-sectional study	SCI; P,T	149	Multivariable logistic regression analyses	Standardized questionnaire	✓		
Tasiemski et al, 2011 ⁷²	Poland	Cross-sectional survey	SCI; P,T	1,034	Chi-square analysis; <i>t</i> tests	AIMS; LSQ	✓		
Peter et al, 2014 ³⁸	Switzerland	Cross-sectional data collection	SCI; P,T	516	Using the R software; a parallel exploratory factor analysis	USER-Participation; GSE; PIL (Short Form); ALE; Brief COPE	✓		
Whiteneck et al, 2004 ⁵³	USA	Cross-sectional, follow-up survey	SCI; P,T	2,726	Descriptive statistics; multivariate logistic regression with the Nagelkerke pseudo R ²	CHIEF-SF; CHART-SF; SWLS	✓		
Noreau et al, 2002 ⁸⁸	Canada	Cross-sectional study	SCI; P,T	1,771	<i>t</i> tests and chi-square tests of independence	LIFE-H; MQE	✓		
Lund et al, 2007 ⁹⁰	Sweden	Survey design	SCI; P,T	157	Spearman's rank-order correlation	IPAQ; LiSat-9	✓	✓	
Lysack et al, 2014 ⁹¹	USA	Cohort study	SCI; P,T	140	Linear regression; logistic regression analysis.	RISCI scores; CIM			
Brown et al, 2002 ⁸⁶	USA	Experimental	SCI and TBI	62/ 219	ANCOVA; ANOVA	CIQ; CHART; TIRR Symptom Checklist; BDI; Bigelow QOL; SF-36; CRQ	✓	✓	
Jetha et al, 2014 ⁶⁰	USA	Comparative survey		1,323	Two multivariable logistic regression models	Internet-based questionnaire	✓	✓	✓
Isaksson et al, 2007 ⁵⁹	Sweden	Narrative method	Women SCI; P,T	13	Paradigmatic analysis of narrative data	X			✓

(Continued)

Table 2. Overview of the 58 reviewed articles (CONT.)

Authors	Countries	Methods	Subjects	Sample size	Data analysis	Tools	Medical model	Social model	Human rights model
Botticello et al, 2012 ²²	USA	Survey design	SCI; PT	1,013	HGLM approach; multilevel logistic regression models used the Bernoulli specification; Laplace iterations in HLM version 7	Self-developed questionnaire; SCI Model System			✓

Note: AIC = Akaike's Information Criterion; AIMS = Athletic Identity Measurement Scale; AIS = American Spinal Injury Association Impairment Scale; ALE = Appraisal of Life Events Scale; ANCOVA = analysis of covariance; ANOVA = analysis of variance; BDI = Beck Depression Inventory; BPI = Brief Pain Inventory; CAC = Community Activities Checklist; CHART = Craig Handicap Assessment and Reporting Techniques; CHART-SF = Craig Handicap Assessment and Reporting Techniques-Short Form; CHIEF = Craig Hospital Inventory of Environmental Factors; CHIEF-SF = Craig Hospital Inventory of Environmental Factors-Short Form; CIM = Community Integration Measure; CIQ = Community Integration Questionnaire; CISS = Coping Inventory for Stressful Situations; C-QUEST = Chinese version of the Quebec User Evaluation of Satisfaction with assistive Technology; CRQ = Community Re-entry Questionnaire; EPQ-RSS = Eysenk Personality Questionnaire-Revised Short Scale-Neuroticism; FIM = Functional Independence Measure; GSE = General Self-Efficacy Scale; HADS = Hospital Anxiety and Depression Scale; HGLM = Hierarchical Generalized Linear Model; HQQ = High Quadriplegia Questionnaire; IPAQ = Impact on Autonomy and Participation Questionnaire; LIFE-H = Assessment of Life Habits; LiSat-9 = Life Satisfaction Questionnaire; LFFDI = Late-Life Function and Disability Instrument; LSA = Life-Space Assessment; LSQ = Life Satisfaction Questionnaire; MANOVA = multivariate analysis of variance; MBI = Modified Barthel Index; MQE = Measure of the Quality of the Environment; NEFF-SF = Nottwil Environmental Factors Inventory-Short Form; NIRAL-SCI = Nattwil Inventory for the Retrospective Assessment of Labour Market Participation in Spinal Cord Injury; P = Paraplegia; PASIPD = Physical Activity Scale for Individuals with Physical Disabilities; PARTS/M = Participation Survey/Mobility; PIL = Purpose in Life Test; POpeak = peak power output; PRQ = Personal Resource Questionnaire; P-Scale = Participation Scale; QOL = quality of life; RISCO = Risk Inventory for persons with Spinal Cord Injury; RNLI = Reintegration to Normal Living Index; RSES = Rosenberg Self-Esteem Scale; SB = spina bifida; SCL-CSQ = Spinal Cord Lesion Related Coping Scale Questionnaire; SCIM-SR = Spinal Cord Independence Measure Self-Report; SF-36 = 36-Item Short Form Health Survey; SIP-68 = Sickness Impact Profile; SIPSOC = Social behavior of the 68-Item Sickness Impact Profile; SHS = Subjective Happiness Scale; SOC = Sense of Coherence Scale; SQOL = Subjective Quality of Life Scale; SSI = Social Skills Inventory; SSQ = Social Support Questionnaire; STROBE = Strengthening the Reporting of Observational Studies in Epidemiology; SWLS = Satisfaction With Life Scale; T = tetraplegia; TBI = traumatic brain injury; UAL = Utrecht Activity List; USER-Participation = Utrecht Scale for Evaluation of Rehabilitation-Participation; VAS = Visual Analogue Scale; WheelCon = Wheelchair Use Confidence Scale; WHOQOL = World Health Organization Quality of Life Questionnaire; WhOM = Wheelchair Outcome Measure; WST = Wheelchair Skills Test; WUSPI = Wheelchair User's Shoulder Pain Index.

Results

Of the 58 articles analyzed, six (10%) related to LMICs (Bangladesh, India, Iran, Nepal, South Africa, and Thailand) and 52 (90%) to HICs (North America, Europe, Australia, and Hong Kong). The analysis resulted in eight categories of facilitators and constraints: four categories fell under the medical model, two categories under the social model, and two categories under the social model (see **Table 2**).

Four categories fell under the medical model of disability:

- 1 *Self-efficacy and adjustment skills.* Robust self-efficacy and adjustment skills were seen as facilitating participation in daily activities. Studies of HICs and LMICs identified skills such as coping, dealing with stressful situations, and social adeptness to regulate emotions.³⁶⁻⁴⁰ Equally, transitioning from hospital to home and lack of support for mental health issues were reported as constraining participation in daily activities.^{30,31,41} However, studies of HICs presented measures for enhancing mental health that facilitated participation, such as motivational counseling that encourages persons with SCI to develop a balanced repertoire of occupations.²² Physical health was also linked to promoting participation through enhancing mental strength.⁴² Only literature on HICs presented interventions for supporting these skills, so interventions appear underresearched and underdeveloped for LMICs.
- 2 *Physical health and functional capacities.* Studies of both HICs and LMICs highlighted physical health and functional capacities as impacting participation in daily activities. The higher and more complete the lesion, the more incontinence and secondary health complications constrained participation, including employment and social gatherings.^{30,43-47} These constraints appeared to be greater in LMICs given the prevalence of health complications, severely limited short- and long-term survival of persons with SCI,¹⁰ and limited outdoor mobility and poor functional capacity leading to sedentary indoor living.^{10,31,40,48} Physical exercise, wheelchair

mobility, and transferring skills practice were identified as assisting in the prevention of health complications in HICs.^{42,49}

- 3 *Availability of cost-effective adaptive equipment.* Adaptive equipment was beneficial in compensating for functional limitations when participating in daily activities. Availability and cost-effectiveness of adaptive equipment was particularly lacking in LMICs. Research results from HICs showed how light-weight wheelchairs, communication devices, adapted cars, information technology, adapted utensils, and home adaptation facilitated participation in indoor and outdoor activities, including leisure and employment.^{20,27,30,49-51}
- 4 *Relearning capacities for performing daily activities.* Relearning performance capacities has great importance for participating in daily activities. Globally, experience living with SCI and lower levels of injury appeared to be important facilitators. Maintaining a dynamic balance between performing routine activities, engaging in various life roles, and family-based activities were found only in HICs.^{50,51} Moreover, functioning in self-care and other activities was facilitated in HICs by appropriate therapeutic goals and discharge planning,²⁷ but no such literature was identified from LMICs.

Two categories related to the social model of disability:

- 5 *Impact of natural and physical environments.* The natural and physical environments were an important influence on participation in daily activities. Globally, inaccessibility of private or public infrastructure, unfavorable climate condition, neighborhood distance, and terrain limit participation.^{10,18,27,52,53} In HICs, accessibility of public buildings, parks, and restaurants were described, while public outdoor spaces, shopping centers, pathways, and housing were also reported as accessible and wheelchair-user friendly.^{18,20,27} However, articles relating to LMICs only reported constraints, some of which are similar to those in HICs, with the lack of accessible toilets, no access to a water source, constraints in transportation, or lack of access to the road from one's home.¹⁰ Globally, accessibility

Table 3. Facilitators and constraints to participation in daily activities

Categories	Medical model of disability		
	High-income countries	Low- & middle-income countries	Constraints
Self-efficacy and adjustment skills	<ul style="list-style-type: none"> – Self-presentation and adjustment with situation^{38,39} – Self-efficacy or self-control against depression: psychological treatment,³⁷ high self-esteem,⁶⁹ coping strategies/skills,^{37,38} resignation and/or revolt as an internal negotiator⁷⁰ – Self-efficacy – belief in own ability³⁶ – Mental health and higher life satisfaction⁴¹ – Client-centered rehabilitation^{69,70,49} – Physical exercise enhances mental strength⁴² 	<ul style="list-style-type: none"> – Lack of motivation, dissatisfaction, and depression after transition to home^{18,39,47,49,38,70,71} – Lack of advanced intervention for depression, neuroticism, feeling of grief⁴¹ – Substance abuse³⁸ – Anxiety, sleep disorders, and frustration interfere with employment^{30,72} 	<ul style="list-style-type: none"> – Loss of control over emotion (eg, attempt suicide), shameful feeling, low level of self-efficacy (loneliness, depression, grief)³¹
	<ul style="list-style-type: none"> – Physical exercise as restitution or medicine, eg, routine exercise, breathing, relaxation, weight lifting,⁴² education⁶⁸ – Bowel and bladder management skills⁷³ – Mobility skills/ability to make transfer^{73–75} – Wheelchair propelling increase functional ability^{74–76,49} – Physical functions^{74,77} – Capacity to work and do sport activities,⁷⁸ associated with functional capacity, and indoor mobility⁷⁹ 	<ul style="list-style-type: none"> – Physically and functionally active⁴⁶ – Indoor mobility for eating, washing, transferring, and toileting^{31,48} 	<ul style="list-style-type: none"> – Secondary health complications, such as pain, urinary tract infections, respiratory complication^{10,31,48} – Poor outdoor mobility^{10,48} – Physical dependency or care dependency⁴⁰
Availability of cost-effective adaptive equipment	<ul style="list-style-type: none"> – Assistive technologies/new technologies^{30,27,51,76,81} – Devices/mobility devices such as adapted car,^{18,27,45,51,82} power/electric wheelchair, light-weight wheelchair, personal assistance^{20,30,51} – Communication devices (writing devices, computer, telephone, mouse)²⁷ – ADL equipment⁴⁵ (reachers, dressing aids, bathing equipment, toileting equipment and IT included adapted utensils,¹⁸ mouthsticks and wrist braces,⁵⁰ adapted bathroom equipment⁵⁰) 	<ul style="list-style-type: none"> – Secondary health complications, eg, increasing pain in the shoulders and muscles,⁴⁴ bowel-bladder problem, progressive muscle weakness, fatigue, apnea,³⁰ poor balance and coordination, spasticity,^{37,68,78,45,80} presence of pressure sores^{75,44} 	<ul style="list-style-type: none"> – Limited devices and advance technologies such as electric devices, mobility aids, mobility/sitting equipment appropriate to terrains^{10,57}

Medical model of disability		
Categories	High-income countries	Low- & middle-income countries
	Facilitators	Facilitators
	Constraints	Constraints
Relearning capacities for performing daily activities	<ul style="list-style-type: none"> - Higher level of functional independence^{47,84,93} - Maintain dynamic balance between occupations⁴⁵ and routines^{30,31} - Retraining occupations⁴⁵ - Modifying occupations, self-selecting occupations^{51,85} - Executing life role occupations^{51,50} inside or outside of home^{20,50,51,55,56,68,71,72,86} - Performing previous valued occupations^{51,55} - Be engaged in various life roles^{21,49} or "occupying time"²² - Be engaged in family-based activities⁵¹ - Appropriate therapeutic goal and discharge planning^{47,56,87} - Regular consultancy and follow-up^{49,21} 	<ul style="list-style-type: none"> - Poor function after injury⁴⁵ - Killing time or wasting time or meaningless occupations^{69,51} - Physical inactivity or activity limitation⁴⁷
Impact of natural and physical environments	<ul style="list-style-type: none"> - Resources (finance, public transport system)^{18,27,81} - Environmental accessibility (public outdoor spaces, shopping centres, pavement,¹⁸ accessibility in home)^{20,51} - Wheelchair-friendly home environment ensured safety,^{9,58} wheelchair-friendly work environment ensured job,⁸⁴ and facilitates access to community resources²¹ 	<ul style="list-style-type: none"> - Inaccessibility in private or public infrastructure, such as in vehicle parking,^{52,54} petrol pump, public buildings,^{18,52} high curbs, stairs, lack of automatic doors, and inaccessible restaurant, transportation^{20,27,51,53,88,89} - Inaccessibility in others/friends home^{49,53} - Inaccessible lake or park and natural environment/ terrain^{53,76} - Geographical distance⁴⁷ - Unfavorable climate conditions (eg, weather, season, temperature, humidity)^{20,27,45}
Social relations based on social skills and mutual understanding	<ul style="list-style-type: none"> - Basic manner, communication skills,^{30,56} relationship skills, and self-control in actual social context³⁹ - Social skill such as "social engineering"⁷ that is feeling comfortable within oneself and in society⁴⁹ - Positive relationship and attitude with neighbors⁴⁷ partner, family members^{56,68,81,87,90} - Intimate relationship, multiple relationships, and supports from family members, friends, and SCI peers^{45,58,59} - Availability of social support^{70,83,55,52,2} - Engaging in different social roles, social acceptance^{55,56,88} - Strong social networks⁵¹ 	<ul style="list-style-type: none"> - Problem in forming relationship⁵⁶ - Negative attitudes (such as prejudice, lack of supportive behavior, or overprotective behaviors)²⁷ - Avoid interactions, negative assumption about disabilities, negative comments, discrimination⁵¹ - Social stigma⁴⁹ - Poor social support networks^{37,91}
		<ul style="list-style-type: none"> - Detach relationship with friends and family, friends escape/withdraw from relationship³¹ - Criticism, negative attitudes, and insulted by other people^{3,157} - Exclusion from society (even family members' negative attitude acts as barrier)^{40,57} - Struggle with social relation and acceptance⁴⁸ (<i>Continued</i>)

Table 3. Facilitators and constraints to participation in daily activities (CONT.)

Categories	Human rights model of disability		
	High-income countries	Low- & middle-income countries	Constraints
Autonomy in daily occupations	<p>Facilitators</p> <ul style="list-style-type: none"> - Autonomy in functioning and decision making^{51,58,68,5} - Freedom of choice^{21,30,58,58} - Contributing in family⁶⁰ - Enfranchisement and empowerment²⁰ - Ability to involve family members, friends in decision making²¹ - Occupational story making (therapist and client make a visionary story of meaningful future)²¹ - Freedom to restructure occupational identity^{22,59} - Availability of home- or community-based adaptation services⁴⁹ - Reciprocity in dealing with community, improving own community, sharing ones' life story, doing volunteer work, or educating each other⁵¹ 	<p>Facilitators</p> <ul style="list-style-type: none"> - Lack of freedom of choice in community life⁶⁶ 	<p>Constraints</p> <ul style="list-style-type: none"> - Unemployment and lack of opportunities^{10,31,57} - Limited resources in community-based rehabilitation¹⁰
Justice through application of policies, advocacy, and negotiation	<p>Facilitators</p> <ul style="list-style-type: none"> - Organizational and social policies, disability acts, health care check-up services, emergency support - Special access rules in public space and transportation^{18,20,30,38} - Community-based rehabilitation service⁶⁸ - Advocacy by themselves for equal opportunities, employment, accessing community resources, universal design, negotiation with government bodies and peer associations^{18,30,51} - Involvement in policy making to ensure rights in society^{18,27,51,18} - Involving in vocational rehabilitation program and income generation^{44,84} - Opportunities to return to work by job adaptation⁸⁴ - Developed social economic condition^{47,58,92} - Social security (such as life insurance, pension, health insurance)^{21,51} 	<p>Facilitators</p> <ul style="list-style-type: none"> - Government housing policies - National disability acts³¹ 	<p>Constraints</p> <ul style="list-style-type: none"> - Acts/laws are not or are partially implemented - Medical-based health care management system⁵⁷ - Inequality and inequity, gender discrimination^{31,57} - Barriers to higher education and employment^{10,31}

issues have significant impact on participation, particularly in involvement in community activities.

- 6 *Social relations based on social skills and mutual understanding.* Social relationships were identified as being an important influence on participation of daily activities. This included social skills of persons with SCI to build and maintain relationships and strong social networks.^{39,51} The literature also highlighted that using social skills facilitated interacting to manage relationships with neighbors and health professionals^{48,54} and perceptions of having a disability in order to feel comfortable within oneself and in society.⁴⁷ Positive and supportive attitudes facilitated persons with SCI venturing out into society; active engagement with other people; and participation in leisure, sports, social events, and jobs.^{21,55} Conversely, the lack of mutual understanding and negative attitudes constrained participation in social activities.^{31,49,51,56} Similar to HICs, the LMIC literature highlighted the importance of family members and friends facilitating participation of persons with SCI in activities of domestic life and in society.^{31,48} Literature relating to LMICs also reported that participation was often limited to an individual's home life as social participation could be gravely impacted by being abandoned; having deteriorating relationships with family; by being kept indoors; by being excluded, such as bus drivers not stopping for persons in wheelchairs; experiencing social stigmatization; and experiencing gender violence especially against women.^{31,40,49,57}

Two categories related to the human rights model of disability:

- 7 *Autonomy in daily occupations.* Following the human rights model, persons with SCI should have a measure of autonomy. Both HIC and LMIC literature highlighted that autonomy was facilitated by freedom of choice, reciprocity, and equality in decision making, in employment, family, and society.^{20,21,30,58} Literature of HICs identified autonomy being expressed through reciprocity, by ways of contributing to improving one's community

through (volunteer) work, educating others, and sharing ones' life story.²⁰ Service providers facilitated autonomy in participation through individual-centered adaptation in home and community, assisting the restructuring of occupational identity, assisting with building strong social networks, and applying a technique called occupational story-making.^{21,49,51,59} There was limited literature on autonomy facilitating participation in daily activities in LMICs.

- 8 *Justice through application of policies, advocacy, and negotiation.* Legislation and human rights action were regarded as facilitating participation in daily activities, for example, structural policy for equal access for persons with disabilities (such as through quotas for government housing and employment).^{18,58} HIC articles reported a plethora of measures aimed at promoting justice, such as disability acts, provision of health care, social security and insurance, and telecommunication and transportation services.^{20,30,51,56} It was also reported that local organizations, service providers, and self-help groups raised awareness of justice issues, participated in decision making in policies, and negotiated with government bodies to modify public spaces, universal design, and disability rights.^{18,51} LMIC articles highlighted that persons with SCI have limited social roles and limited opportunities for employment (except for those with higher education).^{31,57} Implementation of laws and regulations was difficult because of limited resources, initiatives, and awareness; this was reported in both HICs and LMICs.^{52,57,60}

Discussion

The major categories of facilitators and constraints to participation in daily occupations among persons with SCI were self-efficacy and adjustment skills, physical health and functional capacities, availability of cost-effective equipment, and relearning capacities for performing daily activities (under the medical model); impact of natural and physical environment and social relations (under the social model); and autonomy

in daily occupations and justice through application of policies, advocacy, and negotiation to better support participation in daily activities (under the human rights model). These results indicate that relatively much of the knowledge about facilitators and constraints to participation in daily activities is grounded in medical models of understanding disability. Accordingly, there appears to be a particular need for research producing more knowledge pertaining to social and human rights issues.

Next, the results will be discussed by formulating lessons learned from this scoping review for LMICs, such as Bangladesh. However, readers are advised that these lessons might also be relevant for other low-resourced conditions, including in HICs. The interprofessional team members, providers of social support, and policy makers might want to heed these results to better support community-dwelling persons with SCI in their participation in daily activities. The discussion of findings is organized according medical, social, and human rights models of disability. Lessons to better support participation in daily activities among persons with SCI that are drawn from the findings are indicated with a number in square brackets.

Innovative solutions for enhancing health and functional abilities

Lessons for LMICs pertain to [1] developing mental health support and advancing client-centered rehabilitation and [2] promoting physical health and activity. Moreover, researchers in an LMIC have begun developing outreach and telemonitoring follow-up service for pressure sore prevention.⁶¹ Equally, another lesson pertains to [3] developing affordable and advanced adaptive equipment.⁶² In this light, the development of suitable mobility technologies is encouraging.¹² Additionally, [4] individuals need support to improve their performance capacities and daily routines. This study identified a dearth of initiatives in this respect. In addition, improving health, with a focus on improving long-term survival rates, decreasing hospital readmission, and improving functional capacities, has been confirmed as an urgent task. Specific conditions, such as increasing

resources, and innovative solutions should be developed in LMICs by harnessing community-based resources in order to realize the type of support provided by multiple professionals in HICs.

Disability friendly environment through local cooperation

In LMICs, [5] ensuring wheelchair-accessible environments is particularly challenging, primarily due to financial constraints.⁶³ Our findings also point to a lack of knowledge and awareness resulting from widespread stigma and discrimination. Therefore, a priority is [6] training key persons to develop strong social support networks and raising awareness of the importance and possibilities for participation in daily activities among members of the public, local public officers, family, and persons with SCI themselves in LMICs. This would assist in creating conditions to allow persons with SCI to reintegrate into community life and to support health and long-term survival. Enhancing social resilience and getting local cooperation of persons with SCI to navigate such social conditions may also contribute to these aims.

Developing social justice and empowerment

As no facilitators were identified from the LMIC literature, it appears that social justice and empowerment are in urgent need of being addressed through research publications. The UN Convention on the Rights for Persons with Disabilities⁶⁴ and occupational therapy literature on occupational justice⁶⁵ provide policy and conceptual backup for drawing lessons regarding the reality of social exclusion in LMICs. Another lesson [7] pertains to empowering the individuals with SCI to enhance their decision-making capabilities to access health care, to reduce stigma, and to advocate for their rights with organizations and governmental bodies. Additionally, nongovernment organizations are collaborating with the World Health Organization and other international organizations to raise awareness of the importance for persons with disabilities to be able to participate in mainstream society.⁶⁶ Despite governmental disability rights policies having been revised recently, lack of meaningful advances in

equal opportunities in community life⁶⁷ indicates that equal opportunities and social justice are not being enforced or achieved. The final lesson [8] pertains to establishing participation in actual contexts through joint endeavors between persons with SCI and other stakeholders in their communities, including local providers and policy enforcers.

These considerations suggest more effective rehabilitation outcomes are possible if the members of the interprofessional team, providers of social support, policy makers, and persons with SCI themselves, develop collaborative and innovative strategies promoting engagement in life roles, community involvement, and autonomy to achieve full participation.⁶⁸

Limitation

The findings do not reveal the relative impact or prevalence of facilitators and constraints to participation in daily activities. Not included in this study were individualized factors, such as gender, education, employment, personal or national wealth, and health status. These also act as facilitators and constraints to participation in daily activities irrespective of residence in an HIC or LMIC. Second, considering countries from the range of lower and middle incomes as belonging to the same group may not sufficiently reflect the diverse impacts of wealth status and social system to participation of persons with SCI. Third, though this study is focused on lessons learned for LMICs, some of these lessons may also address constraints to participation in HICs. Finally, the included articles might overrepresent reports on data collected from persons with SCI with good functional capacity and societal

involvement, particularly through income-generating activities. It might be that this has resulted in an underrepresentation in the data of the most vulnerable and disadvantaged people.

Conclusion

This scoping review has identified eight major categories of issues and eight accompanying lessons for the participation in daily activities by managing the health of persons with SCI in LMICs. Following the medical model, issues and lessons pertained to enhancing physical health and functional abilities, self-efficacy and adjustment skills, relearning capacities for performing daily activities, and availability of cost-effective adaptive equipment. Following the social and human rights model, lessons pertained to developing accommodating communities (accessible environments and mutual understanding) and autonomy (empowerment) and developing social justice (application of policies, advocacy, and negotiation), respectively. It is important to develop and improve services that also address social and human rights issues to optimize the participation in daily activities of people with SCI in low-resource conditions.

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