Review Article
http://mjiri.iums.ac.ir
Medical Journal of the Islamic Republic of Iran (MJIRI)

Med J Islam Repub Iran. 2020(23 Jun);34.66. https://doi.org/10.47176/mjiri.34.66

Participation instruments in persons with spinal cord injury: A narrative review

Amir Javanmard[1], Kianoush Abdi *[1], Abbas Ebadi[2,3], Samaneh Hosseinzadeh[1]

Received: 15 Sep 2019 Published: 23 Jun 2020

Abstract

Background: Spinal cord injury (SCI) has serious impacts on the patient's function. Therefore, their participation is important as one of the major indicators of the quality of life. This study reviews instruments that evaluate participation among people with spinal cord injury.

Methods: Four electronic databases (WebofScience, Scopus, MEDLINE/PubMed, SID) were searched for studies published in the English language between 2000 and 2019 in one or more peer-reviewed journals on the measurement properties (reliability, validity and/or responsiveness) in all populations including adults with SCI. Instruments assessed based on special criteria designed for disability outcome measures.

Results: Six instruments were included: Incontinence - Activity Participation Scale, Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P), World Health Organization's disability assessment tool-II (WHODAS-II), ICF Measure of Participation and ACTivities Screener (IMPACT-S), Impact on Participation and Autonomy (IPA) , Participation measure for Post-Acute care (PM-PAC). Evidence related to the reliability and validity was reported for all of the instruments. Only WHODAS-II, USER-P, and IMPACT were compared with each other in recent publications. Responsiveness was not obtained for any of the instruments.

Conclusion: As the underlying structure of every instrument is different, the concept of the evaluated participation varies between instruments. The proper instrument for examining participation of the patients with SCI should be selected based on a thorough analysis of the individual's condition and context. Innovative models of disability should be the basis of emerging instruments for evaluation of participation, as well as empirical studies and modern measurement technologies that fill the gap between the perceived participation of the individual and the research's record.

Keywords: Rehabilitation, Participation, Spinal cord Injury, Outcome, Measurement

Conflicts of Interest: *None declared*
Funding: *None*

Cite this article as: Javanmard A, Abdi K, Ebadi A, Hosseinzadeh S. Participation instruments in persons with spinal cord injury: A narrative review. *Med J Islam Repub Iran.* 2020 (23 Jun);34:66. https://doi.org/10.47176/mjiri.34.66

Introduction

Participation has emerged as a basic concept in most paradigms of disability, World Health Organization's ICF (International Classification of Functioning, Disability and Health) included (1). ICF has defined Participation as

Corresponding author: Kianoush Abdi, Ki.abdi@Uswr.ac.ir

1. University of Social Welfare and Rehabilitation Sciences, Tehran, Iran
2. Behavioral Sciences Research Center, Life style institute, Baqiyatallah University of Medical Sciences, Tehran, Iran
3. Nursing Faculty, Baqiyatallah University of Medical Sciences, Tehran, Iran

↑What is "already known" in this topic:
In accordance with ICF (International Classification of Functioning, Disability and Health), several studies have been conducted to define participation instruments for people with disabilities, but there's a lack of comprehensive review to generally conclude on the instruments and their findings in the field.

→What this article adds:
This paper intends to review related participation instruments that measure the performances of persons with spinal cord injury. It helps the reader to better digest the concept of rehabilitation medicine, as well as comprehensively review the participation instruments.

[DOI: 10.47176/mjiri.34.66]

"involvement in a life situation", while participation restrictions, as its opposite, defined as "problems a human may experience in involvement in life circumstances" (2). Besides, the term "participation" remains an impartial concept to narrate social functioning and wellbeing. The latest revision of the ICF combines activities and participation into a single taxonomy and describes 9 scales of participation and activities, instead (3): learning and applying knowledge; general tasks of living; interpersonal communication; mobility; self-care; domestic life; interpersonal relationships, major life areas (education, work, economic); and community, civic, and social life (3). Additionally, ICF defines constraint in activities or restriction in participation as difficulties that an individual can face; It also offers a distinction between the efficiency of a person concerning with a health condition (loss, disease or disorder) with that of an individual without that condition in order to measure the limitation (4). The predecessors of ICF have inspired many researchers to design generic and disorder-specific participation instruments; Nevertheless, there is a lack of certainty in defining participation, as there are considerable diversities in item data, content, contexts, and response options (5). Spinal cord conditions have an important impact on the individual and the society as well. The consequential impairments relative to SCI interrelates with an upcoming risk of secondary health risks such as neuropathic and musculoskeletal pain, pressure ulcers, respiratory and cardiovascular diseases, diabetes, obesity and osteoporosis (6). Persons with SCI demonstrate psychological problems such as depression and anxiety after the occurrence of injury that leads to decreasing levels of life satisfaction and other aspects of quality of life (7). However, social participation is positively related to increased quality of life (8), stronger social connections and reduced psychological problems (9). The rates of occurrence for spinal cord injury are in the rise as the medical technologies improve properly and the survival from accidents and injuries, as well as surveillance of disability increases (10). Thus, participation which has emerged as a main rehabilitation outcome, has attracted extensive exerts for its operationalization and measurement (11) in the past recent years. The criteria which evaluate participation instruments most often are relied on the frequency of usage and their application to particular clinical populations (e.g. spinal cord injury, multiple sclerosis) (12,13). The overall interest in participation measurement has rooted in the prominence of the World Health Organization's ICF, together with the increasing progression of technologies that measure participation. This paper is dedicated to provide a review of contemporary participation instruments that were developed for and/or assessed in a spinal cord injury population and to examine their measurement properties.

Methods

Search strategy: Articles were obtained using a systematic search strategy conducted in popular scientific databases (WebofScience, Scopus, MEDLINE/PubMed, SID) in order to identify studies that assessed and/or developed participation instruments in a population consisting of individuals with spinal cord injury; Therefore, the search phrase 'spinal cord injury' and 'participation' from 2000 to March 2019, were used in each database, as well as following terms which were tailored for each database: validation, assessment, instrument, internal validity, concurrent validity, discriminant validity, content validity, face validity, predictive validity, reliability, inter-rater reliability, intra-rater reliability, test-retest, reproducibility, responsiveness, evidence-based medicine, outcome measures, clinical assessment tools, scales and measures.

Inclusion criteria: Instruments selected for the review if there was sufficient information available regarding their focus on validation and/or reliability on their measurement properties (validity, reliability, and/or responsiveness) in adult participants with SCI and published in one or more peer-reviewed journals. Papers included only if the focus of the article was to evaluate/assess the psychometric properties of a participation instrument and if the papers were published in English and free full texts were available. A full illustration of the inclusion process has shown in Figure 1. Instruments considered to assess participation if their scales covered two or more of the following ICF domains: domestic life (chapter 6); interpersonal interactions and relationships (chapter 7); major life areas (chapter 8); and community, social and civic life (chapter 9).

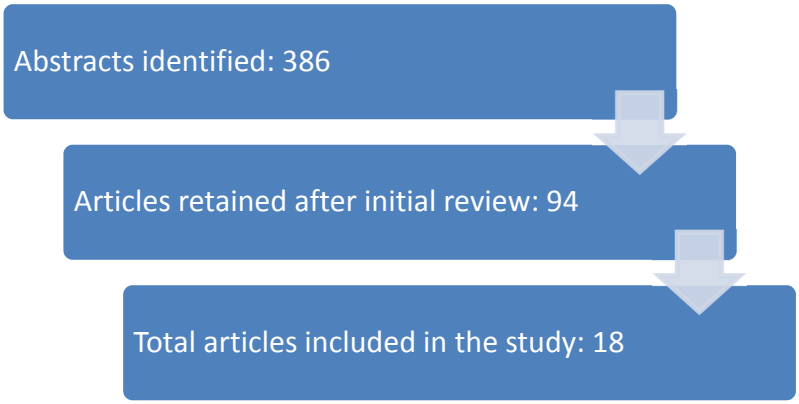

Fig. 1. Diagram of inclusion criteria for evaluated articles

[DOI: 10.47176/mjiri.34.66]

Data abstraction

Andresen has proposed an 11-item criteria for reviewing the tools of disability outcomes research (14). Six criteria (validity, reliability, responsiveness, item/instrument bias and measurement model) have been selected for the purpose of this review (details: Table 1). Each criterion assessed and graded based on the evidence available for persons with SCI. Data related to the measurement model, reliability, validity, and responsiveness of the instruments were summarized by authors. Original papers examined by authors in order to determine if studies have included persons with SCI in the development or examination of the instrument content, as well as study-specific sample characteristics.

Results

Finally, 6 instruments (including 18 related articles) met the inclusion criteria: Incontinence-Activity Participation Scale, Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P), World Health Organization's disability assessment tool-II (WHODAS-II), ICF Measure of Participation and ACTivities Screener (IMPACT-S), Impact on Participation and Autonomy (IPA), and Participation Measure for Post-Acute care (PM-PAC). The reviewed articles were aimed to assess or describe the process that led to the validity and/or psychometric properties of the instruments.

Table 2 presents a summary of each instrument included in the systematic search. Each of the instruments has been designed based on a unique model of disability. In terms of the content, Table 2 demonstrates an overview of the domains mentioned in instruments. All of the instruments assess aspects of mobility (ICF chapter 4), daily activities (related to ICF chapters 5/6), recreation/leisure (related to ICF chapter 9) and work/ education (related to ICF chapter 8). Differences have been found in the types of information asked in the instruments. For example, the I-APS information used to measure activities of daily living and occupation; meanwhile, The USER-P quantifies data for measuring objective and subjective participation (15). All instruments assess aspects of mobility (ICF chapter 4), daily activities (related to ICF chapters 5/6), recreation/leisure (related to ICF chapter 9) and work/ education (related to ICF chapter 8). There are differences in the types of information asked in the six instruments. The I-APS includes questions measuring objective or quantifiable data, for example, "number of times engaged in an activity". In USER-P quantifiable data was analyzed to determine the frequency, perceived satisfaction and perceived restriction. Questions in these instruments require judgment from the respondent, for example asking about restrictions perceived in conducting activities (USER-P). All instruments follow a self-report rule. USER-P also consists of additional questions about perceived satisfaction and restriction in every activity. There was a significant difference in the number of items, ranging from 16 in I-APS to 53 in the PM-PAC, requiring anywhere from 10 to 120min to complete.

All of the instruments were designed for self-report. Three out of six instruments were available in languages other than English (USER-P, WHODAS-II, and IPA). All the instruments include point and percentage in terms of domain scores.

Table 3 provides a specific overview of the participants. The I-APS determined to measure a unique aspect of restriction in participation. The scale was aimed to explore the impact of bladder problems on activity limitation and participation restriction in adults with SCI. This happened by identifying the related ICF chapters and gaining in-depth knowledge through a total of 35 one-to-one interviews. This population consisted of 20 subjects with SCI, 5 caregivers to SCI individuals, and 10 healthcare professionals dealing with SCI patients. Open-ended questions were presented in the form of a semi-structured interview, which probed into the respondent's feelings and opinions regarding the activity limitation and

Table 1. Criteria for evaluating instruments (14)

Criteria	Description	Types	Method
Reliability	The degree to which an instrument is consistent or free from random error	• Test-retest reliability • Internal consistency • comparison with proxy responses	• Test–retest reliability (ICC[1] and K) • Internal consistency (Coefficient α) • Proxy responses (ICC)
Validity	The degree to which an instrument measures what it intends to measure	• Factorial Structure • Convergent correlations • Discriminant groups	Factorial structure (exploratory or confirmatory factor analysis, Rasch analysis) Discriminant (differences by means or %)
Responsiveness	The ability of instrument to measure important changes following intervention (s)	-	Clinical criteria for change
Item/Instrument bias	Assesses in practical terms if individual questions or summary scores are biased for individuals with SCI[2]	-	-
Measurement model	Examines if there are problems with floor effects (lowest level of ability) or ceiling effects (highest level of ability).	-	The instrument has scales or measures where 20% of persons with SCI are grouped at scoring determinations. Also, can demonstratesthe score distribution (mean and standard deviation).

1. Intraclass correlation coefficient
2. Spinal Cord Injury

[DOI: 10.47176/mjiri.34.66]

Table 2. Description of instruments

Instrument	Conceptual Model	Year of Development	Questions	Domains	Mode of Administration	Translated versions	Scoring
I-APS	ICF[1]	2017	16	Activities of daily living; Occupation/education	Self-report	None	Maximum score – 80 Score ≤16: No limitation
IMPACT-S	ICF	2008	32	9 domains according to ICF activities and participation chapters	Self-report	NR[2]	Response categories are scored from 0 (cannot do that at all) to 3 (no limitations whatsoever). All summary scores are converted to a score on a 0 to 100 scale, in which a high score indicates a high level of participation.
WHODASII	ICF	2010	36	understanding and communication, getting around, self-care, getting along with others, life activities, and participation in society	Self-report	NR	Response categories are 0 (no difficulty) to 4 (extreme difficulty/cannot do). Six domain scores and a total disability index can be calculated by converting scores into a score ranging from 0 to 100, in which a lower score demonstrates better participation.
USER-P	ICF	2009	32 items in 3scales; frequency (4*+7**), restrictions (7), satisfaction (10)	chapters 6 through 9 of the ICF	Self-report	Korean	The sum scores of the segregated frequency, restrictions, and satisfaction scales are calculated and converted to a score on a scale ranging from 0 to 100, in which higher scores indicate better levels of participation (higher frequency, fewer restrictions, higher satisfaction).
IPA	ICIDH-2[3]	1999	39	autonomy indoors, autonomy outdoors, family role, social relationships and work and education	Self-report	English, Swedish and German	The items of perceived participation and perceived problems were recorded in 2 different sets of scores, with a range per item of zero to 4 and zero to 2, respectively. A higher score demonstrated greater restriction in participation or greater perceptions of problems in participation.
PM-PAC	ICIDH-2; reconciled with the ICF	2007	53	major life areas/economic life; community, social, and civic participation; mobility	Self-report	NR	7 domain scores and 2 overall scores (social and home; community).The scoring algorithm is not published.

1. International Classification of Diseases, Functioning, and Disability
2. Not reported
3. International Classification of Impairments, Disabilities and Handicaps
*Frequency of behaviors on vocational activities in the last 4 weeks
**Frequency of leisure and social activities in the last 4 weeks

participation restriction due to bladder problems without imposing any bias (16). Participants in the development study of IMPACT-S were survivors of road accidents which were selected from 10 acute care hospitals and rehabilitation facilities (17). USER-P (Utrecht scale for Evaluation of Rehabilitation-Participation) has been developed to fulfill a demand for a generic participation instrument that evaluates both objective and subjective participation in adults living in the community and is applicable in the rehabilitation practice. Therefore, it consists of 3 separate scales: Frequency, Restrictions, and Satisfaction. The study population included adults with SCI and permanent residency in Switzerland (15,18). WHODAS-II developed to enable medical practitioners to conduct cross-cultural comparisons. Therefore, the included items were obtained after identifying how health status is measured in different cultures. This procedure performed using linguistic analysis of every culture in terms of health-related terms, interviews with informants and discussions in the focus group (19). The IPA was developed initially for the Dutch language population. 100 individuals with different disabling conditions were asked from the outpatient facility of the department of rehabilitation of an academic hospital to participate. Items were

[DOI: 10.47176/mjiri.34.66]

Table 3. Description of subjects assessed in studies

Instrument	Country	Number of Subjects (% male)	Age, years (mean, range, SD (if available))	Type of SCI	Time since injury, years (mean, range, SD (if available))
I-APS	India	42 (74)	29.5 Range: 25-46	NR	3.5
IMPACT-S	Netherlands	197 (65.9)	40.4 (18-70)	NR	2.2 (0.9)
WHODASII	Australia	63 (81)	34.7 (SD:14.6)	Paraplegia (21) Tetraplegia (42)	NR
USER-P	Switzerland	1549 (71.5)	52.4 (14.8)	Paraplegia (1063) Tetraplegia (474)	16.9 (12.7)
IPA	Netherlands	100	47.9 (14.6, Range: 23-79)	NR	2 years (range: 2 months-lifetime)
PM-PAC	United States	395 (41)	59.9 (18.2)	NR	NR

Abbreviations: NR, Not reported

Table 4. Reliability of instruments

Instrument	Internal consistency	Test–retest time period	Coefficients	Inter-rater time period
I-APS	0.86 ADL domain= 0.85 Occupation/education= 0.75	NR[1]		NR
IMPACT-S	0.96	4 weeks	Total ICC= 0.94 Knowledge ICC[2]= 0.87 General tasks ICC= 0.72 Communication ICC= 0.75 Mobility ICC= 0.92 Self-care ICC=0.81 Domestic life ICC= 0.86 Interpersonal ICC= 0.86 Major life areas ICC= 0.81 Community life ICC= 0.78 Activities ICC= 0.93 Participation ICC= 0.90	NR
WHODASII	0.95	NR		NR
USER-P	Frequency: 0.65 Restrictions: 0.90 Satisfaction: 0.90	NR		NR
IPA	Perceived participation measure= 0.94 Perceived problems= 0.82	NR		NR
PM-PAC	Mobility= 0.85 Role functioning = 0.83 (29) Community, Social, and Civic Life= 0.89 Domestic Life = 0.76 Economic Life = 0.82 Interpersonal Relationships= 0.72 Communication= 0.79	1–15 days (mean = 4 days, 94% in 1–8 days)	Mobility= 0.85 Role functioning = 0.61 Community, Social, and Civic Life= 0.86 Domestic Life = 0.74 Economic Life = 0.62 Interpersonal Relationships= 0.75 Communication= 0.85	NR

[1]. Not Reported
[2]. Intraclass correlation coefficient

derived based on the descriptions of the 'participation' of the ICIDH-2, clinical expertise of the research team, and qualitative pilot research with adults attending the rehabilitation facility of the Academic Medical Center (AMC) (20). The PM-PAC was designed to measure participation outcomes of rehabilitation practices provided in outpatient or home-care settings. Therefore, PM-PAC developers recruited 395 outpatient rehabilitation patients for psychometric analyses of the instrument (21). Table 4 exhibits the evidence related to the reliability of the participation instruments. All of the instruments were eligible of internal consistency in terms of domains score. Internal consistency for both the IMPACT-S and WHODAS-II were obtained from the person separation index that is similar to internal consistency and were 0.96 and 0.95, respectively. The WHODAS-II had the most evidence with above seven studies assessing test–retest reliability in different populations with disability. The test–retest reliability was higher in the IMPACT-S (ICC=0.94) in comparing with other instruments.

Information regarding validity was available for all of the instruments (Table 5).

All of the instruments (except I-APS) used Rasch analysis in testing the instruments, providing evidence for the factorial structure. Table 6 demonstrates measurement models and item bias for each instrument.

[DOI: 10.47176/mjiri.34.66]

Table 5. Validity of the Participation Instruments

Instrument	Validity--Factorial structure	Validity--convergent correlations	Validity--discriminant groups	Content Validity Index (CVR*)
I-APS	NR	NR	NR	0.84
IMPACT-S	The principal components analysis of the 9 scale scores resulted in 2 components with an eigenvalue above 1.0. A strong first component had an eigenvalue of 5.6 and explained 63.0% of the variance. A weak second component had an eigenvalue of 1.1 and explained 12.9% of the variance.[a]	0.61–0.88. tested by computing Spearman correlations between IMPACT-S and WHODAS-II scales	NR	NR
WHODAS-II	Unidimensionality. Analysis of the 36 items shows that overall items were found to fit the model producing item mean in fit statistics of 0.99 (SD$^{/}$ 0.39) and mean outfit statistics of 1.00 (Sd 0.51) and thus performed satisfactorily. Overall, 86% of the items fit the Rasch measurement model (4)	1 out of 7 hypothesized convergent associations between WHODAS-II and CHART was confirmed (WHODAS II 'self-care" with CHART 'physical') and none of the 6 hypotheized divergent associations were weak enough to present 'no relationship' (r_s<0.20) (4)	The WHODAS-II was able to discriminate between individuals with high and low impairment SCI in terms of getting around, self-care, life activities (household and work) and total score (4)	NR
USER-P	NR, the SCI sample was too small to perform factor analysis (37)	Spearman correlation coefficients between the USER-Participation scales were below 0.60 (range 0.39–0.46), showing that they cover different aspects of participation. Concurrent validity of the USER-Participation was more than 75% (83.3%) of the 24 hypotheses (Spearman correlation coefficients above or below 0.60) with the other measurement instruments were confirmed (24)	Significant differences demonstrated in levels of participation between persons with different health conditions and different levels of functional limitations. Overall, the Restrictions score was sensitive to variations(37)	NR
IPA	Factor analysis with a four-factor solution demonstrated that the structure of subscales would be best interpreted according to the following dimensions of perceived handicap: social relationships, autonomy in self-care, mobility and leisure, and family role (the former subscales family role and financial independence)	NR	The distribution of participants ranged from 2.45 to –6.35 logits. When the whole range of the items is considered in relation to the participant distribution, it shows that persons' perceived participation is not completely covered by the range of the item values, and items that might show differentiatiation ofpersons perceiving most participation are missing	NR
PM-PAC	Confirmatory factor analysis (after excluding 3 items) showed that the data fit a model consisted of seven participation domains as follows: mobility; role functioning; community, social, and civic life; domestic life; economic life; interpersonal relationships; and communication	NR	Pilot tests of known-groups validity indicated that PM-PAC subscales generally variated on the concept of condition severity and underlying ability for mobility	NR

*CVR= Content validity ratio

[a]= One component consisted of Knowledge, General tasks, Communication, Relationships and Major life areas and the other factor included Mobility, Self-care, domestic life and community life.

[b]= tested by computing Spearman correlations between IMPACT-S and WHODAS-II scales

In terms of convergent validity, three out of six instruments (with the exception of the IPA, PM-PAC, and I-APS) were evaluated. Four out of six instruments were assessed in terms of discriminant validity. Various differences detected among the four mentioned.

When one scale contributed to the participation in an instrument (e.g., IPA), ceiling effects became apparent as an issue since a low percentage of participants obtained the best score possible (22). Information regarding responsiveness was available for none of the instruments. Thus, Responsiveness did not mention in the article. The WHODAS-II obtained the most number of supporting

[DOI: 10.47176/mjiri.34.66]

Table 6. Item bias and Measurement models

Instrument	Item bias	Measurement models
I-APS	Items were generated based on the responses of a group including SCI[1] participants, and professionals working with SCI.	NR[2]
IMPACT-S	The first version of IMPACT-S was tested by a small group of road accident survivals (including SCI) and to a panel of rehabilitation professionals	All scale scores of the IMPACT-S, except for the scale Mobility, showed ceiling effects (range 15.2–55.3%). The sub-total scores for Activities and Participation and the total score did not show floor or ceiling effects(38)
WHODAS-II	A number of global studies have been conducted. Over 65000 participants selected from the general participants and from special patient populations were interviewed by educated interviewers who applied the WHODAS 2.0 (with 36 items in its full version and 12 items in a shortened version)	Positive skewness ceiling effect (best score) were obtained for 'understanding and communicating', 'self-care', 'getting along with others', and 'life activities'. major floor effects have not mentioned.
USER-P	NR	No scale showed floor or ceiling effects
IPA	Items were derived based on the 'participation' dimension of the ICIDH-2, using multi-professional field experience, and a minor qualitative pilot study with clients using the services of the rehabilitation department of the Academic Medical Center (not published).	eSignificantfloor (12 persons) and ceiling (15 persons) effects have been found.
PM-PAC	Items were discussed with four focus groups of rehabilitation clients (including persons with SCI) and pilot tests conducted as interviews with eight individuals with disabilities. Feedback from eight rehabilitation research professionals was obtained. Item modifications conducted by using patient and professional feedback.	NR

[1]. Spinal Cord Injury
[2]. Not Reported

evidence in terms of measurement properties. Seven out of eight measurement evaluations obtained a good-to-moderate scale for all categories. Thus, grades were assigned for the mentioned evidence (4,19,23–28). The I-APS and PM-PAC possessed the minimum amount of supportive evidence, with only one and three measurement properties, respectively (16,23,29).

Discussion

While participation counts among the significant outcomes of the rehabilitation practice, it has, however, rarely been selected for measurement (30). This article reviewed six instruments that assess participation in persons with SCI; exploration of each instrument considered critical criteria for measuring participation as an outcome. Instruments counted as a measure tool for participation if their domains included two ICF chapters from 6 to 9, at least. This pragmatic description of participation may not absolutely distinguish the discrimination between activity and participation. With respect to novel guidelines, however, an inventory of activity and participation domains (Titles of ICF chapters) are presented that aid the user with complete, sectional or no overlap within either the domains or sub-domains within each of them. Some participation measurement tools (SCIM III (31), for example) were excluded from this article with regards to this explanation of participation, as they covered questions concerning ICF chapter 4 (Mobility) and chapter 5 (self-care). There were similar instruments such as the Oxford (32) that would comply with the matter of participation if a broader explanation were used. According to ICF, there must be a distinction between activity and participation as they are singular concepts that should be differentiated theoretically and functionally, but the coding structure for both terms is identical (33). Authors of IMPACT-S have defined a comprehensive term for the former parameters as "functioning", which contains physical functioning, body constructions, activity and participation. The latter form of aggregation in redefining concepts would be beneficial for future researches concerning a rehabilitation outcome measurement. "Activity" ascribes as the execution of any action by a person, which defines the individual's tolerance of functioning. "Participation" indicates the contention of a person in any situation of life and exhibits the communal aspect of functioning. According to this manner, disability is supplemental to the functioning and embraces malfunctions or deformities in structure, limitations in activity and restrictions in participation. (17) In the PM-PAC, meanwhile, the team of researchers developing activity and participation measures concluded that activity items would demonstrate concrete task performance that could be seen as being a means to an end. However, participation items would reflect a person's degree of perceived limitation in a particular situation of life, irrespective of the means by which participation takes place (34). Additionally, most instruments are heterogeneous in terms of scales and total scores, namely including items that relate to various ICF chapters; meanwhile, IMPACT (ICF Measure of Participation and ACTivities) was designed as a comprehensive measure to reflect ICF accurately and redefine performance and handicap separate from a health condition (17). However, in the time of designing IMPACT-S items, various sections and domains were classified as too incoherent to be contained in one title. The chapter "mobility", for example, the domain "carrying, moving and handling objects" was counted as heterogeneous. In response, 4 items were constructed to envelop this domain. Then again, 2 do-

[DOI: 10.47176/mjiri.34.66]

mains, "education" and "work/occupation", were combined into one section because only a minor section of study participants are concerned with education (17). This coding structure was weighed for the USER-P, too (18). The World Health organization disability Assessment Scale II (WHODAS II) has developed to evaluate daily performance across 6 domains that correspond with the activities and participation concepts of the International Classification of Functioning, disability and Health (ICF) as a comprehensive model, appropriate for experimentation with different health conditions, in different cultures and nationalities around the world (4). Focusing on the SCI population, the WHODAS II utilized noteworthy features in comparison with other participation measures validated for SCI which employ no subscale structures relevant to components of the ICF (35, 36). IPA depicted as a generic self-reporting inventory, focusing on person-perceived handicaps and autonomy, considering subjective scales as to ascribe meaning to persons' situations (20).

Conclusion

This article explored an in-depth view of 6 participation instruments for people with spinal cord injury, a table describing each instrument in detail, a table providing psychometric properties for each instrument, a table describing participants assessed in the studies, and a table for reliability and validity, individually. The results of this review indicate that subjective participation is emerging as an indicator for determining participation among people with physical disabilities, especially spinal cord injuries. Meanwhile, it has an inconspicuous role in the determinants of existing instruments in the field. In order to determine participation as it relates to ICF, the impression of subjective participation should be elevated in the future studies that aim to evaluate participation or develop instruments for that purpose. Participation items included in the instruments represent different aspects of an ICF chapter; therefore, they should be prescribed based on a careful examination of the person's type of injury, condition and context. Meanwhile, participation instruments must be constructed based on current definitions of disability, pragmatic comparisons with previously developed instruments, and modern measurement technologies that fill the gap between the perceived participation of the individual and examiner's record. Rehabilitation clinician-scientists are encouraged to select the proper instrument based on their research focus and related evidence-based practice. Furthermore, the respected concept of subjective participation should get proper consideration in persons with severe conditions. Due to the low resources in the literature regarding subjective participation, various aspects of this concept, such as expectation, satisfaction and fulfillment should get addressed in any future effort trying to explore and deploy the conceptualization and evaluation of participation in persons with serious physical disabilities. Future studies should also look for cues that result in a more subtle and comprehensive explanation of participation.

In this review, the lack of knowledge and information about environmental factors in different countries and cultures was the most prominent blind spot that did not observed meanwhile in reviewed articles. Finally, the strong point of the reviewed instruments was allegiance to the ICF and their growing interest in dissecting the concepts in it, which leads to defining novel concepts that complement previous agreements.

Acknowledgment

This research was funded by the University of Social Welfare and Rehabilitation. We acknowledge all the colleagues and members of the research and analysis team.

Conflict of Interests

The authors declare that they have no competing interests.

References

1. Church RL, Marston JR. Measuring Accessibility for People with a Disability. Geogr Anal [Internet]. 2003;35(1):83–96. Available from: http://doi.wiley.com/10.1111/j.1538-4632.2003.tb01102.x
2. Heinemann AW. Measurement of participation in rehabilitation research. Arch Phys Med Rehabil [Internet]. Elsevier Inc.; 2010;91(9 SUPPL.):S1–4. Available from: http://dx.doi.org/10.1016/j.apmr.2009.08.155
3. Organization WH. World Health Organization International Classification of Functioning, Disability and Health. Geneva: World Health Organization. 2010. Rejected Body Fem Philos Reflections Disabil. 2013;(October):19–22.
4. De Wolf AC, Tate RL, Lannin NA, Middleton J, Lane-Brown A, Cameron ID. The world health or ganizati on disability assessment scale, WHODAS II: Reliability and validity in the measurement of activity and participati on in a spinal cord injury population. J Rehabil Med. 2012;44(9):747–55.
5. Magasi S, Post MW. A comparative review of contemporary participation measures' psychometric properties and content coverage. Arch Phys Med Rehabil [Internet]. Elsevier Inc.; 2010;91(9 SUPPL.):S17–28. Available from: http://dx.doi.org/10.1016/j.apmr.2010.07.011
6. Chiodo AE, Scelza WM, Kirshblum SC, Wuermser L-A, Ho CH, Priebe MM. Spinal Cord Injury Medicine. 5. Long-Term Medical Issues and Health Maintenance. Arch Phys Med Rehabil [Internet]. W.B. Saunders; 2007 Mar 1 [cited 2019 Apr 25];88(3):S76–83. Available from: https://www.sciencedirect.com/science/article/pii/S000399930601570X
7. Dijkers M. Quality of life after spinal cord injury: a meta analysis of the effects of disablement components. Spinal Cord 1997 3512 [Internet]. Nature Publishing Group; 1997 Dec 4 [cited 2019 Apr 25];35(12):829. Available from: http://www.nature.com/articles/3100571
8. Whalley Hammell K. Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. Spinal Cord [Internet]. Nature Publishing Group; 2007 Feb 7 [cited 2019 Apr 25];45(2):124–39. Available from: http://www.nature.com/articles/3101992
9. Schönherr MC, Groothoff JW, Mulder GA, Eisma WH. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. Spinal Cord [Internet]. Nature Publishing Group; 2005 Apr 9 [cited 2019 Apr 25];43(4):241–8. Available from: http://www.nature.com/articles/3101683
10. World Health Organization. World Report on Disability 2011. Easy read. [Internet]. Vol. 377, World Health Organization. 2011 [cited 2019 Apr 15]. p. 1977. Available from: https://www.who.int/disabilities/world_report/2011/report/en/
11. Brown M. Participation: The insider's perspective. Arch Phys Med Rehabil [Internet]. Elsevier Inc.; 2010;91(9 SUPPL.):S34–7. Available from: http://dx.doi.org/10.1016/j.apmr.2009.11.030
12. Morley D, Dummett S, Kelly L, Dawson J, Fitzpatrick R, Jenkinson C. Validation of the Oxford Participation and Activities Questionnaire. Patient Relat Outcome Meas [Internet]. 2016 Jun [cited 2019 Feb 14];7:73. Available from: http://www.ncbi.nlm.nih.gov/

[DOI: 10.47176/mjiri.34.66]

pubmed/27366108
13. Van De Velde D, Coorevits P, Sabbe L, De Baets S, Bracke P, Van Hove G, et al. Measuring participation as defined by the World Health Organization in the International Classification of Functioning, Disability and Health. Psychometric properties of the Ghent Participation Scale. Clin Rehabil. SAGE Publications Ltd; 2017 Mar 1;31(3):379–93.
14. Andresen EM. Criteria for assessing the tools of disability outcomes research. Arch Phys Med Rehabil. 2000;81(12 SUPPL. 2):15–20.
15. Post MWM, van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JMA, van Berlekom SB. Validity of the Utrecht Scale for Evaluation of Rehabilitation-Participation. Disabil Rehabil [Internet]. 2012 Mar 6 [cited 2019 Mar 5];34(6):478–85. Available from: http://www.ncbi.nlm.nih.gov/pubmed/21978031
16. Walia P, Kaur J. Development and validation of Incontinence - Activity Participation Scale for spinal cord injury. Indian J Urol [Internet]. Medknow Publications and Media Pvt. Ltd.; 2017 [cited 2019 Feb 14];33(2):159. Available from: http://www.ncbi.nlm.nih.gov/pubmed/28469306
17. Post MWM, de Witte LP, Reichrath E, Verdonschot MM, Wijlhuizen GJ, Perenboom RJM. Development and validation of impact-s, an ICF-based questionnaire to measure activities and participation. J Rehabil Med. 2008;40(8):620–7.
18. Mader L, Post MWM, Ballert CS, Michel G, Stucki G, Brinkhof MWG. Metric properties of the utrecht scale for evaluation of rehabilitation-participation (user-participation) in persons with spinal cord injury living in Switzerland. J Rehabil Med. 2016;48(2):165–74.
19. Üstün TB, Chatterji S, Kostanjsek N, Rehm J, Kennedy C, Epping-Jordan J, et al. Developing the World Health Organization disability assessment schedule 2.0. Bull World Health Organ [Internet]. World Health Organization; 2010 [cited 2019 Feb 28];88:815–23. Available from: https://www.scielosp.org/scielo.php?pid=S0042-96862010001100010&script=sci_abstract&tlng=fr
20. de Haan RJ, van den Bos GAM, de Groot IJM, Cardol M, de Jong BA. The development of a handicap assessment questionnaire: the Impact on Participation and Autonomy (IPA). Clin Rehabil. 2003;13(5):411–9.
21. Walia P, Kaur J. Development and validation of Incontinence - Activity Participation Scale for spinal cord injury. Indian J Urol. 2017;33(2):159.
22. Lund ML, Fisher AG, Lexell J, Bernspång B. Impact on participation and autonomy questionnaire: Internal scale validity of the Swedish version for use in people with spinal cord injury. J Rehabil Med. 2007;39(2):156–62.
23. Noonan VK, Kopec JA, Noreau L, Singer J, Mâsse LC, Zhang H, et al. Comparing the validity of five participation instruments in persons with spinal conditions. J Rehabil Med. 2010;42(8):724–34.
24. Van Der Zee CH, Post MW, Brinkhof MW, Wagenaar RC. Comparison of the Utrecht scale for evaluation of rehabilitation-participation with the ICF measure of participation and activities screener and the WHO disability assessment schedule ii in persons with spinal cord injury. Arch Phys Med Rehabil. 2014;95(1):87–93.
25. Noonan VK, Kopec JA, Noreau L, Singer J, Mâsse LC, Zhang H, et al. Comparing the validity of five participation instruments in persons with spinal conditions. J Rehabil Med. 2010;42(8):724–34.
26. Magistrale G, Pisani V, Argento O, Incerti CC, Bozzali M, Cadavid D, et al. Validation of the World Health Organization Disability Assessment Schedule II (WfHODAS-II) in patients with multiple sclerosis. Mult Scler J [Internet]. SAGE PublicationsSage UK: London, England; 2015 Apr 4 [cited 2019 Apr 9];21(4):448–56. Available from: http://journals.sagepub.com/doi/10.1177/1352458514543732
27. Garin O, Ayuso-Mateos J, Almansa J, Nieto M, Chatterji S, Vilagut G, et al. Validation of the "World Health Organization Disability Assessment Schedule, WHODAS-2" in patients with chronic diseases. Health Qual Life Outcomes [Internet]. BioMed Central; 2010 May 19 [cited 2019 Apr 9];8(1):51. Available from: http://hqlo.biomedcentral.com/articles/10.1186/1477-7525-8-51
28. Kutlay Ş, Küçükdeveci AA, Elhan AH, Öztuna D, Koç N, Tennant A. Validation of the World Health Organization disability assessment schedule II (WHODAS-II) in patients with osteoarthritis. Rheumatol Int [Internet]. Springer-Verlag; 2011 Mar 18 [cited 2019 Mar 31];31(3):339–46. Available from: http://link.springer.com/10.1007/s00296-009-1306-8
29. Gandek B, Sinclair SJ, Jette AM, Ware JE. Development and initial psychometric evaluation of the Participation Measure for Post-Acute Care (PM-PAC). Am J Phys Med Rehabil. 2007;86(1):57–71.
30. Hall K, Dijkers M, Whiteneck G, Brooks CA, Krause JS. The Craig Handicap Assessment and Reporting Technique (CHART): Metric Properties and Scoring. Top Spinal Cord Inj Rehabil [Internet]. Thomas Land Publishers Inc. ; 1998 Jul 1 [cited 2019 Apr 13];4(1):16–30. Available from: http://archive.scijournal.com/doi/abs/10.1310/V5RU-FRFE-50E6-E2NA
31. Itzkovich M, Gelernter I, Biering-Sorensen F, Weeks C, Laramee MT, Craven BC, et al. The Spinal Cord Independence Measure (SCIM) version III: Reliability and validity in a multi-center international study. Disabil Rehabil [Internet]. Taylor & Francis; 2007 Jan 7 [cited 2019 Apr 14];29(24):1926–33. Available from: http://www.tandfonline.com/doi/full/10.1080/09638280601046302
32. Kelly L, Morley D, Dawson J, Fitzpatrick R, Jenkinson C, Dummet S. Development of the Oxford Participation and Activities Questionnaire: constructing an item pool. Patient Relat Outcome Meas [Internet]. 2015 May;145. Available from: http://www.dovepress.com/development-of-the-oxford-participation-and-activities-questionnaire-c-peer-reviewed-article-PROM
33. Whiteneck G, Dijkers MP. Difficult to Measure Constructs: Conceptual and Methodological Issues Concerning Participation and Environmental Factors. Arch Phys Med Rehabil [Internet]. Elsevier Inc.; 2009;90(11 SUPPL. 1):S22–35. Available from: http://dx.doi.org/10.1016/j.apmr.2009.06.009
34. Jette AM, Haley SM, Kooyoomjian JT. Are the ICF activity and participation dimensions distinct? J Rehabil Med. 2003;35(3):145–9.
35. Heinemann AW, Tulsky D, Dijkers M, Brown M, Magasi S, Gordon W, et al. Issues in participation measurement in research and clinical applications. Arch Phys Med Rehabil [Internet]. Elsevier Inc.; 2010;91(9 SUPPL.):S72–6. Available from: http://dx.doi.org/10.1016/j.apmr.2009.11.031
36. Noonan VK, Miller WC, Noreau L. A review of instruments assessing participation in persons with spinal cord injury. Spinal Cord [Internet]. Nature Publishing Group; 2009;47(6):435–46. Available from: http://dx.doi.org/10.1038/sc.2008.171
37. Van Der Zee C. Measuring participation outcomes in rehabilitation medicine [Internet]. 2013. 1-168 p. Available from: https://dspace.library.uu.nl/bitstream/handle/1874/279587/van_der_zee.pdf?sequence=2&isAllowed=y
38. Van Der Zee CH, Priesterbach AR, Van Dussen L Der, Kap A, Schepers VPM, Visser-Meily JMA, et al. Reproducibility of three self-report participation measures: The icf measure of participation and activities screener, the participation scale, and the utrecht scale for evaluation of rehabilitation-participation. J Rehabil Med. 2010;42(8):752–7.

[DOI: 10.47176/mjiri.34.66]