Measurement properties of a modified measure of participation for persons with spinal cord injury

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Objective: The primary aim of this study was to examine and refine a modified measure of participation for adults with spinal cord injury (SCI) based on a conceptual model of participation.

Method: This study involved secondary analysis of data from a larger study designed to identify a standard measure of participation for use in SCI research. The larger study recruited 634 community-dwelling adults with SCI from seven collaborating SCI Model Systems Centers, of whom 520 subjects (average age 45.1 ± 13.6 years, 76% were male) completed the survey that is the focus of the present analysis. Content review, confirmatory factor analysis (CFA), Rasch analysis, and precision analysis were employed to select the items for the modified participation measure.

Results: Three participation domains were supported: Productivity, Social, and Community, that displayed good model-fit (CFI=0.984, TLI=0.982, RMSEA=0.043) in CFA and good item-fit (infit= 0.6 to 1.4) in Rasch analysis. Differential Item Functioning (DIF) was found in one item, however its magnitude was small. The precision of each scale was better for participants in the middle range of participation and was lower for participants with extremely low or high participation.

Conclusion: The study results support the proposed three-dimensional construct of participation by demonstrating good model-fit and item-fit. Ongoing efforts are needed to expand the domain coverage and increase the precision of the instrument.

Keywords: Social participation, Spinal cord injuries, Factor analysis, Outcome assessment

Introduction

Improved participation is one of the primary rehabilitation goals for people with disabilities, including spinal cord injury (SCI). SCI is a life-altering event that can dramatically change a person's physical functioning, independence and emotional health. In 2014, the National Spinal Cord Injury Statistical Center estimated that about 276,000 persons in the U.S. were living with SCI, and approximately 12,500 new cases of SCI are reported each year.¹ After the injury, an individual's participation in various life areas may be restricted, and participation restrictions have been shown to

directly influence the physical and mental health and quality of life of people with SCI.^{2,3} Monitoring the extent and nature of restrictions in participation of individuals with SCI is therefore crucial for both rehabilitation practice and policy guidance.

Despite the importance of participation, there is a paucity of appropriate instruments specifically designed for measuring participation in people with SCI.⁴ A recent review of participation measures indicates that the most high-quality and commonly used participation measures in SCI studies include: the Craig Handicap Scale and Reporting Technique (CHART),⁵ Assessment of Life Habits (LIFE-H),⁶ and the Impact on Participation and Autonomy (IPA).^{4,7} Each of these instruments has important limitations. For

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example, both the CHART and the LIFE-H have a ceiling effect in high functioning adults with SCI, while the IPA showed both floor and ceiling effects.⁴ Another significant issue is that there is no agreement on the content areas measured by these instruments. In fact, like many other participation instruments, all these measures cover different domains of participation. For example, the CHART measures six International Classification of Impairments, Disabilities and Handicaps (ICIDH) dimensions of handicap, and the LIFE-H assesses 12 categories of life habits.^{5,6} Moreover, none of these instruments solely measure participation. All include items at the activity level, such as eating meals, mobility and communication, or other areas not considered to be in the domain of participation, such as nutrition and sleep. Such conceptual uncertainty raises questions regarding the content validity and the utility of these instruments.

The National Institute of Neurological Disorders and Stroke (NINDS) has developed the Common Data Elements (CDEs) for SCI, which incorporates recommendations of assessment tools for measuring participation and quality of life.⁸ However, except for the CHART, the recommended instruments, such as the Life Satisfaction Questionnaire and Quality of Life Index (QLI), focus on measuring individuals' global quality of life/ life satisfaction,⁸ which is empirically related to participation but conceptually distinct from objective measures of participation performance and subjective satisfaction with participation.⁹

Beyond these instruments, a number of others have been developed to measure participation, some of which demonstrate good measurement quality.^{4,10} However, most of these instruments fail to clearly define the construct of participation, with the result that instruments purporting to measure participation end up yielding significantly different findings and lead to conceptual confusion.¹⁰ In addition, most of these instruments were not specifically developed for the SCI population and, as a result, their applicability for people with SCI needs to be examined.⁴

One such measure is the Participation Measure for Post-Acute Care (PM-PAC), which was designed to measure participation outcomes of rehabilitation services provided in community-based settings.¹¹ PM-PAC contains 51 self-reported items, which cover nine participation domains outlined in the International Classification of Functioning, Disability and Health (ICF).¹² The items of the PM-PAC were generated from focus groups of rehabilitation patients (including people with spinal cord injury). Initial psychometric analyses showed that the PM-PAC item set had

promising accuracy, precision, and test-retest reliability.¹¹ Item response theory (IRT) was used to enhance the measurement. In addition, exploratory factor analysis (EFA) extracted two subscales from the PM-PAC item set: community participation (including mobility, role functioning, and social and civic activities) and social and home participation (including domestic life, interpersonal relationships, economic life, and communication).¹¹ Although the PM-PAC was not specifically developed for people with SCI, its reliability and validity have been tested in persons with spinal conditions (including people with SCI) in comparison with other participation measures.^{13,14} In these studies, the PM-PAC showed generally good reliability and validity but significant ceiling effects. In addition, like a number of other participation instruments, while the PM-PAC used the ICF as its foundation to develop the item pool, it was limited by the absence of a clear conceptual model to define the distinct areas of participation. Thus, it is unclear why the items were grouped as they were and what the summary scores represent.

In response to critique of the ICF's failure to provide a clear conceptual model of participation, Chang and Coster¹⁵ recently proposed a three domain conceptual model for the construct of participation: Productivity, Social, and Community, with discrete subdomains under each. This model defines participation as: "active involvement in activities that are intrinsically social and occur in a societally-defined context."^{15(p1792)} and, by recognizing the multidimensionality of participation, encourages researchers and clinicians to examine an individual's participation in distinct domains. This model has been suggested as a guide for measurement development, and is used in this study to refine the construct of the PM-PAC. Accordingly, the purpose of the current study was to (1) examine and refine the construct of the PM-PAC based on the Chang and Coster model of participation, (2) evaluate the floor and ceiling effects, content validity, item functioning, and precision of the modified PM-PAC measure in adults with SCI.

Methods

Design and participants

This study involved secondary analysis of data collected between April 2007 and August 2008 on a sample drawn from the SCI Model Systems (SCIMS) National Database, as a supplement to the SCIMS routine telephone data collection using a battery of items that included the PM-PAC.

Subjects included in the SCIMS database were individuals who received their initial inpatient rehabilitation

for new traumatic SCI at one of 14 SCIMS Centers located across the US. The subjects were interviewed when they received their SCIMS routine telephone (or in-person) interviews on the 1st, 5th, 10th, 15th, 20th, 25th, or 30th anniversary of injury.

Eligible participants had to meet the following inclusion criteria: (1) must have had a clinically discernible degree of neurologic deficit; (2) must reside in the geographic catchment area of the SCIMS; (3) must be a U.S. citizen or permanent resident; and (4) must have sustained a SCI due to a traumatic event. All subjects provided informed consent according to protocols approved by the institutional review boards of the SCIMS Center at which they enrolled.

Overall, 520 subjects from five centers (located in Colorado, Georgia, Michigan, New Jersey, and Massachusetts) completed the supplemental instrument battery along with the survey used in the core SCIMS National Database and they compose the sample used for the current study.

Instruments

Participation measure for post-acute care (PM-PAC)

The PM-PAC was developed to measure a person's degree of perceived participation restriction in nine areas: mobility, work, education, economic life, role functioning, domestic life, community, social and civic life, interpersonal relationships, and communication.¹¹

The PM-PAC we used in this study is the 51-item paper version, which takes on average about 15 minutes to complete. Most of the PM-PAC items ask respondents to rate the extent to which they are currently limited in a life situation, using a five-category response scale: 1, not at all limited; 2, a little; 3, somewhat limited; 4, very much limited; and 5, extremely limited. The word "limited" was chosen to capture the experience of restrictions arising from both personal and environmental barriers to participation. Some items measure the frequency of participation (1, Every day to 5, Never); some measure the degree of satisfaction (1, Very satisfied to 5, Very dissatisfied).

IRT methods were applied to develop the PM-PAC which allows PM-PAC scores to be computed from the measure including items that may not be relevant to all respondents (i.e. voting in elections).¹¹

Content review

Each of the 51 PM-PAC items were reviewed independently by two researchers and items were excluded if they did not fit the definition of participation as outlined in Chang and Coster's participation model: "active involvement in activities that are intrinsically social

and occur in a societally-defined context."^{15(p1792)} For example, items such as "How much are you currently limited in: Watching or listening to television and radio?" and "exercising?" did not fit the Chang and Coster definition of participation and so were eliminated from the item set. Some items were too broad and hard to define. For example, an item "how much are you currently limited in: getting around your home?" was unclear, that is, it was uncertain whether "getting around your home" is "intrinsically social" or not. Therefore, we eliminated those items. Additionally, since the majority of the items were measuring the extent of one's participation limitations, we decided to focus on this dimension and excluded items that measured degree of satisfaction (very satisfied–very dissatisfied) or frequency (everyday–never). The remaining items measured the extent of participation limitations using a five-category response scale (1: not at all limited to 5: extremely limited), in which higher score indicates more restrictions of participation. Based on the results of the content review, 31 items were excluded, and 20 items were retained for further analysis. The remaining 20 items were classified into three types of participation using the conceptual model: Productivity (work and school-related participation), Social (structured and unstructured social participation), and Community (public affairs, using/purchasing services, recreation and leisure, and religious participation). Two measurement and rehabilitation experts reviewed the final set of items independently and provided 100% agreement regarding the content of the measure.

Data analysis

Floor and ceiling effects

The floor and ceiling effects were evaluated by calculating the percent at the floor and ceiling using the response data at the participant level. Within each of the domains, participants who responded at the highest category (5: extremely limited) for all of the items were grouped at the ceiling; those who responded at the lowest category (1: not at all limited) for all of the items were grouped at the floor.

Confirmatory factor analysis (CFA)

To examine the measure's content validity, a 3-factor model CFA was employed to test model-data fit. The criteria for acceptable fit included the comparative fit index (CFI) and Tucker-Lewis Index (TLI) >0.90 and root mean square error of approximation (RMSEA) < 0.80.¹⁶ Item fit for each item was also examined using individual parameter estimates calculated in the CFA to reflect the correlations between the item and the

latent variable. Items that explained no or low variance (squared item loadings < 0.30) were considered for elimination from the model.

Rasch analysis

Rasch unidimensional partial credit model was used to calibrate the items of each scale in a common unit. Infit and outfit statistics were examined and any item with fit statistics below 0.7 or beyond 1.4 was flagged for misfit.¹⁷ The Rasch model generated a logit score to transform the ordinal scale to an interval scale. The logit scores represented item difficulty and enabled the items and person abilities (likelihood of endorsing a higher level of participation) to be compared on the same scale.

Differential Item Functioning (DIF) analysis investigated invariance of the Rasch-based item difficulty estimates. DIF analysis is used to detect significant differences in measurement properties for a given subgroup. In this study we examined age (split at median), sex, and SCI characteristics (lesion level: paraplegia vs. tetraplegia and completeness: complete vs. incomplete). The level of significance for DIF was Bonferroni-adjusted for multiple comparisons. Items with significant DIF were further evaluated for impact by considering the weighted area between the expected score curves (“wABC”). For each subgroup, we calculated the subgroup specific wABC by averaging the absolute difference in area between item characteristic curves weighted by the sub-group score distribution. The final wABC reported in this paper was the average of the subgroup specific wABCs weighted by the sample proportions. Items with five response categories with wABC values greater than 0.30 were considered potentially problematic.¹⁸

We evaluated precision of the measure by calculating the person score standard errors. Based on the sample score variance, we also calculated the criterion standard error:

$$\text{Standard error} = \sqrt{\text{Variance} * (1 - \text{reliability})},$$

which corresponds to certain reliability levels (i.e. reliability level=0.7 or 0.8).

Results

The demographic characteristics of the study samples are summarized in Table 1.

Floor and ceiling effects

No participants scored at the ceiling in any domain, while some floor effect was found in each domain:

9.62% of the participants were at floor for Productivity, 21.5% of the participants were at floor for Social, and 13.46% of the participants were at floor for Community.

Confirmatory factor analysis (CFA)

The CFA results suggested that the item “working with others on class projects or assignments” was problematic since its residual variance was negative. Moreover, two items in the Productivity domain (“advancing in your work or getting promoted” and “completing educational requirements”), one item in the Social domain (“socializing with students and teachers”) and one item in the Productivity domain (“getting the training you need for work”) were highly overlapping in item estimates, respectively. Options considered were either to merge the items or to drop one of the two overlapping items. After reviewing the participants’ response distribution, we decided to drop “completing educational requirements” and “socializing with students and teachers.” A greater proportion of the participants reported these two items “not applicable” to them, which made them less informative in the scale and hard to combine with another item.

With the retained 17 items, we re-ran the CFA. The 3-factor model showed good model-fit (CFI=0.984, TLI=0.982, RMSEA=0.043). The correlations between the three factors ranged from 0.44 to 0.55. The factor loading estimates for each item are shown in Table 2. All of the loadings were significant ($P < 0.001$).

Item fit

The item statistics derived from Rasch analysis are summarized in Table 2. In regard to the unidimensionality of each domain, all of the items remaining in the final item set showed good item fit (infit= 0.6 to 1.4), except for one item in the community domain (C7. going to parks or other outdoor recreational areas), which showed borderline misfit (infit=1.58). However, since the infit value was borderline and the content was critical, we decided to retain it.

Differential item functioning

Across all comparisons in each scale, the Rasch DIF methods only identified one social item (S4. socialize with others, like going out or visiting with family and friends) that demonstrated DIF by complete/ incomplete injury. Nonetheless, the DIF impact of this item was relatively small (wABC=0.27, below the 0.30 threshold), which suggests that the item may not need to be eliminated.

Table 1 Demographic characteristics (N=520)

Variable	N (%)
Age	Mean $\pm$ SD = 45.1 $\pm$ 13.6
Year(s) since injury	Mean $\pm$ SD = 14.40 $\pm$ 10.38
Sex	
Male	393 (76.0)
Female	124 (24.0)
Marital status	
Married	195 (38.1)
Single	317 (61.9)
Race/ethnicity	
White	457 (88.4)
Black	47 (9.1)
Other	13 (2.5)
Education	
Less than high school	32 (6.3)
High school graduate	247 (48.3)
Some college or college graduate	232 (45.4)
Neurologic Impairment	
Incomplete paraplegia	91 (17.6)
Complete paraplegia	146 (28.2)
Incomplete tetraplegia	154 (29.8)
Complete tetraplegia	122 (23.6)
ASIA Impairment Scale	
Incomplete – Preserved Sensation Only (Frankel Grade B)	52 (10.2)
Incomplete – Preserved Motor – Non-functional (Frankel Grade C)	70 (13.7)
Incomplete, Preserved Motor – Functional (Frankel Grade D)	122 (23.8)
Complete (Frankel Grade A)	268 (52.3)
Place of Residence	
Private Residence	486 (94.0)
Hospital	5 (1.0)
Nursing home	13 (2.5)
Group Living Situation	12 (2.3)
Hotel/motel	1 (0.2)

Precision

The precision analysis results of the three scales are shown in Figure 1. For all three scales, precision was highest when the logit score was close to 0, as indicated by standard errors. Comparing the results to the criterion standard error, 52% of the subjects had score reliability >0.7 , and 44% of the subjects had score reliability >0.8 in Productivity; in Social, 65% of the subjects had score reliability >0.7 , and 38% of the subjects had score reliability >0.8 ; and there were 67% of the subjects with score reliability >0.7 , and 66% of the subjects with score reliability >0.8 in Community.

Discussion

Over the last two decades, the goal of rehabilitation programs for individuals with SCI has shifted from medical management to enhancing societal participation, which is conceived as the result of the interaction between the individual and his/her environment in the ICF.¹² Although the introduction of the ICF has led to greater attention to and a better understanding of participation, measurement development work has been restricted by the conceptual ambiguity resulting from the unclear distinction between activity and

participation.⁹ To address the need for a clear construct that specifies the content areas of participation, Chang and Coster¹⁵ proposed a conceptual model of participation to provide a consistent guidance for measurement selection and development. The Chang and Coster model put forth two guiding principles also advocated by previous researchers^{12,17}: (1) participation is intrinsically social and occurs in a socially-defined context, and (2) participation is composed of three distinct domains labeled Productivity, Social, and Community.¹³ The current study applied this model to examine the content of the PM-PAC, to refine its content and structure and evaluate its measurement properties in people with SCI.

While no ceiling effect was observed in any domain of PM-PAC, some floor effect was found in the Social domain: 21.5% of the participants responded “1: not at all limited” for the social items. This finding is similar to results from a previous study, in which a great proportion of participants with spinal conditions reported “no difficulty of participation” for the majority of the PM-PAC subdomains, including items measuring interpersonal relationships.¹⁴ Our finding is not surprising since people with SCI usually do not have impaired

Table 2 Item statistics for the final item set (17 items)

Items To what extent are you currently limited in...	Factor loading	Mean threshold	S.E.	Infit	Outfit
Productivity (5 items)					
P4. Working as much as you would like?	0.72	0.85	0.14	1.01	0.91
P3. Doing the kind of work that you would like?	0.78	0.23	0.12	0.93	0.82
P1. Having the flexibility you need to get the work done?	0.71	0.03	0.11	1.17	1.15
P2. Getting the training you need for work?	0.84	-0.49	0.10	0.74	0.71
P5. Advancing in your work or getting promoted?	0.77	-0.62	0.12	1.25	1.18
Social (5 items)					
S2. Keeping in touch with others through letters, e-mail, or internet chat groups?	0.69	1.46	0.11	0.91	0.83
S3. Keeping in touch with others by phone or TTY?	0.71	0.34	0.07	1.01	0.77
S1. Getting together with family or friends in your home?	0.67	0.28	0.08	0.98	1.78
S5. Visiting with family or friends in their homes?	0.73	-0.92	0.07	1.18	1.15
S4. Think about how you currently socialize with others, like going out or visiting with family and friends. Which of the following best describes you?*	0.75	-1.15	0.06	0.88	0.86
Community (7 items)					
C5. Doing recreational or leisure activities?	0.76	0.93	0.09	1.15	1.23
C6. Going to movies, plays, concerts, sporting events, museums, or similar activities?	0.85	0.60	0.09	0.85	0.60
C7. Going to parks or other outdoor recreational areas?	0.60	0.08	0.07	1.58	2.11
C4. Taking part in professional, civic, political, or community groups?	0.90	-0.07	0.07	0.71	0.64
C2. Voting in elections?	0.89	-0.17	0.07	0.75	0.71
C3. Taking part in religious or spiritual activities?	0.90	-0.18	0.07	0.76	0.75
C1. Taking into account any help or services that are available to you, how much are you currently limited in: Getting groceries or other things for your home?	0.74	-1.19	0.07	1.21	1.19

The mean thresholds are shown in logit scores: the higher the logit score the easier the activity for a person to participate in (i.e., less limitations).

*The response options for S4 are: 1=I do not have difficulty doing things socially; 2=I maintain my usual pattern of social activities, despite some difficulties; 3=I am somewhat restricted in the amount or type of social activities I do; 4=I am very restricted in the amount or type of social activities I do; and 5=I do not see family or friends, and I only see those who provide care for me.

cognition or communication functioning that might severely affect one's social interactions. However, this substantial floor effect may limit the usefulness of the measure to assess change or improvement in social participation in the SCI population. Future research should investigate whether it would be possible to add items that are more sensitive to differences in this domain at the lower end of the scale.

The CFA results provide validation of the three-dimensional construct of participation in Chang and Coster's model,¹⁵ and the Rasch analysis results also supported the unidimensionality of items within each domain. The Productivity domain contains work-related items; the Social domain covers content related to socializing with friends and family; the Community domain includes recreational, religious, civic, and other community activities. This result is in agreement with Chang and Coster's model of participation. However, some of the subdomains outlined in the model were not represented in the original PM-PAC item set and thus could not be included in the current measure. For example, beyond work-related domains, Productivity also encompasses "parenting and caregiving," which is particularly important for individuals who are a parent or a caregiver in the family.

Furthermore, two school/education-relevant items were dropped based on the CFA results. As a result, the measure only addressed work-related activities and did not capture participation in other Productivity areas. The limited scope of Productivity could limit the applicability of this measure. Future progress in participation measurement development should consider expanding the item set for broader domain coverage.

The Rasch analysis results showed that the items retained in the final dataset demonstrated good item fit. That is, the items within each domain had adequate probabilistic relationships. Although one item in the Social domain demonstrated DIF between participants with different completeness of injury, its impact was negligible and thus the item did not need to be eliminated. The DIF analysis results are particularly crucial for the SCI population since the findings imply that the items retained in the instrument function the same way for people with different levels of injury, as well as for different sex and age groups.

The Rasch model also demonstrated a hierarchy for the items in each scale. For example, for people who reported the highest restriction of participation in Productivity, the easiest item "Working as much as you would like" would be informative, while

Figure 1 Precision analysis results of (A) Productivity, (B) Social, and (C) Community scales.

“Advancing in your work or getting promoted” would be less informative. In comparison, the most productive people would be more likely to endorse the “working as much as they like” item, making it less informative for them. While there are debates in the literature about whether participation encompasses a hierarchical structure,¹² our findings suggest that it is possible to identify

a hierarchical order within each of the participation domains examined in this study. As the Productivity domain is expanded to include items related to school and homemaking, it will be interesting to see if a hierarchy remains, or whether personal preference plays a larger role. More discussion will also be needed to explore whether these hierarchies are sensible, and what factors are contributing to these response patterns.

The precision analysis results indicated that the precision of each scale was better for participants with the middle range of ability (with logit score close to 0). As is typical in Rasch analysis, the standard error was higher at the extreme ends of each scale, which indicates that the precision was lower for participants with extreme low or high extent of restriction. The relatively small number of items within each scale may contribute to a lower degree of precision. This is a limitation that is commonly seen in fixed-length instruments. While the fixed-length instruments address practical considerations such as lessening administration burden, the brevity of the measure is usually achieved by concentrating items at a certain level of a construct instead of across the full range of a domain, which reduces precision.¹¹ To overcome this limitation, contemporary measurement approaches such as computerized adaptive testing (CAT) can be adopted. A CAT-based measure contains a large item bank which includes items across diverse difficulty levels.¹⁹ The CAT uses a computer algorithm to select and administer a small set of items that are targeted to the individual’s estimated level of the underlying trait or construct. This approach has demonstrated strengths in significantly reducing assessment time while maintaining good precision.¹⁹ A CAT version of the modified PM-PAC, with additional items to provide broader coverage, could be useful.

The current study has several limitations. First, the study involves a secondary analysis and item content was fixed so that the measurement refinement work was done under this restriction. Therefore, some of the subdomains of participation (e.g. parenting/caregiving and education in Productivity) that were not covered by the original PM-PAC also could not be included in the modified measure. Further work will be needed to address this limitation by expanding the item bank to enhance the domain coverage of the instrument. Second, the study only involved cross-sectional data. More validation work will be needed with longitudinal data to test the reliability and validity, including responsiveness to change. The revised instrument only focused on measuring limitations in participation. Additional scales that address dimensions such as frequency,

importance, and satisfaction would provide a more complete profile of a person's participation. Finally, although the sample was drawn from multi sites across the U.S., the generalizability to the population of adults with SCI is unknown. For example, it would be valuable to examine whether the measure is equally applicable for persons with traumatic and non-traumatic SCI.

Conclusion

Considering the limitations of existing measures of participation, this study applied a conceptual model to guide the refinement and validation of a participation measure, the PM-PAC. The study results supported Chang and Coster's proposed construct of participation with three major domains: Productivity, Social, and Community. Selected items from the PM-PAC demonstrated good psychometrics and applicability for people with SCI across different demographic and injury characteristics. The revised PM-PAC provides a good approach for researchers and clinicians to evaluate participation among people with SCI. This measure can potentially help clinicians understand the perceived limitations to participation in different life domains among people with SCI and to monitor intervention effects. Ongoing efforts are needed to expand the domain coverage and increase the precision of the instrument to further support these clinical and research efforts.

Disclaimer statements

Conflicts of interest None.

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