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ORIGINAL ARTICLE

The Pediatric Measure of Participation (PMoP) short forms

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Study design: Multi-center cross-sectional cohort study.
Objectives: The objectives of this study were to develop and validate short forms (SFs) of participation for child- and parent-reported outcomes following spinal cord injury (SCI).
Setting: Three pediatric orthopedic hospitals in the United States.
Methods: The expert panel used calibration data from the pediatric computerized adaptive test (CAT) development study (convenience sample of 381 children and adolescents with SCI and 322 parents or caregivers) to select SF items. The panel selected items for two domains (participation self—relevant to what I want to do; participation friends—relevant to what my friends do), with parent and child versions for each domain. Psychometric analyses included group reliability, Cronbach's alpha, agreement (SFs and item banks), percent of sample with highest (ceiling) and lowest (floor) scores by level of lesion (paraplegia/tetraplegia), and test information function.
Results: Group reliability and Cronbach's alpha values are acceptable (0.74–0.92) and agreement (intraclass correlation coefficients for SFs and total item banks) is strong (0.89–0.95). Floor effects were minimal for people with tetraplegia and paraplegia (0–1.19%). Ceiling effects were minimal for people with tetraplegia (0–3.13%) and slightly higher, but acceptable, for people with paraplegia (8.06–14.02%). Test information function for the SFs was sufficiently high over the range of scores for the majority of the sample.
Conclusion: Pediatric Measure of Participation (PMoP) SFs are acceptable for use when CATs are not feasible.
Sponsorship: The study was funded by the Shriners Hospitals for Children Research Grant 79142 (Mulcahey, PI) and the Boston ROC Grant 5R24HD065688-05 (Jette, PI).
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INTRODUCTION

Adoption of the International Classification of Functioning, Disability and Health (ICF) has catalyzed concerted efforts to conceptualize participation and to develop and validate relevant outcome instruments. The majority of pediatric participation outcome instruments include items that reflect concepts of both participation and activity,[1,2] as described in the ICF and ICF-Child and Youth Version (ICF-CY). Instruments differ in the type and/or breadth of participation measured, response scales and intended respondent, and targeted age groups. As an example, the Activities Scale for Kids (ASK),[3] the Pediatric Activity Card Sort (PACS)[4] and Children's Leisure Assessment Scale (CLASS)[5] use frequency scales; the Children's Assessment of Participation and Enjoyment (CAPE)[6] and the Children Participation Questionnaire (CPQ)[7] use multi-faucet response scales including enjoyment level, intensity and frequency; the Children Adolescent Scale of Participation (CASP)[8] uses a limitation scale, with reference to age expectancy; and the Assistance to Participation Scale (APS) uses a level of assistance by the mother scale.[9] The CPQ, CASP and APS are designed for parent report; the CAPE and ASK, child report via interview format, and the CLASS are designed for child self-report. Most pediatric participation outcome measures are intended for specific age groups such as pre-school and school age children[4,7] and adolescents[5] or have multiple versions for different age groups.[10] Only a few can be administered across the pediatric age continuum.[3,6] Also, although the existing pediatric participation instruments have items that appear to be relevant to children with spinal cord injury (SCI), the majority of instruments measure only one or two dimensions of participation. For example, the Children Helping Out: Responsibilities, Expectations and Supports (CHORES)[11] measures participation in household chores, and the CAPE, CLASS and APS measure participation in play/leisure. Although psychometric properties of the CAPE have not been examined in children with SCI, it has been used in studies with children with SCI[12] even though it only assesses recreation and leisure and omits participation in one's own self-management and in school-related activities, two participation areas with high relevance to children with SCI.

As a direct response to the limitations of existing measures and a recognized void in psychometrically sound and meaningful participation outcome instruments for youth with SCI, we developed and validated item banks of participation for pediatric SCI.[13,14] Development of the Pediatric Measure of Participation (PMoP), described in detail elsewhere,[14,15] assesses 'essential'[16] participation (feeding oneself, caring for oneself) and 'discretionary'[16] participation

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(having sleepovers, being on a sports team) by youth, aged 4–21 years, in home, school and community environments and includes child- and parent-reported versions. The PMoP scales were developed using Item Response Theory and evaluate participation relative to how much a child participates, based on how much he/she wants to participate (*Participation-Self*), and relative to how much his/her friends participate (*Participation-Friend*). As illustrated in Table 1, the '*Participation-Self*' uses a response scale—'I do it as much as I want', 'I do it a little less than I want', 'I do it a lot less than I want'—and the '*Participation-Friends*' uses a response scale—'I do it as much as my friends'; 'I do it a little less than my friends; 'I do it a lot less than my friends'—with separate scales for child and parent report. There are two options for when a child does not do the activity (cannot do or does not want to do). Both responses are scored as 0, so that the response of 'I don't do it' does not impact the PMoP score calculation.

The PMoP item banks were designed for Computerized Adaptive Test (CAT) administration. CATs use a computer program to select appropriate items from a calibrated item bank based on responses to previous items. As the CAT program administers items, the precision of the score estimate increases. The CAT program terminates based on pre-determined rules that specify a level of precision (standard error) or maximum number of items. Short forms (SFs) comprise items carefully selected from the same calibrated item banks used by CATs. SFs have been successfully developed for many CAT measures including the adult SCI-Functional Index.[17] The aim of this study was to develop and evaluate the psychometric properties of SFs for the PMoP item banks in a sample of children and adolescents with SCI and their parent respondents.

METHODS

Participant-expert panel for item selection

An expert panel, comprising 12 professionals (1 medical doctor, 1 psychologist, 4 physical therapists and 6 occupational therapists), was convened to select SF item candidates from the calibrated PMoP item banks.

Participant-calibration sample

The PMoP calibration sample data[14] were used to select SF items and analyze SF psychometric properties. This convenience sample comprised 381 children with traumatic and non-traumatic (that is, transverse myelitis) SCI aged 8–21 years (child scales) and 322 parents/caregivers of children with SCI aged 4–21 years (parent scales). Of the participants, 133 (35.3%) had motor levels between C5 and T1, 35 (9.3%) C1 and C4, 86 (22.8%) T2 and T6, 102 (27.1%) T7 and L2, and 21 (5.6%) L3 and S5. The majority ($n=205$, 54.2%) of children had complete injuries (American Spinal Injury Association Impairment Scale (AIS) A); the remaining were classified as AIS B ($n=60$, 15.9%), AIS C ($n=56$, 14.8%) and AIS D ($n=57$, 13.1%). Five children were not classified because of their young age. Children were included in the calibration study if they had been discharged from initial SCI rehabilitation and returned to their pre-injury environment for at least 3 months. Children and their parents were excluded if the child had a diagnosis of spina bifida, spinal muscle atrophy or other spinal dysfunction and if English was not their primary language; children were further excluded if a concomitant brain injury interfered with the ability to read, comprehend and respond to the PMoP items. Data were collected at three pediatric orthopedic specialty hospitals in the United Sates. The study was approved by the Institutional Review Board of each facility. Prior to enrollment, parents and children provided consent and assent, respectively.

PMoP SF item selection

The pediatric SCI expert panel attended a 1-day meeting to identify SF item candidates. Training involved a review of PMoP item banks and instruction regarding the two item parameters used to select SF item candidates: *item difficulty* (measured in logits); *item discrimination* (measured as the slope of the item characteristic curve). Experts were organized into SF content groups charged with identifying SF item candidates for *Participation-Self* and *Participation-Friend*. Groups used spreadsheets, organized by domain, listing PMoP items with item parameters hierarchically organized based on logit scores and an additional column with item characteristic curve slopes for each item. Logit scores were used to select items with an appropriate range of difficulty, and item characteristic curve slopes were used to select items best able to discriminate among people with different levels of ability. Item candidates were also reviewed from a clinical perspective to ensure that key aspects of participation relevant to children and adolescents with SCI were assessed. Groups presented their initial recommendations and, using an iterative process, items were identified for four SFs: *Participation-Self*, child report; *Participation-Friends*, child report; *Participation-Self*, parent report; and *Participation-Friends*, parent report. Psychometric properties of the four SFs were examined, and a secondary SF items' review was conducted by two investigators (MJM and MDS) to ensure that item selection was optimized based on iterative psychometric analyses focused on minimizing ceiling and floor effects and content gaps.

Table 1 PMoP Participation-Self and Participation-Friends response scales for child and parent report

PMoP scales		*Response scales*				
Child report	*Example items*	*I Don't Do It* [a]		*I Do It*		
Participation-Self	I play or hang out at my friend's house	Because I can't	Because I don't want to	As much as I want	A little less than I want	A lot less than I want
Participation-Friend	I go to the movies with my friends			As much as my friends	A little less than my friends	A lot less than my friends
Parent Report	*Example Items*	*My Child Doesn't Do it*		*My Child Does It*		
Participation-Self	My child plays or hangs out at his/her friend's house	Because he/she can't	Because he/she doesn't want to	As much as he/she wants	A little less than he/she wants	A lot less than he/she wants
Participation-Friend	My child goes to the movies with his/her friends			As much as his/her friends	A little less than his/her friends	A lot less than his/her friends

Abbreviation: PMoP, Pediatric Measure of Participation.
[a]Note: There are two options for when a child does not participate. Responses to each option are scored as 0.

Psychometric analyses

All psychometric analyses were based on calibration sample data.[14] For each SF, we calculated the group (separate for child and parent) level reliability defined as follows:

$$\frac{\sigma_{\hat{\theta}}^2 - E(SE^2)}{\sigma_{\hat{\theta}}^2}$$

where E (SE^2) is the mean of estimated score standard errors in each group and σ^2_{θ} is the variance of the estimated score for each participant group (child and parent respondents). Group-level reliability is an important characteristic of these measures, given that they were developed using Item Response Theory. We also calculated Cronbach's alpha to examine the internal consistency of items for each SF. SF and total item bank scores were calculated, and agreement between scores was determined by calculating intraclass correlation coefficients. For each SF, we calculated the percent of the sample with the highest (ceiling) and the lowest (floor) score for the SF items along with the full item bank. We also calculated the item information function for each SF and compared it with the distribution of scores for participants. Finally, we created transformation tables to transform raw scores to the standardized scores based on the 'T' metric.

RESULTS

For the child-reported participation scales, the mean age (s.d.) of the participants was 15.5 (3.5) years. Most participants were boys (55%) and white (82%); 57.6% had paraplegia and 54.2% had complete injuries, as defined by the American Spinal Injury Association Impairment Scale (AIS). For the parent-reported scales, the mean age (s.d.) of the participating children was 13.6 (4.5) years. Most subjects were boys (55%) and white (82%); 56% had paraplegia and 52% had complete injuries. Details of the sample are reported elsewhere.[14]

Table 2 presents mean values and standard deviations (s.d.) for each of the four SFs, based on scores derived from calibration sample data. Scores were calculated using a 'T' metric with a mean of 50 and a s.d. of 10. Mean values for the SFs were near 50. Group-level reliability (0.74–0.80) and internal consistency (Cronbach's alpha 0.87–0.92) were moderate to high for all SFs. Agreement between SF scores and scores generated from the total item bank was also consistently high (intraclass correlation coefficient values ranged from 0.90 to 0.95).

Table 3 compares ceiling and floor effects for the SFs and the full item banks. Floor effects were low for child and parent *Participation-Self* and *Participation-Friends* scales (range 0–1.19%). Ceiling effects for SFs for children with tetraplegia were low (child and parent versions) (0–3.13%) but higher for children with paraplegia (child 13.66% for *Participation-Self*; parent 14.20% for *Participation-Friends*). Figures 1 and 2 illustrate test information function curves and sample distributions for each of the scales. The test information values are sufficiently high over the range of scores for the majority of the sample, demonstrating that the information function of the SFs is well matched to the participation scores of the children and with SCI. PMoP SFs and conversation tables are provided in the Supplementary Appendix. SFs are scored by adding numeric values associated with each response. For each SF, a conversion table is used to convert the summed raw score to a T-score. Converting raw scores to 'T' scores is a critical step to obtaining the final PMoP SF score. The conversation table also provides the standard error for each score estimate.

DISCUSSION

After survival, among the most important outcomes of pediatric SCI is resumption of typical childhood roles, such as friend, peer-group member and student, and participation in everyday living. Despite the high relevance of these outcomes, and their importance to youth and parents, there is a glaring void in psychometrically sound, low-burden instruments that measure these constructs. As a direct response to this void, we developed and calibrated item banks of pediatric participation, specifically for the pediatric SCI population. CATs developed to administer these item banks have been validated.[14] The PMoP scales are the first to measure child and parent reports of participation following SCI and provide information about

Table 2 Mean and standard deviation values, reliability and accuracy of the short forms

Participation scale	*Respondent*	N	*Mean*	*s.d.*	N *items*	*Group level reliability*	*Cronbach's alpha*	*ICC (CI)*
Self- relative to what I want to do	Child	368	49.94	11.17	17	0.74	0.87	0.93 (0.92–0.95)
	Parent	311	49.47	10.84	12	0.75	0.87	0.889 (0.87–0.92)
Friends-relative to what my friends do	Child	369	49.44	9.82	19	0.82	0.92	0.95 (0.94–0.96)
	Parent	311	50.37	10.92	14	0.80	0.90	0.94 (0.93–0.95)

Abbreviations: CI, 95% confidence interval; ICC, intraclass correlation coefficient; *N*, calibration sample, mean and (s.d.); *N* items, number of items on SF.

Table 3 PMoP scales; score range, % ceiling, % floor by level of SCI

PMoP scale			*Tetraplegia*				*Paraplegia*				
			N	*Range*[a] *(T-score)*	*% Floor*	*% Ceiling*	N *at ceiling*	N	*Range (T-score)*	*% Floor*	*% Ceiling*	N *at ceiling*
Participation-Self	Child	Short Form	154	−2.6–77.2	0.00	3.13	5	214	5.3–77.4	0.62	13.66	30
		Full Item Bank	154	13.3–68.9	0.00	0.00	0	214	8.6–84.8	0.00	6.21	14
	Parent	Short Form	134	−3.8–73.2	1.19	2.38	4	177	13.6–82.9	0.00	8.60	16
		Full Item Bank	134	14.2–81.4	0.00	1.18	2	177	28.8–86.6	0.00	6.45	12
Participation-Friend	Child	Short Form	154	20.3–65.8	0.00	1.55	3	215	20.5–71.2	0.00	14.20	31
		Full Item Bank	154	22.6–66.8	0.00	0.00	0	215	28.0–87.2	0.00	3.09	7
	Parent	Short Form	134	11.1–72.5	0.00	1.19	2	177	24.1–81.4	0.00	12.90	23
		Full item bank	134	13.2–68.8	0.00	1.18	2	177	29.8–86.0	0.00	5.38	10

Abbreviations: *N*, number of subjects from calibration sample; PMoP, Pediatric Measure of Participation.
[a]Negative because of missing data; for example, for participants who responded only to one very easy item with 'can't do.'

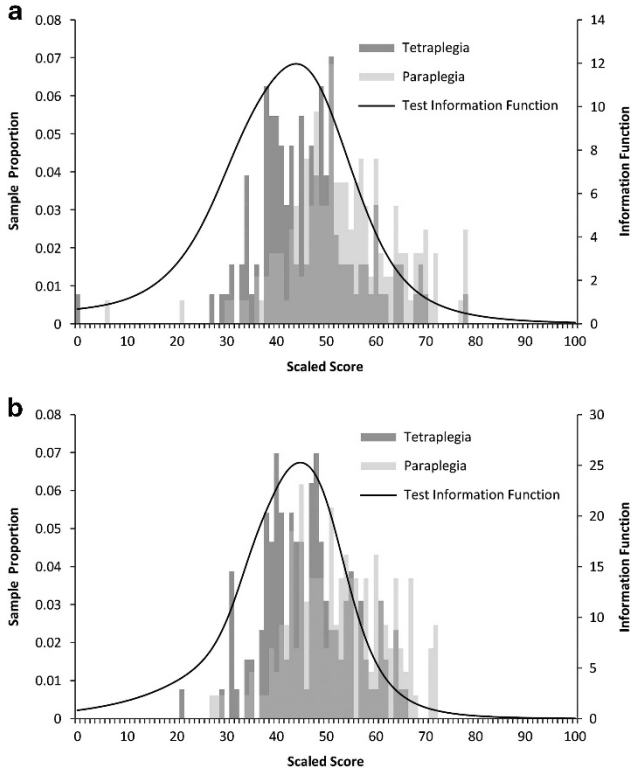

Figure 1 (**a** and **b**) Participation-Self, child report (**a**) and Participation-Friend, child report (**b**). Test information function and sample distribution.

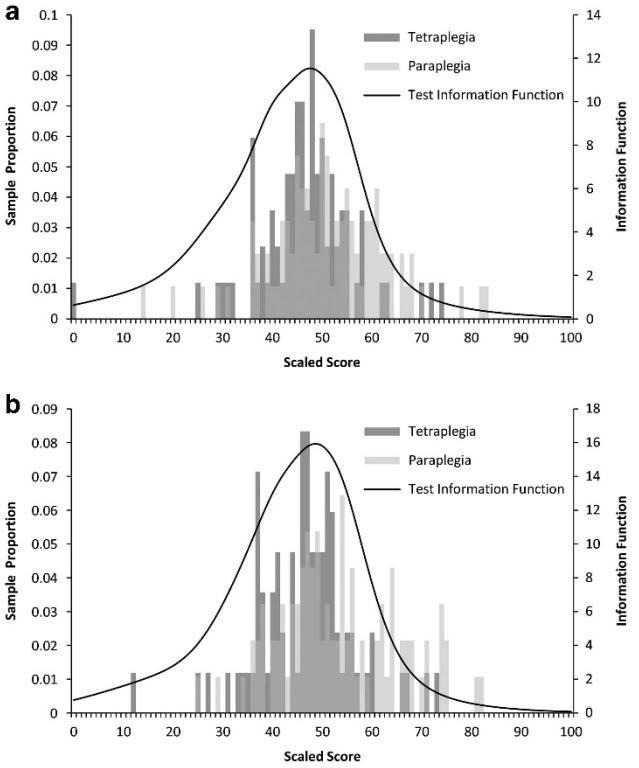

Figure 2 (**a** and **b**) Participation-Self, parent report (**b**) and Participation-Friend, parent report (**b**). Test information function and sample distribution.

participation relevant to what the child wants to do (*Participation-Self*), as well as what his/her friends do (*Participation-Friends*). Owing to the importance of measuring participation and to potential challenges with access to computer tablets for CAT administration, we also created and evaluated the psychometric properties of SFs of participation, which can be administered in a paper-pencil format.

The PMoP SFs, which are available in the Supplementary Appendix, showed strong psychometric properties in terms of reliability and internal consistency. Content range of the *Participation-Self* and *Participation-Friends* scales was good for both child and parent versions and for children with paraplegia and tetraplegia as evidenced by minimal floor $= <1.19\%$ and adequate ceiling effects $= <14.20\%$. (Note: ceiling effects were above 3% only for children with paraplegia.) SF scores correlated with the total item bank scores and test information covered the sample distribution, adding to the psychometric support for their use.

Unlike other pediatric participation instruments that evaluate frequency, intensity, age appropriateness and assistance needed, the PMoP scales evaluate performance of everyday living from the perspective of what a child wants to do (*Participation-Self*) and what they perceive their friends doing (*Participation-Friend*). Another feature of the PMoP that differentiates it from other pediatric instruments is inclusion of items across the broad range of childhood participation, including those that evaluate participation in essential activities of daily living, school, chores/work and leisure/play. Owing to the importance of engaging both children and their parents in assessing outcomes, the PMoP scales are designed for both child and parent report.

The *Participation-friends* scale is of particular relevance in pediatrics given the importance of friends and friendships on youth's identity and feelings of belonging, as well as on socialization and growth and development.[18,19] Although the item banks represent different domains and their scores cannot be compared, the *Participation-Self* and *Participation-Friends* scales are highly correlated ($r_2 = 0.87$–0.92). Given the high correlation and the finding that the test information function was similar for self and friends, future work is planned to better understand the relationship between the two scales and to examine how the information they each provide contributes uniquely to the understanding of participation following childhood SCI.

The response options for 'I don't do it' (Table 1) require prudence in interpretation. 'I don't do it because I can't' should not be interpreted as physically unable to participate. This response may be selected for many reasons including not being allowed to participate (by parents) or not having access to participate. Likewise, 'I don't do it because I don't want to' may reflect the choice not to participate but may also be owing to other considerations. For these reasons, follow-up is recommended for understanding the selection of 'I don't do it' and, as previously suggested,[16] other assessments that evaluate capacity, environment, coping and other factors that may impact that participation should be administered. We have described SFs of physical function and daily routines that measure capacity of children and youth with SCI[20] that can be administered in concert with the PMoP SFs to provide a more complete picture of the factors that may affect participation after SCI.

It is important to note that the calibration sample was drawn from three pediatric facilities in the United States and may not be representative of all children with SCI and their parents; this is particularly important as the majority of the sample was white and non-Hispanic. Further work is needed to determine the relevance of the PMoP to people with different ethnicities and from other cultures. The sample is relatively small but was appropriate given the overall number of children with SCI. Another limitation is that SF scores were

simulated; actual SF administration to children and parents may yield different scores. Also, inclusion in the calibration study required children to have been discharged from their initial rehabilitation and to have resumed everyday living in their pre-injury environments for at least 3 months. The 3-month time frame was determined based on the practice patterns of the three participating facilities that involved discharging children within 4–6 weeks. This may not have been sufficient time to experience all opportunities related to participation. Longitudinal administration of the PMoP CATs and SFs may provide important insight about participation, relevant to time since injury. Work is underway to validate the SFs in a cohort of children with SCI and their parents.

SFs offer an attractive alternative to CAT for clinicians. They are administered using familiar methods (for example, paper/pencil) and are low burden to the patient and the clinician. As a way to facilitate scoring and interpretation, we have created tables to convert the summed raw scores into T scores. Future work is planned on using the PMoP to examine participation trajectories of youth with SCI in relationship to trajectories of youth without SCI and to evaluate the PMoP in other pediatric clinical populations with chronic conditions.

CONCLUSION

The PMoP uses contemporary measurement approaches to advance SCI research and practice. For the first time, participation outcomes can be assessed with a measure developed specifically for children and adolescents with SCI. SFs of child-reported and parent-reported participation have been developed and validated. Clinicians and researchers can utilize the conversation tables to convert summed raw scores to T-scales.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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Supplementary Information accompanies this paper on the Spinal Cord website (http://www.nature.com/sc)