

ORIGINAL ARTICLE

Patient Participation in Rehabilitation Questionnaire (PPRQ)—development and psychometric evaluation

J Lindberg^{1,2}, M Kreuter³, L-O Person¹ and C Taft^{1,2}**Study design:** A cross-sectional postal questionnaire study.**Objectives:** The aim of the study was to evaluate selected psychometric properties of a draft version of the Patient Participation in Rehabilitation Questionnaire (PPRQ) measuring patients' experiences of participation in care and rehabilitation.**Setting:** Sweden.**Methods:** On the basis of previous qualitative analyses of patient interview data, a 32-item questionnaire covering five domains of participation was developed and sent to 268 persons with spinal cord injury, aged 18–80 years and injured 1–12 years previously. In total, 141 (51%) evaluable questionnaires were returned. Multi-trait analysis was used to assess scaling assumptions by testing item convergent and discriminant validity and internal consistency reliability (Cronbach's α) associated with the hypothesized item-scale structure of the questionnaire.**Result:** Nine items failed to meet scaling assumptions and were omitted. Scaling assumptions were thereafter substantiated for the scales: 'respect and integrity' (6 items); 'planning and decision-making' (4 items); 'information and knowledge' (4 items); 'motivation and encouragement' (5 items); and 'involvement of family' (4 items). Item-scale correlations ranged from 0.67 to 0.85 and most items correlated higher or significantly higher with their hypothesized scale than with other scales. Cronbach's α was ≥ 0.89 for all scales.**Conclusion:** The PPRQ appears to adequately assess central aspects of participation in care and rehabilitation from the perspective of patients with spinal cord injury. Further studies using larger samples will be undertaken to confirm the scale structure as well as the sensitivity and responsiveness of the questionnaire.*Spinal Cord* (2013) **51**, 838–842; doi:10.1038/sc.2013.98; published online 17 September 2013**Keywords:** Patient Participation in Rehabilitation Questionnaire (PPRQ); spinal cord injury; person-centered care; self-report; psychometrics

INTRODUCTION

Patient participation is acknowledged as a key component of quality and effective care and rehabilitation. Patient participation is a core element of person-centered care (PCC), an approach to care focusing on the patients' individual needs, wants and preferences.^{1–3} Person centeredness is an important aspect of rehabilitation, particularly at spinal cord injury (SCI) units where it is considered integral to quality rehabilitation.⁴ PCC facilitates and promotes patient participation through its recognition and engagement of the patient as a vital and active partner with unique resources and knowledge essential for optimizing care and rehabilitation.³ Patient participation is fostered by a staff that is not only sensitive and responsive to the patient's needs and desires, but also encourages and motivates them, provides them with adequate and timely information and treats them with respect.^{4–6}

Successful SCI rehabilitation acknowledges and encourages patients to actively participate in planning and decision-making and to take control of their situation.^{4,7} For example, the Needs Assessment and Goal Planning Programme, used in many spinal units and rehabilitation centers, helps the patient to reflect on, and be aware of

his or her needs.⁷ Even if the processes of PCC are regarded as desirable in their own right, it is important to recognize that not all patients prefer the same approach or that the same individual will prefer the same approach in all phases of his/her care and rehabilitation.⁸ In order for SCI rehabilitation to be truly patient centered, it must be tailored to the patient's own unique preferences, capacities and needs, without preconceived notions about what is the best approach for the patient.⁶ Tools to assess patients' perceptions of participation in rehabilitation may be helpful in this endeavor, particularly in cases of long-term care and rehabilitation where the patient may have changing preferences, capacities and needs.

There are several extant questionnaires measuring different aspects of patient participation. Some of these were developed for use in specific settings, for example, in primary care¹ and emergency departments,⁹ whereas others are intended for more general use.¹⁰ There are also a number of staff-rated questionnaires to assess patient participation in rehabilitation.^{11,12} There is, however, a need for questionnaires aimed specifically at assessing patients' own experiences of participation in rehabilitation. The aim of the present study was to evaluate selected psychometric properties of a drafted

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version of the Patient Participation in Rehabilitation Questionnaire (PPRQ) in a sample of patients with SCI.

MATERIALS AND METHOD

Patients and data collection

The target population ($n = 276$) comprised all persons with SCI aged 18–80 years who were injured between 1999 and 2010 and treated at the Spinal Unit, Sahlgrenska University Hospital, Gothenburg, Sweden. Exclusion criteria were psychiatric diagnosis, severe brain injury or inability to understand the Swedish language. Eligible persons with valid telephone numbers ($n = 163$) were contacted by telephone and asked if they were willing to participate. Eight declined. The questionnaire, an information letter and postage-paid return envelope were sent to those who agreed to participate ($n = 155$), as well as to those who could not be reached by phone ($n = 113$). One reminding letter was sent. In total, 141 evaluable questionnaires were returned (response rate = 51.1%). Of these, 94 had been contacted by phone, 41 had not and in 6 cases unknown due to anonymous responses. Table 1 shows demographics of the participants. The participants did not differ significantly from the target population with regard to gender or age.

Measurement

A preliminary version of the PPRQ was developed following recommended procedures for questionnaire development.¹³ Interviews were first conducted with 10 strategically selected persons with SCI.⁶ The interviews took place within a year after injury with the aim to explore the meaning of patient participation from the patient's perspective. Content analyses of the interviews yielded five themes: 'respect and integrity'; 'planning and decision-making'; 'information and knowledge'; 'motivation and encouragement'; and 'involvement of family'. Subsequently, 50 statements were extracted verbatim from the interviews, with about equal numbers of items per theme. Two 5-step Likert scales were used for rating each statement with regard to how often the respondent experienced the care described in each statement (experience ratings; always to never) and how important he or she considered the care to be (importance ratings; extremely important to not at all important).

Table 1 Socio-demographic and clinical characteristics

	Participants ($n = 141$)
<i>Gender</i>	
Men	101 (71.6%)
Women	40 (28.4%)
<i>Age at injury (years)</i>	
Mean (s.d.)	42.7 (16.4)
Median (range)	43.0 (18–75)
<i>Cause of injury</i>	
Traumatic	117 (83.0%)
Nontraumatic	24 (17.0%)
<i>Time since injury (years)</i>	
Mean (s.d.)	6.5 (3.6)
Median (range)	6.0 (1–12)
<i>Mobility (1 missing)</i>	
Wheelchair user	76 (53.2%)
Walk with walking aid	21 (14.9%)
Walk without walking aid	37 (26.2%)
Totally recovered	8 (5.7%)
<i>Education</i>	
High school or less	106 (74.5%)
University	36 (25.5%)

The content validity of the items and response options was tested with regard to relevance and comprehension in cognitive interviews with five persons with SCI (not included in the initial interviews), two close family members to persons with SCI and three staff members of the SCI unit. Based on analyses of the interviews, 18 items were omitted for reasons of content overlap and relevance. A preliminary 32-item version of the PPRQ was then drafted.

Statistical analyses

Descriptive statistics were used to characterize respondent demographics and to evaluate data completeness (item-level, scale-level missing data, and ceiling and floor effects) and scale score distributions (ranges, means and standard deviations). Differences between the participants and the target population were tested by means of Chi-square (gender) and by *t*-test (mean age). Spearman correlations were computed between scale scores and between scale scores and time elapsed since injury.

Multi-trait scaling analysis was used to evaluate the hypothesized scale structure of the PPRQ. It is a straightforward and effective approach to scale analysis that focuses on items as the unit of analysis and uses the logic of convergent and discriminant validity,^{14,15} which are fundamental aspects of construct validity.¹⁶ Item convergent validity was considered to be supported if correlations between items and their postulated scale (corrected for overlap) were >0.40 . Convergent validity was also evaluated in relation to intercorrelations of items within a scale by means of Cronbach's α . Coefficients >0.70 are generally considered acceptable for use in group-level comparisons, while coefficients >0.90 are recommended for individual-level assessments.¹⁶ Item discriminant validity was supported when correlations between an item and its own scale were significantly higher with its own scale than with other scales.

All analyses were performed on experience rating (not importance ratings) because of the larger variation in response distributions. Missing values were imputed using the half-scale method, i.e. when at least half of the items in a scale are endorsed; missing values are replaced with the mean of the remaining items. Cronbach's α was calculated before item imputation.

Importance ratings were used to further assess the content validity of the questionnaire. It was assumed that all items should have mean ratings above the midpoint on the 5-step Likert scale.

Analyses were performed using SPSS version 20 (Statistical Package for the Social Science, Chicago, IL, USA) and MAP version 2.0 (Multitrait analysis program, provided by JE Ware, Jr, New England Research Institute).

The Ethical Board of the University of Gothenburg approved the study.

RESULTS

An initial multi-trait analysis showed that nine items failed to meet criteria for Likert scaling: four items in 'respect and integrity'; three items in 'planning and decision-making'; one item in 'information and knowledge'; and one item in 'motivation and encouragement'. After omitting these items, the analysis confirmed the hypothesized internal structure of the 23-item PPRQ (Table 2 and Appendix). The PPRQ consisted of five scales:

- Respect and integrity (6 items). The staff respects patients' wishes, personality and personal matters. The staff treats each patient as a unique individual and allows the patient to be alone when he or she so desires.
- Planning and decision-making (4 items). The staff acknowledges and is responsive to the patients' suggestions and opinions. The staff enquires about the patients' expectations, capabilities and preferences.
- Information and knowledge (4 items). The staff explains each phase of care and rehabilitation and ensures that the patients receive adequate information. The information is provided in a way that the patient can understand and at the 'right' time.
- Motivation and encouragement (5 items). The staff encourages, gives hope and motivates the patient.

Table 2 Summary of result of multi-trait scaling tests of the PPRQ

	<i>Respect and integrity</i>	<i>Planning and decision-making</i>	<i>Information and knowledge</i>	<i>Motivation and encouragement</i>	<i>Involvement of family</i>
Number of items	6	4	4	5	4
Number of scale levels	24	16	16	20	16
Number of imputations	6	7	3	3	7
Incomplete scale scores (%) ^a	0	0.7	1.4	1.4	4.3
Theoretical range summarized	6–30	4–20	4–20	5–25	4–20
Observed range summarized	6–30	4–20	4–20	5–25	4–20
Mean (s.d.) ^b	24.13 (4.53)	14.70 (3.43)	15.42 (3.35)	18.79 (4.09)	14.56 (4.69)
% At ceiling	9.0	9.0	9.0	9.7	20.1
% At floor	0.7	1.5	1.5	1.5	5.2
Theoretical range mean	1–5	1–5	1–5	1–5	1–5
Observed range mean	1–5	1–5	1–5	1–5	1–5
Mean (s.d.) of mean	4.02 (0.76)	3.69 (0.85)	3.86 (0.83)	3.77 (0.82)	3.63 (1.19)
Mean (R) internal consistency ^c	0.75 (0.68–0.82)	0.78 (0.73–0.81)	0.81 (0.80–0.85)	0.74 (0.67–0.84)	0.80 (0.72–0.85)
Item-scale discriminant validity ^d	0/0/58/42	0/0/63/37	0/0/75/25	0/5/70/25	0/0/0/100
Cronbach's α	0.91	0.89	0.90	0.90	0.91

^aNot meeting half scale criterion.^bMean of summed score.^cPearson correlation between items and hypothesized scale, corrected overlap.^dPercent correlations that are significantly lower/lower/higher/significantly higher with hypothesized scale compared with other scales.**Table 3 Correlation coefficients between the scales**

	<i>Respect and integrity</i>	<i>Planning and decision-making</i>	<i>Information and knowledge</i>	<i>Motivation and encouragement</i>	<i>Involvement of family</i>
Respect and integrity	1.0	0.68**	0.70**	0.58**	0.36**
Planning and decision-making		1.00	0.78*	0.73**	0.51**
Information and knowledge			1.00	0.77**	0.54**
Motivation and encouragement				1.00	0.52**
Involvement of family					1.00

Spearman correlation $P < 0.01$.Table 4 Summary statistics for importance ratings**

	<i>Respect and integrity</i>	<i>Planning and decision-making</i>	<i>Information and knowledge</i>	<i>Motivation and encouragement</i>	<i>Involvement of family</i>
Theoretical range ^a	1–5	1–5	1–5	1–5	1–5
Observed range	2.80–5.00	2.40–5.00	2.00–5.00	2.60–5.00	1.00–5.00
Mean (s.d.)	4.35 (0.50)	4.16 (0.54)	4.42 (0.47)	4.31 (0.51)	3.66 (1.18)

^a1 = not at all important, 2 = not important, 3 = important, 4 = very important, 5 = extremely important.

- Involvement of family (4 items). The staff gives relatives or significant others the opportunity to participate in care and rehabilitation planning if the patient so wishes.

As shown in Table 2, item convergent validity was supported as evidenced by the fact that all item-scale correlations were well above the criterion of 0.40 (range 0.67–0.85) and Cronbach's α coefficients were ≥ 0.89 for all scales. Item discriminant validity was also satisfactory, with most items correlating higher or significantly higher with their hypothesized scale than with other scales. Only one item, 'Helped in goal-setting', correlated lower with its own scale (motivation and encouragement), however, as this item was judged to be of relevance in a rehabilitation context it was kept in the scale. Correlation coefficients between the scales ranged

from 0.36 to 0.78 ($P < 0.01$; Table 3) and between scales and time elapsed since injury from -0.05 to 0.11 ($P > 0.05$).

Content validity was supported by mean item importance ratings all at or above 'highly important'. Importance ratings are shown in Table 4.

DISCUSSION

The PPRQ scales and items were derived from interviews with SCI persons.⁶ The item-scale structure was corroborated in multi-trait analyses. In addition, the content validity of the items was confirmed by high ratings of the items as important aspects for patient participation in care and rehabilitation (importance ratings). An advantage of the PPRQ is that it comprehensively covers relevant and important domains of patient participation in SCI rehabilitation.

Each item in the PPRQ provides unique information about different central aspects of participation. Furthermore, in light of normative changes in patients' and staffs' attitudes toward participation during the last decade,¹⁷ the PPRQ may better reflect and measure present-day patients' attitudes.

The PPRQ is concordant with patients' perspective of rehabilitation reported in other qualitative interview studies with persons with SCI,^{5,18} as well as with the core concepts in general theoretical frameworks of PCC.¹⁻³ The importance of these domains has been emphasized in the rehabilitation literature, and in particular SCI rehabilitation. For the patients to participate in the rehabilitation process they must be given opportunities to use their resources. Thus, the staff must provide such conditions for participation. For example, respect for the patient's unique needs, wants and preferences for care acknowledges the patient's capacity to make decisions about his or her own rehabilitation.¹⁹ However, it must be recognized that the extent to which patients choose to participate is dependent on their vitality and condition, and that their ability and desire to participate may change over time and from situation to situation.^{18,20} Receiving and understanding information about one's condition are necessary to make progress in SCI rehabilitation,²⁰ although the information must be given at the 'right' time for each patient.⁷

The PPRQ may be used for assessing central aspects of patients' experiences of participation in SCI rehabilitation. The experience ratings reflect patients' perceptions of the degree to which they are given opportunities to participate and may serve as quality indicators in evaluating and developing care and rehabilitation programs and strategies. On the other hand, the importance ratings may serve to help the staff to monitor and tailor care and rehabilitation to each patient's unique preferences. There was, however, little variation in the importance ratings. This may owe to the indisputable nature of some questions, for instance, being treated with respect is unquestionably important to everyone. The utility of the importance ratings and experience ratings, and their relation to one another will be further evaluated in forthcoming studies, for example, comparisons between different patient groups and between patients and staff.

There are some limitations to this study. The response rate was relatively low (51.1%). However, the sample did not differ from the target population regarding gender or mean age and thus may be considered representative. Patient ratings were made retrospectively. However, no significant correlations were found in the experience ratings in relation to time since injury. Although ceiling and floor effects were generally acceptable, 'involvement of family' had a ceiling effect of 20%, which probably owes to the emphasis given to family involvement in rehabilitation at the SCI unit. The dimensionality of the PPRQ could not be properly evaluated by means of, for example, factor analysis due to the small sample size. However, an extended study is currently being planned that hopefully will solve this problem as well as provide further evidence about validity. Although conventionally applied criteria were met for use of the scales in individual assessments (that is, $\alpha \geq 0.9$),¹⁶ the usefulness of the PPRQ in clinical settings also needs to be further evaluated.

The PPRQ was developed and validated in patients with SCI. However, we believe that the questionnaire is likely applicable and relevant for use in other patient groups undergoing rehabilitation. The forthcoming validation study will also examine the appropriateness of the PPRQ in other patients groups.

CONCLUSION

The PPRQ appears to adequately assess central aspects of participation in care and rehabilitation from the perspective of patients with SCI. Further studies using larger samples will be undertaken to confirm the scale structure as well as the sensitivity and responsiveness of the questionnaire.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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APPENDIX ITEM-SCALE STRUCTURE OF THE PPRQ (PROVISIONAL TRANSLATION)

Experience ratings	
In your case, how often did you experience that:	
Respect and integrity	<p>The staff respected patient's wishes/desires in all contexts</p> <p>The staff treated the patient with respect</p> <p>The staff respected the patient's personality and way of being</p> <p>The staff left the patient alone when he/she so desired</p> <p>The staff respected the patients private/personal matters, i.e. did not intrude in private life</p> <p>The staff treated each patient as a unique individual</p>
Planning and decision-making	<p>The staff took into account the patient's suggestions regarding care and rehabilitation</p> <p>The staff tried to learn what expectations the patient has about his/her rehabilitation</p> <p>The staff tried to learn what capabilities the patient believes he/she has for care and rehabilitation</p> <p>The staff knew if the patient has any special obstacles/problems that limit good care and rehabilitation</p>
Information and knowledge	<p>The staff provided the patient information in a way that he/she can understand</p> <p>The staff ensured that the patient received adequate information and knowledge to be able to participate</p> <p>The staff took time to give the patient answers to the questions he/she had</p> <p>The staff informed the patient at the 'right' moment for the patient</p>
Motivation and encouragement	<p>The staff encouraged the patient to try/train new things even when the patient was hesitant or reluctant</p> <p>The staff suggested new rehabilitation exercises based on their clinical experiences</p> <p>The staff gave the patient hope</p> <p>The staff motivated the patient</p> <p>The staff helped the patient to set realistic goals for different skills</p>
Involvement of family	<p>The patient was asked if he/she wishes that a relative participated in care and rehabilitation planning</p> <p>The relatives were given the opportunity to take part in care and rehabilitation planning, if the patient so wished</p> <p>The relatives were given the opportunity to take part in special meetings for relatives if the patient so wished</p> <p>The relatives were given the opportunity to take part in planning meetings if the patient so wished</p>

Response options: always—often—sometimes—seldom—never