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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

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Abstract

Objective: To examine the internal consistency, test–retest reliability, construct validity, discriminant validity and responsiveness of the Ghent Participation Scale.
Design: Cross-sectional study with a test–retest sample.
Setting: Six outpatient rehabilitation centres in Belgium.
Subjects: A total of 365 outpatients from eight diagnostic groups.
Measures: The Ghent Participation Scale, the Impact on Participation and Autonomy, the Utrecht Scale for Evaluation of Rehabilitation-Participation and the Medical outcome study Short Form SF-36.
Results: The Ghent Participation Scale was found to have good internal consistency (Cronbach's α between 0.75 and 0.83). At item level, the test–retest reliability was good; weighted kappas ranged between 0.57 and 0.88. On the dimension level intraclass correlation coefficients ranged between 0.80 and 0.90. Evidence for construct validity came from high correlations between the subscales of the Ghent Participation Scale and four subscales of the Impact on Participation and Autonomy (range, $r = -0.71$ to -0.87) and two subscales of the Utrecht Scale for Evaluation of Rehabilitation-Participation (range, $r = 0.54$ to 0.72). Standardized response mean ranged between 0.23 and 0.68 and the area under the curve ranged between 68% and 88%.
Conclusion: The Ghent Participation Scale appears to be a valid and reliable method of assessing participation irrespective of the respondent's health condition. The Ghent Participation Scale is responsive and is able to detect changes over time.

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Introduction

Over the past decades, there has been a gradual shift from a biomedical towards a more bio-psycho-social model in rehabilitation medicine.[1] As a consequence, the concept of participation, as defined by the World Health Organization (WHO) in the International Classification of Functioning, Disability and Health (ICF) became more important in rehabilitation.[2,3] In outpatient clinics there is increasing interest in, and emphasis on, measuring participation.[4]

Despite the emerging consensus about the importance of participation, the concept remains ill-defined and problems with its application persist. Not only is there overlap between participation and other concepts, such as community integration and health-related quality of life,[5,6] but existing instruments for assessing participation also vary greatly in what they actually measure. Some instruments, such as the Keel Assessment of Participation[7] and the Measure of Home and Community Participation,[8] operationalize participation in terms of objective variables (frequency and/or duration) whereas others use a combination of objective and subjective variables. The Participation Objective-Participation Subjective,[9] the Participation Measure for Post-Acute Care[10] and the Utrecht Scale for Evaluation of Rehabilitation-Participation[4] include a set of variables designed to capture perceived satisfaction with each activity performed and the restrictions affecting those activities. The Impact on Participation and Autonomy Questionnaire[11,12] and the Participation Survey/Mobility[13] include variables of choice and control.

Qualitative research, however, has shown that other subjective components are also crucial to experiencing participation, including meaningful engagement, being part of, having responsibilities, having an impact on others,[14] exerting influence, doing things for others, belonging,[15] making challenges, asking for and accepting help, dealing with others[16] and being in the hands of others.[17] These 'missing' components raise questions about the content validity of the existing instruments.

In response to these concerns, a new measure of participation was developed, the Ghent Participation Scale. The scale operationalizes participation using 15 subjective and two objective variables and is organized into three subscales.[18] Subscale 1: 'Self-performed activities in accordance with personal choices and wishes'. Subscale 2: 'Self-performed activities leading to appreciation and social acceptance'. Subscale 3: 'Delegated activities'. The first subscale is closely linked to the concept of 'autonomy', the second is closely linked to the concept of 'satisfaction' and the third is closely linked to 'restrictions in performing activities'.

The objective of this study was to confirm the factor structure of the Ghent Participation Scale and to report its internal consistency, test–retest reliability, construct validity, discriminant validity and responsiveness. We were unable to take advantage of 'gold standard' instruments to investigate criterion validity as there are no other instruments that include all the 15 variables used in the Ghent Participation Scale and so we had to rely on instruments that measure the underlying constructs of 'autonomy' (such as in the Impact on Participation and Autonomy), 'satisfaction' and 'restrictions in performing activities' (such as in the Utrecht Scale for Evaluation of Rehabilitation-Participation). As a measure of discriminant validity, we sought to establish whether the Ghent Participation Scale discriminates between 'participation' and 'health-related quality of life'.

Methods

Study population

Individuals from six outpatient rehabilitation centres in Belgium with various health-related problems were asked to participate in the study. The participating centres were Ghent University Hospital, Leuven University Hospital (Pellenberg), National Multiple Sclerosis Centre (Melsbroek), Rehabilitation Centre AZ Sint-Jan (Bruges) and the Rehabilitation Centre Groeninghe (Kortrijk). Individuals were invited to participate when they were discharged from inpatient rehabilitation. Exclusion criteria were: age less than 18 years, lack of comprehension of Flemish and cognitive impairment or aphasia that might make completing a self-report questionnaire difficult. Because every centre used different instruments to assess cognitive impairment, the multidisciplinary team of the participating centres was asked to base inclusion decisions on patients' medical records and a multidisciplinary consensus that the patient did not have cognitive impairment.

Instruments

Choice of the instruments – we selected two scales to assess the construct validity of the Ghent Participation Scale: The Impact on Participation and Autonomy[11] and the Utrecht Scale for Evaluation of Rehabilitation-Participation.[4] The Impact on Participation and Autonomy was chosen because the first subscale of the Ghent Participation Scale is closely linked to the concepts of autonomy, choice and control. The Utrecht Scale for Evaluation of Rehabilitation-Participation was chosen because the second and third subscales of the Ghent Participation Scale refer to perceived satisfaction and perceived restrictions, respectively. We used the Medical Outcome Study Short Form Health Survey (SF-36)[19] to assess whether the Ghent Participation Scale distinguishes participation from health-related quality of life.

The Ghent Participation Scale is a digital, self-administered instrument, which provides a generic, pathology-independent measure of participation. The respondent is asked to prioritize the five most important activities he or she carried out personally and the five most important activities he or she delegated to others during the last week. Consequenlty, every time a patient completes the Ghent Participation Scale, he starts with a different set of prioritized activities. After prioritizing, the respondent has to appraise these activities in terms of 15 different subjective variables. For example one question asks 'Was it entirely your choice to engage in this activity?' The Item derivation for the Ghent Participation Scale was based on qualitative research with patients who were assumed to have experienced reduction in participation owing to sudden onset of disability. The choice of items was confirmed in a second qualitative study in people with a progressive disability.[20] See additional information for the entire scale (available online).

All items in the scale are scored using a Likert scale ranging from 1 ('I totally disagree') to 5 ('I totally agree'). A total score is calculated by summing the mean scores for the three subscales. Scores for self-performed activities are weighted according to the time spent doing them and delegated activities are weighted according to the number of delegated activities that the respondent wanted to perform personally. The rationale and statistics for use of the weighting indices has been published elsewhere.[18] See additional information for the algorithms, available online. The final score is recalculated as a percentage of participation, higher values indicate greater perceived participation.

Other measures. The Impact on Participation and Autonomy rates two aspects of participation: (1) perceived participation and (2) perceived problems. Perceived participation is rated using a 5-point Likert scale ranging from 1 ('very good') to 5 ('very poor'). Perceived problems are rated using a 3-point Likert scale ranging from 0 ('no problem') to 3 ('severe problems'). Subscale scores are calculated by summing the item scores. Higher scores denote more restrictions on participation and/or more

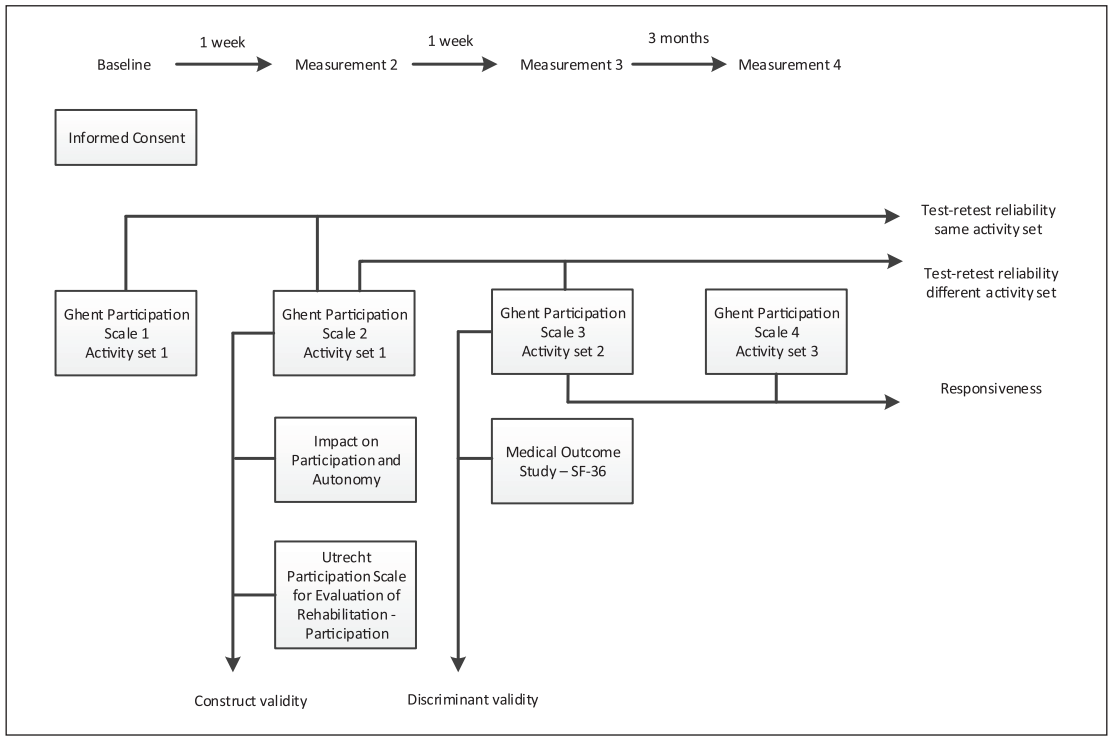

Figure 1. Protocol.

difficulty with participation.[12,21] In this study, we only used the perceived participation subscale. The Utrecht Scale for Evaluation of Rehabilitation-Participation measures three aspects of participation: frequency, restrictions and satisfaction. The frequency scale consists of 12 items and is scored using a Likert scale ranging from 0 ('none at all') to 5 ('36 h or more/19 times or more'). The restriction scale consists of 10 items and is scored on a scale ranging from 0 ('not possible') to 3 ('without difficulty'). The satisfaction scale consists of nine items and is scored on a scale ranging from 0 ('very dissatisfied') to 4 ('very satisfied'). The sum scores for each scale are converted into a score on a 0–100 scale. Higher scores denote higher levels of participation (greater frequency, fewer restrictions and greater satisfaction).[4,22] The SF-36[19] is a 36-item self-report questionnaire on health-related quality of life. It measures health-related quality of life separately in relation to physical and mental health using four subscales for each domain. Scores for both domains are transformed into scores on a 0 (worst health-related quality of life) to 100 (best) scale. The Dutch version of the SF-36 has good psychometric properties.[23] Details of the domains and subscales of these three instruments are given in Table 5, detailed later in this article.

Protocol

Participants were recruited consecutively between January 2013 and April 2014. The various instruments were completed at four different time points (see Figure 1).

- Baseline assessment: Participants provided informed consent and completed the Ghent Participation Scale (activity set 1).
- Second assessment (one week after baseline): Participants completed the Ghent Participation

Scale (to assess its test–retest reliability - participants used the same activity set as in the baseline assessment) and the Impact on Participation and Autonomy and the Utrecht Scale for Evaluation of Rehabilitation-Participation (to assess the construct validity of the Ghent Participation Scale).
- Third assessment (one week after the second measurement): Participants completed the Ghent Participation Scale (activity set 2) (to assess test–retest reliability with a different activity-set) and the SF-36 (to assess the discriminant validity of the Ghent Participation Scale).
- Fourth assessment (three months after the third measurement): The participant completed the Ghent Participation Scale (activity set 3) (to assess its responsiveness).

The choice of a one-week interval between the baseline, second and third assessments was based on similar validation research on instruments assessing participation.[4,12] The choice of a three-month interval between the third and the fourth assessments was also based on other research on the responsiveness of participation instruments.[21] At the baseline and second assessments questionnaires were completed at the rehabilitation centre during a normal therapy session, i.e. while the participant was in an outpatient rehabilitation programme or at the first follow-up meeting after discharge from an outpatient rehabilitation programme. A trained research assistant was present to record the participant's comments about the instruments and any problems the participant had in completing them. For the third and the fourth assessments, participants were sent a link to a website where they could complete the questionnaires. Responses were saved automatically and could be accessed directly by the researcher. Participants who did not use email were not sent paper versions of the questionnaire. The research protocol was approved on 21 December 2012 by the medical ethics boards of all participating centres under the central number B670201214682 for the ethics board of Ghent University Hospital. Informed consent was obtained from all participants.

Statistics

Descriptive statistics were used to show the score distributions for all scales. Floor or ceiling effects were assumed to be present if at least 15% of respondents obtained maximum or minimum scores.[24]

Factorial validity and internal consistency. Confirmatory factor analysis using a varimax rotation was used to confirm the reported structure of the scale based on research in another sample.[18] To check whether the sample was large enough to yield distinct and reliable factors, we calculated the communalities after extraction (values should be above 0.5).[25] Internal consistency was performed using Cronbach's α and item-total correlation. The internal consistency was considered good if the Cronbach's α ranges between 0.70 and 0.95 and if the item-total correlation is higher than 0.70.[24]

Test–retest reliability. It is important to note that when completing the Ghent Participation Scale respondents are asked to list the five most important self-performed and delegated activities from the last week. That means that at each measurement participants could prioritize another set of activities. To test the assumption that the item difficulty was stable across the levels of this given factor (in this case the different activity-set chosen by the respondent), the test–retest reliability was therefore twice calculated: (1) test–retest reliability at a one-week interval with no change in activity set (between baseline and the second assessments) and (2) test–retest reliability at a one-week interval with a different activity set selected independently for the test and retest (between second and the third assessments). Item-level score agreement was quantified with weighted kappa (K_w) and scale-level intraclass correlation coefficient (ICC) with the way mixed method. Test–retest reliability was considered good if both for K_w and the ICC $\geqslant 0.70$.

Construct validity and discriminant validity. To provide evidence for the construct validity of the Ghent Participation Scale scores, the various subscales of the Ghent Participation Scale were

correlated (using Pearson's correlation coefficient) with the corresponding subscales of the Impact on Participation and Autonomy and the Utrecht Scale for Evaluation of Rehabilitation-Participation. We hypothesized that: (1) 'self-performed activities in accordance with choices and wishes' would correlate with 'autonomy indoors' and 'autonomy outdoors' from the Impact on Participation and Autonomy and with 'satisfaction' from the Utrecht Scale for Evaluation of Rehabilitation Participation; (2) 'self-performed activities leading to appreciation and social acceptance' would correlate with 'family role' and 'social relations' from the Impact on Participation and Autonomy and with 'satisfaction' from the Utrecht Scale for Evaluation of Rehabilitation Participation; and (3) 'delegated activities' would correlate with 'restrictions' from the Utrecht Scale for Evaluation of Rehabilitation Participation. To provide evidence of the discriminant validity, the Ghent Participation Scale scores were correlated with scores on the various SF-36 subscales. Based on the assumption that 'participation' and 'health-related quality of life' are distinct constructs, we hypothesized that the subscales of the Ghent Participation Scale would show lower correlations with health-related quality of life as measured by the SF-36 than the the participation instruments.

Responsiveness. Standardized response mean was used to express the responsiveness of the Ghent Participation Scale to change in participation. Standardized response means were interpreted using Cohen's criteria: >0.80 indicates substantial responsiveness, >0.50 indicates good to moderate responsiveness and <0.20 indicates poor responsiveness.[26] Transition indices[27] were also used as an external standard against which to compare change scores on the Ghent Participation Scale. Following the other research on responsiveness,[21] we used five transition indices consisting of a single question to which responses were given using a 7-point ordinal scale, as has been proposed in similar research on the topic:[21] (1) 'much better'; (2) 'better'; (3) 'slightly better'; (4) 'the same'; (5) 'slightly worse'; (6) 'worse'; (7) 'much worse'. One index concerned perceived participation in general: 'with regard to my overall level of participation in daily life my level of functioning is … than three months ago?' The other four indices dealt with specific factors measured by the Ghent Participation Scale; (1) 'At the moment I feel … about performing activities compared with three months ago', (2) 'At the moment my feeling of social appreciation when performing activities is … than three months ago', (3) 'At the moment my ability to choose my activities is … than three months ago' and (4) 'delegating activities to other people is now … than when I had to delegate activities to other people three months ago'. Receiver operating characteristic curves were used and the area under the curve was calculated to analyse the Ghent Participation Scale's ability to detect improvement according to the transition indices. Following Deyo and Inui,[27] an area under the curve of 50% means that the scale in question does not perform better than chance, whereas an area under the curve of 100% represents perfect accuracy in distinguishing improved respondents from unimproved respondents.

All statistics were administered with SPSS version 22,[28] the level of significance was predefined on 0.05.

Results

Study population

A total of 365 individuals were included in the sample. The population was heterogeneous with respect to diagnosis (see Table 1). As a trained researcher was present at the baseline and second assessments, there were no missing values for these assessments and the response rate was 100%. The response rate for the third assessment, which was completed online, was 79% ($n = 270$); 26 participants did not use email. Of the 270 individuals who completed the third assessment, 50 were invited to complete the Ghent Participation Scale a fourth time, three months later. The response rate for this fourth assessment was 82% ($n = 41$). The mean age of the whole sample ($n = 365$) was 62.2 years (SD = 12). When recruited to the study, 27 participants (7.4%) reported that

Table 1. Characteristics of the participants ($n = 365$).

Age: mean (SD)	58.4 (12.0)
Gender: male/female	153/212
Diagnosis *n* (%)	
Stroke	82 (22.5)
Multiple sclerosis	25 (6.8)
Neuromuscular disorder	19 (5.2)
Spinal cord injury	26 (7.1)
Polytrauma	64 (17.5)
Parkinson	56 (15.3)
Rheumatic disorder	52 (11.2)
Other musculoskeletal disorders	41 (11.3)
Highest level of education *n* (%)	
General secondary education (12 to 18 years)	26 (7.2)
Technical and vocational secondary education (12 to 18 years)	167 (45.7)
University college (18 plus)	98 (26.8)
University (18 plus)	74 (20.3)
Readiness to live independently *n* (%)	
Completely ready to live independently	27 (7.4)
Ready but feeling slightly insecure	76 (20.8)
Ready but feelings moderately insecure	147 (40.3)
Ready but feeling severely insecure	109 (29.8)
Not at all ready to live independently	6 (1.7)

SD: standard deviation.

they were ready to live independently, 76 participants (20.8%) reported that they were prepared to do so but were feeling slightly insecure, 147 participants (40.3%) reported that they were prepared to live independently but felt moderately insecure about doing so, 109 participants (29.8%) reported that they were prepared to live independently but were extremely insecure about doing so. Six (1.7%) reported that they felt totally unprepared to live independently. Before admission and after discharge, all participants were living in their own home; 314 were living with a partner, 51 were living alone.

Score distributions for the various instruments are shown in Table 2. The distribution of scores on the Ghent Participation Scale was symmetric at all timepoints, as the skewness statistics and the small differences between mean and median scores indicate. There were no floor or ceiling effects and the distributions of scores showed a similar level of skewness to score on the Impact on Participation and Autonomy and Utrecht Scale for Evaluation of Rehabilitation-Participation.

Factorial validity and internal consistency. Communalities after extraction ranged between 0.63 and 0.71, so our sample of 365 was large enough for factor analysis. Factor analysis confirmed that the scale could be structured around three factors: (a) social appreciation and acceptance; (b) choice and wishes; and (c) delegated activities. This three-factor solution accounted for 55.64% of the variance in scores, see Table 3.

Analysis showed that the three subscales had good statistical coherence; Cronbach's α ranged from 0.75 to 0.83. Item-total correlations ranged between 0.67 and 0.86, which indicates good internal consistency.

Test–retest reliability. Values of K_w ranged between 0.57 and 0.88 when test–retest reliability was calculated with no change in activity set on retest. There was good to very good agreement between scores on all items except one ('I felt very safe during this activity') from the self-performed activities leading to appreciation and social acceptance subscale), for which there was only moderate agreement ($K_w = 0.57$). At the scale level, the ICC ranged from 0.80 (delegated activities) to 0.88 (activities leading to appreciation and acceptance) and 0.92 (activities in accordance with choices and wishes) indicating that all subscales had good test–retest reliability.

When activity sets were chosen separately for test and retest, values of K_w ranged between 0.47 and 0.72, being less than 0.60 on 12 of the 15 items. This indicates that at the item level agreement between the two assessments is poor; however, at the scale level the intraclass correlation ranged from 0.79 (delegated activities) to 0.88 (activities leading to appreciation and acceptance) and 0.87 (activities in accordance with choices and wishes) indicating that test–retest reliability was as good as when the same activity set was used at test and retest (Table 4).

Table 2. Score distribution of the Ghent Participation Scale, the Impact on Participation and Autonomy, the Utrecht Scale for evaluation of Rehabilitation-Participation and the SF-36 at the different time-points (baseline measurement and measurement 2: $n = 365$; measurement 3: $n = 270$, measurement 4: $n = 41$).

	Mean (SD)				Range				Median				Skewness			
	Baseline	M2	M3	M4	Baseline	M2	M3	M4	Baseline	M2	M3	M4	Baseline	M2	M3	M4
Ghent Participation Scale (0–100)																
Total score	50.0 (17.2)	49.8 (19.1)	50.1 (17.6)	58.4 (18.0)	22.0–98.4	22.2–97.8	21.9–98.2	25.7–97.6	53.2	54.1	53.7	54.2	0.23	0.26	0.24	0.52
Self-performed activities	54.6 (26.2)	53.6 (25.8)	54.8 (24.5)	67.0 (23.4)	20.4–100	20.0–100	25.2–100	24.4–100	60.2	59.4	61.5	64.2	0.07	0.07	0.10	0.06
Leading to appreciation and social acceptance	50.6 (17.2)	48.9 (16.8)	50.5 (18.0)	53.8 (16.8)	15.6–100	16.0–100	15.4–100	16.2–100	54.0	56.4	55.4	55.0	0.20	0.21	0.23	0.24
In accordance with choices and wishes	58.0 (16.2)	58.2 (19.2)	59.4 (18.4)	65.6 (19.2)	24.0–100	24.0–100	25.6–100	24.4–100	76.2	69.4	68.4	65.5	−0.76	−0.56	−0.78	−0.81
Delegated activities	48.0 (24.2)	48.8 (23.5)	48.2 (25.0)	52.4 (22.2)	12.8–100	14.0–100	13.4–100	14.2–100	39.0	47.9	42.7	43.5	0.70	0.65	0.74	0.71
Impact on Participation and Autonomy[a]																
Autonomy indoors (0–35)		16.3 (5.2)				6.0–21.0				16.0				0.29		
Autonomy outdoors (0–25)		12.8 (3.1)				5.0–17.0				13.2				−0.63		
Family role (0–35)		19.9 (4.8)				6.0–28.0				18.0				0.16		
Social relations (0–30)		14.9 (3.3)				3.0–22.0				14.8				0.17		
Work and education (0–30)		23.6 (4.4)				6.0–25.0				21.4				0.34		
Utrecht Scale for Evaluation of Rehabilitation Participation (0-100)																
Frequency		29.3 (10.2)				3.7–64.2				28.2				0.23		
Restrictions		73.4 (19.5)				7.2–100				74.2				−0.57		
Satisfaction		68.7 (17.6)				5.0–100				69.5				−0.43		
SF-36 (0–100)[b]																
Physical component summary			49.7 (8.9)													
Mental component summary			45.4 (10.7)													

[a]A higher score means a lower perceived participation score – only the perceived participation domains and not the perceived problems are given in this overview.
[b]Only the two dimensions and not the subscales are given in this overview.
M2: Measurement 2; M3: Measurement 3; M4: Measurement 4; SD: standard deviation.

Table 3. Homogeneity as indicated by Cronbach's α and item-total correlation of the items and the factorial validity calculated with a principal component analysis: Rotated loadings for a three-factor analysis ($n = 365$).

	Internal consistency		Factorial validity[a]		
	Item-total correlation	Cronbach's α	Factor 1 activities in accordance with choices and wishes	Factor 2 activities leading to appreciation and social acceptance	Factor 3 Delegated activities
			19.34%	18.77%	17.52%
Subscale 1: Self-performed activities		0.81			
Subscale 1a: Activities in accordance with choices and wishes		0.83			
It was entirely my choice to engage in this activity	0.78		0.71		
I performed this activity (or I was part of it) exactly as I wished	0.72		0.82		
During this activity I was completely able to be myself	0.77		0.75		
This activity was completely fulfilling for me	0.78		0.60	0.39	
During this activity, I felt completely in control	0.78		0.77		0.32
Subscale 1b: Activities leading to appreciation and social acceptance		0.81			
I felt very safe during this activity	0.79		0.39	0.44	
I felt a strong appreciation during this activity	0.80			0.80	
During this activity, it felt as if I were an important person	0.80			0.77	
During this activity, I really felt I belonged (was part of the group)	0.72			0.78	
Subscale 2: Delegated activities		0.75			
It was entirely my choice to let someone else perform this activity	0.86				0.56
I completely trust the person(s) who performed this activity for me	0.67				0.37
Because others performed this activity, I did not have to worry about it	0.69				0.75
I felt that those doing so loved performing this activity for me	0.78				0.68
I felt safer by asking someone else to do this activity for me	0.84				0.83
I felt more in control because I asked someone else to do this activity for me	0.73			0.31	0.70

[a]Percentages of variance explained by each factor. For each factor, scores beneath 0.3 have been left out of this matrix to increase the interpretability.

Table 4. Results for the test–retest reliability. Range of weighted kappa for the items in each subscale–intraclass correlation on scale level (same activity set: $n = 365$; different activity set: $n = 270$).

	Weighted Kappa		Intraclass correlation		Confidence interval ICC	
	Same activity set	Different activity set	Same activity set	Different activity set	Same activity set	Different activity set
Ghent Participation Scale total	0.57–0.88	0.47–0.72	0.83	0.82	0.79–0.92	0.75–0.88
Self-performed activities:	0.57–0.81	0.47–0.62	0.87	0.86	0.77–0.88	0.76–0.91
In accordance with choices and wishes	0.69–0.81	0.54–0.62	0.92	0.87	0.81–0.95	0.84–0.92
Leading to appreciation and social acceptance	0.57–0.79	0.47–0.59	0.88	0.88	0.75–0.89	0.69–0.91
Delegated activities	0.78–0.88	0.58–0.72	0.80	0.79	0.74–0.84	0.67–0.82

All scores were from 0 to 100; higher scores indicate better perceived participation.

Construct validity and discriminant validity. Evidence for the construct validity of the Ghent Participation Scale came from the high correlations between the 'self-performed activities in accordance with personal choices and wishes' subscale of the Ghent Participation Scale and the 'autonomy indoors' subscale ($r = –0.87$) and 'autonomy outdoors' subscale ($r = –0.71$) of the Impact on Participation and Autonomy and the 'satisfaction' subscale ($r = 0.72$) of the Utrecht Scale for Evaluation of Rehabilitation-Participation. The 'self-performed activities leading to appreciation and social acceptance' subscale of the Ghent Participation Scale was also highly correlated with the 'family role' subscale ($r = –0.76$) and the 'social relation' subscale ($r = –0.82$) of the Impact on Participation and Autonomy and with the 'satisfaction' subscale ($r = 0.62$) of the Utrecht Scale for Evaluation of Rehabilitation-Participation; these results were consistent with our hypotheses. A moderate correlation ($r = 0.54$) between the 'delegated activities' subscale of the Ghent Participation Scale and the 'restrictions' subscale of the Utrecht Scale for Evaluation of Rehabilitation-Participation were also consistent with the hypothesis, but we had expected a higher correlation.

The discriminant validity of the Ghent Participation Scale was supported by small correlations between scores on the Ghent Participation Scale and the 'bodily pain' component of the SF-36 ($r = 0.08$ to 0.019). Correlations between the Ghent Participation Scale total score and other subscales of the SF-36 were higher than expected: 'physical component summary' ($r = 0.32$ to 0.42), 'physical functioning component' ($r = 0.21$ to 0.62), 'role limitations component' ($r = 0.42$ to 0.62), 'general health component' ($r = 0.24$ to 0.36), 'social functioning component' ($r = 0.45$) and 'mental well-being component' ($r = 0.23$ to 0.51), but lower than the correlations between the Ghent Participation Scale and the corresponding components of the Impact on Participation and Autonomy and the Utrecht Scale for Evaluation of Rehabilitation-Participation (Table 5).

Responsiveness. Standardized response mean scores for the subscales 'activities in accordance with personal choices and wishes' (standardized response mean = 0.32) and the subscale 'delegated activities' (standardized response mean = 0.42) indicated moderate responsiveness and the standardized response mean for the 'activities leading to appreciation and social acceptance' subscale (standardized response mean = 0.64) indicated good responsiveness. The Ghent Participation Scale total score showed good responsiveness (standardized response mean = 0.68). The Ghent Participation Scale is good at distinguishing improved respondents from unimproved respondents; area under the curve ranged from 0.68 ('delegated activities) to 0.88 ('activities leading to appreciation and social acceptance'); area under the curve for the Ghent Participation Scale total score was 0.75 (Table 6).

Table 5. Construct and discriminative validity: Pearson's correlations coefficients between the subscales of the Ghent Particiaption Scale and the Impact on Participation and Autonomy, the Utrecht Scale for Evaluation of Rehabilitation-Participation and the SF-36 measuring similar or different constructs.

	Ghent Participation Scale total	Subscale: Self-performed activities	Subscale: Activities in accordance with choices and wishes	Subscale: Activities leading to appreciation and social acceptance	Subscale: Delegated activities
Impact on Participation and Autonomy					
Autonomy indoors	−0.40[a]	−0.45[a]	−0.87[a]	−0.46[a]	−0.65[a]
Autonomy outdoors	−0.32[a]	−0.51[a]	−0.71[a]	−0.36[a]	−0.54[a]
Family role	−0.38[a]	−0.54[a]	−0.44[a]	−0.76[a]	−0.21
Social relations	−.0.26	−0.48[a]	−0.32[a]	−0.82[a]	−0.14
Work and education	−0.10	−0.16	−0.18	−0.24	−0.09
Utrecht Scale for Evaluation of Rehabilitation-Participation					
Frequency	0.14	0.06	0.02	−0.05	0.1
Restrictions	0.29	0.47[a]	0.13	0.15	0.54[a]
Satisfaction	0.45[a]	0.54[a]	0.72[a]	0.62[a]	0.45[a]
SF-36					
Physical component summary	0.36[a]	0.42[a]	0.42[a]	0.32	0.27
Physical functioning	0.52[a]	0.45[a]	0.44[a]	0.45[a]	0.21
Role-limitations (physical)	0.42[a]	0.32	0.24	0.52[a]	0.62[a]
Bodily pain	0.12	0.15	0.08	0.18	0.19
General health	0.31[a]	0.24	0.24	0.32	0.32
Mental component summary	0.19	0.21	0.12	0.24	0.25
Role limitations (mental)	0.32[a]	0.23	0.34[a]	0.10	0.51[a]
Vitality	0.12	0.24	0.31[a]	0.25	0.21
Social functioning	0.45[a]	0.34[a]	0.21	0.41*	0.30
Mental wellbeing	0.51[a]	0.32[a]	0.23	0.42*	0.45[a]

[a]Significant at the 0.05 level.

Table 6. Mean scores at measurement 3 and measurement 4, means change scores for improvement and responsiveness of the Ghent Participation Score domains expressed in standardized response mean and area under the curve ($n = 41$).

	Measurement 3 (SD)	Measurement 4 (SD)	Change score (SD)[a]	Change score for improvement (SD)[b]	95% CI	SRM	AUC (%)
Ghent Participation Score total	50.1 (17.6)	58.4 (18.0)	8.3 (13.2)	0.4 (0.68)	−0.38 to 2.06	0.68	75
Self-performed activities	54.8 (24.5)	67.0 (23.4)	6.6 (27.6)	0.61 (1.38)	−1.81 to 2.61	0.57	82
In accordance with choices and wishes	50.5 (18.0)	53.8 (16.8)	3.3 (10.6)	0.14 (0.85)	−1.39 to 1.15	0.32	79
Leading to appreciation and social acceptance	59.4 (18.4)	65.6 (19.2)	6.2 (23)	0.37 (1.15)	−1.51 to 2.54	0.64	88
Delegated activities	48.2 (25.0)	52.4 (22.2)	4.2 (22.4)	0.21 (1.12)	−2.19 to 2.51	0.43	68

[a]Change score: Measurement 4 score minus the Measurement 3 score.
[b]Change score related to improvement as indicated by the corresponding transition index.
AUC: area under the curve to distinguish improved vs. unimproved; CI: confidence interval; SD: standard deviation; SRM: standardized response mean for the improved group.

Discussion

The results of this study indicate that the Ghent Participation Scale can be considered a valid method of measuring perceived participation irrespective of the health status and pathology of the respondent. The Ghent Participation Scale has a good internal consistency, good to excellent test–retest reliability and is able to detect changes in participation over time. These features suggest that it could be used by practitioners to enhance their evaluation of the effectiveness of their interventions by enabling them to assess participation.

The Ghent Participation Scale is related to other participation questionnaires, but differs in structure. First, when completing the Ghent Participation Scale respondents begin by prioritizing the activities that are most important to them and it is this personalized list of activities which is rated rather than the predefined sets used in related measures, e.g. those we used to assess the construct validity of the Ghent Participation Scale.[4,11] Second, the instrument is multidimensional and incorporates 15 subjective and two objective variables; this makes the instrument unique, and meets healthcare providers' and researchers' increasing demands for measures of participation, which include subjective variables.[2] This study has provided evidence that the experience of participation is similar regardless of the activities selected for evaluation, but that it is the subjective appraisal of them that is of utmost importance. Considering these features and the differences with existing measures, our study adds to the discourse on measuring participation in a outpatient rehabilitation setting. However, some aspects need to be discussed.

To begin with, the scale as a whole and the various subscales had good to excellent internal consistency. However, the subscale 'delegated activities' had lower internal consistency than the subscales of 'self-performed activities'. This was owing to the low item-total correlations for the items 'I experience trust by delegating activities' and 'I worry less when I delegate activities'. We considered removing these items, but decided to retain them after a member check with the participants and a discussion with an expert panel of healthcare professionals. Both groups considered these items to reflect key aspects of participation. In addition, removing them did not substantially increase Cronbach's α for the subscale.

The test–retest reliability of the Ghent Participation Scale was good to excellent at scale level and at item level if the scores being

compared were based on the same set of activities. When comparing the results with a different activity set, the test–retest reliability was equally strong on the scale level, but not on the item level. This finding clearly indicates that scores on the Ghent Participation Scale are independent of the activities chosen for evaluation. This provides evidence that it is not the activity itself that is important to perceptions of participation, but the individual's ability to choose his or her autonomy, the relationship between activities and identity and other relevant subjective values. This argument has been made before, but until now remained largely theoretical rather than evidence-based.[14,15,29] To our knowledge this is the first study to provide evidence that activities and participation belong to the same chapter in the ICF. Depending on the subjective appraisal of activities, all of them can be the trigger to experience participation. However, our data provide only limited evidence and future research should focus on this issue. In addition, further analysis is needed to explore how activity changes over time.

The construct validity of the Ghent Participation Scale was supported by the high correlation between its subscales and four subscales of the Impact on Participation and Autonomy (autonomy indoors; autonomy outdoors; family role; social relations) and two subscales of the Utrecht Scale for Evaluation of Rehabilitation-Participation (restriction; satisfaction), which theoretically measure the same constructs. There was, however, no correlation between any of the Ghent Participation Scale subscales and the 'work and education' subscale of the Impact on Participation and Autonomy. This may be owing to the fact that 'work and education' is by definition relevant to relatively young people who might expect to return to employment or education. The mean age of our sample was 58.4 years and the participants were still recovering from their illness. It may be that this sample had chosen to strive for participation in activities other than work and education. One might find a correlation between the Ghent Participation Scale and this subscale in a sample containing more people of working or school age. We expected to find a higher correlation between the 'delegated activities' subscale of the Ghent Participation Scale and the 'restrictions' subscale of the Utrecht Scale for Evaluation of Rehabilitation-Participation, but the relatively low correlation observed might be related to differences in how restriction and the need to delegate were interpreted. We specifically intended not to focus on the experienced problems when asking to rate their level of participation. The Ghent Participation Scale does not ask specifically about restrictions on activities, although participants were asked to indicate whether they would have preferred to perform delegated activities themselves; delegating an activity one would prefer to perform oneself might be assumed to indicate that one's ability to do so is restricted in some way. We deliberately focused on the positive aspects of human functioning and asked 'what did you delegate to someone else?' rather than 'what was not possible for you?', mainly because the Ghent Participation Scale is intended to measure patients' capacities and abilities and their autonomy when it comes to delegating activities. This difference in looking at limitations that might have caused the lower correlation.

The best evidence for the discriminant validity of the Ghent Participation Scale was its low correlation with the 'bodily pain' subscale of the SF-36. As participation and perceived general health are not considered to belong to the same theoretical construct, this low correlation was expected. However, the other SF-36 subscales were more highly correlated with the Ghent Participation Scale than expected, indicating that participation and health-related quality of life are more closely related constructs than we had assumed. To further support discriminant validity, it would have been better to have included other instruments measuring totally different constructs.

Finally, the results of the preliminary analysis of responsiveness show that the Ghent Participation Scale can detect improvements over time. Our results suggest that the Ghent Participation Scale is responsive and can be used to distinguish patients who have improved from those who have not, although overall within-subject improvements were small in our sample. There are several

possible reasons for the small change scores. First, an interval of three months may be too short to detect substantial changes in participation. Second, the relative lack of change may be owing to the composition of the sample, which included both patients with acute conditions and those with more chronic conditions; temporal changes in participation might vary as a function of pathology. Unfortunately, the numbers were too small to calculate separate standardized response means and area under the curves for the different subgroups separately. Future studies should leave a longer interval between the baseline and follow-up assessments. Furthermore, because our sample was relatively small, the findings on responsiveness must be confirmed in a larger sample.

Limitations of the study and future research

First, as the Ghent Participation Scale is meant to be pathology-independent, we had no a priori hypotheses about possible group differences in participation. The suggestions made above about group differences require further investigation. There is also no information about how a healthy population would score on the Ghent Participation Scale. Second, this study was carried out in the Flemish-speaking part of Belgium and only Flemish speakers with a physical limitation who felt prepared to go home were included. Further research is needed to establish whether our findings generalize to persons with more severe physical or cognitive limitations, and to other countries and cultures. Finally, responsiveness was only measured in a small sample, further research on the Ghent Participation Scale's sensitivity to change in different diagnostic groups is necessary.

Implications

The bio-psycho-social model of rehabilitation encourages us to view disability as a bio-psycho-social construct rather than a purely personal construct made up of behavioural, biological and genetic factors. Many rehabilitation centres focus not only on the medical restoration of individuals, but also on the long-term consequences of their illness or accident and their participation in their community. This is only possible if a valid, reliable measure of participation is available. The goal of this study was to report the psychometric properties of the Ghent Participation Scale. We found that the scale has excellent internal consistency, excellent test–retest reliability and good responsiveness. These features suggest that it can be used by practitioners to evaluate how effective their interventions are at improving participation.

Clinical messages

- The Ghent Participation Scale is a valid, reliable instrument that can be used in outpatient rehabilitation irrespective of pathology.
- In measuring participation, the activities themselves are not of primary interest, but rather the subjective appraisal of them; every activity can be the trigger to experience participation.

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