Measuring participation outcomes in rehabilitation medicine

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Measuring participation outcomes in rehabilitation medicine

Het meten van participatie als uitkomst in de revalidatie

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de Universiteit Utrecht op gezag van de rector magnificus, prof.dr. G.J. van der Zwaan, ingevolge het besluit van het college voor promoties in het openbaar te verdedigen op donderdag 29 augustus 2013 des middags te 2.30 uur

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Rehabilitation medicine is about minimising the consequences of chronic disabling conditions to improve independence and ultimately social participation.^{1,2} Patients with various health conditions follow multi-disciplinary treatment programmes in which both physical and cognitive impairments are dealt with if necessary. Rehabilitation programmes are patient-tailored, guided by the impairments, activity limitations, and individual goals of the patient. Treatment goals in the inpatient clinic usually focus on improving independence, whereas goals in the outpatient clinic are likely to be at the level of participation.

In the Netherlands, there is a growing pressure, especially from regulatory agencies, to gain insight in the quality of rehabilitation practice, and the use of performance indicators is becoming more and more mandatory. Performance indicators can be useful in assessing quality of structures, processes, and outcomes. Structure indicators asses health care organisation's facilities, equipment, personnel, and administration which are used to deliver health care. Process indicators assess primary processes in health care like management procedures, record keeping, diagnosis, treatment planning, and treatment delivery. Outcome indicators refer to the changes in a patient's health condition and well-being, as a result of the health care.^{3,4} Outcome indicators can both guide clinical decision making and the documentation of outcomes of interventions, thereby facilitating the sharing of medical performance information in order to improve our health care system. Heinemann states that outcome indicators become more and more important in assessing performance, assuming that good outcomes are the product of well organised and managed health care.³

In 2007 De Hoogstraat Rehabilitation conducted a study which aimed at the choice for a generic measurement instrument as outcome indicator for the inpatient setting.⁵ Since the common goal of inpatient rehabilitation programmes is to regain functional independence, functional status measurement instruments were compared in order to identify instruments most suitable to measure the effects of inpatient rehabilitation. The results of that study showed that a newly developed measurement instrument, named the Utrecht Scale for Evaluation of Rehabilitation (USER), was most suitable to measure functional independence as compared to several frequently used generic and diseasespecific measurement instruments.⁵ Both Revalidatie Nederland (RN) and the Vereniging voor Revalidatieartsen (VRA) support the use of the USER as outcome measure.⁶

The abovementioned clinical study was the starting point of the study that led to the present thesis. Outcome measurement is not only relevant to inpatient, but also to

outpatient rehabilitation programmes. We wondered if it was possible to identify a generic measurement instrument as outcome indicator for the outpatient rehabilitation setting. Consistent with the goals in the outpatient rehabilitation setting we were looking for a suitable generic measurement instrument to assess participation.

Participation in the ICF

The concept of participation was introduced in the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization (WHO) in 2001.⁷ The ICF provides an unified and standard language and framework for the description of health and health-related states.^{7, p3} The ICF is organised into two parts: the first part describes Functioning and Disability, comprising the components 'Body Functions and Structures' and 'Activities and Participation'; the second part describes Contextual Factors, comprising the components 'Environmental Factors' and 'Personal Factors'. In the ICF, Activities and Participation are two different concepts. Activity is defined as 'the execution of a task by an individual' and Participation is defined as 'involvement in a life situation'.^{7, p10} The interaction of the ICF components is shown in Figure 1.1.

Unfortunately, unlike this figure, in the ICF taxonomy both concepts are merged into one component with 9 chapters/domains: 1) learning and applying knowledge; 2) general



Figure 1.1 Interaction of the ICF components.

tasks and demands; 3) communication; 4) mobility; 5) self-care; 6) domestic life; 7) interpersonal interactions and relationships; 8) major life areas; and 9) community, social and civic life. Each chapter is specified in more detailed categories. For example, chapter 8 on major life areas includes separate broad categories on education, work and employment, and economic life, each of which comprise a number of more detailed subcategories.

Merging the concepts of Activities and Participation into one single component that covers the whole spectrum of life domains, hampers the conceptualisation of participation and makes participation a difficult to measure construct. The ICF is ambiguous in how to separate Activities from Participation. One way is the use of qualifiers. The first one is capacity, which describes the individual's ability to execute a task or an action in a standardised setting, thereby reflecting the individual's highest level of functioning. The second qualifier is performance, which describes what an individual actually does in his/ her environment. Other ways to separate Activities from Participation are to either assign some domains to Activities and others to Participation, with or without any overlap; or to assign every detailed subcategory as Activities and the broad categories as Participation; or to assign every domain as both Activities and Participation.

In order to develop a participation measurement instrument, each researcher needs to decide how to separate Activities from Participation when conceptualising participation. For example, both Whiteneck and Dijkers⁸ and Post et al.⁹ provide a distinction between Activities and Participation without overlap, but both are slightly different. Whiteneck and Dijkers⁸ stated that activity is at the person level while participation is at the societal level involving other people. Based on this difference, they suggested to assign chapter 1 to 5 (ICF chapters are described above) to Activities, and chapter 7 to 9 to Participation. Chapter 6 on domestic life should mainly be assigned to Activities, except from the category 'assisting others' and an extra Participation chapter should be added including homemaking for others.⁸ Post et al.⁹ also made a distinction not allowing any overlap, but this distinction was more straight forward; chapters 1 to 5 were assigned to Activities, and the chapters 6 to 9 were assigned to Participation.

In this thesis, we accepted the abovementioned categorisation, which is in agreement with a recent review, showing that all current ICF-based participation measurement instruments cover the ICF chapters 6 to 9, but differ on the coverage of ICF chapters 1 to 5.¹⁰ This implies that chapter 6–9 are most characteristic of participation.

Besides the challenges in conceptualisation of participation, we are also challenged with how to rate levels of participation; the ICF does not describe whether participation should be assessed from an objective perspective or a subjective perspective. Objective participation refers to observable behaviours, whereas subjective participation represents the subjective appraisal of the person involved.^{11,12} This distinction is important, since both perspectives are only weakly related^{13,14} and therefore it is preferred to measure both as distinct concepts.^{8,13} Both perspectives are necessary to get insight in someone's participation. Objective participation describes an individual's participation pattern in frequency in a specific time frame, while subjective participation reveals information about how this pattern is valued by the person. Moreover, Bennekom et al. even stated that the subjective perspective is of great importance to the design of the rehabilitation programme.¹⁵

In search of a participation outcome measure

Since the introduction of the ICF many participation measurement instruments have been developed. At the start of this research project, we did not have the intention to develop a new instrument, adding to this mass of newly developed and not-yet extensively tested instruments.¹⁶ We intended to select and compare a maximum of four existing measurement instruments that were short, were suitable for self-report, had good psychometric properties, and assessed objective as well as subjective participation. This selection process consisted of the following steps: i) collection of generic participation measurement instruments from the literature, which resulted in over forty instruments. In doing this, we excluded instruments of Quality of Life including one or more social health or social integration scales; ii) first rough selection based on their psychometric properties, availability and use of the instruments in Dutch. Some promising new measurement instruments were not available in Dutch, but were nevertheless added to the selection. This step resulted in eleven instruments;¹⁷ iii) creating an overview of these eleven instruments summarising properties on applicability in different diagnostic groups, number of items, suitability for self report, ability to measure both objective and subjective participation, and the coverage of Participation chapters of the ICF; iv) arranging a meeting with experts (physicians, researchers) to discuss the benefits and disadvantages of these eleven instruments; v) final selection of three instruments by the research team. A more detailed description of this selection process can be found in Revalidata.¹⁷

This examination of existing participation measurement instruments made us realise that none of the generic measurement instruments met all our criteria. Therefore, we developed

a new instrument; the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation). It is a brief self-report instrument for adult patients, designed to be suitable for self-report and to measure both objective and subjective participation. Since the USER-Participation is a new measurement instrument, its psychometric properties have to be tested and need to be satisfactory before it can be used in research or clinical practice.

Psychometric properties

Psychometrics is the field of developing, evaluating and applying measurement instruments.¹⁸ The psychometric properties of a measurement instrument reflect certain qualities of this instrument. The aim of the instrument determines which psychometric properties are important: discriminant validity is important for diagnostic purposes, discrimination on longitudinal basis is important for prognostic purposes, and detecting changes over time (also called responsiveness) is important for evaluation.

Content validity examines the extent to which the concept of participation is represented by the items in the instrument.¹⁹ To develop the USER-Participation we determined what domains of the concept of Activities and Participation comprise participation. In this way we were able to determine which domains should be assessed by the items in the instrument.

Internal consistency evaluates the extent to which items in an instrument are correlated (homogeneous), and thus measuring the same concept.¹⁹ It is important to evaluate the internal consistency of participation measurement instruments because these often consist of both Activity and Participation related items.

Criterion validity refers to the extent to which scores on a particular instrument relate to a gold standard.¹⁹ Golden standards are very rare in constructs being measured by instrument. Construct validity can be determined if no gold standard is available and refers to the extent to which scores on a particular instrument relate to other instruments measuring the same construct. Due to the unclear definition by the ICF, participation instruments have been developed that are ICF-based but nevertheless differ in their coverage of ICF domains. Examining construct validity gives insight into how the various measurement instruments are similar or different.

Reproducibility concerns the degree to which repeated administrations of the same instrument provide similar answers, assuming the person does not show change in the construct measured. Reproducibility is expressed in two terms: agreement, which reflects

the amount of measurement error, and reliability, which is the degree to which patients can be distinguished from each other.¹⁹ Small measurement error is needed in order to assure that changes in participation can be detected. The ability to distinguish between patients is important for diagnostic purposes, i.e. to identify patients with participation problems.

And finally, responsiveness is the property to detect changes over time, thus to which an improvement or decline is reflected in the score on an instrument.¹⁹ Responsiveness is a very important property for an instrument when it is used as an outcome indicator.

Aims and outline of this thesis

The general aim of the present thesis was to evaluate the validity, reproducibility, and responsiveness of the USER-Participation in an adult outpatient rehabilitation sample with various health conditions.

Different psychometric properties of the USER-Participation are addressed in chapters 2 to 7. Chapter 3 describes the development of the USER-Participation and assesses its construct validity by a comparison of scores on this instrument with scores on the Frenchay Activities Index (FAI),²⁰ the ICF Measure for Activities and Participation (IMPACT-S)⁹ and the Participation Scale²¹ in a sample with various health conditions. Chapter 2 focuses on the reproducibility of this instrument, also in a sample of different health conditions. Following Terwee et al.¹⁹ we examined reproducibility by evaluating both reliability and agreement for the USER-Participation, the IMPACT-S⁹ and the Participation Scale.²¹ Chapter 4 reports on responsiveness, assessed in the same set of health conditions as used in Chapter 2. Responsiveness statistics are calculated and compared between the USER-Participation, the FAI,²⁰ the IMPACT-S,⁹ and the Participation Scale.²¹ Chapter 5 also focuses on responsiveness, but in a different sample of outpatients with brain injury or neuromuscular diseases from the University Medical Center Utrecht. In this study we had the opportunity to compare the USER-Participation to the Impact on Participation and Autonomy (IPA).²² The IPA²² is a commonly used measurement instrument in the field of rehabilitation medicine in the Netherlands. Chapter 6 focuses on the comparison of psychometric properties of the USER-Participation, again the IMPACT-S,9 and the WHO Disability Assessment Scale (WHODAS II)²³ in a sample of persons with spinal cord injury. The development of the WHODAS II²³ was guided by the ICF framework, and it was a specific interest of the WHO collaborating centre in Nottwil, Switzerland to test the USER-Participation against these two ICF-based instruments. In Chapter 7 we applied

the USER-Participation to show how it can be used to describe participation outcomes after rehabilitation. This chapter focuses on the persisting participation problems in a chronic stroke population. The thesis concludes in **Chapter 8** with a general discussion of the main findings.

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Chapter 1 Introduction

2

Reproducibility of three self-report participation measures: the ICF Measure of Participation and Activities Screener, the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation

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Abstract

Objective: To assess the reproducibility of 3 participation measures.

Design: Repeated administration of a postal questionnaire with a 2-week interval.

Participants: Outpatients (n= 47) from 2 rehabilitation centres and a university hospital in The Netherlands.

Methods: Measures were the ICF Measure of Participation and Activities Screener (IMPACT-S), the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation). Test-retest reliability was analysed using Cohen's weighted kappa and the intraclass correlation coefficient (ICC). Agreement was expressed as the standard error of measurement and the smallest detectable change (SDC), substantiated as the ratio between the SDC and the standard deviation (SDC/SD).

Results: ICC values of the IMPACT-S were 0.54–0.90 for the scale scores, 0.92 and 0.74 for sub-total scores Activities and Participation, and 0.88 for the total score. The ICC of the Participation Scale was 0.82. The ICC of the USER-Participation was 0.65 for the Frequency scale, 0.85 for the Restrictions scale, and 0.84 for the Satisfaction scale. The SDC/SD ratios for all measures were small (0.11–0.28) at the group level, but large (0.96–1.91) at the individual level. Most participants found all measures relevant and easy to complete.

Conclusions: All 3 measures showed generally satisfying reproducibility and were acceptable to the participants.

Introduction

Most patients are referred to rehabilitation because of conditions that cannot be cured. Their treatment will be aimed at minimizing the consequences of these conditions to improve independence and, ultimately, social participation.¹ In the outpatient clinic in particular, re-establishment of social participation is a key aim of rehabilitation programmes. Measurement of participation outcomes is, however, not common in rehabilitation research.^{2,3} This discrepancy has been related to the nature of participation as being affected by many factors outside the control of the rehabilitation team, but also to measures of participation being less developed than measures of more basic activities.⁴ Since the introduction of the International Classification of Functioning, Disability and Health (ICF) in 2001,⁵ many instruments to measure participation have been developed, but psychometric evidence on these measures is still incomplete.³ A participation measure, like any measure, must be valid, reproducible, and responsive in order to be used as an outcome measure.⁶ Existing participation measures have generally showed validity, but their reproducibility and responsiveness have rarely been established.^{2,3,7}

In response to this lack of data, we started a prospective multi-centre study to identify a valid and responsive instrument to measure participation outcomes of outpatient rehabilitation.⁸ Participation measures were selected for this study using the following criteria: (i) applicable in various diagnostic groups; (ii) feasible (being brief and suitable for self-report) for use in routine outcome monitoring; (iii) providing both objective and subjective ratings of participation; (iv) covering the ICF participation chapters;⁵ and (v) having sound psychometric properties. No measure met all criteria, but we identified several promising measures, 4 of which were selected for our responsiveness study.8 The Frenchay Activities Index (FAI)9 was selected because it is the most often used participation measure in rehabilitation research,³ and the only participation measure used in clinical practice in The Netherlands. The ICF Measure of Participation and Activities Screener (IMPACT-S)¹⁰ was selected because it is the only participation measure that covers all Activities and Participation chapters of the ICF.⁵ It is a measure we developed in earlier research.⁸ The Participation Scale¹¹ was selected because it is the only participation measure that asks people to rate their participation using an explicit frame of reference, namely "the peer group". Finally, since we found no instrument measuring both objective and subjective participation and which satisfied most other criteria, we developed a new measure, the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation).⁸ Our study into the responsiveness of these 4 measures is ongoing.

However, except for the FAI,¹² there was also a need for data on the reproducibility of these measures. The reproducibility of the IMPACT-S has been studied previously,¹⁰ but some alterations have been made to this measure since then. Evidence of the reproducibility of the Participation Scale is incomplete and, to include this scale in our responsiveness study, we had to translate it into Dutch and transform it from an interviewer-administration into a self-report measure so that the reproducibility of this Dutch self-report version also had to be assessed. The same was true for the USER-Participation as a newly developed measure. The aim of the present study was therefore to assess the reproducibility of the IMPACT-S, the USER-Participation, and the Participation Scale.

Methods

Sample

A total of 104 candidate-participants with physical disabilities were selected from the outpatient clinics of rehabilitation centres De Hoogstraat and De Trappenberg, in Almere, and the University Medical Centre Utrecht, The Netherlands. Inclusion criteria were a minimum age of 18 years and the ability to read and comprehend self-report measures in Dutch. Exclusion criteria were severe cognitive impairments, aphasia, and a rapidly progressive disorder.

Procedure

Candidate-participants received a written invitation to participate in the study along with the questionnaire. Participants who did not respond within two weeks received a once-only reminder. Participants who replied with a completed questionnaire, received the second questionnaire two weeks after completing the first. Participants who did not return this second questionnaire within two weeks received a reminder. The study protocol was approved by the local medical ethics board of Rehabilitation Centre De Hoogstraat.

Instruments

The IMPACT-S, the Participation Scale, and the USER-Participation were combined in random order in the questionnaire and it was ensured that participants would receive the measures in different order on both administrations. In addition to these measures,

the first questionnaire contained questions on diagnosis and demographic characteristics and the second questionnaire contained questions on the respondent's opinion about the measures, asking for the most relevant and easiest measure as well as asking for possible irrelevant or obtrusive questions.

The IMPACT-S assesses experienced limitations in activities and participation comprising 32 items covering all 9 chapters of the Activities and Participation component of the ICF.⁵ All items are rated on a score of 0 (cannot do that at all) to 3 (no limitations whatsoever). Nine scale scores, two sub-total scores for Activities and Participation and a total score can be computed. All summary scores are converted to a score on a 0–100 scale, in which a high score indicates a high level of participation. The test-retest reliability of IMPACT-S has been assessed in road accident victims and was found to be good at item level (kappa= 0.44–0.72), scale level (Intraclass Correlation Coefficient (ICC)= 0.72–0.92), sub-total score level (0.90–0.93), and total score level (0.94).¹⁰ However, after finishing this study 1 item was omitted from this measure and the number of response options has been inceased from 3 to 4 because it was expected that separating the previously merged categories "considerable limitations" and "I cannot do that at all" would make it easier for respondents to choose the category that best reflects their situation.

The Participation Scale measures experienced participation restrictions.¹¹ It covers 8 out of 9 ICF Activities and Participation chapters. Originally the Participation Scale was an interview-based instrument. It was translated into Dutch and re-designed as a self-report measure in cooperation with the author. The Participation Scale contains 18 items, each measuring the level of participation compared with peers and, in case of a lower level of participation, the extent to which the respondent experiences this as a problem. "Peers" are defined as: people who are similar to the respondent in all aspects (socio-cultural, economic, and demographic) except for the health condition or disability.¹³ Both answers are combined in an item score between 0 (same level of participation) and 5 (lower level of participation and experienced as a large problem). A total Participation Scale score is obtained as the sum of the item scores, ranging from 0 to 90, with a high score indicating severe participation restrictions. The Participation Scale was found to be valid and reliable, with a Cronbach's α of 0.92, a test-retest reliability ICC of 0.83, and inter-tester reliability of 0.80.¹¹

The USER-Participation is a newly developed participation measure that aims to measure both objective and subjective participation. It is an extension of the USER, which is a measure of activity limitations.¹⁴ The USER-Participation consists of 31 items, covering

8 out of 9 ICF Activities and Participation chapters. It assesses 3 aspects of participation: frequency, experienced restrictions, and satisfaction. (i) Frequency of participation consists of two parts: the first part contains 4 items on frequency of vocational activity measuring the amount of time the respondent spends on paid work, unpaid work, study, and housekeeping in a typical week. Each item is scored from 0 (not at all) up to 5 (36 hours or more). The second part contains 8 items on frequency of leisure and social activity measuring the frequency of performing activities in the past 4 weeks such as visiting family or friends. Each item is scored from 0 (not at all) to 5 (19 times or more), with higher scores reflecting higher levels of participation. (ii) Participation restrictions are assessed by asking the respondent for experienced restrictions as a result of his/her health condition in 10 activities, such as making day-trips and other outdoor activities. Each item score ranges from 0 (not possible at all) to 3 (no difficulty at all), with a higher score indicating less participation restrictions. (iii) Satisfaction with participation is determined by asking the respondent to indicate the satisfaction with 9 aspects of life, such as contacts with family members. Items are rated on a scale of 0 (not satisfied at all) to 4 (very satisfied), with a higher score indicating more satisfaction. The sum scores for the Frequency, Restrictions, and Satisfaction scales are all converted to scores on a 0-100 scale. There is no USER-Participation total score.

Statistical analyses

Data were analysed using SPSS 16.0. Floor and ceiling effects were considered present if 15% of respondents scored, respectively, the lowest or highest score on a scale.¹⁵ The skewness of the score distribution was assessed and considered acceptable if the skewness was between -1 and 1. Parametric tests to assess reproducibility were used since almost all scores were normally distributed and there are no non-parametric alternatives for these tests.

Reproducibility is the extent to which similar scores are obtained on repeated administration of a measure when no substantial change has occurred in the time between the measurements. Reproducibility consists of two different, but related, aspects: reliability and agreement.⁶ Reliability concerns the degree to which patients can be distinguished from each other despite measurement error. The test-retest reliability on item level was analysed using Cohen's weighted kappa. A weighted kappa of 0.21–0.40 was considered fair, 0.41–0.60 moderate, 0.61–0.80 substantial, and 0.81–1.00 almost perfect.¹⁶ The test-retest reliability on the level of scale scores, sub-total scores, and total scores were examined using the ICCs, using the model for absolute agreement.⁶ An ICC was considered satisfactory if above 0.75.¹⁷

Agreement concerns the absolute measurement error, i.e. how similar scores on repeated administrations are, expressed in the unit of the measurement scale at issue. Small measurement error is required for evaluation purposes, in which one wants to distinguish clinically important change from measurement error.⁶ Agreement was analysed using the standard error of measurement (SEM) and the smallest detectable change (SDC). The SEM equals the square root of the error variance, including systematic differences.⁶ The SEM was considered small if it represented less than 10% of the score range.¹⁸ The SEM can be converted into the smallest detectable change (SDC_{ind}) by multiplying the SEM by 1.96 $\sqrt{2}$. The SDC_{ind} reflects the smallest change in score of an individual that can be interpreted as "real" change, i.e. change above measurement error at an alpha level of 0.05.6 To determine the SDC on group level (SDC_{group}), the SDC_{ind} is divided by $\sqrt{n.^6}$ To assess responsiveness, the SDC should ideally be compared with the score difference representing clinically relevant change. However, this figure is not available for the measures under study. Alternatively, we used the ratio of the SDC and the average standard deviation (SD) of the scores on both measurements to substantiate the SDC. An SDC/SD of more than 0.8 was interpreted as requiring large score differences to exceed chance.^{10,19}

Results

A total of 104 individuals (42 men, 62 women) were invited to participate in this study of which 47 individuals participated in both measurements. Three individuals completed the first questionnaire and 54 individuals did not participate at all. The response of the males (33%) was somewhat lower than that of the females (52%). The mean age of the non-responders and responders was similar, with 50.9 (SD= 14.5) and 50.6 (SD= 11.8) years, respectively. Response rate was significantly related to diagnosis, from 34% in patients with a stroke up to 72% in patients with a musculoskeletal condition. Participants' characteristics are shown in Table 2.1.

Psychometric properties of each measure are displayed in Table 2.2. The main findings are summarized for each measure separately.

Gender, n (%) Men Women	15 (32) 32 (68)
Mean age, years (SD)	50.6 (11.8)
Diagnosis, n (%) Musculoskeletal disease Traumatic brain injury Stroke Neuromuscular diseases Chronic pain Heart failure	8 (17.0) 5 (10.6) 12 (25.5) 11 (23.4) 10 (21.3) 1 (2.1)
Median time since diagnosis, years (range)	1.7 (0.7–15.6)
Paid job before condition, n (%) Yes No, reason: Housekeeping Retirement Student Health problems Other	31 (66) 4 (8.5) 4 (8.5) 2 (4.3) 4 (8.5) 2 (4.3)
Current marital status, n (%) Married/living together Other	34 (72.3) 13 (27.7)
Education, n (%) Lower Higher	19 (40.4) 27 (57.4)
Median time between measurements, days (range)	16.0 (13–49)

Table 2.1 Participants' characteristics

SD: standard deviation.

IMPACT-S

The proportion of missing item responses was small (1.1%). The means and medians of all IMPACT-S scores were high, considering the score range. All scale scores of the IMPACT-S, except for the scale Mobility, showed ceiling effects (range 15.2–55.3%). The sub-total scores for Activities and Participation and the total score did not show floor or ceiling effects (data not displayed). The skewness was acceptable for all scores, except the scale score Community (-1.03), the sub-total score Participation (-1.45), and the total score (-1.09). The mean percentage of exact agreement between individual items on the two measurements was 73.1% (range 56.5–89.1%). Weighted kappa values for the

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	Score range	Median (IQR)	Mean (SD)	Difference test- retest M (SD)	ICC (95% CI)	SEM	SDC _{ind}	SDC _{ind} /SD	SDC _{group}	SDC _{group} /SD
IMPACT-S Total	0-100	82.3 (72.9–88.5)	79.6 (12.3)	0.3 (6.2)	0.88 (0.80-0.93)	4.4	12.1	0.96	1.8	0.14
Activities	0-100	80.4 (70.4–88.9)	78.4 (12.6)	0.4 (4.9)	0.92 (0.86–0.93)	3.5	9.7	0.78	1.4	0.11
Participation	0-100	83.3 (75.6–88.1)	81.1 (14.5)	0.4 (10.9)	0.74 (0.58–0.92)	7.7	21.3	1.42	3.1	0.21
Knowledge	0-100	77.8 (66.7–88.9)	79.7 (15.6)	1.4 (12.6)	0.70 (0.52–0.82)	8.9	24.7	1.52	3.6	0.22
General tasks	0-100	83.3 (50.0–100.0)	72.3 (23.9)	2.8 (19.8)	0.67 (0.48–0.80)	14.0	38.7	1.59	5.6	0.23
Communication	0-100	88.9 (66.7–100.0)	84.8 (17.5)	-0.4 (9.7)	0.85 (0.74–0.91)	6.9	19.1	1.09	2.8	0.16
Mobility	0-100	71.4 (61.9–85.7)	71.8 (19.7)	0.0 (8.9)	0.90 (0.84–0.95)	6.3	17.4	0.86	2.5	0.12
Self-care	0-100	88.9 (77.8–100.0)	90.2 (11.5)	-0.8 (11.0)	0.58 (0.36-0.74)	7.8	21.5	1.80	3.1	0.26
Domestic life	0-100	83.3 (66.7–91.7)	76.3 (18.9)	-0.4 (12.2)	0.80 (0.68–0.89)	8.6	23.8	1.23	3.5	0.18
Relationships	0-100	91.7 (83.3–100.0)	88.0 (15.8)	-0.4 (11.9)	0.68 (0.49–0.81)	8.4	23.3	1.58	3.4	0.23
Major life areas	0-100	83.3 (66.7–100.0)	78.6 (19.5)	4.0 (18.3)	0.54 (0.30-0.71)	13.1	36.4	1.91	5.3	0.28
Community	0-100	83.3 (66.7–93.8)	80.3 (18.5)	0.2 (17.9)	0.59 (0.37–0.75)	12.6	35.0	1.79	5.1	0.26
Participation Scale	06-0	15.0 (6.0–27.0)	17.1 (12.9)	-0.3 (7.9)	0.82 (0.70–0.90)	5.6	15.5	1.18	2.3	0.17
USER-Participation										
Frequency	0-100	32.5 (27.5–38.8)	33.8 (9.8)	0.7 (7.8)	0.65 (0.45–0.79)	5.5	15.2	1.65	2.2	0.24
Restrictions	0-100	73.3 (63.0–80.0)	70.6 (17.9)	-1.8 (9.2)	0.85 (0.75–0.92)	6.6	18.2	1.07	2.7	0.16
Satisfaction	0-100	63.9 (50.0–77.8)	63.6 (17.3)	-1.5 (9.7)	0.84 (0.73–0.91)	6.8	18.9	1.12	2.8	0.16
Mean and SD are shown score on the Participatio	for first n n Scale in	neasurement. Note th dicates large particip	ation restriction	s on the IMPACT-S a ons.	and USER-Participa	tion indi	cate high	levels of part	ticipation a	nd that a high

 Table 2.2
 Reproducibility of the IMPACT-S, Participation Scale, and USER-Participation (n= 47)

IQR: interquartile range; SD: standard deviation; M: mean; CI: confidence interval; SEM: standard error of measurement; SDC: smallest detectable change; IMPACT-S: ICF Measure for Activities and Participation-Screener; USER-Participation: Utrecht Scale for Evaluation of Rehabilitation-Participation.

Chapter 2 | Reproducibility of three self-report participation measures

individual items ranged from 0.22 to 0.82 and were fair for 3 items, moderate for 7 items, substantial for 19 items, and almost perfect for 3 items.

Differences between scores on the first and second measurements were small (Table 2.2). Three out of 9 scale scores, the sub-total scores, and the total score showed satisfactory ICC values (Table 2.2). The SEM was below 10% of the score range for all scores, except for 3 out of 9 scale scores. The SDC_{ind}/SD ratio was above 0.8 for all scores, except for the sub-total score Activities of the IMPACT-S. The SDC_{group}/SD ratio was small for all scores (range 0.11–0.28).

Participation Scale

The proportion of missing item responses was somewhat larger than that for the other measures (2.8%). The mean and median scores of the Participation Scale were low (indicating less participation restrictions), considering the score range. The skewness of this score was acceptable and there were no floor or ceiling effects. The mean percentage of exact agreement between individual items was 70.3% (range 51.5–93.2%), weighted kappa values of the individual items ranged from 0.00 to 0.87 and were slight for 2 items, moderate for 5 items, substantial for 8 items, and almost perfect for 3 items. The Participation Scale showed a satisfying ICC (Table 2.2). Agreement expressed by the SEM was well below 10% of the score range. The SDC_{ind}/SD ratio was above 0.8 and the SDC_{eroup}/SD was small.

USER-Participation

The proportion of missing item responses was small (1.3%). The mean and median scores on the Restriction scale were fairly high, considering the score range. The skewness of all scales was acceptable and there were no floor or ceiling effects. Exact agreement between the items was 67.2% (range 39.1–95.3%). Weighted kappa values of the individual items ranged from 0.30 to 0.95 and were fair for 2 items, moderate for 9 items, substantial for 13 items, and almost perfect for 7 items. The differences between mean scores on the first and second measurements were very small. The Restrictions and the Satisfaction scales showed satisfying reliability, but the Frequency scale showed less than satisfying ICC values. Agreement expressed by the SEM was well below 10% of the score range. The SDC_{ind}/SD ratio was above 0.8 and the SDC_{group}/SD was small.

Respondent's opinion

More than half of the respondents considered all 3 measures to be a relevant measure for their participation. Respondents who preferred one of the measures, judged the USER-Participation to be the best and the Participation Scale to be the least favourable. One respondent found none of the measures relevant for measuring participation. Furthermore, more than half of the respondents considered all 3 measures to be easy to complete. Most respondents who preferred one of the measures, found the USER-Participation the easiest and the Participation Scale the least easy to complete. Four respondents found none of the measures easy. A common comment concerned the layout of the Participation Scale, which was perceived as confusing. Few respondents mentioned obtrusive items, but it was mentioned that items confronted them with their restrictions and that items on partner relationship were frustrating, especially when they were single due to other reasons than their condition (e.g. widowhood).

Discussion

This study showed generally satisfactory reproducibility of all 3 measures. The SDC was small at the group level, but large at the individual level for all measures, which means that at individual level, large score differences are required to exceed change, while at group level, small score differences will already exceed change. This study adds to the literature by providing psychometric evidence on 3 recently developed participation measures. Agreement figures of the Participation Scale have not been published previously, and this is the first replication of psychometric evidence for both the self-report version of the Participation Scale and the IMPACT-S after their original publication. Furthermore, this study is the first to report psychometric properties of the USER-Participation.

The test-retest reliability of the IMPACT-S in this study was lower than in the earlier validation study¹⁰ for most scale scores and the sub-total score Participation (0.74 against 0.90). A possible explanation is that the time since diagnosis in the earlier study was longer so that their respondents might have had a more stable level of participation. The agreement figures of the earlier study, calculated with a slightly different method, namely the Smallest Detectable Difference (SDD), however, were similar to the results found in our current study.¹⁰

The test-retest reliability of the Participation Scale in this study was satisfactory and was similar to the figures found in the earlier validation study.¹¹ Data on agreement are not available, thus no comparison can be made.

This is the first study to assess the reproducibility of the USER-Participation. Comparisons can therefore only be made with other measures. The reliability of the Frequency scale was lower than that of the Restrictions and the Satisfaction scales. This is consistent with the finding of Brown et al.²⁰ that the subjective component of the Participation Objective, Participation Subjective instrument showed better reliability coefficients than the objective component. An explanation for this finding might be that actual participation, such as, for example, going to the cinema or doing shopping for fun, is more variable over time than the experience of being restricted in performing these and other activities. The SEM and SDC figures of the Frequency scale were however similar to those of the other USER-Participation scales. Furthermore, the reliability of the Restrictions scale was similar to the reproducibility of the IMPACT-S (ICC= 0.88)¹⁰ and the Dutch version of Life Habits Questionnaire (ICC range 0.78–0.80),²¹ which are both also measures of perceived participation restrictions. The test-retest reliability of the Satisfaction score was similar to the ICC of the Personal Wellbeing Index (0.84), which is also a measure of satisfaction with different life domains.²²

Limitations

The sample size in this study was small, but the number of respondents was just slightly below the recommended number of 50.¹⁵ Secondly, a heterogenic study sample was used, and the sample size was too small to compute diagnostic group-specific results. However, this heterogeneity of the sample also means that it is easier to generalize the results of this study to the whole population of persons with disabilities treated in outpatient clinics of rehabilitation centres.

Implications for a choice of a measure

The 3 participation measures included in this study were selected because they appeared applicable in various diagnostic groups, feasible for use in routine outcome monitoring, covered the ICF participation chapters, and had sound psychometric properties. This study did not reveal a clear "best" among the 3 selected participation measures with respect to reproducibility. However, some differences exist. The separate IMPACT-S scales and

the Frequency scale of the USER-Participation appear less reproducible than the other scores. The IMPACT-S showed a stronger ceiling effect than the other two measures. The USER-Participation was slightly favoured by the participants. Other differences between these 3 measures are also relevant to make a choice. The Participation Scale, containing 18 items, is the shortest measure, but the length difference will be smaller in practice because each item of the Participation Scale has a follow-up item in case of an experienced restriction. All measures list were suitable for self-report, but the layout of the Participation Scale was confusing for some of the respondents. An internet-based version of the questionnaire might solve this problem. All measures cover the participation chapters of the ICF, but the IMPACT-S was the only measure covering all 9 chapters, while both USER-Participation and Participation Scale covered 8 out of 9 chapters. Both the IMPACT-S and the Participation Scale measure subjective participation by asking experienced restrictions. The USER-Participation measured both objective participation (with the Frequency scale) and subjective participation (with the Restrictions and Satisfaction scales). Potential users of a participation measure can use this information to make a well-informed choice.

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3

Validity of the Utrecht Scale for Evaluation of Rehabilitation-Participation

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Abstract

Purpose: There is still a need for a generic participation instrument that measures both objective and subjective participation in adults living in the community and that is feasible for use in rehabilitation practice. The Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) was developed to satisfy this need, comprising 31 items in three scales: Frequency, Restrictions and Satisfaction. The aim of this study was to examine the validity of this measure.

Methods: Cross-sectional study involving former rehabilitation outpatients from five rehabilitation facilities in the Netherlands (n= 395). The Frenchay Activities Index (FAI), the participation subtotal score of the ICF Measure of Participation and Activities Screener (IMPACT-SP), and the Participation Scale were included as reference measures.

Results: Internal consistency of the USER-Participation scales was satisfactory (α 0.70–0.91). Spearman correlations between these scales were between 0.36 and 0.52. Concurrent validity was shown by strong correlations between the Frequency scale and the FAI (0.59), the Restrictions scale and the IMPACT-SP (0.75) and the Satisfaction scale and the Participation Scale (-0.73). Discriminant validity was shown by significant differences in USER-Participation scores between participants with different levels of independence and between participants with different health conditions.

Conclusion: The USER-Participation appears to be a valid measure to rate objective and subjective participation in persons with physical disabilities.

Introduction

Rehabilitation treatment is aimed at improvement of functional independence and, ultimately, social participation.¹ Especially in the outpatient clinic, rehabilitation goals are on the level of participation instead of the level of activities. However, despite the consensus on the importance of participation as an outcome of rehabilitation,² the measurement of participation is not common in rehabilitation research.³ One reason for this discrepancy might be that participation is not easily adopted as an outcome measure because participation is affected by many factors outside the control of the rehabilitation team.⁴ Second, measures of participation are less developed than measures of more basic activities of daily living like, for example, self-care and mobility.⁵

Conceptual and measurement issues hamper the measurement of participation. In the International Classification of Functioning, Disability and Health (ICF),6 "Activity" is the execution of a task or action by an individual and represents the individual perspective of functioning. "Participation" refers to the involvement of an individual in a life situation and represents the social perspective of functioning. Conceptual and definitional ambiguity regarding the concepts of Activities and Participation, however, has made the operationalization and measurement of participation a challenge.⁷ One issue is the distinction between Activities and Participation. Originally conceived of as two distinct components, the final version of the ICF merged Activities and Participation into a single series of categories in nine chapters. Since then, no consensus has emerged on how best to distinguish between Activities and Participation, and on the aspects of functioning which comprise Participation.⁶⁻⁹ Whiteneck and Dijkers⁷ advocated a distinction between Activities and Participation, and suggested the chapters 1 (Learning and Applying Knowledge), 2 (General Tasks and Demands), 3 (Communication), 4 (Mobility) and 5 (Self-Care) be designated as Activities, and the categories in the chapters 7 (Interpersonal Interactions and Relationships), 8 (Major Life Areas) and 9 (Community, Social and Civic Life) be designated as Participation, and to designate some categories in chapter 6 (Domestic Life) as Activities and other categories as Participation (the latter to be added to the Major Life Areas chapter). Earlier, we used a largely similar distinction between Activities (ICF chapters 1–5) and Participation (ICF chapters 6–9).9 Further, a recent review showed that all current ICF-based participation measures cover the ICF chapters 6-9, whereas they diverge on the coverage of the other ICF chapters.¹⁰ This suggests that the ICF categories classified in these chapters 6–9 are the most characteristic of participation.

Another issue is how to rate levels of participation. In the ICF, the extent of participation restrictions is rated on a five-point scale ("no problem" up to "complete problem").⁶ It is, however, not specified whether an outsider ("objective"), or an insider ("subjective") perspective should be used.⁶ From an outsider point of view, objective behaviours, such as return to work are of utmost importance. From an insider perspective, however, the subjective opinion of the persons themselves about their participation matters most.¹¹ This distinction between objective and subjective participation is of importance, as research shows that both are only weakly related,^{12,13} and are best measured as distinct concepts.^{7,13} The ICF suggests adding satisfaction with participation as a second qualifier to the rating of participation problems as a way of marking the subjective experience of participation.⁶

These considerations guided our search for a participation measure that is useful to measure rehabilitation outcomes in adults who are living in the community.¹⁴ We searched for measures that (i) are applicable in various diagnostic groups, (ii) are feasible for use in routine outcome monitoring (being brief and suitable for self-report), (iii) provide both objective and subjective ratings of participation, (iv) provide good coverage of the ICF chapters 6–9, and (v) have sound psychometric properties.

Of the many participation measures available,^{10,15,16} only four include questions on both objective and subjective participation, and none of these satisfied all of our other criteria. The Assessment of Life Habits Questionnaire (LIFE-H) rates accomplishment and satisfaction with daily activities and social roles.¹⁷ However, with 69 items and a total of 207 questions, LIFE-H is much too long to be feasible in routine outcome monitoring. LIFE-H is a reliable and valid measure, but its responsiveness has not been established¹⁸ and there was no evidence at all of the psychometric properties of the satisfaction score available at the time of our study.¹⁹ The Participation Survey/Mobility (PARTS/M)²⁰ provides measurement of performance, perceived limitations, and satisfaction, but this measure covers the mobility domain only. The Participation Measure for Post-Acute Care (PM-PAC)²¹ includes questions on performance and satisfaction, but satisfaction is only asked regarding interpersonal relationships and the satisfaction items do not make up a separate scale. Finally, the Participation Objective Participation Subjective (POPS)¹³ comprises 26 items (78 questions) and provides scores on both frequency and satisfaction. However, satisfaction is not directly asked for. Instead, respondents are asked to rate their desire to change their current level of participation. The correlation between satisfaction and desire for change is not more than moderate.¹² Further, the POPS has

been developed for use in persons with traumatic brain injury (TBI) and its scores are based on scores of US reference samples (TBI and healthy), limiting its international use and use in different diagnostic groups.

Since we found no instrument measuring both objective and subjective participation and satisfying most of our other criteria, we developed a new measure, the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation).^{14,22} The aim of this study was to examine the construct, concurrent and discriminative validity of the USER-Participation in adults with physical disability living in the community.

Methods

Sample

Consecutive rehabilitation outpatients were selected through five rehabilitation centres in The Netherlands: De Hoogstraat (Utrecht), Sophia Revalidatie (The Hague and Delft), and the Libra group (Eindhoven and Tilburg). Patients were invited for the study if they (i) started a multidisciplinary outpatient rehabilitation programme which was expected to last at least four consecutive weeks (ii) were at least 18 years of age, and (iii) were able to read Dutch. Exclusion criteria were (i) severe aphasia or severe cognitive impairments because these patients might have trouble responding to a self-report questionnaire, and (ii) a fast progressive condition because improvement in participation is less likely in these patients. Patients participated in the study on a voluntary basis. The presence of aphasia or cognitive impairments were evaluated by the responsible physiatrist.

Procedure

The data of this study stem from a prospective cohort study. Participants were included between May 2008 and February 2009. The first measurement was performed within 2 weeks after the start of the outpatient rehabilitation programme, the second at the end of this programme, and the third after 4 months follow-up. At the third measurement, participants with internet access were sent an e-mail with a link that they could use to log in on a website to complete the questionnaire including all participation measures. Participants without internet access received a similar postal questionnaire. A reminder was sent, if applicable, 2 weeks after the initial invitation. For the current study, we used the participation data from the third measurement. Data on diagnosis were retrieved from medical files. Participants' functional independence was assessed by trained research assistants at the second measurement. The research protocol was approved by the Medical Ethics Board of Rehabilitation centre De Hoogstraat and informed consent was obtained from all participants.

Instruments

USER-Participation

The USER-Participation covers three aspects of participation with three separate scales: Frequency, Restrictions and Satisfaction. The USER-Participation covers only the ICF chapters 6-9 (except for two items on satisfaction with mobility and with self-care). This was done for two reasons. First, these can be considered the domains most characteristic for participation, as described in the Introduction. Second, the USER-Participation was designed to complement the USER,23 a measure of functional independence in the domains of cognition, mobility and self-care so that there was no need to incorporate these domains in the USER-Participation. The first version was designed using our experience with existing participation measures. The Frequency scale was inspired by the Craig Hospital Assessment and Reporting Technique,²⁴ and with a brief Dutch version of this measure we developed earlier, the Utrecht Activities List.²⁵ The Restrictions scale was inspired by the ICF Measure of Activities and Participation-Screener (IMPACT-S), which we developed earlier.⁹ The Satisfaction scale was inspired by our experiences with the Life Satisfaction Questionnaire (LiSat-9).²⁶ Pilot testing and expert review led to several revisions. The current version consists of 31 items and was tested for reproducibility in a convenience sample of 47 former rehabilitation outpatients by repeated administration of a postal questionnaire with a 2-week interval.²² Results of this study were favourable: there were few missing responses (1.3%) and reproducibility was generally good (Intra Class Correlations (ICC) 0.65-0.85). The large majority of participants found the USER-Participation relevant and easy to complete, and there were no reports of obtrusive items.²²

The Frequency scale consists of two parts. Part A comprises four items on vocational activities, measuring the number of hours the respondent has spent on paid work, unpaid work, volunteer work and housekeeping in a typical week. Each item is scored from 0 (not at all) up to 5 (36 hours or more). Part B comprises eight items on the frequency of leisure and social activities such as going out, leisure activities indoors and visiting
family or friends in the past 4 weeks. Each item is scored from 0 (not at all) to 5 (19 times or more). A sample item is, "In the last four weeks, how many times did you visit your family or friends?" The Restrictions scale comprises 10 items on experienced participation restrictions in vocational, leisure and social activities as a result of the person's health or disability. Each item score ranges from 0 (not possible at all) to 3 (independent without difficulty). A "not applicable" option is available for each item and can be used in case the item is not relevant to the person or if experienced restrictions are not related to the person's health status or disability. A sample item is, "Are you, because of your disease or condition, limited in doing sports or other physical exercise?" The Satisfaction scale comprises nine items on satisfaction with vocational, leisure and social relationships. Items are rated on a scale of 0 (very dissatisfied) to 4 (very satisfied). A "not applicable" option is available for the items on vocational activities and partnership relations. A sample item is, "How satisfied are you about the relationship with your partner?" The sum scores of the Frequency, Restrictions, and Satisfaction scales are based on the items that are applicable to the person's situation and each sum score is converted to a 0-100 scale. This transformation ensures that all scales have the same minimum and maximum score, higher scores indicating good levels of participation (higher frequency, less restrictions, higher satisfaction). There is no USER-Participation total score.

Other measures

Three criterion measures were used to study the concurrent validity of the USER-Participation. These measures can be ordered on an objective – subjective dimension of participation²⁶ as they respectively rate frequency, restrictions and problem perception, respectively. The Frenchay Activities Index (FAI) measures the frequency of activities, such as washing the dishes, cleaning and visiting friends.²⁷ It comprises 15 items and one total score ranging from 0 (no participation) up to 45 (frequent participation). The FAI showed good internal consistency (α 0.78–0.85), test retest reliability (0.79–0.80), inter-rater reliability (0.90–0.93), and validity.^{28,29} An exhaustive description of the psychometric properties of the FAI is provided on the Stroke Engine website (http:// www.medicine.mcgill.ca/strokeengine-assess/module_fai_psycho-en.html; accessed 24 December 2010). The Dutch Modi-FAI was used, which has a shorter time frame, asking for the execution of activities in the previous 4 weeks instead of in the previous 3 months or 6 months (dependent on the item), to make it more suitable as an outcome measure of outpatient rehabilitation.²⁸

The IMPACT-SP is the participation subtotal score of the IMPACT-S and measures experienced restrictions comprising 15 items.⁹ A high score on the IMPACT-SP (range 0–100) indicates few participation restrictions. The IMPACT-S was validated in a Dutch multi-diagnostic group of road accident victims.⁹ Internal consistency of the IMPACT-SP ($\alpha 0.92-0.93$) and test-retest reliability (ICC 0.90) of the total score were excellent in that study. Also, a very strong correlation (0.86) was found between the total scores of the IMPACT-SP and the WHO Disability Assessment Schedule II.⁹

The Participation Scale (P-Scale) measures the level of participation with 18 items compared to peers and, in case of a lower level of participation, the extent to which the respondent experiences this as a problem.³⁰ The total score ranges from 0 to 90, with a high score indicating severe participation restrictions. The P-Scale was validated in Nepal, India and Brazil in patients with leprosy or other types of disabilities and was found to be valid and reliable, with an α of 0.92, a test-retest ICC of 0.83, and inter-tester ICC of 0.80.³⁰ We translated and adapted the P-Scale for use as a self-report measure, and showed that this self-report version also had a good test-retest reliability (ICC 0.82).²²

Finally, physical (mobility, self-care) and cognitive (communication, applied cognition, behaviour) independence and subjective complaints (pain, fatigue, mood) were measured with the USER.²³ The USER is a reliable measure and its physical and cognitive independence scales showed very high correlations with the Barthel Index and Functional Independence Measure (range 0.84–0.94).²³

Statistical analyses

Descriptive statistics were used to show score distributions for items and scales. Floor and ceiling effects were considered present if 15% or more of respondents scored the minimum or the maximum score on a scale, respectively.³¹ Internal consistency was analysed using Cronbach's α and item-rest correlations. The α values of at least 0.70 and item-rest correlations of at least 0.30 are satisfactory.³¹ Further, exploratory factor analyses with oblimin rotation were performed. Non-parametric Spearman correlations between the USER-Participation scales were computed. The three scales were designed to measure different constructs, so that it was hypothesized that these correlations would be below 0.60, this figure being the minimum correlation indicating measurement of similar constructs.³² We tested for concurrent validity by computing Spearman correlations between the three USER-Participation scales and the FAI, IMPACT-SP and the P-Scale. It was hypothesized that these correlations would be at least 0.60,³² and that the highest correlations would be seen between Frequency scale and the FAI, Restrictions scale and the IMPACT-SP, and Satisfaction scale and the P-Scale. Discriminant validity was examined by comparing USER-Participation scores of different subgroups using the non-parametric Mann-Whitney and Kruskal-Wallis tests. First, participation scores of participants with different health conditions were compared. Second, participants cores of participants with different levels of activity limitations were compared. Participants were labelled as scoring low (≤ 65) or high (66–70) on the physical independence scale of the USER and as scoring low (≤ 48) or high (49–50) on the cognitive independence scale of the USER. The median score was used to establish these cut-off points.

Results

Participants

A total of 509 patients participated in the prospective study, of whom 395 (77.6%) completed the follow-up measurement 4 months after finishing the outpatient rehabilitation programme. Reasons for drop-out were: early stop of the rehabilitation programme due to re-hospitalization or worsening of the participants' condition (17), deceased (2), not finishing the rehabilitation programme in time for the study (21), and declined or no response (74). Two-thirds (66%) of the 395 participants completed the internet questionnaire and the others completed the postal questionnaire. Participants' characteristics are displayed in Table 3.1. Non-response analysis showed that response was associated with being married or living together (75.7% versus 61.4%; p= 0.002), rehabilitation centre (range 54% in Sophia up to 86.1% in De Hoogstraat; p< 0.01), and diagnosis (66.3% in the group with musculoskeletal conditions up to 90.7% in the group with heart conditions; p< 0.01). Response was also associated with better physical independence, pain and mood, but not with cognitive independence and fatigue, as measured with the USER at the start of the outpatient rehabilitation programme.

The score distribution of all participation measures are displayed in Table 3.2. The distributions of the USER-Participation scores were reasonably symmetric, as shown by the skewness figures and the small differences between the mean and median scores. There were no floor effects and only the Restrictions scale showed a ceiling effect. Scores on the USER-Participation were less skewed than scores on the IMPACT-SP and the P-Scale.

Gender (n; %)	
Men	211 (53.4)
women	184 (46.6)
Age in years (Mean; SD)	52.8 (13.5)
Education (n; %)	
Lower	256 (64.8)
Higher (at least finished high school)	139 (35.2)
Marital status (n %)	
Married/living together	299 (75.7)
Other	96 (24.3)
Paid job before onset of disability (n; %)	
Yes	272 (68.9)
No: Housekeeping	17 (4.3)
Retirement	57 (14.4)
Student	6 (1.5)
Disability pension	9 (8.6)
	9 (2.3)
Rehabilitation center (n; %)	
De Hoogstraat, Utrecht	124 (31.4)
Sophia Revalidatie, Den Haag	30 (7.6)
Sophia Revalidatie, Delft	/3 (18.5)
rt Leijpark, Hiburg Rivembesch, Eindheven	59 (14.9) 100 (27.6)
blixembosch, elhonoven	109 (27.8)
Diagnosis (n; %)	
Musculoskeletal	69 (17.5)
Brain injury	138 (34.9)
Neurological	87 (22.0)
Chronic pain	39 (9.9) 58 (14 7)
Other unknown	4 (1)
Time since diagnosis in months (Median; IQR)*	13.5 (9.8–31.1)
Activity limitations (Median; IQR)**	
USER physical independence (0–70)	64 (55–70)
USER cognitive independence (0–50)	48 (43–50)
Subjective complaints (Median; IQR)**	
USER Pain (0–100)	20 (0–50)
USER Fatigue (0–100)	30 (20–50)
USER Mood problems (0–100)	10 (2.5–25)

Table 3.1 General characteristics of participants (n= 395)

Note: Musculoskeletal includes multiple trauma, amputation, hand injury, etc.; Brain injury includes stroke and traumatic brain injury; Neurological includes multiple sclerosis, spinal cord injury, and neuromuscular diseases.

USER: Utrecht Scale for Evaluation of Rehabilitation.

*Time between diagnosis and the administration 4 months after completion of the outpatient rehabilitation program.

**Measured at the administration directly after completion of the outpatient rehabilitation programme.

	Range	% floor	% ceiling	Mean (SD)	Median (IQR)	Skewness
USER-Participation						
Frequency (0–100)	3.8–61.8	0.0	0.0	28.8 (11.2)	28.7 (20.0–36.3)	0.24
Restrictions (0–100)	6.7–100	0.0	19.0	75.1 (20.4)	76.7 (62.5–93.3)	-0.61
Satisfaction (0–100)	0.0-100	0.3	5.4	69.2 (18.7)	69.4 (56.9–82.1)	-0.52
FAI (0-45)	3–43	0.0	0.0	26.7 (7.5)	27.0 (22.0–32.0)	-0.46
IMPACT-SP (0-100)	14.3–100	0.0	15.0	83.0 (16.1)	88.1 (73.8–95.2)	-1.19
P-Scale (0–90)*	0-80	10.8	0.0	17.1 (16.2)	13.0 (3.8–25)	1.08

 Table 3.2
 Scores on the USER-Participation, FAI, IMPACT-SP, and the P-Scale (n= 395)

*Higher scores indicate worse participation.

USER-Participation: Utrecht Scale for Evaluation of Rehabilitation-Participation; FAI: Frenchay Activities Index; IMPACT-SP: ICF Measure of Participation and Activities Screener, participation domain.

Construct validity

Internal consistency figures are displayed in Table 3.3. The Frequency scale showed an acceptable alpha, but the item-rest correlations of the items on work, education and housekeeping were below the criterion of 0.30. These four items were also not correlated to each other (range -0.04 to 0.18) and did not make up an acceptable separate scale (α = 0.13). Factor analysis on all 12 items showed a four-factor solution, with one strong factor on which most items loaded, and three weak factors. Without the four vocational items, alpha of the Frequency scale became only slightly higher (0.74), with little change in the item-rest correlations of the remaining items.

Internal consistency of the Restrictions and Satisfaction scales was very good, with high alphas and all item-rest correlations well above the criterion. For both scales, the factor analyses showed one strong first factor explaining more than 50% of the variance and a weak second factor on which the social contacts/relations items loaded highest (Table 3.3).

As expected, the correlations between the USER-Participation scales were below 0.60: 0.46 between the Frequency and the Restrictions scales, 0.36 between the Frequency and the Satisfaction scales, and 0.52 between the Restrictions and Satisfaction scales.

Concurrent validity

As hypothesized, the Frequency scale was most strongly associated with the FAI, the Restrictions scale was most strongly associated with the IMPACT-SP and the Satisfaction

	Intern	al consistency		Dimensi	onality **	
	Cronbach's α	Item-rest correlations	Factor 1	Factor 2	Factor 3	Factor 4
Frequency (n= 390) *	0.70		26.9%	10.9%	10.3%	8.4%
Paid work		0.18		0.85		
Unpaid work		0.08			0.87	
Education		0.16			0.62	
Housekeeping		0.19				0.69
Physical exercise		0.40				0.47
Going out		0.48	0.48			
Outdoor activities		0.52	0.42	0.43		0.45
Chores in/around house		0.39				0.74
Leisure indoors		0.43	0.58			
Visits to family or friends		0.56	0.77			
Visits from family or friends		0.35	0.78			
Telephone/computer cont.		0.45	0.73			
Restrictions (n= 183) *	0.91		57.8%	13%	ı	·
Work, education		0.69	0.50			
Housekeeping		0.69	0.89			
Physical exercise		0.62	0.87			
Going out		0.84	0.53			
Outdoor activities		0.83	0.61			
Chores in/around house		0.72	0.89			
Leisure indoors		0.66		0.72		
Visits to family or friends		0.78	0.47	0.51		
Visits from family or friends		0.56		0.84		
Telephone/computer cont.		0.51		0.90		

 Table 3.3
 Dimensionality and internal consistency of the USER-Participation

Chapter 3 Validity of the USER-Participation

	Interna	al consistency		Dimensic	onality **	
	Cronbach's α	Item-rest correlations	Factor 1	Factor 2	Factor 3	Factor 4
Satisfaction (n= 275) *	0.88		52.1%	16.8%		
Self-care		0.60	0.74			
Mobility		0.64	0.87			
Cognition		0.59	0.57			
Work/housekeeping		0.71	0.82			
Outdoor		0.74	0.88			
Leisure indoors		0.68	0.78			
Partner relationship		0.52		0.90		
Family relationships		0.58		0.95		
Friends and acquaintances		0.63		0.81		
Note: *The number of participants varie:	s because only particip	ants with valid answers on all it	tems (without any	v missing or non-	applicable items)	could be used in

these analyses. **Percentages of variance explained by each factor, and for each factor, the factor loadings > 0.40 are displayed.

	USER-P Frequency	USER-P Restrictions	USER-P Satisfaction
FAI	0.59	0.51	0.42
IMPACT-SP	0.48	0.75	0.64
P-Scale*	-0.40	-0.71	-0.73

 Table 3.4
 Concurrent validity of the USER-Participation

Note: Expected highest correlations in bold.

USER-P: Utrecht Scale for Evaluation of Rehabilitation-Participation; FAI: Frenchay Activities Index; IMPACT-SP: ICF Measure of Participation and Activities Screener Participation domain.

*In contrast to the other measures, a high score on the P-Scale indicates severe participation restrictions.

scale was most strongly associated with the P-Scale (Table 3.4). However, the correlation between the Restrictions scale and the P-Scale was also high. The very high correlation between the IMPACT-SP and the P-Scale (-0.79) showed considerable similarity of these two criterion measures.

Discriminative validity

USER-Participation scores differed between participants with different functional ability and between participants with different health conditions (Table 3.5). The Frequency scale discriminated least between these groups. Closer inspection revealed that the frequency of vocational activities differed more strongly between these groups than the frequency of leisure activities and that the frequency of social contacts did not differ between these groups (data not shown). As shown by the magnitude of the test statistics, the Restrictions scale was the most sensitive, participants with neurological conditions perceiving most, and participants with heart conditions perceiving least participation restrictions. The Satisfaction score showed least satisfaction in participants with chronic pain and highest satisfaction in participants with heart conditions.

Discussion

The USER-Participation is a new generic instrument that is unique in its concise measurement of three aspects of participation: Frequency, Restrictions and Satisfaction. The results of this study on construct, concurrent and discriminative validity were generally good.

	Frequency	Restrictions	Satisfaction
Diagnosis			
Musculoskeletal (n= 69)	27.5	73.3	69.4
Brain injury (n= 138)	26.3	80.9	72.2
Neurological (n= 87)	28.7	66.7	66.7
Heart condition (n= 39)	32.5	100	80.6
Chronic pain (n= 58)	28.7	71.9	64.8
Kruskal-Wallis Chi-square	8.91	57.62	22.72
p-value	0.063	< 0.001	< 0.001
Physical independence			
Low (≤ 65) (n= 198)	26.3	70	63.9
High (66–70) (n= 191)	31.3	88.2	77.8
Mann-Whitney Z	-6.34	-10.63	-7.27
p-value	< 0.001	< 0.001	< 0.001
Cognitive independence			
Low (≤ 48) (n= 205)	25	71.8	63.9
High (49–50) (n= 184)	30	83.3	77.8
Mann-Whitney Z	-3.74	-4.35	-6.58
p-value	< 0.001	< 0.001	< 0.001

Table 3.5Median USER-Participation scores in subgroups of participants with different levelsof independence and with different health conditions

Note: Musculoskeletal includes multiple trauma, amputation, hand, injury, etc; Brain injury includes stroke and traumatic brain injury; Neurological includes multiple sclerosis, spinal cord injury, and neuromuscular diseases.

Construct validity

The internal consistency of the Frequency scale was just satisfactory but lower than the internal consistency of the Restrictions and Satisfaction scales. The items on vocational activities showed very low item-rest correlations. The POPS-study also revealed lower internal consistency of the objective scale compared to the subjective scale.¹³ The reason for this finding is probably that performing one activity (e.g. work) competes with performing another activity (e.g. education). Strong correlations between such items therefore cannot be expected.⁷ We considered removing these items from the Frequency scale, but this would not result in a substantially higher alpha of the remaining items. Moreover, this would imply exclusion of key aspects of participation from this scale, seriously affecting its content validity.

The Restrictions and the Satisfaction scales showed good internal consistency. The factor analyses revealed strong first factors explaining most of the variance but also revealed that it would be possible to create distinct domains representing "active participation" and "social contacts".

The scores on the three USER-Participation scales were not strongly associated with each other. This demonstrates the usefulness of a distinction between these three aspects of participation and thereby supports arguments to measure objective and subjective measurement as separate aspects of participation.^{7,13,26}

Concurrent validity

The hypothesized correlations between USER-Participation scales and other corresponding participation measures were found supporting its concurrent validity. The somewhat lower correlation of 0.59 between the Frequency scale and the FAI might be attributed to the many (8/15) items on domestic activities in the FAI,³³ against 2 out of 12 items in the USER-Participation. Both the Restrictions and the Satisfaction scales showed high correlations with both the IMPACT-SP and the P-Scale. The intercorrelation between both reference scales was also very high. Apparently, the conceptual difference between measurement of participation restrictions (IMPACT-SP) and participation problems (P-Scale) is not that large in our data. Using a more subjective measurement of participation, such as the Impact on Participation and Autonomy³⁴ or a domain-specific life satisfaction measure²⁶ instead of the P-Scale might have showed lower correlations with the Restrictions scale and higher correlations with the Satisfaction scale.

Discriminant validity

Even in our study population of persons with generally mild physical or cognitive limitations, the USER-Participation showed significant differences in levels of participation between persons with different health conditions and different levels of functional limitations. Overall, the Restrictions score was most sensitive to these differences. Concerning the Frequency scale, activities such as having visits from family or friends, were less influenced by health problems than other activities, such as going out. The Satisfaction scale was also somewhat less sensitive than the Restrictions scale to level of physical independence and health condition, but more sensitive to the level of cognitive independence. It is possible that satisfaction is a more remote measurement of the consequences of physical health problems than the experience of restrictions and more strongly influenced by other factors, in particular someone's personality.³⁵

Application of the USER-Participation

The USER-Participation was designed as a rehabilitation outcome measure to be used in adults living in the community that can be used regardless of the health condition of the person involved. We tested it in a physical medicine and rehabilitation population, so that its usefulness in, for example, persons with psychiatric illnesses is unclear. It was designed for use in adult populations and further research is necessary to examine its applicability in adolescents and in the elderly. In epidemiological studies, the USER-Participation can be used to collect data on long-term participation restrictions. For disability studies, the measurement of three aspects of participation might allow study of the inter-relationships between objective and subjective participation and thereby to broaden our understanding of participation of persons with disabilities. In health-care settings, the USER-Participation might provide a more comprehensive insight into the care needs of persons with functional limitations than data on objective or subjective participation alone, and it might be a tool to set rehabilitation targets in an outpatient setting.

Limitations of this study

First, this study was performed in persons with only mild physical and cognitive limitations. The latter was necessary because the study used a self-report questionnaire. Further research is necessary to establish the applicability of the USER-Participation in persons with severe disabilities, including the potential use of proxy report. Second, we did not have *a priori* expectations about differences in participation between diagnostic groups, and therefore this part of the results is exploratory rather than confirmative. Third, the functional ability measure was not administered at the same administration as the other measures used in this paper, but 4 months earlier at discharge from outpatient rehabilitation. Changes in functional ability during these 4 months might have obscured associations between functional ability and USER-Participation scores, so that otherwise even stronger correlations might have been found. Finally, the USER-Participation has been developed and validated in the Netherlands and its usefulness in other countries and cultures has to be examined.

Conclusion

This study has shown that the USER-Participation is a valid participation measure in adults with mild functional limitations. The results of this study complement evidence reported elsewhere on reproducibility²² and responsiveness (forthcoming).

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Responsiveness of four participation measures to changes during and after outpatient rehabilitation

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Abstract

Objective: To assess the responsiveness of 4 participation measures.

Design: Longitudinal study with repeated measurements at the start (t1) and at the end (t2) of a multidisciplinary outpatient rehabilitation programme, and at 4 months follow-up (t3).

Subjects: Outpatients with different diagnoses (n= 395) from 5 rehabilitation centres in The Netherlands.

Methods: Measures were the Frenchay Activities Index (FAI), the Participation subscale of the ICF Measure of Participation and Activities Screener (IMPACT-SP), the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation). Responsiveness was analysed using the effect size and the standardized response mean.

Results: Comparing scores at t1 and t2, the standardized response mean was 0.54 for the USER-Participation Restriction scale, 0.41 for the FAI, 0.40 for the IMPACT-SP, 0.39 for the USER-Participation Satisfaction scale, -0.36 for the Participation Scale, and 0.21 for the USER-Participation Frequency scale. Effect size values were generally somewhat smaller than the standardized response mean values. Effect size and standardized response mean values were negligible between t2 and t3. Responsiveness parameters varied between diagnostic groups, with participants with acquired brain injury showing the largest change and participants with neuromuscular disease or chronic pain showing least change.

Conclusion: Overall and across the different diagnostic groups, the USER-Participation Restriction scale showed the best responsiveness.

Introduction

Most patients are referred to rehabilitation treatment because of chronic disabling conditions. Their treatment will be aimed at minimizing the consequences of these conditions to improve independence and ultimately social participation.^{1,2} In particular in the outpatient clinic re-establishment of participation is a key aim of rehabilitation programmes. Measurement of participation outcomes is necessary to evaluate the accomplishment of this goal.³ Outcome measurement may help clinicians to document the results of their interventions, provide a valuable tool in developing standardized clinical practices, guide clinical decisions regarding care, improve organizational performance, and provide a basis for outcome standards.³ Furthermore, there is growing pressure from a variety of stakeholders, including sponsors, regulatory agencies and service recipients, to share medical performance information to improve our health care system.³ However, even though participation is generally considered an important goal, measuring participation as outcome of rehabilitation is not common.^{4,5} This discrepancy has been related to the nature of participation as being affected by many factors outside the control of the rehabilitation team, but also to measures of participation being less developed than measures of more basic activities of daily living.6

One major problem is the conceptualization of participation. In the International Classification of Functioning, Disability and Health (ICF),7 "Activity" is the "execution of a task or action by an individual" and represents the individual perspective on functioning. "Participation" refers to "the involvement of an individual in a life situation" and represents the social perspective on functioning. Originally conceived of as 2 distinct components, the final version of the ICF merged the 2 taxonomies of Activities and Participation into a single series of categories in 9 chapters. Since then, no consensus has emerged on how best to distinguish between Activities and Participation, and on the aspects of functioning that comprise Participation.⁸⁻¹⁰ We largely agree with Whiteneck and Dijkers,⁸ who advocated a distinction between Activities and Participation, and suggested to designate the ICF categories in the chapters 1 (Learning and Applying Knowledge), 2 (General Tasks and Demands), 3 (Communication), 4 (Mobility) and 5 (Self-Care) as Activities, the categories in the chapters 7 (Interpersonal Interactions and Relationships), 8 (Major Life Areas) and 9 (Community, Social and Civic Life) as Participation, and to designate some categories in chapter 6 (Domestic Life) as Activities and other categories as Participation (the latter to be added to the Major Life Areas chapter). Earlier, we advocated a largely similar distinction between Activities (ICF chapters 1-5) and Participation (ICF chapters

6–9).¹⁰ Furthermore, a recent review showed that all current ICF-based participation measures cover the ICF chapters 6–9, whereas they diverge in the coverage of the other ICF chapters.⁵ This suggests that the ICF categories classified in these chapters 6–9 are the most characteristic of participation.

Another issue is that it is not specified in the ICF whether participation problems should be rated from an outsider ("objective") or an insider ("subjective") perspective.⁷ Objective rating concerns observable behaviours, such as the number of hours a week doing paid work or the frequency of visiting friends in the previous 4 weeks. Subjective rating concerns the subjective appraisal of the person involved. The difference between objective and subjective rating is of importance, as these are, usually, only weakly related.^{11,12} Objective ratings of participation appear straightforward as they concern observable behaviours. However, what constitutes appropriate participation is highly culture-dependent. It is therefore difficult to determine which behaviours fall inside or outside a "normal range" of objective participation because, in modern societies, a wide variety of lifestyles exist together.^{8,13} For this reason, problems with participation as perceived by the person and satisfaction about performance might be at least as relevant as actual performance for those parts of life that involve choice instead of necessity.^{5,8}

Finally, like any measure, a participation measure must be valid, reproducible, and responsive to be useful as an outcome measure.¹⁴ Many participation measures have been developed since the introduction of the ICF and have been tested for validity, but their responsiveness has rarely been established.⁵

In response to this lack of data, we started a prospective multi-centre study to identify a valid and responsive instrument to measure participation outcomes of outpatient rehabilitation.¹⁵ We searched for participation measures that satisfied the following criteria: (i) applicable in various diagnostic groups; (ii) feasible, being brief and suitable for self-report, for use in routine outcome monitoring; (iii) providing both objective and subjective ratings of participation; (iv) covering the ICF Participation chapters;⁷ and (v) having sound psychometric properties. Covering ICF Participation chapters was determined by linking the items to the ICF.^{16,17} This linking was done by a single author (CZ) and, in case of any doubt consensus was reached with the last author (MP). The few participation measures rating both objective and subjective participation unfortunately did not meet other selection criteria, and therefore, we selected 3 measures rating either objective or subjective participation and meeting other selection criteria.¹⁵ The Frenchay Activities Index (FAI)¹⁸ was selected because it is part of the Dutch core set

measurement instruments in post-acute stroke care and is therefore the only participation measure frequently used in clinical practice in The Netherlands. Eighty percent of the items were linked to categories in the ICF Participation chapters.¹⁷ Although the FAI has been developed for use in stroke patients, it has also been used in other diagnostic groups and in elderly people living in the community.⁴ The ICF Measure of Participation and Activities Screener (IMPACT-S)¹⁰ was selected because it is the only participation measure that covers all Activities and Participation chapters of the ICF,⁷ for this study we only used the Participation subscale of the IMPACT (IMPACT-SP). All IMPACT-SP items have been linked to the Participation chapters of the ICF.⁵ The Participation Scale¹⁹ was selected because it is the only participation measure that asks people to rate their participation using an explicit base of comparison, namely "the peer group", which is defined as "those who are similar to the respondent in all respects (socio-cultural, economic and demographic) except for the disease or disability".¹⁹ For the Participation Scale, 77.8% of the items cover the Participation chapters of the ICF.⁵ Finally, since we found no instrument measuring both objective and subjective participation and which satisfied most other criteria, we developed a new measure, the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation).²⁰ The USER-Participation is based on the ICF and therefore all items cover the Participation chapter of the ICF. In an earlier study, the IMPACT-S, the Participation Scale, and the USER-Participation showed good reproducibility,²¹ but this is only indirect evidence for responsiveness. Evidence on responsiveness of the FAI is contradictory.4

The aim of the present study was to compare the responsiveness of the FAI, the IMPACT-SP, the Participation Scale, and the USER-Participation in patients who took part in an outpatient rehabilitation programme by comparing effect sizes (ES) and standardized response means (SRM) of these measures in a longitudinal design. It is assumed that undergoing such a programme is associated with improved participation. This assumption enables a direct comparison between the measures, namely that the measure that shows the highest ES and SRM values can be considered the most responsive.

Methods

Sample

Patients were selected from 5 rehabilitation centres in The Netherlands: De Hoogstraat (Utrecht), Sophia Revalidatie (The Hague and Delft), and Libra Zorggroep (Eindhoven and Tilburg). Patients were eligible to participate in the study when they: (i) started a multidisciplinary outpatient rehabilitation programme in the period from May 2008 until February 2009, which was expected to last for at least 4 consecutive weeks; (ii) were at least 18 years of age; and (iii) were able to read and write Dutch. Multidisciplinary was defined as the involvement of at least 2 different disciplines beside the physiatrist. Exclusion criteria were: (i) severe aphasia; (ii) severe cognitive impairments; or (iii) a fast progressive medical condition. Aphasia and cognitive impairments were assessed by the treating physiatrist.

Procedure

Eligible participants were informed by their physiatrist about the project and invited for the first measurement by first author. After signing informed consent, patients completed the first measurement within the first 2 weeks of the programme (t1), the second measurement at the end of the programme (t2), and the third measurement 4 months after t2 (t3). The end of the programme was defined as either completion of the programme or when the multidisciplinary programme switched to a monodisciplinary programme. The questionnaire was computer administered. T1 and t2 were completed at the centre in the presence of a research assistant. The research assistant assisted the patient in the use of the computer to complete the questionnaire, if necessary. T3 was sent by e-mail to all participants with internet access. In the e-mail was a link that could be used to log in on a website to complete the questionnaire. Participants without internet access received the questionnaire by regular post. Reminders were sent 2 weeks after the initial invitation to participants not returning the questionnaire. The study protocol was approved by the Medical Ethics Board of Rehabilitation Centre De Hoogstraat.

Instruments

The FAI measures lifestyle after stroke.¹⁸ It comprises 15 items on frequency of activities, for example "how often did you prepare the meal?" All items are rated on a scale with

response options ranging from 0 to 3, in which a high score indicates a higher level of activity. The Dutch Modi-FAI was used, which has a shorter time frame of 4 weeks instead of 3–6 months and was developed to make it more suitable as an outcome measure of outpatient rehabilitation.²² A total score is calculated by adding up the item scores, with a total range from 0 to 45. Previous research showed a moderate ES (0.59) and SRM (0.5) of the FAI in stroke patients.^{23,24} Cronbach's α for the FAI ranged from 0.74 to 0.78 in the current study.

The IMPACT-S comprises items assessing experienced activity limitations and participation restrictions. Nine domain scores, 2 subtotal scores (for Activity and Participation) and 1 total score can be computed.¹⁰ In line with our conceptualization of participation, we only used the IMPACT-SP, which comprises 15 items, for example "do you experience any restrictions due to your health or disability with the acquisition of necessities?" All items are rated on a scale from 0 (cannot do that at all) to 3 (no limitations whatsoever). A total score is calculated by converting the summed score to a score on a 0–100 scale, in which a higher score indicates fewer participation restrictions. Internal consistency (α 0.92–0.93) and test-retest reliability (intraclass correlations (ICC) 0.90) of the IMPACT-SP score were excellent.^{10,21} A very strong correlation (0.86) was found between the IMPACT-SP and the World Health Organization (WHO) Disability Assessment Schedule II.¹⁰ Cronbach's α of the IMPACT-SP ranged from 0.84 to 0.89 in the current study.

The Participation Scale measures experienced participation restrictions.¹⁹ Eighteen items asses the level of participation compared to peers and, in case of a lower level of participation, the extent to which the respondent experiences this as a problem. For example "do you have opportunity to take care of yourself (appearance, nutrition, health, etc.) as well as your peers?" If sometimes or no: "how big a problem is it to you?" Both answers are combined in an item score between 0 (same level of participation) and 5 (lower level of participation and this is experienced as a large problem). A response option "not applicable" is available in case a respondent does not want or need to do the activity, and is scored and interpreted as 0. A total Participation Scale score is obtained as the sum of the item scores, ranging from 0 to 90, with a high score indicating severe participation restrictions. Originally the Participation Scale was an interviewer-administered instrument. For this study it was translated into Dutch and re-designed as a self-report measure in cooperation with the authors of this measure. The interview version of the Participation Scale has been found to be valid and reliable, with an α of 0.92, a test-retest ICC of 0.83, and inter-tester ICC of 0.80.¹⁹ The Dutch self-report version

had a good test-retest ICC of 0.82.²¹ Cronbach's α of the Participation Scale ranged from 0.90 to 0.94 in the current study.

The USER-Participation consists of 31 items and measures 3 aspects of participation: frequency of behaviours, experienced participation restrictions, and satisfaction with participation.²⁰ The Frequency scale consists of 12 items on frequency of vocational activity (4 items) and leisure and social activity (8 items). For example "how many hours per week do you spend on household duties" or "how often did you do sports or any other physical exercise in the last 4 weeks?" Each item is scored from 0 (none at all) to 5 (36 hours or more/19 times or more). The Restriction scale contains 10 items asking for experienced participation restrictions as a result of the health condition. For example "does your illness or condition currently limit you in doing household duties?" Each item score ranges from 0 (not possible) to 3 (without difficulty). A "not applicable" option is available for every item and can be used if the item is not relevant to the person or if experienced restrictions are not related to the person's health status or disability. The Satisfaction scale consists of 9 items asking for satisfaction with various aspects of participation, for example "how satisfied are you with work, education or household duties?" Items are rated on a scale from 0 (very dissatisfied) to 4 (very satisfied). A "not applicable" option is available for the items on vocational activity and partnership relation. The sum scores for the Frequency, Restrictions, and Satisfaction scales are based on the items that are applicable and each sum score is converted to a score on a 0-100 scale, higher scores indicating good levels of participation (higher frequency, less restrictions, higher satisfaction). The USER-Participation showed generally good reproducibility (ICC 0.65–0.85).²¹ Cronbach's a of the USER-Participation in the current study ranged from 0.60 to 0.75 for the Frequency scale, from 0.85 to 0.91 for the Restrictions scale, and from 0.78 to 0.88 for the Satisfaction scale.

Finally, physical and cognitive independence and subjective complaints (pain, fatigue, and mood) were measured with the Utrecht Scale for Evaluation of Rehabilitation (USER).²⁵ The physical independence scale consists of 14 items on mobility and self-care and the cognitive independence scale consists of 10 items on communication, applied cognition, and behaviour. Items are scored from 0 (with help, < 50% independent) to 5 (without difficulty, without aids or adaptations). Subjective complaints consist of pain (1 item), fatigue (1 item) and mood (4 items) and are rated on a scale from 0 (not at all) to 100 (worst/most imaginable). The physical and cognitive independence score are the sum scores of all items in that scale (score range 0–70 and 0–50, respectively). The mood

score is calculated by taking the mean of the 4 items. The USER is a reliable measure and the physical and cognitive independence scales showed very high correlations with the Barthel Index and Functional Independence Measure (range 0.84–0.94).²⁵

Statistical analyses

All analyses were performed with the data of patients who completed all 3 measurements (n= 395). Floor and ceiling effects were considered present if 15% of respondents scored respectively the lowest or highest score on a scale, respectively.²⁶ Score distributions were considered normal if the skewness was between -1 and 1. Responsiveness of the measures was compared using the ES and the SRM. The ES is calculated as the mean difference score divided by the standard deviation (SD) of the baseline score.²⁷ Following Cohen, an ES of 0.2 is considered as small, 0.5 as moderate, and 0.8 as large.²⁸ The SRM is calculated by dividing the mean difference score by the SD of the difference score.²⁹ Cohen's interpretation of the ES has often been applied to the SRM,³⁰ although SRM and ES values are statistically not equivalent.³¹ ES and SRM for the total group and for the different diagnostic groups were calculated for t1-t2 and t2-t3. Since a large variety of diagnoses was seen, these were categorized as: (i) musculoskeletal, including multiple trauma, amputation, hand injury etc.; (ii) brain injury, including stroke and traumatic brain injury; (iii) other neurological disorder, including multiple sclerosis, spinal cord injury, and neuromuscular diseases; (iv) heart condition; (v) chronic pain; and (vi) other. Data were analysed using SPSS 16.0.

Results

A total of 509 patients were included in the study, of whom 427 (83.9%) completed t2, and 395 (77.6%) completed the t3 measurement. Mean time between t1 and t2 was 135 days (SD= 72) and between t2 and t3 was 128 days (SD= 15). Reasons for drop-out were: early cessation of the rehabilitation programme due to hospitalization or worsening of the condition (n= 17), not finishing the multidisciplinary rehabilitation programme in time for the study (n= 21), refusal (n= 47), death (n= 2), and unknown reasons (n= 27). Two-thirds (261/395) of all participants completed the internet questionnaire at t3. Characteristics of participants who completed all 3 measurements are shown in Table 4.1. Between t1 and t2 the participants showed a moderate improvement in physical independence (ES 0.32; SRM 0.52) and a small improvement in cognitive independence (ES 0.20; SRM 0.27).

Characteristics	
Gender, n, (%) Men Women	211 (53.4) 184 (46.6)
Age, years, mean (SD)	52.1 (13.6)
Rehabilitation centre, n, (%) De Hoogstraat, Utrecht Sophia Revalidatie, Den Haag Sophia Revalidatie, Delft Libra Zorggroep, Tilburg Libra Zorggroep, Eindhoven	124 (31.4) 30 (7.6) 73 (18.5) 59 (14.9) 109 (27.6)
Diagnosis, n, (%) Musculoskeletal disorder Brain injury Neuromuscular diseases Chronic pain Heart failure Other	69 (17.5) 138 (34.9) 87 (22.0) 58 (14.7) 39 (9.9) 4 (1.0)
Months since diagnosis, median (IQR)	4.9 (2.8–25.7)
Healthcare history, n, (%) Inpatient rehabilitation programme Other	114 (28.9) 281 (71.1)
Paid job before condition onset, n, (%) Yes No, reason: Housekeeping Retirement Student Health problems Other	272 (68.9) 17 (4.3) 57 (14.4) 6 (1.5) 34 (8.6) 9 (2.3)
Current marital status, n, (%) Married/living together Other	291 (73.7) 104 (26.3)
Education, n, (%) Lower Higherª	256 (64.8) 139 (35.2)
Activity limitations, median (IQR) USER physical independence (0–70) USER cognitive independence (0–50)	59 (49–67) 47 (40–50)
Subjective complaints, median (IQR) USER Pain (0–100) USER Fatigue (0–100) USER Mood problems (0–100)	30 (0–50) 50 (30–70) 15 (5–32.5)

Table 4.1 Participants' characteristics at the first measurement (t1)

^a At least higher general education (HAVO).

IQR: interquartile range; SD: standard deviation.

Score distributions of all participation measures are shown in Table 4.2. There were no floor or ceiling effects, except for the USER-Participation Restriction scale on t3 and for the IMPACT-SP on t2 and t3, which showed a slight ceiling effect (18.7%, 15.4%, and 15.0%, respectively).

Responsiveness parameters for t1–t2 and for t2–t3 for the total group are displayed in Table 4.3. The largest values for responsiveness were found between t1 and t2. Responsiveness values between t2 and t3 were negligible. SRM values were slightly higher than ES values. The USER-Participation Restriction scale and the IMPACT-SP showed the highest SRM and the USER-Participation Frequency scale showed the lowest SRM.

Responsiveness parameters for the different diagnostic groups are shown in Table 4.4. The USER-Participation Restriction scale was the most responsive measure in most diagnostic groups, while the Participation Scale and the USER-Participation Frequency scale were least responsive across diagnostic groups. ES and SRM values were largest in the Brain injury group, and were smallest in the Chronic pain group.

Discussion

In this study, the USER-Participation Restriction scale showed the highest responsiveness, both in the whole group and in different diagnostic groups.

This is the first study providing data on responsiveness of the IMPACT-SP, the Participation Scale and the USER-Participation. A few limitations apply to this study. First, an external criterion of change in participation was not included, so that it was not possible to compute and compare minimal important change (MIC) values of these measures. Further research is necessary to establish MIC values of the various measures, although this methodology itself has not been established yet.³² Second, there was heterogeneity of administration at t3, as part of the questionnaires was computer-administered and others were sent by ordinary post. However, it has been found that internet and posted paper questionnaires are answered similarly.³³ Finally, this study was performed in persons with mild physical and cognitive limitations. The latter was necessary because the study used a self-report questionnaire. Further research is necessary to establish the responsiveness of these measures in persons with severe disabilities.

The responsiveness of the FAI has been studied previously²³ in a stroke population and that study showed a higher responsiveness of the FAI (ES 0.59) than the present study

		-		-			
		t1	t2	t3		Skewness	
	Theoretical score range	Mean (SD)	Mean (SD)	Mean (SD)	t1	t2	t3
FAI	0-45	23.7 (8.6)	26.2 (7.4)	26.7 (7.5)	-0.43	-0.48	-0.46
IMPACT-SP	0-100	80.2 (15.2)	85.1 (14.4)	83.0 (16.0)	-1.06	-1.56	-1.19
Participation Scale	06-0	20.4 (15.5)	16.0 (14.8)	17.1 (16.2)	0.92	1.13	1.08
USER-Participation							
Frequency	0-100	27.4 (10.4)	29.3 (10.1)	28.7 (11.2)	0.37	0.24	0.25
Restrictions	0-100	66.5 (19.3)	76.1 (19.1)	75.1 (20.5)	-0.13	-0.78	-0.61
Satisfaction	0-100	63.1 (16.7)	69.2 (17.7)	69.2 (18.7)	-0.17	-0.35	-0.52
FAI: Frenchay Activities Inde	k; IMPACT-SP: Participation sub	scale of the ICF N	Aeasure of Partic	ipation and Activ	vities Screener; US	SER-Participation:	

 Table 4.2
 Score distribution of the FAI, IMPACT-SP, Participation Scale, and USER-Participation (n= 389–395)

Evaluation of Rehabilitation-Participation; SD: standard deviation.

lable 4.3	Mean score differen	ce, effect size (I	=5), and stand	ardized resp	onse mean (SK	(M) between mea	asurements to	r the total grc	up (n= 386–395)
		t1	-t2	-		ť	2-t3		
		diff (SD)	p-value	ES	SRM	diff (SD)	p-value	ES	SRM
FAI		2.5 (6.0)	0.000	0.29	0.41	0.4 (4.1)	0.036	0.06	0.11
IMPACT-SP		4.9 (12.3)	0.000	0.32	0.40	-2.1 (10.3)	0.000	-0.14	-0.21
Participatio	n Scale	-4.4 (12.2)	0.000	-0.28	-0.36	1.2 (10.1)	0.021	0.08	0.12
USER-Partic Frequenc	cipation	1.9 (9.3)	0.000	0.19	0.21	-0.6 (9.4)	0.224	-0.06	-0.06
Restrictic	suc	9.6 (17.8)	0.000	0.49	0.54	-1.0 (16.2)	0.219	-0.05	-0.06
Satisfact	ion	6.1 (15.6)	0.000	0.36	0.39	0.0 (13.0)	0.979	<01	< -0.01
USER		(1/ 2) 0 0	0000	(C V	5				
Cognitiv	e independence	1.6 (6.1)	0.000	0.20	0.27				
A positive scc for the Partic ES and SRM ≥	ore difference for the FA ipation Scale means a 2 0.50 are displayed in l	N, the IMPACT-SP decrease in the l bold.	and the USER-F evel of particip	² articipation so ation.	cales means an i	ncrease in the leve	l of participatio	n, while a positi	ve score difference

SD: standard deviation; FAI: Frenchay Activities Index; IMPACT-SP: Participation subscale of the ICF Measure of Participation and Activities Screener; USER-Participation: Utrecht Scale for Evaluation of Rehabilitation-Participation; USER: Utrecht Scale for Evaluation of Rehabilitation.

(c65-085 = 1)										
	Musculos.	keletal (n= 69)	Brain injury	(n=135-138)	Neuromus	cular (n= 87)	Heart condi	tion (n= 38–39)	Chronic p	ain (n= 58)
	ES	SRM	ES	SRM	ES	SRM	ES	SRM	ES	SRM
FAI	0.24	0.31	0.46	0.63	0.31	0.36	0.21	0.32	0.08	0.13
IMPACT-SP	0.27	0.28	0.45	0.54	0.29	0.37	0.39	0.38	0.15	0.22
Participation Scale	-0.32	-0.38	-0.30	-0.36	-0.25	-0.31	-0.38	-0.46	-0.29	-0.42
USER-Participation										
Frequency	0.27	0.28	0.47	0.49	0.01	0.02	0.09	0.11	-0.10	-0.11
Restrictions	0.56	0.47	0.70	0.79	0.44	0.53	0.58	0.65	0.07	0.08
Satisfaction	0.36	0.35	0.40	0.37	0.33	0.35	0.37	0.44	0.47	0.53
ES: effect size; SRM: sta Screener; USER-Particiţ FS and SRM > 0 50 are o	ndardized re vation: Utrech displaved in l	sponse mean; F. ht Scale for Eval ⁱ hold	Al: Frenchay A uation of Reh	vctivities Index; abilitation-Parti	IMPACT-SP: I icipation.	Participation su	ubscale of the	ICF Measure of Pa	articipation a	and Activities

Table 4.4 Responsiveness between t1 and t2 of the FAI, IMPACT-5P, Participation Scale and USER-Participation in 5 different diagnostic groups

ES

A positive score difference for the FAI, the IMPACT-SP and the USER-Participation scales means an increase in the level of participation, while a positive score difference for the Participation Scale means a decrease in the level of participation.

found in the Brain injury group (0.46). However, in that study the ES was calculated using the absolute value of score differences, not taking into account that this score difference can either be a decline or an improvement. In the present study some patients showed a decrease of the FAI score, resulting in smaller mean difference scores and thereby in lower, but more realistic, responsiveness values. If we would have used the absolute value of the score difference to calculate the ES, the value would have been 0.66. The reason for this value being somewhat higher compared to the study of Schepers et al.²³ might be that our sample received a rehabilitation programme compared with no rehabilitation programme in the study of Schepers et al. In contrast, a recent study in stroke survivors²⁴ showed a slightly lower SRM (0.5) for the FAI than this study (0.63). This might be due to the longer intervention period, probably causing larger mean differences, in the present study.

The IMPACT-S, Participation Scale, and the USER-Participation were previously tested for reproducibility, which is an indirect measure of responsiveness.²¹ The mean score differences of all measures in the present study were larger than the smallest detectable change at group level found in the reproducibility study, but were smaller than the smallest detectable change at individual level. This means that the responsiveness of these measures is sufficient for evaluation studies, but that caution is needed if they are applied in individual patient care.

The responsiveness data for the measures included in this study can be compared with data on responsiveness of other participation measures that did not fit our selection criteria. The responsiveness of the London Handicap Scale³⁴ was examined in persons with progressive multiple sclerosis in inpatient rehabilitation.³⁵ A small ES of 0.23 was found, but the inpatient setting is not the ideal context to examine responsiveness of a participation measure, since different aspects of participation (like grocery shopping, working, and household tasks) are not applicable. The responsiveness of the Impact on Participation and Autonomy (IPA)³⁶ was studied in a multi-diagnostic group of 49 persons following an outpatient rehabilitation programme with measurements at the start and 3 months later. Small SRM values (range 0-0.28) were found in the whole study group.³⁷ We did not select the IPA for this study because it measures another construct, i.e. autonomy, and because the questionnaire is relatively difficult to complete. The responsiveness of the Participation Measure for Post-Acute Care (PM-PAC)³⁸ was tested in a multi-diagnostic sample of 94 patients who were discharged from an inpatient rehabilitation programme and of whom 83% received some form of outpatient rehabilitation services.³⁹ The PM-PAC showed higher SRM values (range 0.65-0.82) than the responsiveness values found

in the present study.⁴⁰ We did not include the PM-PAC in this study because with a total of 52 items the measure is quite long. Furthermore, the PM-PAC includes questions on performance and satisfaction, but satisfaction is only asked regarding interpersonal relationships and the satisfaction items do not make up a separate scale.

In the study group as a whole, responsiveness parameters were small to moderate. Responsiveness parameters for the scales of the USER-Participation and the USER are similar. This might be due to the heterogeneity of the population. Heterogeneity in diagnosis may result in larger SD values of baseline and change scores, and thereby in smaller ES and SRM values. Therefore, we analysed responsiveness parameters separately for different diagnostic groups. The figures were highest in the Brain injury group, and lowest in the Musculoskeletal group and the Chronic pain group. These differences might be explained by differences in the goals, contents and intensity of rehabilitation programmes for different diagnostic groups. For example, acceptance of pain and maintaining a balance between activity and rest as treatment goals in persons with chronic benign pain are more likely to result in improvement of satisfaction with participation than in a higher frequency of participation. This example underscores that more participation is not necessarily better.¹³

The responsiveness parameters were largest for the rehabilitation period and negligible for follow up. In The Netherlands, there is little financial pressure to limit the duration of rehabilitation, so that treatment can continue until the desired level of functioning is reached. A further improvement of participation after finishing the rehabilitation programme was nevertheless expected because patients might have less time and energy to participate during the rehabilitation programme itself, but such an improvement was not found. In retrospect, this might be attributed to the long duration and gradually decreasing intensity of outpatient rehabilitation in The Netherlands, so that most patients might already have reached their desired level of participation and treatment frequency is already low at the moment of discharge. If so, the stability of participation scores during the follow-up period might imply that patients are able to maintain their level of participation after finishing the rehabilitation programme.

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Chapter 4 Responsiveness of four participation measures

5

Responsiveness of two participation measures in an outpatient rehabilitation setting

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Abstract

Objective: The responsiveness of a new participation measure, the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) was compared with that of the Impact on Participation and Autonomy (IPA). Furthermore, the concurrent validity of these two measures was assessed.

Method: Participants were patients with brain injury or neuromuscular disease, who received occupational therapy as part of a multidisciplinary outpatient rehabilitation programme. They completed the IPA and the USER-Participation at the start and end of the programme, and at three-month follow up. Responsiveness was analysed using the effect size (ES) and the standardized response mean (SRM).

Results: Responsiveness figures were small to moderate (-0.4 to 0.5) and similar for the IPA and the USER-Participation. The USER-Participation showed a consistent result, with Frequency scores declining and Restriction and Satisfaction scores inclining over time, and the IPA showed mixed results, with the different domain scores both inclining and declining over time. Correlations between IPA and USER-Participation scales were all significant, but by far strongest for the USER-Participation Satisfaction scale (-0.64 to -0.81).

Conclusion: The USER-Participation was at least as responsive as the IPA. Further, satisfaction with participation as measured with the USER-Participation is highly similar to the concept of autonomy in participation as measured with the IPA.
Introduction

Participation has become an important construct in health care, rehabilitation, and occupational therapy.¹ It is defined by the International Classification of Functioning, Disability and Health (ICF) as "the involvement in a life situation", and participation restrictions as "problems an individual may experience in involvement in life situations".² Participation restrictions are the basis for occupational therapy,³ and re-establishing participation is the main goal of occupational therapy.⁴ Measurement of participation outcomes is therefore necessary to evaluate the effects of treatment.⁵ However, measuring participation outcomes is not common.⁶ One of the reasons for this discrepancy is that measures of participation have been less developed than measures of activities of daily living, like dressing and walking.⁷ In particular insufficient knowledge exists on the responsiveness of participation measures, also called sensitivity to change.^{6,8}

Participation problems can be rated from an "objective" or a "subjective" perspective. Objective perspective concerns observable behaviours, such as the number of hours a week doing paid work, or the frequency of visiting friends in the previous four weeks. Subjective perspective concerns the subjective appraisal of the person involved, such as experienced restrictions.^{9,10} The difference between objective and subjective perspective is of importance, as these are, usually, only weakly related.^{2,11} Objective perspectives of participation appear straightforward as these concern observable behaviours. However, what constitutes optimal participation is highly culture-dependent and in modern societies a wide variety of lifestyles exist together.^{13,14} The way people participate is within certain boundaries determined by their own preferences. Therefore, the concept of participation is connected to the concept of autonomy.¹⁵ Consequently, while re-establishing participation is the main goal of occupational therapy, occupational therapists need to work in a client-centred way, with respect for the autonomous functioning of their clients.^{16,17}

The first measure developed to rate participation from the perspective of autonomous functioning was the Impact on Participation and Autonomy (IPA).^{18,19} The IPA measures autonomy in participation from a subjective perspective, with a focus on choice and control. This makes the IPA a very relevant instrument for occupational therapy.^{1,20} The IPA has already been validated in different languages¹⁸⁻²⁴ and its validity and reliability are good.⁶ Moderate responsiveness of the IPA has also been shown.²⁵ One drawback of the IPA, however, is that it does not document objective participation.⁶ The Utrecht Scale

for Evaluation of Rehabilitation-Participation (USER-Participation) is a newly developed measure of participation, which has the advantage of measuring in a concise way both objective and subjective participation with three scales: frequency of participation, perceived restrictions, and satisfaction. The USER-Participation showed generally good reproducibility,²⁶ validity by strong correlations with other participation measures,²⁷ and moderate responsiveness in a large multi-diagnostic group of rehabilitation outpatients.²⁸ A comparison between the IPA and the USER-Participation has never been performed.

Responsiveness is an important characteristic for any outcome measure.⁶ There is a need for data on responsiveness of the IPA and the USER-Participation, because for each instrument only one study is available to date.^{25,28} Therefore, the first aim of the present study was to compare the responsiveness of the IPA and the USER-Participation in patients who followed an outpatient rehabilitation programme. It was assumed that the USER-Participation and the IPA would show similar responsiveness. The second aim was to examine the concurrent validity of the USER-Participation as compared to the IPA. It was assumed that the IPA scales would show strong correlations with the Satisfaction scale, and weak correlations with the Frequency scale, because the concept of the IPA is closest to satisfaction with participation.

Materials and methods

Sample

Patients were included who received occupational therapy as part of a multidisciplinary rehabilitation programme from June 2008 to January 2010 at the outpatient rehabilitation clinic of the University Medical Center Utrecht (UMCU), the Netherlands. Inclusion criteria were: having brain injury (BI) or neuromuscular disease (NMD), a minimum age of 18 years, and the ability to read and write in Dutch in order to comprehend self-report measures. Exclusion criteria were aphasia or a fast progressive disorder, judged by the treating physiatrist. All participants were community dwelling and were able to walk at least for short distances, if applicable with crutches or orthoses. The typical participant had a score of at least 24 points on the Mini-Mental State Examination²⁹ and a score of at least 7 points on the shortened version of the Aphasia Scale of the Dutch Aphasia Foundation.³⁰

Procedure

Patients meeting the inclusion criteria completed a questionnaire including the IPA and the USER-Participation at the start of the rehabilitation programme (t1). At the end of the programme (t2), participants received the questionnaire once more by mail. Participants who did not complete the second questionnaire within three weeks received a once-only reminder. Participants who completed the t2 questionnaire received the questionnaires three months later for the third and last time (t3). All measurements were completed without assistance.

Rehabilitation programme

On average participants visited the clinic twice a week for at least four consecutive weeks. Treatment was multidisciplinary, occupational and physical therapy being the most important disciplines, focusing on education, enhancing fitness and participation in daily and social activities by training, and teaching compensation strategies. The typical participant had two hours of physical therapy and one hour of occupational therapy each week, and, if necessary, additional psychology. Treatment was both undertaken individually and in groups.

Instruments

The first questionnaire also contained questions on basic demographic data (age, gender, education, marital status) and diagnosis.

The IPA measures two aspects of autonomy in participation: perceived participation and the experience of participation problems.¹⁸ Perceived participation is assessed by 32 items in five domains: autonomy indoors, family role, autonomy outdoors, social life and relationships, and work and education. For example: "My chances of washing, dressing, and grooming the way I wish are ___ and "My chances of washing, dressing, and grooming when I want to are ___ ." IPA scores range from 0 (very good) up to 4 (very poor), with higher scores indicating more restrictions in participation. Experienced participation problems are assessed by nine single items that are not part of the IPA score and therefore not used in this study.

The USER-Participation addresses the frequency of behaviours, experienced participation restrictions, and satisfaction with participation with 31 items in total²⁷ (see Appendix 5.1).

The Frequency scale consists of 12 items on vocational activity (four items) and leisure and social activity (eight items). For example: "How many hours per week do you spend on household duties?" and "How often have you undertaken sports or other physical exercise in the last four weeks?". Each item is scored from 0 (none at all/never) up to 5 (36 hours or more/19 times or more). The Restriction scale contains 10 items on experienced participation restrictions as a result of the health condition. For example: "Does your illness or condition currently limit your daily life concerning household duties?". Each item score ranges from 0 (not possible) to 3 (without difficulty). The Satisfaction scale consists of nine items on satisfaction with various aspects of participation. For example: "How satisfied are you with your current daily life concerning work, education or household duties?". Items are rated on a scale from 0 (very dissatisfied) to 4 (very satisfied). The sum scores for the Frequency, Restriction, and Satisfaction scales are based on the items that are applicable and each sum score is converted to a 0-100 scale. Higher scores indicate good levels of participation (higher frequency, fewer restrictions, higher satisfaction). In previous studies, the USER-Participation showed a satisfactory internal consistency (alpha 0.70-0.91), good concurrent validity with other measures (Spearman rhos 0.59-0.75), and good discriminant validity.27 Furthermore its reproducibility was satisfactory, with intraclass correlations coefficients ranging from 0.65 for the Frequency scale to 0.85 for the Restriction scale.²⁶ Responsiveness for outcomes of outpatient rehabilitation was moderate, with the standardized response mean (SRM) ranging from 0.2 for the Frequency scale to 0.5 for the Restriction scale.²⁸ The USER-Participation is available at http://www.dehoogstraat.nl.

Statistical analyses

Analyses of responsiveness between t1 and t2 were performed on the data of participants who completed the first two measurements. Analyses of responsiveness between t1 and t3 were performed on the data of participants who completed all three measurements. Floor and ceiling effects were considered present if 15% or more of respondents scored respectively the worst possible or the best possible score on a scale.³¹ Score distributions were considered normal if the Skewness was between -1 and 1. Since no scores showed a skewed distribution, differences between the scores between t1 and t2 and between t1 and t3 were calculated using t-tests, and correlations between the questionnaires were determined by Pearson's r. Correlations of at least 0.70 were considered strong and indicative of concurrent validity.³¹ Responsiveness of the measures was compared

using the effect sizes (ES) and the SRM for both diagnostic groups separately to check whether they reveal different results. The ES was calculated as the mean difference score divided by the standard deviation (SD) of the baseline score.³² Following Cohen,³³ an ES of 0.2 was considered small, 0.5 moderate, and 0.8 large. The SRM was calculated by dividing the mean difference score by the SD of the difference score.³⁴ The two statistics might reveal different results, because the ES is sensitive to variation in baseline scores, or the heterogeneity of the study sample, whereas the SRM is sensitive to variation in change scores, or the heterogeneity of the intervention and the participant's response to the intervention. Cohen's interpretation of the ES has often been applied to the SRM,³⁵ although SRM and ES values are statistically not equivalent.³⁶ Data were analysed using SPSS 16.0.

Results

A total of 69 participants were included in the study and completed the questionnaires at t1, of whom 47 (68.1%) completed the questionnaires at t2, and 37 (53.6%) completed the questionnaires at t3. Participants' characteristics are shown in Table 5.1. Sixty percent

	t1 (n= 47)	t3 (n= 37)
Gender, n (%): Men Women	22 (46.8) 25 (53.2)	17 (45.9) 20 (54.1)
Mean age, years (SD)	53.0 (12.9)	53.4 (14.0)
Diagnosis, n (%) Brain injury Neuromuscular disease	28 (60.0) 19 (40.0)	20 (54.1) 17 (45.9)
Paid job before condition (n; %) Yes No, reason: Housekeeping Retirement Student Health problems Other	23 (48.9) 24 (51.1) 2 11 1 9 1	18 (48.6) 19 (51.4) 2 11 2 6 0
Current marital status, n (%) Married/living together	36 (76.6)	27 (73.0)

 Table 5.1
 Participants' characteristics of respondents at t1 and t3

of the participants had BI (cerebral contusion n= 4, stroke n= 18, cerebellar ataxia n= 2, astrocytoma n= 2, other n= 2) and 40% suffered from NMD (polyneuropathy n= 11, myotonic dystrophy n= 3, multiple sclerosis n= 2, other n=3). The most frequent reason for drop out was participation in other trials. Responders did not differ from non-responders, defined as dropout between t2–t3, with regard to gender (χ^2 = 0.052, p= 0.820), age (t= -0.447, p= 0.657), diagnosis (χ^2 = 2.201, p= 0.138), job status (χ^2 = 0.006, p= 0.940), and marital status (χ^2 = 1.273, p= 0.259). The median time between t1 and t2 was 192 days (interquartile range [IQR] 99–240), and the median time between t2 and t3 was 110 days (IQR 96–124).

Score distributions of the IPA and the USER-Participation are shown in Table 5.2. Dividing the sample into BI and NMD showed similar results and therefore subgroup data are not presented. Only the IPA Autonomy indoors scale showed a ceiling effect on all three measurements (27.7% at t1, 23.4% at t2, and 24.3% at t3) and the USER-Participation Restriction scale showed a ceiling effect at t2 (15.5%). No other ceiling effects were seen (data not shown).

Score differences between t1 and t2 were generally small with large SD, showing substantial variation in the course of participation over time between participants. A significant increase in participation was shown only on the Autonomy outdoors domain of the IPA and the Satisfaction scale of the USER-Participation (see Table 5.3). Between t1 and t3, there were no significant differences in participation at all.

Responsiveness parameters are displayed in Table 5.3. SRM and ES values were generally small and similar for the IPA and the USER-Participation. Between t1 and t2 the USER-Participation Restriction and Satisfaction scales and the IPA Autonomy outdoor scale showed the best responsiveness. Between t1 and t3 the USER-Participation Restriction scale and the IPA Social life & relationships scale showed the best responsiveness. Two IPA scales, Autonomy indoors and Family role, did not show any responsiveness statistic of 0.20 or above.

Concurrent validity between the IPA domain scores and the USER-Participation scales at t2 is given in Table 5.4. All correlations were significant. IPA scores correlated strongest with the USER-Participation Satisfaction scale, 3/5 correlations being higher than 0.70 (mean correlation -0.72), whereas no correlations with the Frequency scale (mean correlation -0.46) and only 1/5 correlations with the Restrictions scale (mean correlation -0.55) were higher than 0.70.

Table 5.2 Score distr	ibution of the ll	PA an	d USER-Partic	ipation at all th	ree me	easurements				
			t1			t2			t3	
			Mean (SD)	Skewness	⊆	Mean (SD)	Skewness	۲	Mean (SD)	Skewness
IPA (0-4)										
Autonomy indoors	4	2	0.7 (0.6)	0.319	47	0.8 (0.7)	0.466	37	0.8 (0.7)	0.567
Family role	4	Ŀ.	1.5 (0.9)	0.289	46	1.5 (1.1)	0.484	37	1.4 (0.9)	0.210
Autonomy outdoors	4	Ŀ.	1.8 (0.9)	0.140	47	1.6 (0.9)	0.564	37	1.7 (0.8)	-0.055
Social life & relations	4 4	L.	1.1 (0.6)	0.662	47	1.2 (0.7)	0.260	37	1.2 (0.6)	0.619
Work & education	2	2	2.2 (1.0)	-0.289	24	1.9 (0.9)	0.680	19	1.9 (1.0)	0.604
USER-Participation (0–1	(00)									
Frequency	4	5	32.0 (10.6)	0.119	47	31.3 (9.3)	-0.390	37	31.3 (10.0)	-0.215
Restrictions	4	5	65.9 (20.8)	-0.328	45	69.5 (22.4)	-0.343	36	71.3 (19.6)	-0.762
Satisfaction	4	Ń	61.1 (16.5)	-0.287	47	66.5 (18.8)	-0.110	37	67.2 (19.6)	-0.045
Notes: Higher scores on th	e IPA indicate moi	re rest	rictions in partic	ipation and autor	A.Ymor	higher score on t	he USER-Particip.	ation inc	dicates good leve	ls of participation.

of the IPA and USER-Participation at all three measurements
Score distribution of
ble 5.2

		t1-t2				t1-t3	~	
	⊆	Mean difference (SD)	ES	SRM	۲	Mean difference (SD)	ES	SRM
IPA								
Autonomy indoors	47	0.1 (0.6)	0.10	0.10	37	0.1 (0.7)	0.19	0.17
Family role	46	-0.0 (0.7)	-0.04	-0.05	37	0.0 (0.7)	0.01	0.02
Autonomy outdoors	47	-0.2 (0.7)*	-0.28	-0.34	37	-0.1 (0.7)	-0.11	-0.13
Social life & relationships	47	0.1 (0.7)	0.17	0.16	37	0.2 (0.6)	0.30	0.31
Work & education	19	-0.1 (0.7)	-0.14	-0.17	17	-0.2 (0.9)	-0.21	-0.24
USER-Participation								
Frequency	47	-0.7 (10.5)	-0.07	-0.07	37	-2.4 (11.4)	-0.23	-0.21
Restrictions	45	3.8 (17.6)	0.18	0.21	36	5.4 (17.2)	0.27	0.31
Satisfaction	45	5.7 (17.5)*	0.34	0.32	36	4.0 (17.0)	0.26	0.24
Notes: A positive score difference o increase and on the USER-Participa * Significant at p< 0.05.	n the IPA i tion is a de	s a decrease and on the US crease in participation.	ER-Participa	tion is an incre	ease in pa	rrticipation. A negative sco	ire difference	on the IPA is an

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				IPA		
		Autonomy indoors	Family role	Autonomy outdoors	Social life & relationships	Work & education
USER-Participation	Frequency	-0.43**	-0.62**	-0.50**	-0.34*	-0.43*
	Restrictions	-0.56**	-0.71**	-0.65**	-0.40**	-0.45*
	Satisfaction	-0.64**	-0.71**	-0.81**	-0.78**	-0.68**
Notes: * Significant at p	<pre>i< 0.01, ** Significar</pre>	nt at p< 0.05.				

Chapter 5 Responsiveness of participation measures

Discussion

The first aim of the study was to compare the responsiveness of the IPA and the USER-Participation in patients who followed an outpatient rehabilitation programme. This study showed that the responsiveness of the USER-Participation was at least similar to, and to some extent better than, the responsiveness of the IPA in patients with BI or NMD following a hospital-based outpatient rehabilitation programme. Both measures showed small to moderate responsiveness parameters. The USER-Participation scores showed a consistent pattern of changes, with Frequency scores declining and Restriction and Satisfaction scores increasing over time. In contrast, the IPA showed mixed results, with the different domain scores both increasing and declining over time. The second aim of the study was to examine the concurrent validity of the USER-Participation as compared with the IPA. This study showed that the IPA scores and the USER-Participation Satisfaction scores showed good concurrent validity, since the mean correlation was -0.72, indicating strong empirical similarity between autonomy in participation and satisfaction with participation. This means that the IPA scores and the USER-Participation Satisfaction scores are more or less interchangeable and that there is no need to administer both measures to rate subjective participation.

The responsiveness of the IPA was studied before in a multi-diagnostic group of 49 persons following an outpatient rehabilitation programme.²⁵ The SRM values obtained in the whole group ranged from 0.0 up to 0.3, which is about the same as the figures obtained in the current study. The responsiveness of the USER-Participation has been studied before in a sample of outpatients with different diagnoses from a number of rehabilitation clinics (n= 395).²⁸ The ES and SRM for the Frequency (0.19; 0.21) and Restriction (0.49; 0.54) scale were higher, and responsiveness parameters for the Satisfaction scale were similar (0.36; 0.39). That study population, however, was on average more severely disabled and received more intensive rehabilitation than participants in the current study.

Figures on responsiveness of other participation measures are sparse and the use of different methods to calculate responsiveness hampers comparisons. There is no consensus on which method should be used.³⁷ Wu et al.³⁸ found a moderate SRM of the Frenchay Activities Index (FAI)³⁹ (0.5) in a clinical trial in stroke survivors, but in a highly homogeneous sample and intervention, which makes it easier to show responsiveness. Freeman et al.⁴⁰ found a weak ES (0.23) of the London Handicap Scale⁴¹ in an inpatient rehabilitation setting, which is comparable to the ES found in the present study. Other studies found higher responsiveness for the FAI⁴² or the Participation Measure for Post-

Acute Care,⁴³ but these authors reversed the change scores of persons who showed worse participation before computing the responsiveness statistics, which obviously results in higher figures. Likewise, SRM values of the IPA were higher (0.1-1.3) in the subgroup of participants who showed improvement on a global subjective rating of change than in the complete study group.²⁵

The results of the present study therefore do not deviate much from the available literature, suggesting that all standardized participation measures show small to moderate changes in participation during outpatient rehabilitation. For those who state that the ultimate aim of rehabilitation is to improve participation,^{44,45} this might be a disappointing result. It may be that standardized participation measures are insufficiently sensitive to outcomes of rehabilitation because rehabilitation goals vary widely between patients, implying the potential use of individualized measures like, for example, the Canadian Occupational Performance Measure⁴⁶ or Goal Attainment Scaling⁴⁷ as outcome measures. More likely, participation is influenced by many other factors, including environmental factors, than rehabilitation alone.⁴⁸

Concurrent validity was shown by high correlations between the IPA and USER-Participation. Correlations between the IPA domain scores and the USER-Participation Satisfaction scale were higher than for the USER-Participation Restriction scale, which implies that the IPA is similar to measures of satisfaction with participation,¹⁰ rather than a measure of participation frequency or restrictions. The lower correlations between IPA domains and the USER-Participation Restrictions and Frequency scales show that the objective and the subjective perspective on participation are relatively independent from each other, and that it is preferable to measure both to be able to assess this complex phenomenon. Furthermore, the USER-Participation scales showed fewer ceiling effects than the IPA domain scores, which enables the measurement of increase in participation over time.

A few limitations apply to this study. First, the sample size of this study was small. Therefore it was not possible to evaluate responsiveness parameters in the different diagnostic groups. However, the heterogeneity of the sample reflects clinical practice and the number of participants was only just below the recommended number of 50.³¹ Second, an external criterion of change in participation was not included, so that it was not possible to compute and compare Minimal Important Change (MIC) or Area under the Curve (AUC) values. Further research is necessary to establish MIC values of the various measures.⁴⁹

Conclusion

The USER-Participation was at least as responsive as the IPA. Further, concurrent validity showed that satisfaction with participation as measured with the USER-Participation is highly similar to the concept of autonomy in participation as measured with the IPA. However, the participation frequency and the experienced restrictions in participation seemed to be different from this concept. Since participation is a multi-dimensional concept, the USER-Participation seemed to be more able to assess this complex phenomenon.

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Appendix 5.1 Example items from the USER-Participation

FREQUENCY SCALE: How many hours per week do you spend on the following activities?

Paid work

All forms of paid work, including work for your own business	None at all	1–8 hours	9–16 hours	17–24 hours	25–35 hours	36 hours or more
Unpaid work Volunteering for a society, community centre, at school or any other voluntary activities	None at all	1–8 hours	9–16 hours	17–24 hours	25–35 hours	36 hours or more

FREQUENCY SCALE: How often have you undertaken the following activities in the last 4 weeks?

Sports or other physical exercise Such as: tennis, cycling, gym, long walks Never 6–10 1–2 3–5 11–18 19 times Please note: do not include e.g. cycling to work times times times times or more **Going out** Such as: eating out, visiting a cafe, cinema, Never 1–2 6–10 11–18 19 times 3–5 concert, alone or with others times times times times or more

RESTRICTIONS SCALE: Does your illness or condition currently limit your daily life?

Paid work, unpaid work or education	NA	Not possible	With assistance	With difficulty	Without difficulty
Household duties Such as: cooking, cleaning, shopping, taking care of or supervising children, DIY, gardening	NA	Not possible	With assistance	With difficulty	Without difficulty
Outdoor mobility Such as: driving a car, travelling by bus or train, cycling to work or going shopping, etc	NA	Not possible	With assistance	With difficulty	Without difficulty
Sports or other physical exercise Such as: tennis, cycling, gym, long walks	NA	Not possible	With assistance	With difficulty	Without difficulty
Going out Such as: eating out, visiting a cafe, the cinema, a concert, alone or with others	NA	Not possible	With assistance	With difficulty	Without difficulty

SATISFACTION SCALE: How satisfied are you with your current daily life?

Paid work, unpaid work or education <i>Please note: complete for the most</i> <i>important activity</i>	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	NA
Household duties Such as: cooking, cleaning, shopping, taking care of or supervising children, DIY, gardening	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Outdoor mobility Such as: driving a car, travelling by bus or train, cycling to work or going shopping, etc	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Sports or other physical exercise Such as: tennis, cycling, gym, long walks	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Going out Such as: eating out, visiting a cafe, the cinema, a concert, alone or with others	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	

Note: the USER-Participation with instructions is available on www.dehoogstraat.nl.

6

Comparison of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) with the ICF Measure of Participation and Activities Screener (IMPACT-S) and the WHO Disability Assessment Scale II (WHODAS II) in persons with spinal cord injury

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Submitted for publication

Abstract

Objective: To validate the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) in persons with spinal cord injury (SCI) using two ICF-based instruments: the ICF Measure of Participation and Activities-Screener (IMPACT-S) and the WHO Disability Assessment Scale (WHODAS II). The USER-Participation was developed to assess three aspects of participation: frequency of behavior, experienced participation restrictions, and satisfaction with participation.

Design: Validation study. Score distributions, internal consistency, concurrent and discriminant validity were evaluated.

Setting: The Netherlands.

Participants: Convenience sample of 157 persons with long-term SCI living in the community.

Interventions: Not applicable.

Main outcome measure(s): USER-Participation, IMPACT-S, and WHODAS II.

Results: No instruments showed floor effects, and three out of six WHODAS II domains showed ceiling effects. Most scores showed adequate internal consistency (alpha ≥ 0.70), except for the USER-Participation Frequency scale (0.51) and two WHODAS II domains (0.58–0.60). Spearman correlation coefficients between the segregate USER-Participation scales were below 0.60 (range 0.39–0.46), showing that they cover separate aspects of participation. Concurrent validity of the USER-Participation was shown since more than 75% (83.3%) of the 24 hypotheses (Spearman correlation coefficients above or below 0.60) with the other measurement instruments were confirmed. Concurrent validity between the IMPACT-S and WHODAS II was not shown (53.8% of 13 hypotheses confirmed). All scores except four WHODAS II domains showed significant differences in participation between persons with paraplegia and tetraplegia.

Conclusions: The USER-Participation showed generally satisfactory psychometric properties in Dutch persons with long-term SCI living in the community. The IMPACT-S showed the best psychometric properties, and the WHODAS II showed less favorable results. Future research on the USER-Participation should focus on validation in other languages and different diagnostic groups.

Introduction

Spinal cord injury (SCI) is usually a severely disabling condition, leading to a whole range of impairments and secondary health conditions.¹ People with SCI experience problems across various participation domains such as work and leisure activities,²⁻⁴ and participation is therefore an important outcome of SCI rehabilitation. Participation has been defined in the International Classification of Functioning, Disability, and Health (ICF) as 'the involvement in life situations',^{5, p10} Participation is distinct from activities, which is defined as 'the execution of a task or action by an individual',^{5, p10} However, in the classification itself the categories of activities and participation have been merged together into nine chapters: 1) learning and applying knowledge; 2) general tasks and demands; 3) communication; 4) mobility; 5) self-care; 6) domestic life; 7) interpersonal interactions and relationships; 8) major life areas; and 9) community, social and civic life.

Despite its relevance, the measurement of participation in persons with SCI is still underdeveloped.^{3,6} Few participation instruments have been validated for use in persons with SCI^{2,3,6} and comparative psychometric studies are sparse.^{4,7,8} There is an ongoing need for a comprehensive participation measure that contains both objective and subjective information, and has minimal floor and ceiling effects in persons with SCI.⁶ The Life-Habits⁹ is a measure for both objective and subjective participation that has been used in the SCI population.^{3,6} However this measure is quite long which hampers the use in clinical practice.

The USER-Participation¹⁰ is a recently developed ICF-based participation measurement instrument that might fulfill the need for a brief instrument containing both objective and subjective participation. Developing the USER-Participation, we considered chapter 6–9 as most characteristic for participation.^{11,12} With a total of 32 items it measures the frequency of participation, experienced participation restrictions, and satisfaction with participation. This instrument has been validated in a heterogeneous sample of rehabilitation outpatients.^{10,13,14} However, psychometric properties can vary between different health conditions.¹⁵ The focus of the present study is therefore to evaluate the score distributions, internal consistency, concurrent and discriminant validity of the USER-Participation compared to two other ICF-based participation measurement instruments; the ICF Measure of Participation and Activities-Screener (IMPACT-S)¹⁶ and the WHO Disability Assessment Scale (WHODAS II)¹⁷ in persons with SCI in the Netherlands.

Methods

Sample

Participants were identified and recruited through one of two routes. First, we searched the database of De Hoogstraat Rehabilitation for eligible former SCI patients. Inclusion criteria were minimum age of 18, living in the community, and ability to read and comprehend the questionnaire as judged by the physiatrists of the SCI department. Second, we evaluated all persons with SCI who participated in the ALLRISC study. ALLRISC is a study on long-term secondary health conditions, fitness and active lifestyle in persons with a SCI.¹ Inclusion criteria were: onset of SCI between 18 and 35 years of age, duration of SCI at least 10 years, living in the community, and being wheelchairdependent, at least for long distances.

Procedure

Candidate-participants received written information and an invitation to participate in the study along with the questionnaire. Persons who did not respond within 2 weeks received one reminder. Data collection took place between May 2012 and December 2012. The study protocol was approved by the Medical Ethics board of De Hoogstraat Rehabilitation.

Instruments

First, questions were asked on demographic and SCI characteristics. After that, the USER-Participation, the IMPACT-S and the WHODAS II were presented. The questionnaire was printed in different versions to randomize the order of the participation instruments. Finally, the respondents were asked to rate each instrument on its relevance in assessing participation, ease of use, and appropriateness of the items with respect to irrelevancy or obtrusiveness.

The USER-Participation¹⁰ is a self-report measure consisting of 32 items in three scales: Frequency, Restrictions and Satisfaction. It covers the chapters 6–9 of the ICF (see the introduction). The frequency of behaviors is assessed by 4 items on hours per week spend on vocational activities and 7 items on the frequency of leisure and social activities in the last 4 weeks. For example, "How many hours per week do you spend on household duties?" and "How often have you undertaken sports or other physical exercise in the last 4 weeks?" Each item is scored on a scale from 0 (not at all) to 5 (36 hours or more/19 times or more). Experienced participation restrictions due to health condition are assessed by 11 items. For example, "Does your illness or condition currently limit your daily life concerning household duties?" Items are scored on a 4-point scale (0= not possible at all; 1= with help from others; 2= with difficulty; 3= no difficulty at all). A not applicable option is available for every item and can be used if the item is not relevant to the person or if experienced restrictions are not related to the person's health status or disability. Satisfaction with participation is assessed by 10 items. For example, "How satisfied are you with your current daily life concerning work, education, or household duties?" Items are rated on a scale from 0 (not satisfied at all) to 4 (very satisfied). A not applicable option is available for the items on vocational activities and partnership relations. The sum scores of the Frequency, Restrictions, and Satisfaction scales are calculated and converted to a score on a scale ranging from 0 to 100, in which higher scores indicate better levels of participation (higher frequency, less restrictions, higher satisfaction). There is no total USER-Participation score, since all three scales measure independent aspects of participation (Spearman correlation coefficients range 0.36–0.52).¹⁰ The preliminary version of the USER-Participation has been validated for measuring participation in an outpatient rehabilitation sample with various health conditions.^{10,13,14} The slightly modified final version was used in the current study.

The IMPACT-S¹⁶ is an ICF-based self-report measurement instrument assessing experienced limitations in activities and participation. It comprises 32 items in nine domains, each representing one of the 9 ICF Activities and Participation chapters. Two sub-total scores for Activities (ICF chapters 1–5) and Participation (ICF chapters 6–9) and a total score can be computed. Response categories are 0 (*cannot do that at all*) up to 3 (*no limitations whatsoever*). All summary scores are converted to a score on a 0–100 scale, in which a high score indicates a high level of participation. The IMPACT-S showed good reproducibility and moderate responsiveness in an outpatient rehabilitation sample with various health conditions^{13,14} and good internal consistency and test-retest reliability in a sample of road traffic accident victims.¹⁶

The WHODAS II¹⁷ is a 36-item self-report instrument which assesses experienced difficulties in 6 life domains during the previous 30 days. The six domains are: Understanding and communication, Getting around, Self-care, Getting along with others, Life activities, and Participation in society. Response categories are 0 (*no difficulty*) up to 4 (*extreme difficulty/cannot do*). Six domain scores and a total disability index can be calculated by converting scores into a score ranging from 0 to 100, in which a lower score indicates better participation. The WHODAS II showed acceptable psychometric properties in most domains in two SCI studies.^{4,18}

Statistical analyses

Data were analyzed using SPSS 19.0. In case of multiple answers on the same item (see results), the worst score was used. Replication of the analyses after recoding multiple answers as missing showed identical results. Floor and ceiling effects were considered present if 15% of respondents scored the worst or the best possible score on a scale, respectively.¹⁹ The skewness of the scale score distribution was considered acceptable if between -1 and 1. Internal consistency was assessed using Cronbach's alpha and itemrest correlation coefficients. An alpha between 0.70 and 0.95 is favorable¹⁹ and item-rest correlation coefficients of at least 0.30 are satisfactory.²⁰ Concurrent validity was assessed using Spearman correlation coefficients (rho) between the three USER-Participation scales, and between the USER-Participation, the IMPACT-S, and the WHODAS II. Concurrent validity is confirmed by correlation coefficients of above 0.60.²¹ Concurrent validity is shown if at least 75% of the hypotheses are confirmed.¹⁹ We expected that all three scales show similar results on psychometric properties. We predicted that the three USER-Participation scales, which measure different aspects of participation show limited correlation, and accept a correlation coefficient of 0.60 or less as supportive of concurrent validity. Further, the way participation is measured by the IMPACT-S and WHODAS II matches the Restrictions scale of the USER-Participation better than other the two other scales of the USER-Participation. Therefore, correlation coefficients of at least 0.60 were expected between the USER-Participation Restrictions scale and the Participation sub-total of the IMPACT-S, and the Getting along with others, Life activities, and Participation in society domains of the WHODAS II. Correlation coefficients below 0.6 were expected between the USER-Participation Restrictions scale and the Activities sub-total score of the IMPACT-S and the remaining three WHODAS II domains, and between the USER-Participation Frequency and Satisfaction scale and the sub-total scores of the IMPACT-S and the domains of the WHODAS II. Furthermore, correlation coefficients of at least 0.6 were expected between the Activities subtotal score of the IMPACT-S and the WHODAS II domains Understanding and communicating, Getting around, and Self care and between the Participation subtotal score of the IMPACT-S and the WHODAS II domains Getting along with others, Life activities, and Participation.

Also a correlation coefficient of at least 0.6 was expected between the total score of the IMPACT-S and the total disability index of the WHODAS II. Expected high correlations are represented in bold in Table 6.3.

Discriminant validity was tested by comparing scores of persons with tetraplegia with those of persons with paraplegia using the Mann-Whitney U-test. Non-parametric statistics were used since not all scores were normally distributed. A p-value < 0.05 is considered as a statistically significant difference.

Results

A total of 157 individuals (66.2% men) with a mean age of 50.6 years (SD 10.5) participated in this study. Mean time after SCI was 25.3 years (SD 26.8). Other characteristics are displayed in Table 6.1.

Few missing values were seen (0.4-1.9%). The item with most missing values was Religious/spiritual activities of the IMPACT-S (n= 16).

Characteristics	Participants (n= 157)
Demographic characteristics	
Gender (% men)	66.2
Age, years, mean (SD)	50.6 (10.5)
Highest education level ^a (% high)	50.3
Having a paid job (%)	40.8
Mean % of full-time job (SD) ($n=64$)	71.8 (27.4)
SCI characteristics	
Mean time since injury, years (SD)	25.3 (26.8)
Mean age at injury, ^b years (SD)	25.4 (27.6)
Lesion level (% paraplegia)	59.2
Motor completeness (% complete)	69.4
Cause of SCI (%)	
Road traffic	46.5
Sports/leisure	18.5
Fall	12.1
Work-related	7.0
Violence	1.3
Non-traumatic	14.6

Table 6.1 Participants' characteristics

^a Dichotomous variable; high being at least higher general education. ^b Skewed distrubtion: skewness 1.426, median 24.0, range 8–72.

 Table 6.2
 Score distributions and internal consistency of the USER-Participation, the IMPACT-S, and the WHODAS II

	۲	Mean (SD)	Median (IQR)	Skewness	Range	Floor effects (%)	Ceiling effects (%)	Cronbach's alpha	ltem-rest correlations > 0.30
USER-Participation Frequency	157	34.8 (10.0)	36.1 (29.1–41.4)	-0.5	7.1-55.7	0	0	0.51	4/11
Restrictions	157	72.6 (19.3)	75.8 (60.3–87.9)	-0.6	21.2-100.0	0	5.7	0.89	11/11
Satisfaction	156	69.9 (14.3)	72.2 (60.0–79.5)	-0.4	25.0-100.0	0	1.9	0.78	8/10
IMPACT-S									
Total	155	69.6 (13.0)	70.8 (60.4–79.2)	-0.5	31.3–96.9	0	0	0.92	29/30
Activities	155	66.1 (12.7)	66.7 (55.6–75.9)	-0.3	33.3-94.4	0	0	0.84	12/18
Participation	154	73.9 (15.1)	76.2 (64.3–85.7)	-0.8	23.8-100.0	0	0.6	0.88	14/14
WHODAS II									
Total disability index	157	28.0 (13.0)	27.1 (17.5–36.2)	0.6	3.5-64.3	0	0	0.90	30/36
Understanding and communicating	156	8.3 (14.3)	0.0 (0.0–8.3)	2.4	0.0-75.0	0	53.2	0.91	6/6
Getting around	157	61.1 (14.9)	60.0 (60.0–70.0)	-0.6	0.0-100.0	3.2	0.6	0.58	4/5
Self-care	156	25.6 (28.0)	12.5 (0.0–50.0)	1.0	0.0–93.8	0	28.2	0.84	4/4
Getting along with others	157	15.8 (13.9)	15.0 (5.0–25.0)	1.0	0.0-70.0	0	18.5	0.60	4/5
Life activities	157	34.3 (29.7)	25.0 (12.5-53.1)	0.9	0.0-100.0	8.3	13.4	0.90	8/8
Participation	157	26.5 (16.8)	25.0 (12.5-37.5)	0.7	0.0-81.3	0	3.8	0.82	8/8
Note that high scores on the USER-Particips particips participation; ceiling effects are in bold.	ation and	d the IMPACT-S	s indicate high level	s of participa	tion, and that l	high score	s on the Wh	HODAS II indica	ate low levels of

In 0.8% and 0.7% of the USER-Participation and the IMPACT-S data respectively, participants ticked multiple response categories of the same item. In both measurement instruments multiple examples per item are given to clarify the contents of the item, and respondents indicated that therefore more than one response category applied. Score distributions of all scales and total scores are shown in Table 6.2. There were no floor effects and few ceiling effects; only 3 out of 6 scales of the WHODAS II showed ceiling effects and skewed distributions.

Internal consistency

Cronbach's alpha was below the recommended value of 0.70 for the Frequency scale, but above this value for the Restrictions and Satisfaction scale (Table 6.2). All IMPACT-S scores showed sufficient internal consistency. Two domains of the WHODAS II, Getting around and Getting along with others, showed too low alpha values, but alpha of the other 4 scales and the total score were sufficient (Table 6.2).

Concurrent validity

Spearman correlation coefficients between the three USER-Participation scales were all below 0.60: 0.39 between the Frequency and the Restrictions scales; 0.40 between the Frequency and the Satisfaction scales; and 0.46 between the Restrictions and the Satisfaction scales.

Spearman correlation coefficients between the three measurement instruments are shown in Table 6.3. The USER-Participation Restrictions scale showed generally higher correlations with the IMPACT-S and the WHODAS II than the Frequency and Satisfaction scales. In total, 83.3% of the hypotheses were confirmed. In contrast, only 53.8% of the hypotheses concerning relationships between the IMPACT-S and the WHODAS II were confirmed. In particular the WHODAS II scales Getting along with others and Participation in society showed weaker correlations than expected, and the WHODAS II scale Self-care showed stronger correlations with participation scales than expected.

Discriminant validity

Differences between participants with paraplegia and participants with tetraplegia are shown in Table 6.4. All scores except 4 out of 7 WHODAS II scores showed differences between participants with tetraplegia and paraplegia.

he IMPACT-S, and the WHODAS II (Spearman's rho)
Concurrent validity of the USER-Participation, t
able 6.3

		USER-Participatio	on		IMPACT-S	
	Frequency	Restrictions	Satisfaction	Total	Activities	Participation
IMPACT-S						
Total	0.32 **	0.73 **	0.38 **	ı	ı	ı
Activities	0.30 **	0.67 **	0.28 **	ı	ı	ı
Participation	0.34 **	0.74 **	0.47 **		ı	ı
WHODAS II						
Total disability index	-0.37 **	-0.76 **	-0.52 **	-0.78 **	-0.70 **	-0.77 **
Understanding and communicating	-0.30 **	-0.36 **	-0.33 **	-0.35 **	-0.28 **	-0.38 **
Getting around	-0.08	-0.36 **	-0.15	-0.36 **	-0.33 **	-0.34 **
Self-care	-0.31 **	-0.68 **	-0.34 **	-0.72 **	-0.70 **	-0.66 **
Getting along with others	-0.24 **	-0.45 **	-0.45 **	-0.38 **	-0.29 **	-0.45 **
Life activities	-0.25 **	-0.67 **	-0.40 **	-0.68 **	-0.62 **	-0.67 **
Participation	-0.27 **	-0.55 **	-0.50 **	-0.54 **	-0.46 **	-0.58 **
* p< 0.05; ** p< 0.01; - not assessed.						
Expected high correlations are in bold.						

	Paraplegia	Tetraplegia	Mann Whitney U (Z)	р
USER-Participation				
Frequency	36.1	32.8	-2.29	0.022
Restrictions	76.7	66.7	-3.17	0.002
Satisfaction	71.8	67.2	-1.99	0.047
IMPACT-S				
Total	73.8	63.3	-5.23	0.000
Activities	70.7	59.3	-5.62	0.000
Participation	77.5	68.5	-4.23	0.000
WHODAS II				
Total disability index	25.5	31.6	-3.38	0.001
Understanding and communicating	9.2	6.9	-1.37	0.172
Getting around	61.0	61.3	-0.05	0.964
Self-care	15.2	41.1	-5.84	0.000
Getting along with others	15.3	16.4	-0.98	0.328
Life activities	27.2	44.7	-3.81	0.000
Participation	25.8	27.5	-0.90	0.369

Table 6.4 Discriminant validity of the USER-Participation, the IMPACT-S, and the WHODAS II

Significant p-values are in bold.

Respondent's opinions

A total of 44.8% of all respondents considered all measurement instruments equally suitable to assess their participation, 23.8% judged the USER-Participation best suitable, 12.6% the IMPACT-S, 5.6% the WHODAS II, and 10.5% judged none of the three suitable to assess their participation. Several participants commented that the questionnaires were quite generic so that items were not applicable to them and some indicated the lack of items on wheelchair use. A total of 44.5% considered all three measurement instruments equally easy to complete, 21.9% said the USER-Participation was the easiest to complete, 17.1% the IMPACT-S, 8.2% the WHODAS II, and 7.5% considered none easy to complete. Explanations included that having multiple examples per item caused difficulties and some respondents suggested a digital version in which items can be left out when they are not applicable. Asked for the presence of obtrusive items, 5% thought the USER-Participation, 6% thought the IMPACT-S and 7% thought the WHODAS II contained one or more obtrusive items.

Discussion

Concerning score distributions, internal consistency, concurrent and discriminant validity the USER-Participation showed generally satisfactory psychometric properties in Dutch persons with long-term SCI living in the community. The IMPACT-S showed the best properties, and the WHODAS II showed less favorable results.

Internal consistency

Most scales showed satisfying internal consistency. Cronbach's alpha was only below the recommended 0.70 for the Frequency score of the USER-Participation and the domains Getting around and Getting along with others of the WHODAS II. De Wolf et al.¹⁸ also found an unsatisfying alpha in a SCI sample for the domain Getting around (0.61) and a just above satisfying alpha for the domain Getting along with others (0.73), while the alpha values for all other domains and the total disability index ranged from 0.93 to 0.97. The other study on the WHODAS in a SCI sample⁴ found satisfying alpha values for all domain scores and the total disability index (range 0.78–0.96), however, the alpha values for the domains Getting around and Getting along with others were obviously the lowest.

The USER-Participation Frequency score also showed an alpha value of below 0.7, and also showed the lowest alpha in the initial validation study.¹⁰ However, items in the Frequency scale cannot show high positive correlations with each other, given the boundaries of a 24-hour day. When items do not have to correlate, internal consistency is less relevant.¹⁹ Correspondingly Noonan et al.⁸ and De Wolf et al.¹⁸ did not calculate alpha values in their psychometric studies of the Participation Objective, Participation Subjective (POPS)²² and the Craig Handicap Assessment and Reporting Technique (CHART),²³ respectively.

Concurrent validity

Concurrent validity of the USER-Participation was shown; 83.3% of the hypotheses were confirmed. The usefulness of distinguishing between frequency, restrictions and satisfaction with participation was confirmed by the relatively low correlations between the three USER-Participation scales, and by the generally lower correlations between the USER-Participation Frequency and Satisfaction scales and the IMPACT-S and the

WHODAS II. The USER-Participation was designed to measure the chapters 6–9 of the ICF, whereas the IMPACT-S and the WHODAS II cover a broader range of ICF chapters. This theoretical distinction between activities and participation was however not reflected in the correlations between the measurement instruments, and the total scores of the IMPACT-S and the WHODAS II correlated very high (0.73 and 0.76, respectively) with the USER-Participation Restrictions scale. Unexpectedly, two WHODAS II domains, Getting along with others and Participation in society, showed correlations below 0.60 with both the USER-Participation Restrictions scale and the sub-total score Participation of the IMPACT-S. The items of the domain Participation of the WHODAS II comprised items on the environment, other peoples' attitude, time spend on health condition and effect of the health condition on mood. This might have led to these low correlation coefficients.

Discriminant validity

All three scales of the USER-Participation and the IMPACT-S, and the total disability index of the WHODAS II were able to show significant differences between participants with paraplegia and tetraplegia. However, only two out of six domains of the WHODAS II showed differences, namely the domains Self-care and Life activities. Previous study of the USER-Participation¹⁰ showed that, although the Restrictions and Satisfaction scales were able to discriminate between different diagnostic groups, the SCI group was included in musculoskeletal disorders.

A previous study on discriminant validity of the WHODAS II in a SCI sample¹⁸ showed that the total disability index and the domain Self-care were able to distinguish between high and low impairment. The domain Life activities showed a trend towards a significant difference. These findings are similar to the findings in the present study.

Study limitations

First of all, the sample size of the study was too small to perform factor analysis, which is a way to determine the dimensionality of an instrument. Second, we did not perform Rasch analysis, that has become a standard in questionnaire development,^{11,24} because this method assumes that the scale is unidimensional and that items show a hierarchical pattern. Participation is not hierarchical because it is influenced by personal preference, so that the frequency of performance of an item is not a good indicator of difficulty.¹¹ Domains of participation are neither easily scaled on one dimension because people

cannot perform different participation categories simultaneously, e.g. doing paid work, shopping and visiting one's grandparents. Therefore correlations between participation items and internal consistency tend to be low, as is shown for the Frequency scale. This might be considered a weackness of this scale. However, high internal consistency is less relevant when items reflect different aspects of a complex clinical phenomenon that do not have to correlate with each other.^{11,19} Determining the dimensionality of the USER-Participation would be a helpful way to further validate this measure and to conceptualize participation.

Third, assessment of the construct validity of the USER-Participation was limited, because we could not include a measurement instrument to assess objective participation, like the CHART,²³ and an instrument that measures satisfaction with participation, like the LiSat.²⁵ Fourth, both the USER-Participation and the IMPACT-S were developed and validated in the Netherlands. Even though English versions of both measures are available, they have not yet been validated in English and other languages.

Conclusion

Noonan et al.⁶ stated that the ideal participation instrument is comprehensive, contains objective and subjective information, and has minimal floor and ceiling effects. The USER-Participation fits these criteria. Even though the IMPACT-S showed the best psychometric properties the great advantage of the USER-Participation as compared to the IMPACT-S is that it measures both objective and subjective participation. Future research should focus on the dimensionality and scoring of the USER-Participation, to further assess the construct validity of the Frequency and Satisfaction scales, and to validate the USER-Participation in other languages and other diagnostic groups.

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Participation in the chronic phase of stroke

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Abstract

Background: Participation is a multidimensional concept, consisting of an objective and a subjective dimension. Many studies have focused on determinants of only 1 dimension of participation post stroke.

Objective: To describe participation (both objective and subjective) and to determine how physical and cognitive independence and subjective complaints (pain, fatigue, and mood) influence participation in community-dwelling stroke survivors in the Netherlands.

Methods: The Utrecht Scale for Evaluation of Rehabilitation (USER) measures physical and cognitive independence and subjective complaints. The USER-Participation measures 3 dimensions of participation: frequency (objective perspective), restrictions (subjective perspective), and satisfaction (subjective perspective). Spearman correlations and backward linear regression analyses were used to analyze associations between the 3 USER-Participation scores with demographics, stroke characteristics, physical and cognitive independence, and subjective complaints.

Results: Of the 111 participants, 48.5% returned to work post stroke, but mostly for only 1 to 16 hours a week. Experienced participation restrictions were most prevalent in physical exercise, chores in/around the house, housekeeping, and outdoor activities. On average, participants were relatively satisfied with their participation, but dissatisfaction occurred in cognition, activities outdoors, and work/housekeeping. Regression analysis revealed that objective participation was determined by physical and cognitive independence, age, and education, whereas subjective participation was determined by physical and cognitive independence, fatigue, and mood.

Conclusions: Most participants experienced participation problems, despite relatively good physical recovery. In addition to physical and cognitive factors, subjective complaints of persons with stroke should be addressed in the rehabilitation program.

Introduction

Stroke is a major cause of death and disability worldwide.¹⁻³ Many persons with stroke perceive activity limitations and participation problems.^{4,5} Studies reviewed in the Evidence-Based Review of Stroke Rehabilitation (EBRSR)⁶ reported deterioration in different domains of participation; decrease in interpersonal relationships; inoccupation during the day; inability to resume previous social activities or be involved in any new activities; and decrease in physical activities, mood, and quality of life.⁶ Clinical rehabilitation of patients with stroke is aimed at minimizing its consequences to improve independence and ultimately social participation.^{7,8} The EBRSR stated that day service programs as well as active case management may help to increase patients' participation in leisure activities.⁶

The International Classification of Functioning, Disability and Health (ICF) defines *participation* as "the involvement in a life situation" and *participation restrictions* as "problems an individual may experience in involvement in life situations."^{9, p10} Participation is a multidimensional concept that can be measured from an objective or a subjective perspective.⁹ The objective perspective concerns observable behaviors, such as the frequency of participation in several aspects of daily life; the subjective perspective concerns the subjective appraisal of the person involved, such as experienced restrictions in participation and satisfaction with participation.^{10,11} Acknowledging the difference between the objective and subjective perspectives is important, because these are usually only weakly related.^{12,13} Furthermore, information on both objective and subjective participation, and this might help the clinician to formulate clear treatment goals for the rehabilitation program.

Many studies have described determinants of participation after stroke.¹⁴⁻²⁰ Important significant determinants seem to include age, gender, and depression,^{15,17-19} as well as functional/physical ability, dependency in activities of daily living, and severity of the stroke.^{14,16-20} However, most of these studies focus on 1 dimension of participation only, such as the frequency of performance¹⁴ or perceived participation restrictions.^{16,19,20} Only a few studies included multiple participation dimensions.^{15,21}

In a previous study,²² we developed an instrument that measures participation from both an objective and a subjective perspective: the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation). In this study, we use this measure to (1) describe the frequency of participation, of persisting perceived restrictions, and of dissatisfaction in various participation domains; and (2) determine how physical and cognitive independence and subjective complaints influence participation in communitydwelling persons in the Netherlands in the chronic phase of stroke. This information might serve as feedback for the stroke team and reveal health care needs in this chronic phase.

Methods

Sample

Patients were selected from a larger study in 5 rehabilitation centers in the Netherlands.²² Inclusion criteria for the current study were diagnosis of stroke (as confirmed by computed tomography or MRI), at least 18 years of age, and the ability to read and write in Dutch. Exclusion criteria were severe aphasia, severe cognitive impairments, or a fast progressive medical condition (eg, amyotrophic lateral sclerosis). Aphasia and cognitive impairments were assessed by the treating physiatrist.

All patients completed a multidisciplinary individually based outpatient rehabilitation program between October 2008 and September 2009, which lasted at least 4 consecutive weeks and had a mean duration of 5.5 months (SD 2.5). A total of 136 stroke patients participated in the larger study, and 111 patients completed the follow-up measurement. Data of these 111 stroke patients were included in the current analyses. Patients were referred to the outpatient rehabilitation program from an acute care hospital (n= 17), from an inpatient rehabilitation program (n= 65), or from home (n= 29). At the start of the outpatient rehabilitation program, the median time since stroke was 1.4 months (range, 0.6-4.0), 3.5 months (range, 1.1-10.5), and 6.1 months (range, 0.3-150.0), respectively. Participants' characteristics are shown in Table 7.1. Over 80% of the participants had an infarction, and patients were nearly equally distributed over left- and right-sided stroke. Participants scored high on physical and cognitive independence and showed few subjective complaints except for fatigue. Over 75% of the participants had the maximum Barthel Index (BI) score of 20, indicating independence in basic activities of daily living.

A multidisciplinary outpatient rehabilitation program was defined as the involvement of at least 2 different disciplines in addition to the physiatrist. Programs were patient tailored and therefore very different. However, occupational and physical therapy were the most important disciplines, focusing on education, enhancing fitness and participation in daily and social activities by training, and teaching compensation strategies. If necessary,
Characteristics Participants (n= 111)	
Demographics	
Gender (% men) 69.4	
Mean age, ^a years (SD) 57.2 (10.7)	
Current marital status (% married/living together) 82.0	
Education ^b (% lower) 63.1	
Paid job before condition (%)	
Yes 61.3	
No, because of	
Housekeeping 1.8	
Retirement 25.2	
Health problems 9.0	
Other 2.7	
Stroke characteristics	
Median time since stroke, ^a months (IOR) 3.4 (2.4–4.6)	
Stroke type (% infarction) 80.2	
Stroke hemisphere (% left) 47.7	
Activities and subjective complaints ^{cd} (scores)	
USER physical (0–70) 67.0 (59.8–70.0)	
USER cognitive (0–50) 46.0 (39.0–50.0)	
USER pain (0–100) 0.0 (0.0–20.0)	
USER fatigue (0–100) 30.0 (17.5–50.0)	
USER mood (0–100) 8.8 (0.0–18.1)	

 Table 7.1
 Participants' characteristics at the time of the study

Note: IQR = interquartile range; USER = Utrecht Scale for Evaluation of Rehabilitation.

^a At the start of the outpatient rehabilitation program.

^b At least high school.

^c High scores indicate high independence or many subjective complaints.

^d At the end of the rehabilitation program.

additional psychology, cognitive training, and/or speech therapy were included in the program. Treatment was given both individually and in groups.

Procedure

All participants signed informed consent, and the study protocol was approved by the Medical Ethics Board of De Hoogstraat Rehabilitation. Data on activity limitations were collected at discharge from the multidisciplinary outpatient rehabilitation program using USER-Activities, and data on participation were collected 4 months after discharge using USER-Participation. Additional data on demographics and stroke characteristics were collected from the medical charts.

Measures

USER-Participation

The USER-Participation is a self-report measure consisting of 31 items and measuring 3 aspects of participation: (1) frequency of behaviors, (2) experienced participation restrictions due to health condition, and (3) satisfaction with participation.²³ The Frequency scale consists of 12 items on frequency of vocational activity in the last week (4 items) and leisure and social activity in the last 4 weeks (8 items), for example, "How many hours per week do you spend on household duties?" and "How often have you undertaken sports or other physical exercise in the last 4 weeks?" Each item is scored from 0 (not at all) to 5 (36 hours or more/19 times or more). The Restrictions scale contains 10 items asking for experienced participation restrictions because of the health condition, for example, "Does your illness or condition currently limit your daily life concerning household duties?" Each item score ranges from 0 (not possible at all) to 3 (no difficulty at all). A "not applicable" option is available for every item and can be used if the item is not relevant to the person or if experienced restrictions are not related to the person's health status or disability. The Satisfaction scale consists of 9 items asking for satisfaction with various domains of participation, for example, "How satisfied are you with your current daily life concerning work, education, or household duties?" Items are rated on a scale from 0 (not satisfied at all) to 4 (very satisfied). A "not applicable" option is available for the items on vocational activities and partnership relations. The sum scores for the Frequency, Restrictions, and Satisfaction scales are based on the items that are applicable, and each sum score is converted to a score on a scale ranging from 0 to 100. Higher scores indicate good levels of participation (higher frequency, less restrictions, higher satisfaction). The USER-Participation showed generally good reproducibility (intraclass correlation [ICC], 0.65–0.85).²⁴ Concurrent validity was shown by strong Spearman correlations between the USER-Participation Frequency scale with the Frenchay Activities Index²⁵ (0.59), the USER-Participation Restrictions scale with the Participation subtotal score of the ICF Measure for Participation and Activities Screener²⁶ (0.75), and the USER-Participation Satisfaction scale with the Participation Scale²⁷ (0.73), good discriminant validity,²³ and moderate responsiveness (standardized response mean, 0.2-0.5).²² Cronbach's alpha of the USER-Participation in the current study was 0.73 for the Frequency scale, 0.93 for the Restrictions scale, and 0.89 for the Satisfaction scale.

USER-Activities

Physical and cognitive independence and subjective complaints were assessed by USER-Activities,²⁸ which was evaluated by trained research assistants. The Physical Independence scale (range, 0–70) consists of 14 items on mobility (eg, sitting, transfers, wheelchair mobility) and self-care (eg, grooming, toileting, urinary incontinence). The Cognitive Independence scale (range, 0–50) consists of 10 items on communication (eg, expressing), applied cognition (eg, visual perception, task execution), and behavior (eg, behavior control). Items are scored on a 6-point scale from 0 (< 50% independent) to 5 (independent without difficulty and without using aids or adaptations), with higher scores reflecting more independence. Subjective complaints consist of pain (1 item), fatigue (1 item), and mood (4 items: depressed mood, grief, anxiety, and anger), all rated on a scale from 0 (not at all) to 100 (worst/most imaginable), with higher scores reflecting more subjective complaints. USER-Activities is a reliable measure (ICC range, 0.79-0.97), and the Physical Independence and Cognitive Independence scales showed very high correlations with the BI and FIM (range, 0.84-0.94).²⁸ Cronbach's alpha of the USER-Activities in the current study was 0.88 for the Physical Independence scale, 0.83 for the Cognitive Independence scale, and 0.81 for the Mood scale.

Statistical analyses

To quantify the presence of persisting restrictions and dissatisfaction in different domains of participation, we dichotomized the item scores of the USER-Participation Restrictions and Satisfaction scales. For the Restrictions scale, "with assistance," "with difficulty," and "not possible" were defined as "restrictions" and "without difficulty" and "not applicable" were defined as "no restrictions." For the Satisfaction scale, "very dissatisfied," "dissatisfied," and "neutral" were defined as "dissatisfaction," and "satisfied" and "very satisfied" were defined as "satisfaction."

Spearman correlations were computed to determine relationships between the 3 USER-Participation scales and between potential determinants and participation. Potential determinants were gender, age, marital status (dichotomous), level of education (6 categories), time since stroke (continuous), type of stroke (dichotomous), hemisphere (dichotomous), and the 5 USER-Activities scales (continuous). A check on possible collinearity was performed by analyzing Spearman correlations between all determinants, but none of these showed a correlation coefficient of 0.8 or higher with each other. Potential determinants that showed a p-value below .2 in the bivariate correlation analyses were included as independent variables in the regression analyses. This limited the number of variables for inclusion and so satisfied the rule of thumb of a minimum 10 subjects per variable. Analyses were performed using SPSS version 16.0 (SPSS, Inc, Chicago, Illinois). Determinants and outcome variables are displayed in Figure 7.1.



Figure 7.1 Determinants and outcome variables.

Results

The 3 scales of the USER-Participation showed weak to moderate correlations, from 0.33 between the Frequency and Restrictions scales to 0.53 between the Restrictions and Satisfaction scales.

Frequency of participation

The mean Frequency scale score was 26.1 (SD 10.7). Over 60% of the participants worked prestroke, but only half (48.5%) of them returned to paid work post stroke. Participants who did have paid work post stroke mostly worked 9 to 16 hours a week, and only 5 participants worked 36 hours a week or more. Almost 25% had unpaid work, and 87.3% did housekeeping for mostly 1 to 16 hours a week. Leisure and social activities that were performed twice a week or more included telephone/computer contact (52.3%), leisure activities indoors (48.7%), physical exercise (41.3%), visits to family or friends (35.2%), visits from family or friends (26.6%), chores in/around the house (23.9%), outdoor activities (14.7%), and going out (2.7%).

Persisting restrictions in and dissatisfaction with participation

The mean Restrictions scale score was 78.7 (SD 21.6). The most common perceived persisting restrictions concerned physical exercise (50.0%), chores in/around the house (49.1%), housekeeping (44.5%), and outdoor activities (40.9%). Less than 20% reported visits from family or friends and telephone/computer contact as persisting restrictions (both 18.2%) (Table 7.2). The mean Satisfaction scale score was 71.7 (SD 17.8). Most dissatisfaction was expressed regarding cognition (41.7%) and outdoor activities (41.1%). A minority of the participants reported dissatisfaction with their partner relationships, family relationships, and contacts with friends and acquaintances (14.5%, 16.8%, and 18.7% respectively) (Table 7.2).

Influence of activities on participation

Bivariate testing showed significant correlations between the USER-Activities scales Physical and Cognitive Independence and all USER-Participation scales (Table 7.3). Patient characteristics showed significant bivariate correlations with the Frequency scale (objective perspective), whereas stroke characteristics, physical and cognitive

Restrictions scale	Persisting problems
Work/education	32.7
Housekeeping	44.5
Physical exercise	50.0
Going out	31.8
Outdoor activities	40.9
Chores in/around house	49.1
Leisure indoors	34.9
Visits to family or friends	28.2
Visits from family or friends	18.2
Telephone/computer contact	18.2
Satisfaction scale	Dissatisfaction ^a
Self-care	21.3
Mobility	32.4
Cognition	41.7
Work/housekeeping	36.4 ^b
Outdoor	41.1
Leisure indoors	28.0
Partner relationship	14.5 ^c
Family relationships	16.8
Friends and acquaintances	18.7

Table 7.2 Persisting participation problems for the USER-Participation Restrictions and Satisfaction scale items using dichotomized item scores (in %)

Note: USER = Utrecht Scale for Evaluation of Rehabilitation.

^a Did not include the answer option "not applicable."

^b Not applicable for 19.6% of the participants.

^c Not applicable for 13.1% of the participants.

independence, and subjective complaints showed significant bivariate correlations with the Restrictions and Satisfaction scales (subjective perspective). Multivariate testing showed that higher physical and cognitive independence were significant predictors for higher scores on all USER-Participation scales. For the Frequency scale (objective perspective), lower age, higher education, and higher physical and cognitive independence were independent determinants of better participation, explaining 21% of the variance. For the Restrictions scale (subjective perspective), higher physical and cognitive independence and less fatigue were independent determinants of better participation, together explaining 31% of the variance. For the Satisfaction scale (subjective perspective), a shorter time since stroke, higher physical and cognitive independence, and less mood problems were determinants of better participation, explaining 30% of the variance (Table 7.3).

	Frequency of pai	rticipation	Participation res	trictions	Satisfaction with	participation
Characteristics	Bivariate (Spearman's p)	Multivariate (standardized β)	Bivariate (Spearman's ρ)	Multivariate (standardized β)	Bivariate (Spearman's p)	Multivariate (standardized β)
Determinants						
Gender (1= man, 2= woman)	0.21**	NS	-0.10		-0.02	
Age	-0.23**	-0.27***	0.04		0.14*	NS
Marital status (1= married/living together, 2= living alone)	0.02	I	-0.09	I	-0.03	
Education	0.30***	0.21**	0.03		0.07	
Stroke characteristics						
Time since stroke	-0.05	1	-0.43***	NS	-0.41***	-0.19**
Type of stroke (1= hemorrhage, 2= infarction)	0.02		0.08		0.14*	NS
Hemisphere (1= left/both sides, 2= right)	0.16*	NS	0.04		0.16*	NS
Activities and subjective complaints						
USER physical	0.31***	0.19**	0.45***	0.40***	0.43***	0.20**
USER cognitive	0.22**	0.20**	0.31***	0.21**	0.48***	0.25**
USER pain	-0.04		-0.22**	NS	-0.18*	NS
USER fatigue	-0.03		-0.39***	-0.20**	-0.35***	NS
USER mood	-0.13*	NS	-0.27***	NS	-0.45***	-0.19*
Note: High USER-Participation scores indicate high and cognitive independence or many subjective c *p<.20.**pc.05.***pc.01. Dash indicates that de	levels of participa complaints. NS = n eterminant is not ii	tion (high frequency ot significant; USER ncluded in regressio	/, few restrictions, = Utrecht Scale fo m analysis.	nigh satisfaction). Hi r Evaluation of Reha	gh USER scores ind Ibilitation.	licate high physical

 Table 7.3
 Univariate and multivariate analysis of the USER-Participation scales

Discussion and conclusion

This study shows that almost 1 out of 2 stroke survivors experience participation problems in physical exercise, household tasks, and outdoor activities 1 year post stroke, and 1 out of 3 stroke survivors are dissatisfied about their cognition, outdoor activities, and work/ housekeeping. About half of the prestroke working participants did not return to work post stroke, and the participants returning to work mostly worked only 1 to 16 hours a week.

The score of the Frequency scale is much lower than the scores of the Restrictions and Satisfaction scales. However, these are ordinal scales; therefore, it is not possible to compare these scores straightforwardly. Furthermore, although the maximum score for all 3 scales is 100, it is not possible to score a maximum of 100 on the Frequency scale, whereas it is possible to score 100 on the Restrictions and Satisfaction scales. The percentages of participants who experienced persisting restrictions were generally higher than the percentages who experienced persisting dissatisfaction, indicating that part of this group of participants showed an adaptation to their condition.

Both the small to moderate correlations between the 3 USER-Participation scales and the regression analyses support the difference between objective and subjective participation. Objective participation, as measured by the Frequency scale, is determined by physical and cognitive independence, age, and education, whereas subjective participation, as measured by the Restrictions and Satisfaction scales, is determined by physical and cognitive independence and subjective complaints. This apparent contradiction might be due to adaptation, also called response shift.²⁹

Previous research showed that the proportion of people returning to work after a vocational rehabilitation program ranged from 12% to 49%.³⁰ We found a similar return-to-work rate of 48.5%. The number of patients who perform domestic chores in another 1-year poststroke population (range, 37.3–63.7%)³¹ is comparable to our results for housekeeping and doing chores in/around the house. Furthermore, our result of 61.4% of participants barely doing outdoor activities is similar to the percentage of participants performing outdoor activities in that study (range, 26.8–75.3%). This low frequency of leisure activities is supported by a review on the social consequences of stroke for working-age adults.³² Satisfaction with partner relations and family life was high and similar to figures found in a 3-year poststroke population measured by the Life Satisfaction Questionnaire.³³ Using the same measure, Laurent et al³⁴ also found high scores for partner relationship and family life, and they found that the score for partner

relationship did not differ between chronic stroke patients and healthy controls. We found a relationship between level of physical and cognitive independence and satisfaction with leisure, and a similar relationship was found by Boosman et al.³³

Physical and cognitive independence were significant predictors of all types of participation. Pain was not related to any participation score, fatigue was only related to participation restrictions, and mood was only related to satisfaction with participation. Apparently, fatigue and mood do not influence the frequency of participation, although they do influence the subjective experience of participation restrictions and satisfaction. We found 21% explained variance for the Frequency scale (by the determinants age, education, and physical and cognitive independence), 31% explained variance for the Restrictions scale (by the determinants physical and cognitive independence and fatigue), and 30% explained variance for the Satisfaction scale (by the determinants time since stroke and physical and cognitive independence). Several recent studies showed a higher explained variance on participation, ranging from 37% up to 71%.¹⁴⁻¹⁹ In these studies, however, different determinants were analyzed. Other factors, for example, social support, personality characteristics, and environmental factors, have been predictors of participation, but these were not measured in our study. Moreover, the composition of the study population might be of crucial importance. We selected stroke patients without serious cognitive problems because we used self-report measures, and the majority of participants were independent in basic activities of daily living.

The multivariate regression analyses revealed that a longer time since stroke was related to lower satisfaction with participation. Apparently, at least some patients with chronic stroke have not adapted well to their situation.

Clinical message

This study showed that being independent in basic activities of daily living is no guarantee of participation without problems in the chronic phase of stroke. Rehabilitation services are prominent in the first year after stroke, and most stroke patients do not visit health care professionals in the chronic phase.³⁵ This study encourages a structured follow-up program in the chronic phase of stroke and not only in the acute and subacute phases. It is important to identify the factors that contribute to those persisting restrictions and dissatisfaction, so that these can be addressed during the rehabilitation program and in a structured follow-up program for chronic stroke patients.

Furthermore, the regression analyses revealed that objective participation was influenced by physical and cognitive independence, whereas subjective participation was also influenced by fatigue and mood complaints. Therefore, rehabilitation should focus not only on physical and cognitive complaints but also on subjective complaints such as fatigue and mood.³⁶ Environmental factors, for example, the patient's family, should also be taken into account.³⁷

Limitations

One limitation is that the current study was performed on a restricted study population, which hampers generalizability of the results. BI and USER-Activities scores suggest that our study concerned patients with mild problems in basic activities of daily living 1 year post stroke. A high BI score does not mean good physical recovery because the index does not assess the use of compensation strategies;³⁸ someone can be completely hemiplegic but be able to function independently in activities of daily living because of various adaptation strategies. Another limitation is that the USER-Participation we used is a new scale, thus hampering comparisons with other studies. It is also not possible to compare scores with those of a matched healthy population. Without such comparisons, only the Restrictions scale scores have a straightforward interpretation. However, this disadvantage will disappear if more USER-Participation results become available.

A final limitation is that we did not collect information on psychological and environmental determinants of participation. As a result, the amount of explained variance of participation was lower than in other studies. However, it was our goal to analyze relationships between physical and cognitive independence and subjective complaints with participation.

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Chapter 7 | Participation after stroke



General discussion



We developed the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) to fulfil the need for a generic measurement instrument to assess outcomes of outpatient rehabilitation programmes. The USER-Participation is unique in its concise assessment of three different aspects of participation, thereby measuring both objective and subjective participation.

The general aim of this thesis was to evaluate the validity, reproducibility, and responsiveness of this new participation instrument. This last chapter includes a summary of the main results, a discussion of our findings in relation to psychometric properties of other participation instruments, a discussion of the general challenges in measuring participation, methodological considerations, implications for clinical practice, and directions for future research.

Main results

Summarising the main results on the USER-Participation we can conclude that it has generally satisfactory psychometric properties so that it can be used to measure participation in adult outpatient rehabilitation samples. The three scales (Frequency, Restrictions, and Satisfaction) measure different aspects of participation and construct validity was confirmed for all three scales (**Chapter 3** and **Chapter 6**). Furthermore, all three scales were sensitive to detect score differences between patients with different levels of independency and between persons with lumbar/ thoracic and cervical spinal cord injury (**Chapter 3** and **Chapter 6**). Reproducibility was good for all three scales at group level, but not sufficient at individual level (**Chapter 2**). Internal consistency (**Chapter 3** and **Chapter 6**) and test-retest reliability (**Chapter 2**) were good for the Restriction and Satisfaction scales, but insufficient for the Frequency scale. Responsiveness was small to moderate in two different outpatient rehabilitation samples (**Chapter 4** and **Chapter 5**). Furthermore the USER-Participation showed its applicability in clinical practice (**Chapter 7**) by detecting persisting participation restrictions and dissatisfaction in the chronic phase of stroke.

Our findings in relation to other participation measures

The Frequency scale of the USER-Participation showed small responsiveness figures during an outpatient rehabilitation programme in our heterogeneous sample. However, all instruments showed small responsiveness figures, except for the Restriction scale of the USER-Participation. The Frenchay Activities Index (FAI),¹ the other objective participation instrument assessed in this thesis, showed somewhat higher responsiveness figures than the Frequency scale. Comparing responsiveness across different diagnostic groups, the FAI¹ showed more favourable results for the neuromuscular and heart condition groups as compared to the Frequency scale. For all other diagnosis groups, outcomes on responsiveness are comparable between the FAI¹ and the Frequency scale (**Chapter 4**).

The Restriction scale of the USER-Participation showed similar reproducibility figures (**Chapter 2**) and better responsiveness figures (**Chapter 4**) as compared to the ICF Measure of Participation and Activities Screener (IMPACT-S)² and the Participation Scale.³ Furthermore, the reliability of the Restrictions scale was similar to the reproducibility of the IMPACT-S² and the Dutch version of Life-Habits⁴ (**Chapter 2**), which are both also instruments of perceived participation restrictions. The responsiveness of the Participation Measure for Post-Acute Care⁵ showed higher responsiveness values than the Restrictions scale (**Chapter 4**). Additionally, internal consistency and discriminant validity for the Restriction scale were similar to those of the IMPACT-S² and the total disability index of the WHO Disability Assessment Scale (WHODAS II)⁶ (**Chapter 6**). Discriminant validity was confirmed for the Restrictions scale, while this was not confirmed for the IMPACT-S² and the WHODAS II⁶ (**Chapter 6**).

The Satisfaction scale of the USER-Participation showed good test-retest reliability, and the intraclass correlation coefficient (ICC) value was similar to the ICC of the Personal Wellbeing Index,⁷ which is also an instrument of satisfaction with different life domains (**Chapter 2**). **Chapter 5** showed that satisfaction with participation as measured with the Satisfaction scale is highly similar to the concept of autonomy in participation as measured with the Impact on Participation and Autonomy (IPA).⁸ Responsiveness of the Satisfaction scale was to some extent better than the responsiveness of the IPA⁸ (**Chapter 5**).

The psychometric properties of the USER-Participation were generally satisfying and those of the Restrictions and Satisfaction scales were better than those of the Frequency scale. The Frequency scale showed less favourable internal consistency, test-retest reliability, and responsiveness than the two other scales. However, we do not recommend to remove the Frequency scale from the USER-Participation since it contributes to content validity. Assessing the frequency of participation is important to gain insight in someone's participation pattern. Low correlation coefficients between the three scales showed that the scales measure different aspects of participation and a profile of multiple scores is therefore

necessary to get a clearer perception of such a complex phenomenon as participation. An alternative way to measure the frequency of participation would be to observe participants in their daily life, but that is a very labour-intensive method. Self-report of the frequency of participation might also become more reliable if participants would record their behaviours on a daily or weekly basis, for example by keeping a diary. This is however also labour intensive and at risk of attrition.⁹ Modern technology enables continuous monitoring of activities by use of accelerometers or GPS-tracking. However, these instruments only give information on the amount of activity. No information can be obtained about whether or not this activity concerns participation. GPS-tracking in combination with a diary might provide a valid and detailed measurement of the frequency of participation and provide a criterion standard to judge the validity of self-report instruments.¹⁰

There are however indications that the less favourable psychometric figures of the Frequency scale are not due to a poorly developed scale, but might be unavoidable. First of all, internal consistency is less relevant when items reflect different aspects of a complex clinical phenomenon that do not have to correlate with each other.¹¹ This applies to the Frequency scale, since one cannot fully participate in all domains given the boundaries of a 24-hour day. The validation study of the Participation Objective, Participation Subjective (POPS)¹² showed that within-scale correlation coefficients for both the overall objective scale and the objective subscales were close to zero or even negative. They claim this is because of the disparate nature of the items. Moreover, alpha values were not even calculated at all for the same reason in two recent validation studies.^{13,14} Alpha values for the FAI¹ were only marginally adequate.¹⁵

Second, leisure and social items are probably not done on a regular two-week base and are more variable. Therefore these items are less likely to be answered similarly with a two-week interval, causing the less favourable results for the test-retest reliability of the Frequency scale. Lower ICC values of objective scores as compared to subjective scores were also found for the POPS.¹² However, test-retest reliability was variable¹⁵ for the Craig Hospital Assessment and Reporting Technique,¹⁶ which is another instrument for objective participation. The FAI¹ showed average outcomes,¹⁵ but a recent study found a large smallest real difference value and this instrument has a much longer time frame of 3 to 6 months, limiting its use as a rehabilitation outcome measure.¹⁷

Third, low responsiveness values for the Frequency scale might be due to the fact that the follow-up time was 3 to 4 months. It might even take longer to increase vocational activities. Furthermore, shifts in participation pattern, for example a return to paid work

with a corresponding decrease of leisure time activity, cannot be detected by the total scale score. Inspection of changes on individual items will be useful to detect subtle changes in participation. Finally, the use of different methods to calculate responsiveness hampers a clear and extensive comparisons with other objective participation instruments.

The great advantage of the USER-Participation is that it measures several aspects of participation, thereby assessing both the objective and subjective perspective. Hardly any other measurement instruments to assess both objective and subjective participation exist. One is the POPS.¹² The POPS¹² assesses subjective participation by asking for the satisfaction with the current level of participation and by asking for importance of this participation to the patient's well-being and satisfaction. However, the POPS¹² was only validated in traumatic brain injury and is no longer under development (personal communication M. Dijkers). Based on this POPS,¹² that same research team developed the Participation Assessment of Recombined Tools-Objective and Subjective (PART-O/S).^{18,19} However, the PART-S¹⁸ never passed the validation stage, and therefore the PART-O¹⁹ remains objectively only.

General challenges in measuring participation

When choosing a measurement instrument to assess participation, not only psychometric properties should be taken into account. Both conceptualisation and operationalisation are important. The lack of a clear conceptualisation of participation by the International Classification of Functioning, Disability and Health (ICF) hampers the measurement of participation. Each researcher needs to decide how to distinguish Activities from Participation and which chapters of the component Activities and Participation of the ICF should be represented when developing a participation instrument or choosing from the large number of available instruments. Therefore it is possible that participation instruments differ on the chapters that they cover. Thus, even though on the surface, by using a "participation measurement instrument", we all seem to measure the same construct, we actually are not. This is endorsed by the results on construct validity in the SCI study (Chapter 6). Some correlation coefficients between the scales of the USER-Participation and the domains of the WHODAS II⁶ were lower than expected even though both instruments were developed using the same framework. Operationalisation determines which kind of information is obtained by the measurement instrument, and the research question decides which instrument to use.

Since participation depends on many variables, including culture and one's position in society, it is very hard to define 'normal' participation.²⁰ However, normative data for different diagnostic groups and the general population could be helpful to facilitate the interpretation of the results. For the USER-Participation, this mainly applies to the Frequency and Satisfaction scales. For the Restrictions scale, general population norms seem less relevant, since the items in this scale assess experienced restrictions due to the health condition. We would expect that the majority of the general population would not experience participation restrictions and therefore the scores would show a very skewed distribution in the general population and be uniform and maximal in persons without health conditions.

Furthermore, USER-Participation scores are of ordinal measurement level. Even though all scales have a score range of 0–100, a score of 50 cannot be interpreted as 50% participation, and a score of 50 on one scale has not the same meaning as a score of 50 on another scale. For the Frequency scale, to obtain the maximum score of 100 someone should participate fully in all participation domains (i.e. 36 hours a week or more, or more than 19 times in four weeks). This is not possible since a day is limited to 24 hours. Besides, more participation is not always better; an adequate frequency of participation depends on culture and one's position in society, and also on the person's own preferences to maintain a balance between load and capacity. This is different for everyone, for example patients with chronic pain often strain their body too much. In order to restore the balance between load and capacity, these patients are encouraged to decrease the frequency of participation.

Participation is also influenced by environmental factors. These factors make up the physical, social, and attitudinal environment in which people live and conduct their lives.²¹ The environment can either facilitate or barrier participation and can not be directly influenced by the rehabilitation team. However, the rehabilitation team can guide and advice on the use suitable aids or a wheelchair, thereby neutralising barriers and facilitating participation.

Methodological considerations

We wanted to develop a generic participation measurement instrument, which is suitable across different diagnostic groups. Participation is however influenced by age, gender, and culture. For example, not everyone wishes to do grocery shopping, when the alternative is spending this time with grandchildren. Moreover, if someone can barely participate in sports, but is satisfied with this, should the rehabilitation programme really attempt this goal? With this in mind, we developed the USER-Participation; to assess not only someone's participation pattern, but also to assess how someone values this pattern. In order to make sure that the items address everybody, we gave some different examples in every domain of participation. We hoped that people were capable of recognising their own participation behaviour in these examples, which more or less personalised the USER-Participation.

Even though this study has some considerable strengths, there are also some limitations. First, this study was performed in the outpatient rehabilitation setting in the Netherlands. Therefore it is not possible to generalise these results to other settings (like geriatrics or mentally disabled patients) or to other countries. We translated the USER-Participation into English, with a decent back-translation. However this version has not been validated yet.

Second, our study sample did not included patients with severe cognitive limitations. Validation of an instrument needs a starting point and since the USER-Participation is a self-report questionnaire, this was a logical first step to start with. From here it is possible to adapt the instrument for patients with, for example, aphasia or more severe cognitive limitations, or to develop a version for report by proxies.

Third, in our calculations on responsiveness, we could have used an anchor, or external criterion, to measure the magnitude of change.²² This is done by the patient's global rating, by just one simple question, like 'do you feel that your participation has changed due to the rehabilitation programme?'. The use of such a question enables the definition of the minimum amount of change that is important to the patient. However, we feel that the use of such a question is problematic. First of all, the concept of participation is not unambiguous. When professionals have troubles with conceptualising participation, how can we expect patients to have a common understanding of this concept. Second, participation takes place in many different domains, so that the responses by patients on a single question are unlikely to be comparable. Also, the major part of our patients are very satisfied with the care the rehabilitation team provides.²³ There is a major chance that patients not rate their change in participation but their satisfaction with the rehabilitation team. Finally, this question requires that the patient compares the level of participation before and after the rehabilitation programme and this can lead to recall bias,²⁴ which means that the level of participation before the start of the rehabilitation programme is influenced by the memory of the patient.

Implications for clinical practice

With the assessment of frequency of behaviour, experienced participation restrictions and satisfaction with participation, the USER-Participation is suitable to use as guide in the physiatrist's consult. On the one hand, it is useful to get insight in someone's participation pattern. On the other hand, it is even more relevant to know whether the patient experiences restrictions and is satisfied with his/ her participation. For example, if a patient does not participate or does not experience restrictions in a certain domain but is satisfied with this, it would not be necessary to make this a goal of the rehabilitation programme.

It should be noted that all psychometric properties reported in this thesis were determined at the group level. The results on reproducibility show that results on group level are satisfying but large standard deviations reflect great variation between individual patients. Large differences on scores are therefore necessary to exceed change. It should therefore be kept in mind when using the USER-Participation at individual level that score changes can be due to error variation instead of change.

Furthermore, at the individual level the use of separate items scores might be more relevant than the use of the scale scores, since the scale score is the sum score of all separate items in that scale and therefore shifts in participation pattern can not be detected by the scale scores.

Responsiveness is the most important property for an outcome measure and these figures were least conclusive. However, figures of the USER-Participation were better than these of the other participation instruments included in this thesis and similar to responsiveness figures of other participation instruments available in the literature. The weak to moderate responsiveness figures in **Chapter 4** and **Chapter 5** might either show that standardised participation instruments are less powerful to measure change after rehabilitation, or that at best moderate improvement in participation can be expected for those who follow an outpatient rehabilitation programme. With respect to both options, ideally an individualised instrument, such as the Canadian Occupational Performance Measure (COPM)²⁵ or Goal Attainment Scaling (GAS)²⁶ should be used together with a standardised outcome measure such as the USER-Participation. This way it is possible to measure both the accomplishment of individual goals and the effects of the rehabilitation programme at group level.

Responsiveness improved when we separated the different diagnostic groups (**Chapter 4** and **Chapter 5**). However, we saw that not every diagnostic group showed the same

outcomes. Most diagnostic groups showed an improvement on the Restriction scale, except for the chronic pain group which showed improvement on the Satisfaction scale. This might be due to the goals in this group. Often these patients are encouraged to decrease their frequency in participation in order to restore the balance between capacity and load. This is a nice illustration of the value of measuring three different aspects of participation.

It might be useful to also assess the environment,²⁷ since this can hamper participation as well. Our understanding of the complex interrelationships between environmental factors and participation is still limited, and further research in this area is necessary. This could be helpful in identifying where the patient should be supported by the rehabilitation team with aids.

To measure outcomes of rehabilitation, it is necessary for every patient to complete the USER-Participation both at the start and the end of the programme. Structurally implementing the USER-Participation into daily practice demands some changes in the present rehabilitation process and support of the ICT department. Decisions should be made on when and where the patient should complete the USER-Participation. Furthermore, when the USER-Participation is used to monitor progress during rehabilitation to help guiding the rehabilitation process, it is also necessary to complete it at regular moments during the programme. This way either the goals or the process can be adjusted using the scores as feedback.

If patients complete the USER-Participation digitally before the first consultation with the physiatrist, either at home or in the waiting room, the results of the USER-Participation can be processed immediately so that these are available for review at the consult. This way the USER-Participation can also be used for goal setting. If the USER-Participation is completed again at the end of the outpatient rehabilitation programme, the results can be compared and discussed between doctor and patient to reflect on the process and outcomes. Scores should be graphically supported to facilitate interpretation by patients.

It is noteworthy that to date the USER-Participation is being implemented in several rehabilitation centres, and in all outpatient rehabilitation teams in De Hoogstraat Rehabilitation and is used by the neurorehabilitation team in the outpatient clinic of the University Medical Center Utrecht. Moreover, geriatric institutions and hospitals are also interested in a valid measurement instrument to assess participation.

Directions for future research

As discussed earlier in this chapter, participation is a difficult to measure construct and without a clear definition it remains a difficult to measure construct. Whiteneck and Dijkers²⁷ give their elaborated opinion on how to distinguish Activities from Participation. In the development of the USER-Participation we made almost, but not completely, the same separation. With this thesis we hope to contribute to, and influence the discussion on the conceptualisation of participation.

Since participation depends on many variables, it is very hard both to develop a generic measurement instrument and to define 'normal' participation. Advanced techniques like computer adaptive testing could help to effectively and generically measure participation in a way being appropriate with respect to age, gender, and culture. Furthermore additional data should be collected in both different diagnostic groups as well as in the able-bodied population in order to facilitate the interpretation of the scores on all three scales. It might be useful to also assess the environment,²⁷ since this can hamper participation as well. In order to enhance our understanding of the complex interrelationships between environmental factors and participation further research in this area is necessary.

Furthermore, it would be very useful to compare the USER-Participation to outcomes which focus on the individual goals of a patient, like for example the COPM²⁵ and GAS²⁶ to enlighten the additional value of both approaches for research purposes. In addition more knowledge about minimal important changes and clinical relevant differences of the USER-Participation needs to be obtained in order to make this measure suitable for evaluation of the effectiveness of the rehabilitation programme at the individual level.

The moderate responsiveness figures raise the question whether participation only is the most suitable outcome in measuring the effects of outpatient rehabilitation programmes. It might be possible that the patient's perspective on the disease or conditions changes or that the patient's adapts to the health condition by the use of compensation strategies. Moreover, it even might be possible that the rehabilitation programmes has goals on the level of activities in order to facilitate participation. Actual participation needs to be implemented in daily living by the patient him/ herself. It is extremely important that an outcome indicator measures the right concept, since these outcome indicators reflect the performance of the rehabilitation practice. Moreover, when comparing rehabilitation centres it is very important to keep in mind that the target population is of great importance in measuring effects.

Additional validation of the USER-Participation in samples with different health conditions, for example different diagnostic groups in the field of rehabilitation, geriatrics, oncology, etc., is necessary to provide information of the suitability of the USER-Participation in that specific population. Furthermore, the USER-Participation should be adapted to patients with aphasia, should be validated in the use of proxy report, and should be translated into the languages of the major ethnic minorities in the Netherlands. In this manner, the USER-Participation is not restricted to the Dutch-speaking rehabilitation population without or with mild cognitive and aphasic problems.

Finally, the use of Rasch analysis would benefit the item scoring. Rasch analysis is a powerful way to graphically show whether respondents are able to distinguish between answer options. Right now, for the Restrictions scale we rated the response option *'with assistance*' as more restricted as the response option *'with difficulty*'. Rasch analysis could give us more insight into whether or not respondents can separate these different response options. This information can lead appropriate item scoring, and this improves the psychometric properties of the USER-Participation. Since Rasch analysis is only applicable to unidimensional concepts, the Restrictions and Satisfaction scales might benefit most from this approach.

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Chapter 8 General discussion



Summary

We developed the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) to fulfil the need for a generic measurement instrument to assess outcomes of outpatient rehabilitation programmes. In **Chapter 3** we described the development of the USER-Participation and assessed its validity in a heterogeneous sample of outpatient rehabilitation patients. In **Chapter 6** we did the same in a sample of persons with spinal cord injury (SCI). Spearman correlation coefficients between the three USER-Participation scales were in both studies low to moderate (maximum 0.52), indicating that these scales measure different aspects of participation and thereby provide complementary information.

Internal consistency in terms of Chronbach's alpha showed satisfactory figures, except for the Frequency scale. Factor analysis in the heterogeneous sample showed for the Frequency scale a four-factor solution, with one strong factor and three weak factors. For both the Restrictions and Satisfaction scales, the factor analyses showed one strong first factor explaining more than 50% of the variance and a weak second factor. All items on vocational activities and most items on leisure activities loaded on the first factor, and the items on social activities loaded on the second factor. Unfortunately, the SCI sample was too small to perform factor analysis.

Construct validity was shown in both studies by an expected pattern of high correlation coefficients between the USER-Participation scales and those (sub)scales of other measurement instruments. The Frequency scale showed high correlation coefficients with the measurement instrument assessing objective participation, and the Restrictions and Satisfaction scales showed high correlation coefficients with other subjective participation instruments.

Results on discriminant validity of the USER-Participation were good; all three scales were able to discriminate between patients with different levels of independency in the heterogeneous sample, and between persons with lumbar/ thoracic lesions and cervical lesions in the SCI sample.

The reproducibility of the USER-Participation was assessed in the heterogeneous sample in **Chapter 2**, with generally satisfactory results. Intraclass correlations coefficients (ICCs) were good for the Restrictions and Satisfaction scales, and close to satisfactory for the Frequency scale. Results for the Restrictions and Satisfaction scales of USER-Participation were similar to those of the ICF Measure of Participation and Activities Screener (IMPACT-S) and the Participation Scale. The standard error of measurement and the smallest detectable change related to the standard deviation (SDC/SD ratio) at group level were good for all three USER-Participation scales. However, the SDC/SD ratio was not satisfactory at the individual level, which means that at the individual level large score differences are necessary to exceed chance. The reproducibility of the USER-Participation scales was comparable to that of the IMPACT-S and Participation Scale.

Responsiveness figures of the USER-Participation were presented in Chapter 4 for our heterogeneous sample and in Chapter 5 in a different sample, mainly consisting of persons with brain injury or neuromuscular disease, recruited from the outpatient clinic of the University Medical Center Utrecht (UMCU). Changes of USER-Participation scores between start and completion outpatient rehabilitation were moderate. However, compared to the Frenchay Activities Index (FAI), the IMPACT-S and the Participation Scale, the USER-Participation Restrictions scale showed similar responsiveness, the USER-Participation Satisfaction scale showed higher responsiveness figures, and the USER-Participation Frequency scale showed less responsiveness than these other measurement instruments. Unravelling these responsiveness outcomes for the different diagnostic groups, we saw major differences between these groups. Chapter 5 showed smaller responsiveness values for both the USER-Participation and the Impact on Participation and Autonomy (IPA) in the UMCU sample. However, changes in the USER-Participation scores were consistent, with Frequency scores declining and Restrictions and Satisfaction scores inclining over time, whereas the IPA showed domain scores both inclining and declining over time. Furthermore, the high correlation coefficients between the Satisfaction scale of the USER-Participation and the IPA showed that the concept of autonomy in participation is highly correlated with satisfaction in participation.

In **Chapter 7** the USER-Participation showed its applicability as a measure of participation in the persons with stroke from our heterogeneous sample. Even though most participants showed relatively good physical recovery, most experienced participation problems. Summary



Samenvatting

Het wordt steeds belangrijker voor revalidatie-instellingen en behandelaars om het effect van de revalidatiebehandeling inzichtelijk te maken voor consumenten, verzekeraars en de overheid. Een vragenlijst is een goede manier om dit te doen. In de poliklinische revalidatie liggen de doelen vaak op het niveau van maatschappelijke participatie. Wanneer je het effect van de revalidatiebehandeling in kaart wil brengen, is het nodig om een participatievragenlijst af te nemen aan het begin en het einde van de revalidatiebehandeling. Een vragenlijst voor participatie moet zo beknopt mogelijk en goed van kwaliteit zijn. Wat wij verder nog belangrijk vonden is dat de vragenlijst zowel objectieve als subjectieve participatie meet. Objectieve participatie gaat over waarneembaar gedrag, bijvoorbeeld het aantal keer in de week dat iemand iets doet. Subjectieve participatie gaat om de beleving van degene die de lijst invult, bijvoorbeeld ervaren beperkingen of tevredenheid. Er zijn een hoop vragenlijsten ontwikkeld om participatie mee te meten, maar er was geen enkele lijst die aan al onze eisen voldeed en daarom hebben wij een nieuwe vragenlijst ontwikkeld; de Utrechtse Schaal voor Evaluatie van Revalidatie-Participatie (USER-Participatie). De USER-Participatie bestaat uit drie schalen voor respectievelijk de frequentie van participatie (Frequentieschaal), ervaren participatiebeperkingen (Beperkingenschaal) en tevredenheid met participatie (Tevredenheidschaal).

Dit proefschrift gaat over de ontwikkeling en de kwaliteit van de USER-Participatie, welke in verschillende deelonderzoeken getest is. In **Hoofdstuk 3** hebben we beschreven hoe wij de USER-Participatie hebben ontwikkeld en hoe we de validiteit daarvan in een heterogene groep poliklinische revalidanten hebben bepaald. In **Hoofdstuk 6** hebben we hetzelfde gedaan in een groep mensen met een dwarslaesie. De samenhang tussen de drie schalen van de USER-Participatie hebben wij gemeten met Spearman correlatiecoëfficiënten. Deze waren in beide studies zwak tot matig (maximaal 0.52), wat aanduidt dat de drie schalen ieder een ander aspect van participatie meten en daarbij aanvullende informatie geven.

De interne consistentie van de drie schalen – uitgedrukt in Cronbach's alfa – was voldoende, behalve voor de Frequentieschaal. Factoranalyse in de heterogene groep laat voor de Frequentieschaal vier factoren zien, met één factor die meer dan 50% van de variantie verklaart en een zwakke tweede factor. Voor zowel de Beperkingen- als de Tevredenheidschaal laat de factoranalyse twee factoren zien, één factor welke meer dan 50% van de variantie verklaart en een zwakke tweede factor. De eerste factor bestaat uit alle items over beroepsmatig functioneren en de meeste items over vrijetijdsbesteding. De tweede factor bestaat uit de items over sociale participatie. De groep mensen met een dwarslaesie was te klein om een factoranalyse uit te kunnen voeren.

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Constructvaliditeit van de USER-Participatie is in beide studies aangetoond door een verwacht patroon van hoge en lage correlatiecoëfficiënten tussen de USER-Participatieschalen en (sub)schalen van andere instrumenten. De Frequentieschaal laat hoge correlatiecoëfficiënten zien met andere objectieve participatie-instrumenten, de Beperkingen- en Tevredenheidschaal laten hoge correlatiecoëfficiënten zien met andere subjectieve participatie-instrumenten.

De resultaten van de discriminante validiteit van de USER-Participatie waren goed; alle drie de schalen waren in staat om onderscheid te maken tussen revalidanten met verschillende niveaus van onafhankelijkheid in de heterogene groep, en tussen mensen met een lumbale/thoracale en cervicale dwarslaesie in de groep mensen met een dwarslaesie.

Reproduceerbaarheid van de USER-Participatie is bepaald in de heterogene groep in Hoofdstuk 2 en is over het geheel genomen voldoende. Intraclasscorrelaties (ICC's) waren goed voor de Beperkingen- en Tevredenheidschaal, en bijna voldoende voor de Frequentieschaal. Resultaten voor de Beperkingen- en Tevredenheidschaal waren vergelijkbaar met die van de ICF Maat voor Participatie en Activiteiten Screener (IMPACT-S) en de Participatie Schaal. De meetfout en de kleinst detecteerbare verandering (buiten de meetfout) gerelateerd aan de standaarddeviatie (SDC/SD ratio) op groepsniveau waren goed voor alle drie de USER-Participatieschalen. Echter, de SDC/SD ratio was niet toereikend op individueel niveau. Dit betekent dat er bij individueel gebruik grote scoreverschillen nodig zijn om te kunnen zeggen dat een bepaald verschil in scores met 95% zekerheid geen toeval kan zijn. De reproduceerbaarheid van de USER-Participatieschalen zijn vergelijkbaar met die van de IMPACT-S en de Participatie Schaal.

Ons onderzoek naar de responsiviteit van de USER-Participatie is gepresenteerd in Hoofdstuk 4 voor onze heterogene revalidatiecentrumgroep en in Hoofdstuk 5 voor een ziekenhuisrevalidatiegroep, voornamelijk bestaande uit mensen met hersenletsel of een neuromusculaire aandoening. Deze revalidanten zijn benaderd via de polikliniek Revalidatiegeneeskunde van het Universitair Medisch Centrum Utrecht. Veranderingen in USER-Participatiescores tussen start en ontslag van de revalidatiecentrumgroep waren over het algemeen matig groot. Wanneer we de responsiviteit echter vergelijken met de Frenchay Activiteiten Index (FAI), de IMPACT-S en de Participatie Schaal, zien we dat de USER-Participatie Beperkingenschaal een vergelijkbare, de USER-Participatie Tevredenheidschaal een grotere, en de USER-Participatie Frequentieschaal een kleinere responsiviteit laat zien. Wanneer deze responsiviteit berekend wordt voor de verschillende diagnosegroepen in de onderzoeksgroep, zien we grote verschillen tussen deze groepen,

Samenvatting

met de grootste scoreverschillen in de groep mensen met hersenletsel. **Hoofdstuk 5** laat een kleinere responsiviteit zien voor zowel de USER-Participatie als de Impact op Participatie en Autonomie (IPA) in de ziekenhuisrevalidatiegroep. Echter, de veranderingen in USER-Participatiescores waren consistent over de tijd, met afnemende Frequentiescores en toenemende Beperkingen- en Tevredenheidscores, terwijl de IPA domeinscores zowel afnemen als toenemen over de tijd. Verder laat de hoge correlatiecoëfficiënt tussen de Tevredenheidschaal en de IPA zien dat het concept van autonomie in participatie in grote mate samenhangt met tevredenheid in participatie.

In **Hoofdstuk** 7 is de bruikbaarheid onderzocht van de USER-Participatie als participatiemeetinstrument bij mensen met een beroerte. Ondanks het feit dat de meeste deelnemers relatief goed fysiek hersteld zijn, ervaren de meesten participatieproblemen, met name op het gebied van sporten of andere lichaamsbeweging, huishoudelijke taken en dagtochtjes en andere activiteiten buitenshuis.

De bevindingen van dit proefschrift worden in **Hoofdstuk 8** samengevat en besproken in de context van literatuur over andere meetinstrumenten. De eindconclusie is dat de kwaliteit van de USER-Participatie voldoende is en daarmee is de USER-Participatie een geschikte vragenlijst om uitkomsten van poliklinische revalidatie te meten. Verder onderzoek is nodig om de kwaliteit van de USER-Participatie in andere diagnosegroepen te bepalen (binnen de revalidatie, maar ook in bijvoorbeeld de oncologie of geriatrie), om de lijst geschikt te maken voor mensen met taalstoornissen en om de lijst te vertalen naar andere talen.

Appendix I

Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation) Appendix I

Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation)

Final version, August 2010

This questionnaire is about your daily life and consists of four parts: (1A) how much time you spend working, studying and attending to household duties, (1B) how often you undertake certain activities, (2) whether you experience any limitations in your daily life and (3) how satisfied you are with your daily life.

Please answer all the questions by circling the answer that best describes your situation.

1A. How many hours per week do you usually spend on the following activities?

Explanation:

- This is about a normal week, and holidays do not count.
- Please do not include any travelling time.

Please note: This is the number of hours per week

Paid work All forms of paid work, including work for your own business	None at all	1-8 hours	9-16 hours	17-24 hours	25-35 hours	36 hours or more
Unpaid work Volunteering for a society, community centre, at school or any other voluntary activities	None at all	1-8 hours	9-16 hours	17-24 hours	25-35 hours	36 hours or more
Education Only training courses taken in the context of your paid work or to help you obtain paid work	None at all	1-8 hours	9-16 hours	17-24 hours	25-35 hours	36 hours or more
Household duties Such as: cooking, cleaning, shopping, caring for or supervising children, DIY, gardening etc	None at all	1-8 hours	9-16 hours	17-24 hours	25-35 hours	36 hours or more

1B. How often have you undertaken the following activities in the last 4 weeks?

Explanation:

- Example: if you have taken a walk twice a week, this is equivalent to eight times in four weeks and you should therefore choose the category "6-10 times".
- -
- Do not include any activity in more than one category. Activities for work, school or household duties should not be included here -

Please note: this is about the number of times in the last four weeks

Sports or other physical exercise Such as: tennis, cycling, gym, long walks Please note: do not include e.g. cycling to work	Never	1-2 times	3-5 times	6-10 times	11-18 times	19 times or more
Going out Such as: eating out, visiting a cafe, cinema, concert, alone or together with others	Never	1-2 times	3-5 times	6-10 times	11-18 times	19 times or more
Day trips and other outdoor activities Such as: shopping, attending events, going to the beach, church or mosque	Never	1-2 times	3-5 times	6-10 times	11-18 times	19 times or more
Leisure activities at home Such as: crafts, needlework, reading, puzzles, playing computer games	Never	1-2 times	3-5 times	6-10 times	11-18 times	19 times or more
Going to visit family or friends	Never	1-2 times	3-5 times	6-10 times	11-18 times	19 times or more
Family or friends coming to visit at your home	Never	1-2 times	3-5 times	6-10 times	11-18 times	19 times or more
Contacting others by phone or computer Such as: talking on the phone, texting, e- mailing	Never	1-2 times	3-5 times	6-10 times	11-18 times	19 times or more

2. Does your illness or condition currently limit your daily life?

Explanation:

NA (not applicable): You do not take part in this activity, but this is <u>not</u> because of your condition. Not possible: You cannot not take part in this activity, and this is because of your condition. With assistance: You perform this activity partly by yourself, but need assistance because of your condition. Such as: a home help to perform heavy household duties, your family helps by taking you to places etc. This includes paid help and unpaid help from family or friends. Difficulty: If your condition means this activity is considerably more difficult for you.

Such as: it takes much more time, you need to rest halfway through an activity, you now do it less frequently, for a shorter time or in a less taxing way.

Paid work, unpaid work or education	NA	Not possible	With assistance	With difficulty	Without difficulty
Household duties Such as: cooking, cleaning, shopping, taking care of or supervising children, DIY, gardening	NA	Not possible	With assistance	With difficulty	Without difficulty
Outdoor mobility Such as: driving a car, travelling by bus or train, cycling to work or going shopping, etc	NA	Not possible	With assistance	With difficulty	Without difficulty
Sports or other physical exercise Such as: tennis, cycling, gym, long walks	NA	Not possible	With assistance	With difficulty	Without difficulty
Going out Such as: eating out, visiting a cafe, the cinema, a concert, alone or with others	NA	Not possible	With assistance	With difficulty	Without difficulty
Day trips and other outdoor activities Such as: shopping, attending events, going to the beach, church or mosque	NA	Not possible	With assistance	With difficulty	Without difficulty
Leisure activities at home Such as: crafts, needlework, reading, puzzles, playing computer games	NA	Not possible	With assistance	With difficulty	Without difficulty
Your relationship with your partner Such as: communication, sexuality	NA	Not possible	With assistance	With difficulty	Without difficulty
Going to visit family or friends	NA	Not possible	With assistance	With difficulty	Without difficulty
Family or friends coming to visit at your home	NA	Not possible	With assistance	With difficulty	Without difficulty
Contacting others by phone or computer Such as: talking on the phone, texting, e-mailing	NA	Not possible	With assistance	With difficulty	Without difficulty

3. How satisfied are you with your current daily life?

Explanation:

- NA (not applicable): only enter this if you are unable to work or study or do not have partner.

Paid work, unpaid work or education Please note: complete for the most important activity	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	NA
Household duties Such as: cooking, cleaning, shopping, taking care of or supervising children, DIY, gardening	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Outdoor mobility Such as: driving a car, travelling by bus or train, cycling to work or going shopping, etc	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Sports or other physical exercise Such as: tennis, cycling, gym, long walks	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Going out Such as: eating out, visiting a cafe, the cinema, a concert, alone or with others	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Day trips and other outdoor activities Such as: shopping, attending events, going to the beach, church or mosque	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Leisure activities at home Such as: crafts, reading, computer	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Your relationship with your partner	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	NA
Your relationship with your family	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	
Your contacts with friends and acquaintances	Very dissatisfied	Dissatisfied	Neutral	Satisfied	Very satisfied	

Appendix I

Appendix II

Utrechtse Schaal voor Evaluatie van Revalidatie-Participatie (USER-Participatie)

Utrechtse Schaal voor Evaluatie van Revalidatie-Participatie (USER-Participatie)

Definitieve versie, augustus 2010

Deze vragenlijst gaat over uw dagelijks leven en bestaat uit vier onderdelen: (1) hoeveel tijd u besteedt aan werk, studie en huishouden, (2) hoe vaak u bepaalde activiteiten doet, (3) of u beperkingen in uw dagelijks leven ervaart en (4) hoe tevreden u over uw dagelijks leven bent.

U kunt alle vragen beantwoorden door het antwoord te omcirkelen dat het beste bij uw situatie past.

1A. Hoeveel uur per week bent u bezig met de volgende activiteiten?

Toelichting:

- Het gaat om een normale week, waarbij vakantie niet meetelt.
- Eventuele reistijd telt u niet mee.

Let op: Het gaat om het aantal uren per week

Betaald werk Alle vormen van betaald werk, ook werken in eigen bedrijf	Helemaal niet	1-8 uur	9-16 uur	17-24 uur	25-35 uur	36 uur of meer
Onbetaald werk Actief zijn in een vereniging, buurthuis, op school en ander vrijwilligerswerk	Helemaal niet	1-8 uur	9-16 uur	17-24 uur	25-35 uur	36 uur of meer
Opleiding Alléén opleidingen of cursussen voor betaald werk of om betaald werk te krijgen	Helemaal niet	1-8 uur	9-16 uur	17-24 uur	25-35 uur	36 uur of meer
Huishoudelijke taken Zoals: koken, schoonmaken, boodschappen doen, kinderen verzorgen of begeleiden, klusjes in huis doen, tuinieren en dergelijke	Helemaal niet	1-8 uur	9-16 uur	17-24 uur	25-35 uur	36 uur of meer

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1B. Hoe vaak heeft u in de afgelopen 4 weken de volgende activiteiten gedaan?

Toelichting:

- Als u bijvoorbeeld ongeveer twee keer per week een wandeling maakt is dat 8 keer in 4 weken en kiest u de categorie "6-10 keer".
- Tel elke activiteit maar in één categorie mee.
- Activiteiten voor werk, school of huishouden tellen hier niet mee.

Let op: het gaat om het aantal keren in de afgelopen 4 weken

Sporten of andere lichaamsbeweging Zoals: tennissen, fietsen, fitnessen, een stuk wandelen Let op: fietsen naar bijv. werk telt niet mee	Helemaal niet	1-2 keer	3-5 keer	6-10 keer	11-18 keer	19 keer of meer
Uitgaan Zoals: uit eten gaan, bezoeken van café, bioscoop, concert, alleen of met anderen	Helemaal niet	1-2 keer	3-5 keer	6-10 keer	11-18 keer	19 keer of meer
Dagtochtjes en andere activiteiten buitenshuis Zoals: winkelen, evenementen bijwonen, naar strand, kerk- of moskeebezoek	Helemaal niet	1-2 keer	3-5 keer	6-10 keer	11-18 keer	19 keer of meer
Vrijetijdsbesteding thuis Zoals: knutselen, handwerken, lezen, puzzelen, computerspelletjes doen	Helemaal niet	1-2 keer	3-5 keer	6-10 keer	11-18 keer	19 keer of meer
Op bezoek gaan bij familie of vrienden	Helemaal niet	1-2 keer	3-5 keer	6-10 keer	11-18 keer	19 keer of meer
Bezoek krijgen van familie of vrienden	Helemaal niet	1-2 keer	3-5 keer	6-10 keer	11-18 keer	19 keer of meer
Via de telefoon of computer contact hebben met andere mensen Zoals: bellen, chatten, e-mailen	Helemaal niet	1-2 keer	3-5 keer	6-10 keer	11-18 keer	19 keer of meer

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2. Wordt u, vanwege uw ziekte of aandoening, beperkt in uw huidige dagelijkse leven?

Toelichting:

NVT (nieť van toepassing): U doet deze activiteit niet, maar dat is <u>niet</u> vanwege uw aandoening. Niet mogelijk: U doet deze activiteit niet, en dat is wel vanwege uw aandoening. Met hulp: U doet deze activiteit gedeeltelijk zelf, maar krijgt daar hulp bij vanwege uw aandoening. Zoals: een hulp doet het zware huishoudelijk werk, u krijgt hulp van familie bij vervoer ergens naar toe en dergelijke. Het gaat zowel om betaalde hulp, als om onbetaalde hulp van familie of vrienden. Moeite: Als u vanwege uw aandoening aanzienlijk meer moeite hebt met deze activiteit. Zoals: het kost u aanzienlijk meer tijd, u moet tussendoor uitrusten, u doet dit nu minder vaak, of minder lang of u doet dit nu in een minder belastende vorm.

Betaald werk, onbetaald werk of opleiding	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Huishoudelijke taken Zoals: koken, schoonmaken, boodschappen doen, kinderen verzorgen of begeleiden, klusjes in huis doen, tuinieren	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Verplaatsen buitenshuis Zoals: autorijden, met de bus of trein reizen, fietsen naar werk of om boodschappen te doen, en dergelijke	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Sporten of andere lichaamsbeweging Zoals: tennissen, fietsen, fitnessen, een stuk wandelen	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Uitgaan Zoals: uit eten gaan, bezoeken van café, bioscoop, concert, alleen of met anderen	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Dagtochtjes en andere activiteiten buitenshuis Zoals: winkelen, evenementen bijwonen, naar strand, kerk- of moskeebezoek	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Vrijetijdsbesteding thuis Zoals: knutselen, handwerken, lezen, puzzelen, computerspelletjes doen	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Uw relatie met uw partner Zoals: communicatie, seksualiteit	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Op bezoek gaan bij familie of vrienden	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Bezoek krijgen van familie of vrienden	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite
Via de telefoon of computer contact hebben met andere mensen Zoals: bellen, chatten, e-mailen	NVT	Niet mogelijk	Met hulp	Met moeite	Zonder moeite

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3. Hoe tevreden bent u met uw huidige dagelijks leven?

Toelichting:

NVT (niet van toepassing): vul dit alleen in als u helemaal geen werk of studie heeft of als u
geen partner heeft.

Betaald werk, onbetaald werk of opleiding Let op: vul in voor de belangrijkste activiteit	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	NVT
Huishoudelijke taken Zoals: koken, schoonmaken, boodschappen doen, kinderen verzorgen of begeleiden, klusjes in huis doen, tuinieren	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	
Verplaatsen buitenshuis Zoals: autorijden, met de bus of trein reizen, fietsen naar werk of om boodschappen te doen, en dergelijke	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	
Sporten of andere lichaamsbeweging Zoals: tennissen, fietsen, fitnessen, een stuk wandelen	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	
Uitgaan Zoals: uit eten gaan, bezoeken van café, bioscoop, concert, alleen of met anderen	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	
Dagtochtjes en andere activiteiten buitenshuis Zoals: winkelen, evenementen bijwonen, naar strand, kerk- of moskeebezoek	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	
Uw vrijetijdsbesteding thuis Zoals: knutselen, lezen, computer	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	
Uw relatie met uw partner	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	NVT
Uw relatie met uw gezin of familie	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	
Uw contacten met vrienden en bekenden	Zeer ontevreden	Ontevreden	Neutraal	Tevreden	Zeer tevreden	

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Appendix II



Dankwoord

Daar ligt het proefschrift dan eindelijk, *mijn* proefschrift. Ik heb al die tijd moeite gehad te geloven dat dit moment echt zou komen. En hier is het dan! Het voelt nog steeds als niet-waar, maar het ligt er echt. Het is niet zonder slag of stoot gegaan, maar ik heb het voltooid en wat vooral belangrijk is: ik kijk er met plezier op terug. Ik heb het niet allemaal alleen gedaan en hier, in dit dankwoord, wil ik daarom een aantal mensen persoonlijk bedanken.

Allereerst wil ik alle revalidanten bedanken voor de moeite die zij gedaan hebben om alle vragenlijsten in te vullen. Tijdens de metingen die ik zelf heb uitgevoerd binnen het revalidatiecentrum, heb ik met een aantal van hen persoonlijk kennis mogen maken. Ik vind het ongelooflijk hoe veerkrachtig de psyche van de mens is, en ik heb hier erg veel bewondering voor.

Ook dank aan de Quadrugby-spelers die geparticipeerd hebben in mijn onderzoek. Zij hebben geholpen de data voor dit proefschrift compleet te maken. Speciale dank aan Reda, die ik menige woensdag bij kon staan als ADL-er. Buiten het feit dat dit praktisch was, heb ik er een hoop van geleerd en was het bovendien erg gezellig. Ik heb genoten van deze tijd, Reda, thx!

De data voor het onderzoek waren ook niet binnengehaald zonder steun van een hoop collega's binnen de Hoogstraat; artsen en assistenten zijn ruim een jaar lang wekelijks lastig gevallen door mij met de vraag of ik revalidanten kon benaderen om mee te doen aan mijn onderzoek, de huiskamerverpleegkundigen waren altijd even behulpzaam bij het traceren van revalidanten, de planning heeft heel wat werk verzet om te zorgen dat de metingen in het rooster van de revalidant kwam te staan en de ICT heeft ervoor gezorgd dat onze papieren vragenlijsten soepel overgingen naar digitale vragenlijsten. Dank!

Mijn bijzondere dank gaat uit naar de onderzoeksassistenten: Aja, Hanneke en Petra. Zonder jullie was het nooit gelukt. Hanneke en Petra, door jullie kon ik met een gerust hart gewoon op vakantie gaan! Ook de onderzoeksassistenten van Sophia Revalidatie (Den Haag en Delft) en de Libra Zorggroep (Blixembosch en Leijpark) ben ik dankbaar: Rixt, Annette, Saskia, Magda, Judith, Judit en Anja. Dankzij jullie hebben we zoveel mensen in het onderzoek kunnen includeren!

Steven van Berlekom ben ik dankbaar voor de kans die ik bij de Hoogstraat heb gekregen. Ik ben aangenomen met de woorden: 'Je bent onervaren, maar jong en enthousiast, we willen het wel proberen.' Zie hier het resultaat... Prof. dr. F.J.G. Backx, beste Frank. Ik ben erg blij en dankbaar dat jij zonder enige vorm van twijfel of terughoudendheid de rol van promotor op je hebt genomen, ondanks het feit dat het raakvlak tussen sportgeneeskunde en mijn proefschrift nagenoeg nihil is. Het is ontzettend fijn dat het proefschrift er nu echt is.

Prof. dr. E. Lindeman, beste Eline. Wat heb ik ontzettend veel bewondering voor je, hoe je je met zoveel passie tot het einde in hebt kunnen zetten voor je vak.

Prof. dr. R.C. Wagenaar, beste Robert. Ik ben nog steeds verbijsterd dat ook jij er vandaag niet bij bent. In die korte tijd heb ik zoveel van je kunnen leren, helaas is het niet langer geweest!

Dr. M.W.M. Post, Marcel, allerbeste Marcel. Grote, grote dank gaat uit naar jou. Zonder jou was ik nooit zover gekomen. Wanneer ik dacht dat ik van alles achter mijn computertje zat te bedenken terwijl de buitenwereld toch niet geïnteresseerd was, lukte het jou altijd weer om me te motiveren. Om te zorgen dat ik de meerwaarde er weer van in zag. Dat ik er weer zin in had. Dat ik weer inspiratie kreeg. Maar ook het vertrouwen dat ik dit wel kon. Ik heb ontzettend veel van je geleerd, dit is een mooie basis om een (wetenschappelijke) carrière voort te zetten.

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Naast de huidige junior-onderzoekers, wil ik ook de junior-onderzoekers die eerder mijn pad gekruist hebben (Olaf, Christel, Maureen, Dirk-Wouter, Sacha, Lotte, Casper, Annerieke, Rutger, en iedereen die ik in dit rijtje nog vergeet) danken. Ik heb een hoop van jullie geleerd en wat nog belangrijker is: ik heb me door jullie onderdeel van een team gevoeld. Hieraan hebben ook de onderzoeksassistenten (Margreet, Lenneke en Hanneke), Carlijn en Andrie, en de vele stagiaires die zijn voorbij gekomen bijgedragen.

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Om de circel van beroepsmatige participatie rond te maken, sluit ik deze af met mijn nieuwe collega's van de VU: Riekie, Caroline, Sanna en Elsje. Ik had me geen welkomer onthaal kunnen bedenken na het warme bad van de Hoogstraat! Daarbij is de cursus Klinimetrie die ik 2009 bij Riekie en Caroline heb gevolgd een belangrijke bron van inspiratie en enthousiasme geweest tijdens mijn promotie.

De laatste loodjes wegen het zwaarst; ik ben mijn collega's, mijn paranimfen en een aantal vrienden erkentelijk dat zij mijn manuscript nogmaals hebben doorgelezen en hiermee de minuscuulste foutjes eruit hebben gefilterd. Verder ben ik Renate dankbaar dat zij mij een hoop slapeloze nachten heeft bespaard door de opmaak van het proefschrift zorgvuldig (en zeer snel) te verzorgen. En Jan-Willem is een held met plaatjes en kleuren; hij heeft de voorkant kunnen maken zoals ik het van te voren nooit had kunnen bedenken, thx!

Zoals jullie inmiddels weten, bestaat participatie niet alleen uit beroepsmatige participatie, maar ook uit sociale participatie en vrijetijdsbesteding. Mijn ervaring is dat deze het beste met elkaar afgewisseld kunnen worden om zo in balans te blijven. Anderzijds is mijn ervaring ook dat het niet geheel te scheiden is. Vele vrienden ben ik dankbaar voor alle andere leuke dingen die ik heb gedaan naast het schrijven van mijn proefschrift. Jullie zijn een belangrijke bron van ontspanning en plezier geweest. Daarbij wil ik me alvast verontschuldigen voor de mensen die ik daarbij niet met naam en toenaam noem; dit maakt jullie niet minder belangrijk.

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About the author

Curriculum vitae

Carlijn van der Zee werd geboren op 12 oktober 1980 in Gouda. Zij is opgegroeid in het pittoreske dorpje Haastrecht, waar zij naar de basisschool ging. Na de basisschool ging zij naar het Christelijk Lyceum te Gouda, later Goudse Waarden genoemd. Na het behalen van haar gymnasiumdiploma in 1998, heeft zij een jaar high school gedaan in Chippewa Falls, Wisconsin, Amerika. Van 1999 tot 2002 heeft zij de HBO-opleiding Oefentherapie Cesar aan de Hogeschool Utrecht gevolgd en succesvol afgerond. In 2002 is zij gestart aan de opleiding Bewegingswetenschappen aan de Vrije Universiteit Amsterdam, waarbij zij de afstudeerrichting Revalidatie heeft gekozen. In 2006 heeft zij deze opleiding met een Master diploma afgerond.

In december 2007 is Carlijn begonnen aan een onderzoeksproject bij het Kenniscentrum Revalidatiegeneeskunde De Hoogstraat. Toen bleek dat beide partijen tevreden waren, dat er een grote hoeveelheid data was verzameld en dat er nog subsidie verkregen kon worden, is dit onderzoeksproject in 2011 voortgezet in een promotietraject. Echter vanaf januari 2010 heeft zij deeltijd aan haar onderzoek gewerkt en deeltijd een functie gehad in een looplaboratorium, eerst bij de afdeling Revalidatie in het Erasmus MC te Rotterdam, later in De Hoogstraat te Utrecht.

Vanaf februari 2013 is Carlijn werkzaam als postdoc-onderzoeker bij de afdeling Epidemiologie en Biostatistiek, EMGO⁺ Instituut, VUmc te Amsterdam.

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About the author