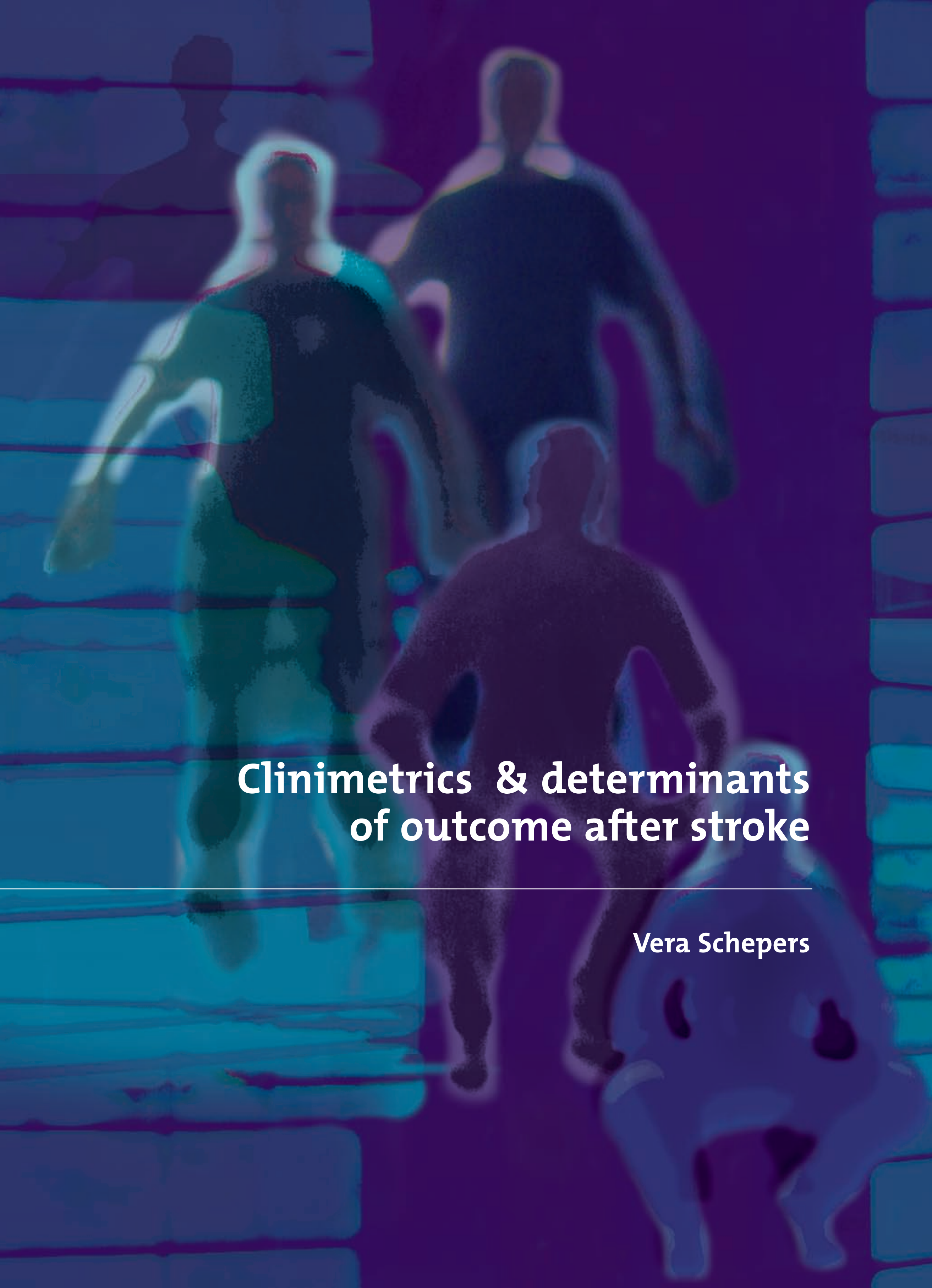

Clinimetrics & determinants of outcome after stroke

Vera Schepers

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Clinimetrics & determinants of outcome after stroke

Klinimetrie & determinanten van uitkomst na CVA

(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor aan de universiteit van Utrecht
op gezag van de rector magnificus, prof. dr. W.H. Gispen,
ingevolge het besluit van het college voor promoties in het openbaar te verdedigen
op donderdag 14 december 2006 des namiddags om 03.00 uur

door

Virginie Philomena Maria Schepers
geboren op 21 mei 1973 te Roosendaal

Promotor
Prof. Dr. E. Lindeman

Co-promotores
Dr. M. Ketelaar
Dr. J.M.A. Visser-Meily

Contents

1

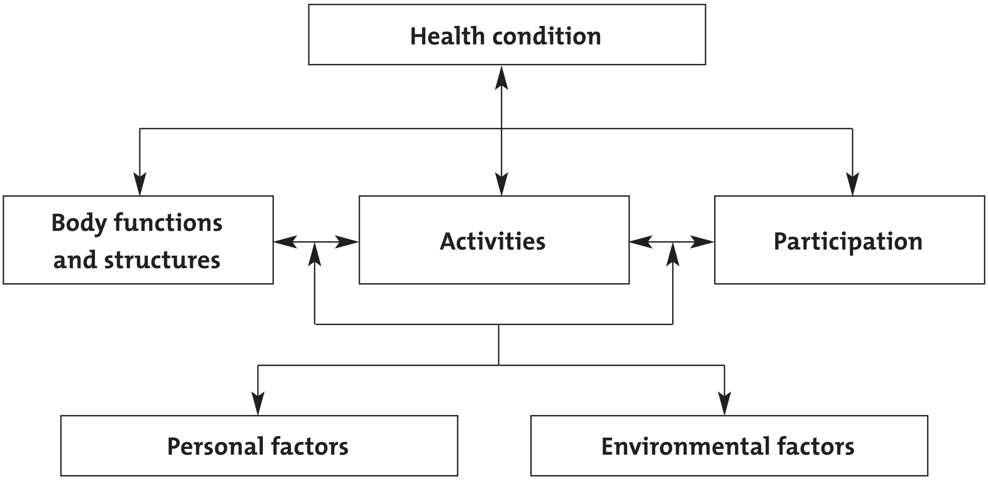
General Introduction

Stroke is the second leading cause of death in Western societies[1]. In the Netherlands, the current annual incidence is about 41,000 persons and the absolute mortality is 11,000 persons per year[2].
After the onset of a stroke, most stroke patients are referred to a hospital. Almost one quarter of these patients die during their hospital stay[3]. Many of the survivors have to face the consequences of stroke, which are usually complex and heterogeneous, and can result in problems across multiple functional domains. After discharge from hospital, about 14% of the survivors are referred to inpatient rehabilitation[3,4].
Rehabilitation can be defined as the active participation of a disabled person and others to reduce the impact of disease and disability on daily life[5]. The assessment of functional outcome is an important issue in rehabilitation medicine, in care as well as in research. Over the last 25 years, many measurement instruments have been developed for use in stroke rehabilitation, and satisfactory psychometric qualities have been reported for many of them in terms of reliability and validity[6,7]. However, one important aspect of validity, namely responsiveness, has hardly been studied so far. The responsiveness of a measurement instrument is its ability to detect change over time. It is especially in rehabilitation, which generally aims to achieve positive changes in a patient's functioning over time, that instruments are needed with adequate responsiveness.
Besides the lack of knowledge about responsiveness, another major issue in rehabilitation is how to predict functional recovery and outcome. Early information about the long-term consequences of a stroke is important for goal-setting and the effective planning of rehabilitation programmes. Moreover, prognostic knowledge is needed to adequately inform patients and their families. Until now, whereas many prognostic studies have focused on activities of daily living[8,9], little is known about the prognosis of other areas of functioning, like social activity.

ICF

Both in clinimetrics and in rehabilitation medicine, the International Classification of Functioning, Disability and Health (ICF)[10] is a widely used conceptual model. The ICF, published by the World Health Organization in 2001, is a globally agreed framework and classification system, which provides a unified and standardised language to describe the components of health (Figure 1). It describes health from three different perspectives: the perspective of the body, that of the individual and that of society. This results in the following health components: body functions and structures, activities and participation. The ICF also covers environmental and personal factors which interact with the other health components.

Figure 1. The International Classification of Functioning, Disability and Health (ICF) model



In practice, the ICF is a very useful framework, not only to describe health but also to classify measurement instruments or therapy options. The study reported on in this thesis also frequently used the ICF as a conceptual framework, both during the design stage and in the interpretation and presentation of the results.

FuPro-stroke study

The 'Functional Prognostication and disability study on stroke' (FuPro-stroke) was designed to answer two research questions.

(1) Which outcome measures are most appropriate, and especially most responsive, for the assessment of functional outcome in stroke patients?

(2) What are the prognostic determinants of functional outcome and recovery after stroke?

Participants were selected from stroke patients consecutively admitted to four Dutch rehabilitation centers for an inpatient rehabilitation programme in the period April 2000 to July 2002. The inclusion criteria were: (1) a first-ever stroke, (2) a one-sided supratentorial lesion and (3) age above 18. Exclusion criteria were: (1) disabling comorbidity (prestroke

Barthel Index below 18) and (2) a premorbid inability to speak Dutch. Data were collected as soon as possible after admission to the rehabilitation center, and six months and one year post stroke. Additionally, the Barthel Index was scored at 8, 10 and 12 weeks post stroke. A total of 308 stroke patients were included, in the following rehabilitation centers: De Hoogstraat (Utrecht); Rehabilitation Center Amsterdam (Amsterdam); Heliomare (Wijk aan Zee); and Blixembosch (Eindhoven).

The FuPro-stroke study was embedded within the research programme entitled ‘Functional prognostication and disability study on neurological disorders’ (FuPro). The FuPro research programme studied four neurological disorders, viz. stroke, traumatic brain injury (TBI), multiple sclerosis (MS) and amyotrophic lateral sclerosis (ALS).
This programme was supervised by the Department of Rehabilitation Medicine of the VU Medical Center in Amsterdam and supported by the Netherlands Organisation for Health Research and Development (grant no. 1435.0001). The four projects were individually coordinated by the De Hoogstraat Rehabilitation Center and University Medical Center Utrecht (stroke and ALS), the Department of Rehabilitation Medicine of Erasmus Medical Center Rotterdam (TBI) and the Department of Rehabilitation Medicine of the VU medical Center, Amsterdam (MS).

Three studies were associated with to the FuPro-stroke study:
(1) The FuPro-stroke caregiver study[11]. This project examined the prognosis in terms of burden, depression and satisfaction with life among family caregivers (spouses and young children), the role of family caregivers in the stroke rehabilitation process and their satisfaction with the support they received. Subjects included were spouses and young children of the stroke patients of the FuPro-stroke cohort.
(2) The MOVE study[12]. This study aimed to describe the development of mobility status over the second year after stroke among patients who were discharged from inpatient rehabilitation. Eligible participants were patients included in the FuPro-stroke cohort.
(3) The FuPro-stroke II study[13]. This study was an extension of the FuPro-stroke study and examined the patients included in the original FuPro-stroke study, three years after their stroke. Prognostic determinants were studied, mainly focusing on mobility outcome. In addition, care characteristics were studied in relation to unmet demands among this chronic stroke population. (The original FuPro-stroke study is also called the FuPro-stroke I study)

Outline of the thesis

This thesis presents results of the FuPro-stroke study. It consists of two parts, one on clinimetrics and another on determinants of outcome. The major aims of the thesis are as follows.

Clinimetrics

(1) To compare the responsiveness of several functional outcome measures frequently used in stroke research, namely the Barthel Index, Functional Independence Measure, Stroke Adapted-Sickness Impact Profile 30 and Frenchay Activities Index (Chapter 2).

(2) To explore the relationship between the ICF framework and outcome measures that are frequently used in stroke rehabilitation and that focus on activities and participation (Chapter 3).

Determinants of outcome

(3) To develop a prediction rule for social activity one year post stroke (Chapter 4).

(4) To describe the development of fatigue during the first year post stroke and to determine the relation between fatigue at one year post stroke and personal characteristics, stroke characteristics and post-stroke impairments (Chapter 5).

(5) To determine whether there is a difference in functional recovery between patients with a cerebral infarction and patients with an intracerebral haemorrhage (chapter 6).

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2

Responsiveness of functional health status measures frequently used in stroke research

Vera Schepers, Marjolijn Ketelaar, Anne Visser-Meily, Joost Dekker, Eline Lindeman

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Abstract

Purpose To compare the responsiveness of several functional health status measures frequently used in stroke research, namely the Barthel Index (BI), Functional Independence Measure (FIM), Frenchay Activities Index (FAI) and Stroke-Adapted Sickness Impact Profile 30 (SA-SIP 30).

Method Patients with a first-ever supratentorial stroke admitted for inpatient rehabilitation were included. Complete datasets for 163 patients were available for analysis. Floor/ceiling effects and responsiveness, quantified by effect sizes, were studied for the periods between rehabilitation admission and six months post stroke (subacute phase) and between six and 12 months post stroke (chronic phase).

Results Effect sizes in the subacute phase were similar and were classified as large for the BI, FIM total and FIM motor score. The FIM cognitive score showed a considerable ceiling effect and had the smallest effect size in the subacute phase. In the chronic phase, the FAI and SA-SIP 30 detected the most changes and had moderate effect sizes.

Conclusions BI, FIM total and FIM motor score, FAI and SA-SIP 30 were responsive measures. We recommend the use of the BI in the subacute phase and the use of the FAI and SA-SIP 30 in the chronic phase, especially for the stroke rehabilitation population.

Introduction

In addition to measures of neurological functions, measures of functional health status are frequently applied in stroke outcome assessment, especially in neurological rehabilitation. Longitudinal studies require measures that are not only reliable and valid, but also responsive. In contrast to reliability and validity, the clinimetric quality of responsiveness has hardly been studied for functional health status measures. Responsiveness is defined as the ability of a measure to detect changes over time. Unfortunately, there is no consensus about the methods to evaluate responsiveness. After extensive literature research, Terwee et al[1]. found 31 different indices of responsiveness. In the present study, responsiveness was determined by effect sizes, one of the most commonly used indices of responsiveness.

The Barthel Index (BI), Functional Independence Measure (FIM), Frenchay Activities Index (FAI) and Sickness Impact Profile (SIP) are functional health status measures frequently used in stroke research. Little is known about possible differences in responsiveness of these measures in relation to the post-stroke phase. Although some responsiveness assessments have been performed for the subacute phase[2-4], such assessments are lacking for the chronic phase, the period from six months post stroke.

Several studies[2-5] have compared the BI and the motor component of the FIM and concluded that there were no differences between these measures in terms of responsiveness. These studies determined responsiveness in the subacute phase, the period between admission to the rehabilitation ward and discharge. What little evidence is available for the responsiveness of the FAI[6-8] mainly relates to deterioration in functional status between the pre-stroke and post-stroke situations[9-11]. We recently showed that the Stroke-Adapted-SIP 30 is a responsive measure, whose responsiveness proved similar to that of the SIP 68[12].

Comparisons of the responsiveness of various instruments require two aspects to be taken into account. First, the instruments have to be examined in the same study sample during the same period, as responsiveness assessments are likely to be affected by characteristics of the sample, such as the phase of rehabilitation[5]. Secondly, the responsiveness has to be calculated by the same method for all the instruments, since the many different methods for calculating responsiveness all result in different absolute estimates[1].

The aim of our study was to compare the responsiveness of several functional outcome measures frequently used in stroke research, namely the BI, FIM, SA-SIP 30 and FAI. Responsiveness was evaluated by testing certain hypotheses for a sample of patients in whom changes were expected clinically, as they had been selected for inpatient rehabilitation[13-15].

Three hypotheses were tested:

1. The BI and the FIM can detect changes in this population for the time period between rehabilitation admission and six months post stroke (subacute phase).
2. The BI and the FIM will detect fewer changes in the time period between six and 12 months post stroke (chronic phase) than in the subacute phase, as it is known that most ADL changes occur in the subacute phase[16].
3. The SA-SIP 30 and the FAI will detect more changes in the chronic phase than the BI and the FIM, as the SA-SIP 30 and especially the FAI focus particularly on instrumental ADL and social functions, which are more likely to change in the chronic phase than ADL functions.

Methods

Participants. Participants included in the present study were selected from stroke patients consecutively admitted to four Dutch rehabilitation centers. The inclusion criteria were: (1) a first-ever stroke, (2) a supratentorial lesion and (3) age above 18. Exclusion criteria were: (1) disabling co-morbidity (prestroke Barthel Index below 18) and (2) inability to speak Dutch. The medical ethics committees of the University Medical Center Utrecht and the participating rehabilitation centers approved the study.
Procedure. At the start of inpatient rehabilitation, patients were asked by their rehabilitation doctor whether they were willing to participate in the study. After informed consent had been given, the first assessment took place as soon as possible. At six months and one year post stroke the patients were contacted for a face-to-face interview. BI and FIM data were collected shortly after admission, at six months and at one year post stroke. SA-SIP 30 and FAI data were collected at six months and one year post stroke. Since all items of the FAI are only relevant to patients discharged home, we decided not to fill out the FAI for patients still staying in a rehabilitation center at six months post stroke. When communication caused too many problems, proxy scores were used.
Outcome measures. The Barthel Index[17], scored from 0-20, is a frequently used instrument of 10 items, measuring independency in terms of mobility and personal care. The Functional Independence Measure[18] documents the degree of independency for functional activities involving motor and cognitive ability. The scores for its 13 motor items and 5 cognitive items were added up to produce a total score. The SA-SIP 30[19] is a functional health status instrument consisting of 30 items that can be divided into a physical dimension (11 items) and a psychosocial dimension (15 items). Scores are presented as a percentage of maximum dysfunction. The SA-SIP 30 is the only measure in the present study in which a higher

score reflects poorer functioning. The FAI[9] is a 15-item measure assessing complex activities such as those relating to housekeeping, recreation, transportation and work. We only used the sum score.

Analyses. The mean scores, sample ranges and distributions of all measures were examined to evaluate floor and ceiling effects. To quantify responsiveness, effect sizes were calculated for each measure by dividing the mean absolute change score by the standard deviation of the baseline score[20]. The interpretation of the magnitude of the effect size was based on Cohen's rule-of-thumb, in which an effect size of 0.2-0.5 is considered small, 0.5-0.8 represents a moderate effect and 0.8 or greater represents a large effect[21].

Results

A total of 308 patients were included in the present study. Eight patients died before one-year follow-up, 15 had suffered a recurrent stroke and 21 refused further participation. At six months post stroke, 91 patients were still residing in a rehabilitation center and thus had missing FAI scores. Scores on other measures were missing for 10 patients. Complete data sets for 163 patients were available for analysis. Their mean age was 56 (11) years; 63% (102) were men. Three quarters of the patients (121) had had a cerebral infarction and one quarter (42) had had a cerebral haemorrhage. The median time between stroke and first assessment was 41 (15-129) days. The mean length of stay in the rehabilitation center was 81 (33) days.

Table 1 presents mean scores, sample ranges and interquartile ranges of the functional health status measured at baseline and at six and 12 months post stroke. The BI and the FIM total, FIM motor and FIM cognitive scores had considerable ceiling effects at six and 12 months post stroke, while the FIM cognitive score also showed ceiling effects for the first assessment.

Effect sizes in the subacute phase were similar for the BI, FIM total and FIM motor scores, and were classified as large (table 2). The FIM cognitive score had the smallest effect size in the subacute phase. The BI and the FIM detected fewer changes in the chronic phase; effect sizes were smaller compared to those in the subacute phase. A comparison of the effect sizes of all measures in the chronic phase showed that they hardly differed and ranged between 0.47 and 0.64. The effect sizes of the FAI and SA-SIP 30 scores were slightly larger than those of the BI and FIM scores in the chronic phase, and were classified as moderate.

Table 1. Data on functional health status measures applied at baseline and at 6 and 12 months post stroke (n = 163)

	Baseline			6 months post stroke			12 months post stroke		
Measure (scale range)	**Mean (sd)**	**Sample range**	**IQR**	**Mean (sd)**	**Sample range**	**IQR**	**Mean (sd)**	**Sample range**	**IQR**
BI (0-20)	14.8 (4.2)	3-20	11-19	18.7 (1.6)	13-20	18-20	18.9 (1.5)	14-20	18-20
FIM total (18-126)	98.6 (16.6)	53-125	87-112	111.7 (8.3)	81-124	107-118	112.2 (8.3)	83-125	109-119
FIM motor (13-91)	67.8(14.7)	31-91	56-79	80.3 (6.4)	58-91	77-85	80.9 (7.0)	57-91	77-86
FIM cognitive (5-35)	30.7 (4.4)	15-35	28-34	31.4 (3.6)	18-35	29-34	31.2 (3.2)	16-35	30-34
SIP30 total (0-100)				26.6 (15.7)	0-66.7	13.3-36.7	24.2 (16.5)	0-76.7	10-36.7
SIP30 physical (0-100)				29.9 (20.8)	0-90.9	18.2-45.5	26.7 (20.5)	0-100	9.1-36.4
SIP30 psychosocial (0-100)				23.3 (18.0)	0-86.7	6.7-33.3	22.2 (19.0)	0-73.3	6.7-33.3
FAI (0-45)				18.0 (8.5)	0-36	12-25	20.9 (8.7)	2-42	15-28

Sd = standard deviation in brackets; IQR = interquartile range; BI = Barthel Index; FIM = Functional Independence Measure; SIP = Sickness Impact Profile; FAI = Frenchay Activities Index

Table 2. Mean absolute change scores, standard deviations and effect sizes of the functional health status measures for the period between baseline assessment and 6 months post stroke (subacute phase) and the period between 6 and 12 months post stroke (chronic phase) (n = 163)

	Subacute phase			**Chronic phase**		
Measure	**Absolute change score (sd)**	**Sd baseline**	**Effect size**	**Absolute change score (sd)**	**Sd 6 months**	**Effect size**
BI	4.1 (3.5)	4.2	0.98	0.83 (1.1)	1.6	0.52
FIM total	14.0 (12.2)	16.6	0.84	3.9 (3.5)	8.3	0.47
FIM motor	13.0 (11.4)	14.7	0.89	3.3 (2.8)	6.4	0. 51
FIM cognitive	2.1 (2.2)	4.4	0.47	1.7 (1.6)	3.6	0.47
SIP30 total				9.9 (8.1)	15.7	0.63
SIP30 physical				11.1 (10.5)	20.8	0.53
SIP30 psychosocial				11.5 (11.2)	18.0	0.64
FAI				5.0 (4.2)	8.5	0.59

BI = Barthel Index; FIM = Functional Independence Measure; SIP = Sickness Impact Profile; FAI = Frenchay Activities Index

Discussion

The BI, FIM total and FIM motor scores were able to detect the changes predicted for our sample in the subacute phase, thus confirming hypothesis one. There were no differences between these measures in terms of responsiveness as assessed by effect sizes. These findings are in line with those of previous studies[2-5], which found no differences in responsiveness between the BI, FIM total and FIM motor scores. The poor responsiveness of the FIM cognitive score has also been demonstrated in other studies[2,3] and is probably caused by ceiling effects, indicating that this subscale is not very useful for the stroke rehabilitation population.
To our knowledge, no previous studies have evaluated responsiveness in the chronic phase after stroke. The effect sizes of the BI and the FIM scores were smaller for the chronic phase than for the subacute phase, indicating that the measures detected fewer changes for the period between six and 12 months post stroke. In other words, hypothesis two was also confirmed. One reason for the small effect sizes could be the ceiling effects found for the BI and FIM scores in the chronic phase. A considerable ceiling effect interferes with the assessment of responsiveness. As a consequence of these ceiling effects, the BI and the FIM may not have detected changes in patient functioning.
Hypothesis three was confirmed for the FAI and SA-SIP 30 scores, as they detected more changes in the chronic phase than the BI and FIM. Considering only the effect sizes, the differences between the BI and FIM on the one hand and the FAI and SA-SIP 30 on the other hand were smaller than we had expected. In the acute phase, the rehabilitation process particularly focuses on the recovery of self-care and mobility. In the chronic phase, after home discharge, this focus shifts to the resumption of activities in family and social life. As the FAI and SA-SIP 30 focus more on instrumental ADL and social functioning, we expected them to show larger effect sizes in the chronic phase than the BI and FIM. However, for the interpretation of relevant changes it is important not only to consider the effect sizes but also to take into account the variance and ceiling/floor effects. The standard deviations of the BI and FIM at six months post stroke were small, indicating little variance in these measures in this group at six months post stroke. Moreover, the BI and FIM had large ceiling effects. We therefore conclude that hypothesis three has been confirmed.
A limitation of our study is that the FAI was not scored in patients who still resided in a rehabilitation center at six months post stroke. As the FAI assesses functions relating to housekeeping, recreation, transportation and professional activities, it is only relevant to patients discharged home. Hence, the data of 30% of the patients could not be used in the complete case analysis. The fact that we had to exclude these patients, who were

probably more disabled, from the analysis could be a reason for the ceiling effects we found. Thus, the conclusions of our study are merely applicable to the patients who are at home six months post stroke. For patients who still reside in a rehabilitation center, the BI and the FIM might be appropriate measures in the chronic phase.

As stated in the introduction, there are many methods to calculate responsiveness[1]. Unfortunately, there is no consensus on the best method. In general, two approaches can be distinguished. The first approach uses a sample of patients in whom changes are expected clinically. Hypotheses about these changes are formulated in advance and then tested by means of the measure under study. The second approach uses an external criterion to establish whether patients have changed, and subsequently determines whether the measure under study can detect these changes. We had two arguments for our decision to use the first approach. First of all, we had a sample of patients in whom changes could be expected clinically, as they had been selected for inpatient rehabilitation[13-15]. Secondly, we had no adequate external criterion that could discriminate stable patients from patients who changed.

In the present study, proxy scores were used to prevent exclusion of the subgroup of non-communicative patients. There is no consensus on the use of proxy responses in stroke research in the literature[6,8]. Studies evaluating the reliability and validity of proxy ratings have yielded contradictory results[22-24]. However, as the non-communicative patients form a highly relevant subgroup, we decided to use proxy responses instead of excluding these patients[8,25]. Moreover, in clinical practice, the collection of information on these patients also often depends on a proxy.

In conclusion, our results show that the BI and FIM total and motor scores are responsive in the subacute phase and that the FAI and SA-SIP 30 detect the most changes in the chronic phase. Since the BI is the shortest measure, as well as being the easiest to use and requiring no special training, we prefer the BI for use in the subacute phase. For the chronic phase, we would recommend the use of the FAI and the SA-SIP 30. These recommendations are particularly valid for the stroke rehabilitation population. For patients discharged home directly from hospital, the FAI and SA-SIP 30 will probably be of use in an earlier phase.

Responsive functional health status measures should not only be used in research but also in patient care to objectively evaluate the development of functional health. Obviously, the selection of a specific functional health status measure should not only be based on clinimetric characteristics; the aspects of functional health assessed by the various measures should also be taken into consideration. In addition, the feasibility of a measure is an important criterion to consider when choosing between different instruments.

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3

Comparing contents of functional outcome measures in stroke rehabilitation using the International Classification of Functioning, Disability and Health

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Abstract

Purpose To examine the content of outcome measures that are frequently used in stroke rehabilitation and focus on activities and participation, by linking them to the International Classification of Functioning, Disability and Health (ICF).
Method Constructs of the following instruments were linked to the ICF: Barthel Index, Berg Balance Scale, Chedoke McMaster Stroke Assessment Scale, Euroqol-5D, Functional Independence Measure, Frenchay Activities Index, Nottingham Health Profile, Rankin Scale, Rivermead Motor Assessment, Rivermead Mobility Index, Stroke Adapted Sickness Impact Profile 30, Medical Outcomes Study Short Form 36, Stroke Impact Scale, Stroke Specific Quality of Life Scale and Timed Up and Go test.
Results It proved possible to link most constructs to the ICF. Most constructs fitted into the activities and participation component, with mobility being the category most frequently covered in the instruments. Although instruments were selected on the basis of their focus on activities and participation, 27% of the constructs addressed categories of body functions. Approximately 10% of the constructs could not be linked.
Conclusions The ICF is a useful tool to examine and compare contents of instruments in stroke rehabilitation. This content comparison should enable clinicians and researchers to choose the measure that best matches the area of their interest.

Introduction

Stroke is a major public health concern, being among the most common causes of death and disability in industrialized societies[1]. Many survivors are facing the long-term consequences of stroke, which are usually complex and heterogeneous, and can result in problems across multiple domains of functioning. Given the long-term consequences of stroke, the focus on functional outcome measurement for assessment, intervention management and outcome evaluation in stroke rehabilitation is well justified.

In recent years there has been a growing awareness that stroke assessment must extend beyond the traditional outcome of mortality and neurological symptoms to include physical, psychological and social functioning[2]. This biopsychosocial approach is increasingly being applied in health care and research, especially in rehabilitation medicine. Accordingly, in the last decades, numerous measures have been developed to assess functional outcome in stroke. An overview of functional outcome measures was recently published by Salter et al[3,4], who evaluated the psychometric and administrative properties.

The International Classification of Functioning, Disability and Health (ICF)[5], published by the World Health Organization in 2001, also uses this biopsychosocial approach[6]. The ICF is a globally agreed framework and classification system, which provides a unified and standardized language to describe the components of health. It describes health from three different perspectives: the perspective of the body (the body component), that of the individual and that of society (the activities and participation component). The ICF also covers environmental and personal factors which interact with all health components.

Functional outcome measures are primarily concerned with measuring an individual's ability to perform activities required in daily life[7], which is conceptually related to the activities and participation component of the ICF. The term activities as used in the ICF is defined as the execution of a task or action by an individual, and participation is defined as involvement in a life situation[5].

Functional outcome measures and the ICF are concurrently applied in stroke rehabilitation medicine. This simultaneous use necessitates a further understanding of their relationship and compatibility[8]. Using the ICF, it is possible to identify and compare the concepts contained in different outcome measures. Geyh et al.[9] have used this method to identify the concepts of outcome measures in stroke trials and demonstrated the wide variety of concepts in this field. Unfortunately, their review did not include any information on the content of the individual outcome measures, as they did not report which specific ICF categories were represented in each of the measures.

Selecting an outcome measure, whether for clinical practice or for research purposes, requires information on the specific content at item level. Unfortunately, the selection

process is often primarily driven by measures that are readily at hand[10] or is guided only by the evaluation of the psychometric properties. In our opinion, more emphasis should be placed on the question whether an instrument is appropriate[11], i.e. which specific constructs should be measured and which instruments match these constructs? The ICF provides an instrument to evaluate the content of a measure in a systematic way.
The objective of this study was to explore the relationship between the ICF model and outcome measures that are frequently used in stroke rehabilitation and focus on activities and participation. The specific aims were to examine and compare the contents of these measures by linking them to the ICF.

Methods

Outcome measures. We examined outcome measures frequently used in stroke rehabilitation in the area of activities and participation[3,4]. The following 15 functional outcome measures were assessed: Barthel Index (BI)[12], Berg Balance Scale (BBS)[13,14], Chedoke McMaster Stroke Assessment Scale (CMSA)[15,16], Euroqol-5D (EQ5D)[17], Functional Independence Measure (FIM)[18], Frenchay Activities Index (FAI)[19], Nottingham Health Profile (NHP)[20,21], Rankin Scale (RS)[22], Rivermead Motor Assessment (RMA)[23,24], Rivermead Mobility Index (RMI)[25], Stroke Adapted Sickness Impact Profile 30 (SASIP30)[26,27], Medical Outcomes Study Short Form 36 (SF36)[28,29], Stroke Impact Scale (SIS)[30], Stroke Specific Quality of Life Scale (SSQOL)[31] and Timed Up and Go test (TUG)[32]. Salter et al.[3,4] evaluated the psychometric and administrative properties of these 15 instruments.
Linking to ICF. The ICF[5] has two parts, each containing two components. The first part deals with functioning and disability and includes the body functions (b) and body structures (s) component and the activities and participation (d) component. The second part covers contextual factors and includes the environmental factors (e) component and the personal factors component. Each component includes several categories, which are the units of the ICF classification. The personal factors component is only broadly described, as categories have not yet been defined. In the ICF classification, the letters b, s, d and e, which refer to the components, are followed by a numeric code starting with the first-level category, i.e. the chapter number (1 digit), followed by the second (2 digits), third (1 digit) and sometimes fourth (1 digit) levels. The component letter with the suffix consisting of 1, 3, 4 or 5 digits corresponds with the code of the categories. An example selected from the activities and participation component (d) would result in a code with d4 'mobility' at the first level, d420 'transferring oneself' at the second level, and d4200 'transferring oneself while sitting' at the third level.

Linking rules have been developed which allow a reliable linking of items of outcome measures to the ICF[33]. We tried to link each item in the various measures to the most appropriate ICF category. If an item encompassed different constructs, the information in each construct was individually linked. For example, in item 36 of the NHP 'I'm in pain when going up and down stairs or steps', the constructs 'pain' and 'going up and down stairs of steps' were linked to separate ICF categories. If an item could not be linked, this item was assigned an nd (not defined) code.

First, each measure was linked independently by three health professionals working in rehabilitation research. One of them (VS) linked all the 15 measures, one (IvdP) linked eight measures and one (MK) linked the other seven measures. Second, for each measure, the linked categories were compared. In case of consensus the item was linked to the ICF category. In case of disagreement a discussion followed, led by the third person (MK or IvdP) who initially did not link that measure. This person finally decided to which ICF category the item was linked. For the purpose of the present paper, ICF codes of the first- and second-level categories were reported.

Results

It proved possible to link all instruments to the ICF, except for the RS, none of whose constructs could be linked (table 1). These were therefore all coded nd. Six instruments, EQ 5D, NHP, SASIP30, SF36, SSQL and SIS, contained some constructs that could not be linked. The 15 instruments included a total of 364 items, which contained 471 constructs. Of these constructs, 298 (63%) belonged to the activities and participation component (d), for which most constructs, 166, were linked to the first-level category of mobility (d4); followed by 32 constructs linked to self-care (d5). The first-level categories with the fewest links were general tasks and demands (d2) and learning and applying knowledge (d1), with 4 and 6 links, respectively.

Of all linked constructs, 128 (27%) belonged to body functions (b). All first-level ICF categories for body functions were linked, except for one (b4: functions of the cardiovascular, haematological, immunological and respiratory systems). The largest number of constructs (68) were linked to mental functions (b1), followed by 38 constructs linked to neuromusculoskeletal and movement-related functions (b7). Of body structures (s), the only first-level category linked to any constructs was that of structures related to movement (s7).

All instruments, except the RS, covered mobility (d4). The BBS, RMI (except for one construct) and TUG were completely focussed on mobility. The SSQL addressed all domains of activity and participation. The SASIP30, SIS and SF36 also covered a wide range of categories from the activity and participation component, including 8, 8 and 7 of the 9 first-level categories, respectively. Eight instruments (BI, CMSA, FIM, NHP, RS, RMA, RMI and SASIP30) included environmental factors of the products and technology category (e1) and of the support and relationships category (e3). The BBS and SSQL only included the support and relationships category (e3), while the TUG only included products and technology (e1).

Table 1. Links between first-level ICF categories of body functions, body structures and activities and participation on the one hand and outcome measures frequently used in stroke rehabilitation on the other.

ICF Category	BI	BBS	CMSA	EQ5D	FIM
Body functions					
b1 Mental functions				1	1
b2 Sensory functions and pain			1	1	
b3 Voice and speech functions					
b5 Functions of the digestive, metabolic and endocrine systems	1				1
b6 Genito-urinary and reproductive functions	1				1
b7 Neuromusculoskeletal and movement-related functions			15		
Body structures					
s7 Structures related to movement			1		
Activities and Participation					
d1 Learning and applying knowledge					1
d2 General tasks and demands					
d3 Communication					2
d4 Mobility	4	14	25	1	7
d5 Self-Care	5			2	7
d6 Domestic life				1	
d7 Interpersonal interactions and relationships					1
d8 Major life areas				2	
d9 Community, social and civic life				1	
Not definable				3	
Total	11	14	42	12	21

ICF= International Classification of Functioning, Disability and Health; BI = Barthel Index; BBS = Berg Balance Scale; CMSA = Chedoke McMaster Stroke Assessment Scale, EQ5D = Euroqol-5D; FIM = Functional Independence Measure; FAI = Frenchay Activities Index; NHP= Nottingham Health Profile; RS = Rankin Scale; RMA = Rivermead Motor Assessment;

Within the first-level category of mobility (d4), the second-level categories most frequently included in the instruments were changing basic body position (d410) and walking (d450) (table 2b). Within the self-care category (d5), dressing (d540) and washing oneself (d510) were the second-level categories most frequently covered by the instruments. The most frequently linked category of mental functions (b1) was that of emotional functions (b152). The most frequently linked second-level category of neuromusculoskeletal and movement-related functions (b7) was control of voluntary movements (b760) (table 2a).

FAI	NHP	RHS	RMA	RMI	SASIP30	SF36	SSQL	SIS	TUG	Total
	19				4	13	15	15		68
	8					2	2			14
					1		1			2
								1		3
								1		3
			18		1			4		38
										1
					2		1	2		6
					1	2	1			4
					2		6	7		17
3	12		35	18	7	12	10	15	3	166
	1			1	2	2	7	5		32
8	1				4	1	2	4		21
	4				4		2	3		14
1	1					8	1	3		16
5	3				1	4	4	4		22
	9	5			3	16	6	2		44
17	58	5	53	19	32	60	58	66	3	471

RMI = Rivermead Mobility Index; SASIP30 = Stroke Adapted Sickness Impact Profile 30; SF36 = Medical Outcomes Study Short Form 36; SSQL = Stroke Specific Quality of Life Scale; SIS = Stroke Impact Scale and TUG = Timed Up and Go test.

Table 2a. Links between second-level ICF categories of body functions and body structures on the one hand and outcome measures frequently used in stroke rehabilitation on the other.

ICF Category	BI	BBS	CMSA	EQ5D	FIM
Mental functions					
b114 Orientation functions					
b126 Temperament and personality functions					
b130 Energy and drive functions					
b134 Sleep functions					
b140 Attention functions					
b144 Memory functions					1
b152 Emotional functions				1	
b160 Thought functions					
b167 Mental functions of language					
Sensory functions and pain					
b210 Seeing functions					
b280 Sensation of pain			1	1	
Voice and speech functions					
b330 Fluency and rhythm of speech functions					
Functions of the digestive, metabolic and endocrine systems					
b525 Defecation functions	1				1
Genito-urinary and reproductive functions					
b620 Urination functions	1				1
Neuromusculoskeletal and movement-related functions					
b710 Mobility of joint functions			1		
b730 Muscle power functions					
b750 Motor reflex functions			1		
b760 Control of voluntary movements			13		
Structures related to movement					
s720 Structure of the shoulder region			1		

ICF= International Classification of Functioning, Disability and Health; BI = Barthel Index; BBS = Berg Balance Scale; CMSA = Chedoke McMaster Stroke Assessment Scale, EQ5D = Euroqol-5D; FIM = Functional Independence Measure; FAI = Frenchay Activities Index; NHP= Nottingham Health Profile; RS = Rankin Scale; RMA = Rivermead Motor Assessment;

FAI	NHP	RHS	RMA	RMI	SASIP30	SF36	SSQL	SIS	TUG	Total
								1		1
	1				1		4			6
	2					3	2			7
	6									6
							1	1		2
							2	3		6
	10				3	10	5	9		38
								1		1
							1			1
							2			2
	8					2				12
					1		1			2
								1		3
								1		3
										1
								4		4
										1
			18		1					32
										1

RMI = Rivermead Mobility Index; SASIP30 = Stroke Adapted Sickness Impact Profile 30; SF36 = Medical Outcomes Study Short Form 36; SSQL = Stroke Specific Quality of Life Scale; SIS = Stroke Impact Scale and TUG = Timed Up and Go test.

Table 2b. Links between second-level ICF categories of activities and participation on the one hand and outcome measures frequently used in stroke rehabilitation on the other.

ICF Category	BI	BBS	CMSA	EQ5D	FIM
Learning and applying knowledge					
d110 Watching					
d160 Focusing attention					
d163 Thinking					
d172 Calculating					
d175 Solving problems					1
General tasks and demands					
d230 Carrying out daily routine					
d240 Handling stress and other psychological demands					
Communication					
d310 Communicating receiving spoken language					
d329 Communicating receiving other spec/unspec.					1
d330 Speaking					
d345 Writing messages					
d349 Communication - producing other spec/unspec.					1
d350 Conversation					
d360 Using communication devices and techniques					
d369 Conversation and use of communication devices and techniques, other spec/unspec.					
Mobility					
d410 Changing basic body position		7	11		1
d415 Maintaining a body position		6	3		
d420 Transferring oneself	1	1	2		1
d429 Changing and maintaining body positions, other spec/unspec.					2
d430 Lifting and carrying objects					
d440 Fine hand use					
d445 Hand and arm use			1		
d449 Carrying, moving and handling objects, other spec/unspec.					
d450 Walking	1		6	1	1
d455 Moving around	1		2		1
d460 Moving around in different locations					
d465 Moving around using equipment	1				1

FAI	NHP	RHS	RMA	RMI	SASIP30	SF36	SSQL	SIS	TUG	Total
							1			1
					1					1
					1					1
								1		1
								1		2
						2	1			3
					1					1
								1		1
										1
					1		3	3		7
							1			1
										1
					1			1		2
							2	1		3
								1		1
	2		7	4		2	2	1	2	39
	3		3	3			1	2		21
			3							8
				1	2			2		7
			1	1		2		1		5
			8				1	3		12
	1		5			1	2	1		11
			1			1				2
1	4		3	5	1	3	2	3	1	32
	2		4	3	1	3	1	2		20
					1					1
					1		1			4

ICF Category	BI	BBS	CMSA	EQ5D	FIM
d469 Walking and moving, other spec/unspec.					
d470 Using transportation					
d475 Driving					
Self-care					
d510 Washing oneself	1			1	2
d520 Caring for body parts	1				1
d530 Toileting	1				1
d540 Dressing	1			1	2
d550 Eating	1				1
Domestic life					
d620 Acquisition of foods and services					
d630 Preparing meals					
d640 Doing housework					
d650 Caring for household objects					
d660 Assisting others					
d699 Domestic life, unspecified				1	
Interpersonal interactions and relationships					
d710 Basic interpersonal interactions					
d720 Complex interpersonal interactions					
d729 General interpersonal interactions, other spec/unspec.					1
d750 Informal social relationships					
d760 Family relationships					
d770 Intimate relationships					
Major life areas					
d839 Education, other spec/unspec.				1	
d850 Remunerative employment					
d859 Work and employment, other spec/unspec.				1	
d860 Basic economic transactions					
d865 Complex economic transactions					
Community, social and civic life					
d920 Recreation and leisure				1	
d930 Religion and spirituality					
d999 Community, social and civic life, unspecified					

ICF= International Classification of Functioning, Disability and Health; BI = Barthel Index; BBS = Berg Balance Scale; CMSA = Chedoke McMaster Stroke Assessment Scale, EQ5D = Euroqol-5D; FIM = Functional Independence Measure; FAI = Frenchay Activities Index; NHP= Nottingham Health Profile; RS = Rankin Scale;

FAI	NHP	RHS	RMA	RMI	SASIP30	SF36	SSQL	SIS	TUG	Total
				1	1					2
1										1
1										1
				1		1	1	1		8
								1		3
							1	1		4
	1				2	1	4	1		13
							1	1		4
1					1			1		3
1							1			2
4					2			1		7
2					1					3
								1		1
	1					1	1	1		5
					1			1		2
	1				1					2
	1				2					4
	1						1	1		3
								1		1
	1						1			2
										1
1	1									2
						8	1	1		11
								1		1
								1		1
4	3				1	4	3	3		19
1								1		2
							1			1

RMA = Rivermead Motor Assessment; RMI = Rivermead Mobility Index; SASIP30 = Stroke Adapted Sickness Impact Profile 30; SF36 = Medical Outcomes Study Short Form 36; SSQL = Stroke Specific Quality of Life Scale; SIS = Stroke Impact Scale and TUG = Timed Up and Go test; other spec/unspec. = other specified and unspecified.

Discussion

Most constructs of the functional outcome measures were covered by the ICF model, except those of the RS. Most linked constructs fitted into the activities and participation component, with mobility being the category most frequently covered in the instruments, followed by self-care. Although the outcome measures had been selected on the basis of their focus on activities and participation, 27% of the constructs addressed the body functions categories. Approximately 10% of the constructs could not be linked to the ICF.

The ICF turned out to be a useful framework and classification system to categorize health components, as it proved possible to relate many constructs in the functional outcome measures to the ICF categories. Linking the constructs of the instruments to the ICF has resulted in a clear view of the major differences and similarities. Other studies[9,34,35] have also reported positive experiences with the linkage of instruments to the ICF. However, we also encountered specific difficulties in assigning ICF codes to the constructs of outcome measures. One of the difficulties is illustrated by the finding that more constructs than we expected could not be linked to the ICF. Most of the constructs that could not be linked referred to a concept that was too general, for example the construct 'physical health' in item 4 of the SF36 or 'personal life' in item 3 of the Family roles subscale of the SSQL. None of the RS constructs could be linked, as they were all too generally formulated, for instance as 'lifestyle' or 'symptoms'. The RS, which is widely used in stroke research, should only be viewed as a global functional health index[36] and is therefore, in our opinion, of limited value in rehabilitation. A few other constructs, though more specifically described, could not be linked either, for example 'I am confined to bed' in item 1 of the EQ5D or 'I had to stop and rest during the day' in item 2 of the Energy subscale of the SSQL.

A remarkable finding was the substantial number of links to the body functions categories, although the outcome measures examined had been selected by Salter et al.[37] based on their focus on activities and participation. In the NHP, which has the most links to body functions of all instruments (47%), two different types of links to body functions can be distinguished. On the one hand, there are items that solely cover a body function, for example item 9 of part I, 'I feel lonely'. On the other hand, there are items that refer to a connection between a body function and a category of activities and participation, for example item 8 of part I, 'I find it painful to change position'. The latter type of item, combining body functions and activities/participation, can also be found in the RMA, where most items refer to a certain physical movement in the mobility category, sometimes in combination with the quality of movement at the level of body functions. Even though many measures include items of body functions as well as of activities and participation[37], we still conclude that the instruments we examined measure functional outcome. We conclude this, firstly, because none of instruments had more than half of their constructs linked to body functions, and secondly, because some items addressing body functions connected these to activities and participation. However, it is important to realize that when the scores of items measuring body functions and the scores of activities and participation items are added to form one overall score, interpretation of the final result and the real meaning of the finding may be questionable[38,39].

The SASIP30, SF36, SSQL and SIS are examples of measures which enable the user to get a comprehensive picture of health outcome in post-stroke patients[30]. They cover the largest range of ICF categories within the activities and participation component. However, apart from activities and participation, they also include categories of body functions. If an instrument is required that solely measures activities and participation, four instruments can be considered, viz the BBS, FAI, RMI and TUG. Of these four measures, only the FAI yields a wider view of patients' functioning, addressing work, household and social life. The BBS, RMI and TUG only cover a narrow spectrum within the activities and participation component, and are suitable for specific questions regarding mobility. The RMI, for example, was developed with the intention to focus on disability, not impairment, and to span a wide range of reduction in mobility[25]. Evaluating the linked constructs of the RMI allows both intentions to be clearly recognized: a broad range of mobility categories are covered, and there are no linkages to the categories of body functions.

Mobility is the most frequently represented category, with 35% of all the linkages. This emphasis on mobility is understandable, as it has for a long time been a major goal in rehabilitation medicine. However, work, recreation and relationships are becoming more and more important issues in this field. Unfortunately, the present instruments still pay relatively little attention to these topics, resulting in little outcome assessment in this area[40]. Development of measures in these areas is required.

The importance of our findings for rehabilitation practice is that they provide a comprehensive and helpful overview of the content of frequently used functional outcome measures, both for clinicians and researchers. Previously published overviews[3,4,37,41,42] have described primarily the psychometric properties of validity and reliability, whereas Wade[11] already emphasized that information on the concepts contained in the instruments is of great importance. The intention of the present paper is not to give any specific recommendations as to which instrument to use, as this decision depends on the question that needs to be answered. Selection of an outcome measure should start by exactly describing the specific concepts that need to be measured. After these have been clearly described, potential measures matching these concepts must be identified. Tables 1 and 2 could be helpful for this purpose: the required concepts are shown on the left hand side of both tables, where the ICF categories are presented. It can therefore be seen at a glance which instruments cover these concepts, and the outcome measures most frequently used in stroke rehabilitation can easily be compared.

In conclusion, examining and comparing the content of functional outcome measures in stroke rehabilitation using the ICF was found to be a useful approach. Clinicians and researchers who need to select an outcome measure need to be aware of the constructs covered by an instrument and the areas that it does not cover at all. The content comparison presented in this paper should enable clinicians and researchers in stroke rehabilitation to choose the appropriate measure that best matches the area of their interest.

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4

Prediction of social activity one year post stroke

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Abstract

Objective To develop an easy-to-use prediction rule for social activity one year post stroke that can identify patients at risk for social inactivity.
Design Inception cohort.
Setting Rehabilitation center.
Patients Patients with a first-ever supratentorial stroke were selected in four Dutch rehabilitation centers. Data of 250 patients were available for analysis. Potential prognostic factors measured at admission were sex, age, marital status, prestroke employment status, educational level, type of stroke, hemisphere, motor impairment, trunk control, communication and activities of daily living (ADL) dependency.
Interventions Not applicable.
Main Outcome Measure Social activity measured by the Frenchay Activities Index (FAI) at one year post stroke.
Results Multivariate backward linear regression analysis identified sex, age, marital status, motor impairment, communication and ADL dependency as important predictors of the FAI score one year post stroke. An easy-to-use score chart was constructed which could identify patients at risk for social inactivity. The score chart proved to be well able to discriminate poor social functioning from moderate to good social functioning (area under the curve = 0.85.)
Conclusions Identifying patients at risk allows health care professionals to focus on the social activity of this patient subgroup at an early stage in the care process.

Introduction

A stroke can have major consequences for the performance of independent activities in a person's personal and social setting. Until now, most attention has been concentrated on limitations in terms of self-care. Prognostic stroke research has also focussed mainly on ADL dependency[1,2]. However, the focus is currently shifting from activities to participation in social situations. This is particularly true in rehabilitation, where the main goal, apart from returning home with optimal ADL independency, is increasingly the achievement of social reintegration. It is important for patients, families and health-care professionals to have some indication of whether and to what extent social activities can be resumed.
The term social activity is difficult to define. Components underlying the "social" concept can be differentiated into the various domains of life, such as family, work and leisure. Although several outcome measures fit this broad description to some extent, most of them only address certain aspects of the concept[3]. In stroke research, the Frenchay Activities Index (FAI)[4] is widely used for the assessment of social activity. The FAI was specifically developed as an outcome measure for stroke rehabilitation, which is why we chose it for our study.
Earlier studies have identified some predictive factors of social activity. Higher age[5], post-stroke urinary incontinence[6], depression, physical and intellectual impairments[7] were found to be related to reduced social functioning. However, the combined value of predictors has hardly been studied: only three studies have addressed this subject[8-10]. A population-based study has identified prognostic factors for social outcome one year post stroke[8]. These factors, assessed at hospital discharge or within six weeks post stroke, were gait speed, prestroke level of social activities, cognition, sensory neglect, chronic obstructive airways disease and left-sided hemiplegia. Poor social activity in a rehabilitation population three years post stroke was found to be predicted by the presence of concomitant disabling disorders, cognitive deficits and the Barthel Index (BI), all measured at admission to the rehabilitation ward[9]. The BI measured at admission, approximately 10 days post stroke, was also found to be an important predictor of social activity one year post stroke in a population rehabilitated at a geriatric ward[10]. These studies all used the FAI as an outcome measure. However, they all suffered from a number of limitations. Besides limitations regarding sample size[9], description of predictors[9], validation of the model[9,10] and evaluation of the performance of the model[9], another important defect of the studies conducted so far has been the poor presentation of the models. Merely presenting odds ratios or the regression formula makes prediction rules unattractive for use in clinical practice[11].

Our study aimed to develop a prediction rule for social activity one year post stroke that can be easily used in clinical practice. The model had to be able to identify patients at risk for social inactivity.

Methods

Participants

Subjects were selected from stroke patients consecutively admitted to four Dutch rehabilitation centers according to the following inclusion criteria: (1) admittance for inpatient rehabilitation, (2) a first-ever stroke, (3) a one-sided supratentorial lesion and (4) age above 18. Exclusion criteria were: (1) disabling comorbidity (prestroke BI below 18) and (2) inability to speak Dutch. The medical ethics committees of University Medical Center Utrecht and the participating rehabilitation centers had approved the study.

Procedure

At the start of inpatient rehabilitation, patients were asked by their rehabilitation physician whether they were willing to participate in the study. Informed consent was obtained from all patients. For patients with communication problems, both the patient and a proxy gave informed consent. The first assessment took place as soon as possible after admission. This assessment was repeated at one year post stroke. All assesments were carried out by trained research assistants.

Measures

Dependent variable. The Frenchay Activities Index (FAI)[4] was used to assess social activity one year post stroke, among patients living at home. It consists of 15 items measuring complex activities such as household (7), recreation (6), transportation (1) and work (1). The FAI scoring is based upon the frequency with which an activity has been performed in the preceding three or six months and ranges from 0 (inactive) to 45 (highly active). The FAI is considered a valid[12,13] and reliable[12,14,15] measure.

Independent variables. Data on age, sex, marital status, prestroke employment, educational level, type of stroke and hemisphere were derived from medical charts. The educational level was dichotomized, being scored as “high” for patients with a higher professional or university degree. The Motricity Index (MI)[16,17] is a brief assessment method for motor impairment. The score for the level of hemiparesis varies from 0 (paralysis) to 100 (normal strength). The Trunk Control Test (TCT)[17,18] examines sitting balance, ability to roll from a supine position towards both sides and transfer from supine to sitting position. The score varies from 0 (no trunk control) to 100 (good trunk control). One item, derived from the Utrecht Communication Observation (Utrechts Communicatie Onderzoek) (UCO) scale, was used to assess the patient's ability to communicate[19,20]. The level of communication ranges from 1 (no communication) to 5 (normal communication) (see appendix). If a subject scored below 4, proxies were interviewed. The level of ADL dependency was measured with the Barthel Index (BI)[21], scored from 0 to 20. The reliability and validity of the BI have been adequately established[22,23].

Statistical Analysis

The aim of the study was to find the combination of variables that most accurately predicted social activity. First, the data set was split into a derivation and a validation set, based on time of inclusion. The derivation set, containing 200 patients, was used to formulate the prognostic model, whose validity could be tested in the validation set, which consisted of the last 50 patients to be included. Univariate analysis was applied in the derivation set to examine the relations between dependent and independent variables and to derive potential prognostic factors. Then, variables selected on the basis of the univariate analysis were entered into the model. Backward linear regression analysis was applied until the remaining variables had a significance level below 0.1. This selection, with a more liberal significance level, increased the power for selection of true predictors and limited the bias in the selected coefficients[24]. The regression formula thus derived was used to construct an easy-to-use score chart that could be applied to predict an FAI score. Subsequently, the prognostic model was tested in the validation set. Finally, the performance of the model was investigated in the set of 200 patients, by evaluating its ability to discriminate between poor social recovery and moderate to good social recovery. Subjects were categorized by the actual FAI scores based on the FAI categories used in previous studies[25,26]: inactive (range, 0-15), moderately active (range, 16-30) and active or highly active (range, 31-45). We combined the latter two categories, as we were only interested in discriminating poor from moderate to good social functioning. Receiver operating characteristic (ROC) curve analysis was used to evaluate the discriminating ability of the model to predict social inactivity (actual FAI score, 0-15). The larger the area under the curve (AUC), the higher the sensitivity and specificity for the prediction of poor social activity. An AUC of 0.5 is uninformative, greater than 0.7 is considered reasonable and greater than 0.8 is considered good[27]. The optimal cut-off point for the prediction of social inactivity was determined using the associated predictive value, sensitivity and specificity.

Results

A total of 308 patients were included in the study. Eight patients died before one-year follow up, 15 had a recurrent stroke, 21 refused further participation, 13 did not live at home (4 at a rehabilitation center, 9 at a nursing home) and 1 patient had a missing FAI score, leaving data of 250 patients available for analysis.
Patients were relatively young, and the majority were living with a partner. Almost half of the patients had been employed before their stroke (table 1). Infarctions were more frequent than hemorrhages. The hemorrhages included 5% intracerebral hemorrhages and 11% subarachnoid haemorrhages. Communication problems (UCO score, ≤ 4) were present for 21% of the patients. The mean BI of 13.8 ± 4.7 indicates that the patients were moderately disabled at the start of inpatient rehabilitation. The mean BI one year post stroke was 18.2 ± 2.5. The mean one-year FAI score was 18.3 ± 9.4: 37% of the patients were socially inactive (FAI score, 0 – 15), 51% were moderately active (FAI score, 16 – 30) and 12% were active or highly active (FAI score, 31 – 45).

Table 1. Baseline characteristics of stroke patients at admission for inpatient rehabilitation

Characteristic	**Subjects (n = 250)**
Female %	38.4
Mean age ± SD (y)	56.3 ± 10.8
Marital status (% living with partner)	75.6
Prestroke employment status (% employed)	43.6
Educational level (% with higher professional/university degree)	18.0
Days post stroke, median (range)	44.0 (15.0-168.0)
Type of stroke (% infarction)	73.6
Hemisphere (% right)	45.6
Mean Motricity Index score ± SD	52.8 ± 30.2
Trunk Control Test, median (range)	87.0 (0.0-100.0)
Utrecht Communication Observation, median (range)	5.0 (1.0-5.0)
Mean Barthel Index score ± SD	13.8 ± 4.7

NOTE. The range of the Motricity Index is 0 to 100, the range of the Trunk Control Test is 0 to 100, the range of the Utrecht Communication Observation is 1 to 5, and the range of the Barthel Index is 0 to 20.

Abbreviation: SD, standard deviation

Univariate and multivariate analyses

Table 2 presents univariate correlation coefficients between the independent variables and the FAI score one year post stroke. The highest correlation coefficient was found for the MI and BI, followed by the TCT and UCO. All variables, except hemisphere, were included as candidate predictors in the multivariate backward linear regression analysis. The multivariate model (Table 2) included sex, age, marital status, MI, UCO and BI, and explained 43% of the total variance (Adjusted R^2 = .41). The model excluded prestroke employment, educational level, type of stroke and TCT, as their significance levels were above 0.1.

Presentation and validation of the model

A score chart (fig 1) was constructed by rounding the B coefficients indicating the score points. Adding up the score points from the chart allowed the predicted FAI score to be directly determined. We tested the score chart in the validation set by comparing the predicted FAI scores with the actual FAI scores, and found an R^2 of .57.

Table 2. Univariate and multivariate analyses of independent variables assessed at admission to inpatient rehabilitation and FAI score one year post stroke (n=200)

	Univariate analysis		Multivariate analysis	
Determinants	**Pearson r**	**P**	**B**	**P**
Sex (female)	.27	<.001	2.82	.010
Age	-.19	.009	-0.16	.001
Marital status (living with partner)	-.25	<.001	-2.32	.057
Prestroke employment status (employed)	.14	.045		
Educational level (higher professional/ university degree)	.11	.114		
Type of stroke (infarction)	-.22	.001		
Hemisphere (right)	.06	.396		
Motricity Index	.56	<.001	0.10	.001
Trunk Control Test	.43	<.001		
Utrecht Communication Observation	.31	<.001	0.92	.058
Barthel Index	.56	<.001	0.41	.031
Intercept			13.43	

NOTE. For score ranges, see table 1

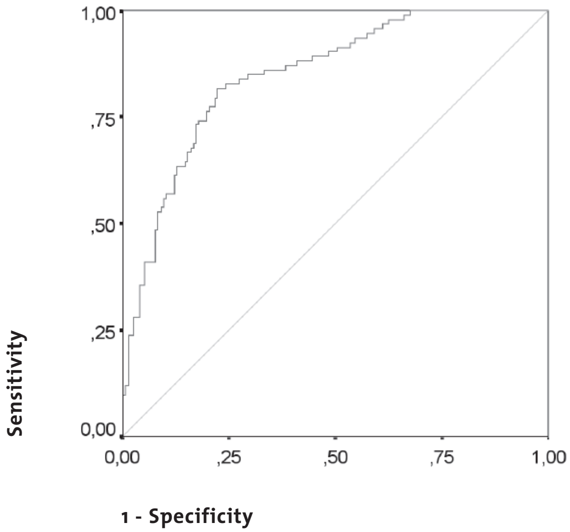
Model performance for identifying patients at risk for social inactivity

The ROC curve had an AUC of .85 (95% confidence interval, .80 – .90), indicating that the average discriminatory power of the model in predicting social inactivity (actual FAI score, 0 – 15) could be regarded as good (fig 2). The optimal cut-off value of the score chart was 19 (fig 1). The predictive value was 67%; the sensitivity at this cut-off point was 82% and the specificity 76%.

Figure 1. The score chart for predicting social outcome among stroke patients. The patient is at increased risk for social inactivity if the score is below 19.

Prognostic factors							Score
Age	30 y + 9	40 y + 7	50 y + 5	60 y + 4	70 y + 2	80 y + 0	
Female			+ 3				
Living with partner			- 2				
Motricity Index divided by 10			+ 0 - 10				
Barthel Index divided by 2			+ 0 - 10				
UCO			+ 1 - 5				
			Predicted FAI score (add score points)				

Figure 2. ROC curve of the score chart predicting social inactivity as measured by the Frenchay Activities Index (AUC = .85)



Discussion

We have developed a score chart that is easy to use in clinical practice for the identification of patients at risk for social inactivity one year post stroke. The chart includes sex, age, marital status, MI, UCO and BI as predictors

Social activity was assessed by the FAI. The mean one-year FAI score of 18.4 was higher than the score of 15 mentioned in the literature[12,28]. Two explanations could be given for this discrepancy. First, it probably reflects differences in study populations, because previous studies were hospital- or community-based, while ours was based on a rehabilitation population. Second, the FAI could not be scored for the eight patients who died and the 13 patients who were still in institutional care. As these patients, who probably had the poorest outcome, were omitted from the analysis, the mean FAI score was presumably somewhat higher. Still, our FAI score of 18.4 reflects deterioration in social activity when compared to FAI scores in the general population, which range from 26 to 28[13,29,30].

Our use of the FAI as an outcome measure of social activity most likely explains why we found female sex to be a positive predictor and living with a partner a negative predictor of social activity. The FAI puts great emphasis on household activities, which are 7 of the 15 items. In the traditional role model, married women do the majority of the housework, leading to higher FAI scores among women. Men, and persons living with a partner, have lower FAI scores in the normal elderly population[29]. Caution must therefore be exercised in interpreting the lower FAI predictions for men and patients living with a partner. A low FAI prediction may indicate future social inactivity as a consequence of stroke, but could also reflect a prestroke situation in which the patient did not engage in any household activities. We therefore recommend taking prestroke social activities into account when establishing patient-relevant rehabilitation goals.

Most studies did not find age to be an independent prognostic factor, but they investigated a relatively old population[8-10]. The fact that our rehabilitation population was younger and the age range was wider allowed us to identify age as a prognostic factor. This was to be expected, because increasing age is associated with a decline in social functioning[5,31,32].

Aphasia has adverse consequences for the recovery of social functioning among stroke patients[8,33]. We found the UCO, which assesses the ability to communicate, to be an important predictor. Communication problems, frequently seen in stroke patients, are not only caused by aphasia but also by cognitive impairments. Therefore, the UCO is an important and comprehensive predictor.

As could be expected, we found the BI to be a predictor of social activity, as have other studies[9,10,34]. It is well known that patients who are more independent in terms of self-care have better FAI scores[12,13,28,32,35].
We used the regression formula to construct an easy-to-use score chart. So far, not many studies have presented prediction rules that were easy to use, even though this should increase the likelihood that a prediction rule will be used in clinical practice. Laupacis et al[11] stated that because a prediction rule is obviously made for use in patient care, it is important that the variables in the prediction rule seem clinically sensible. Moreover, the time needed to apply the rule must be limited and it must be simple to use. To properly interpret our results, one should remember that the model was constructed and validated in a rehabilitation population, which makes the generalizability of the model to patients not selected for rehabilitation debatable. Patients selected for rehabilitation have specific characteristics. Our study showed that they were moderately disabled and relatively young, and that many patients were employed, resulting in a possibly more active lifestyle.

Conclusions
We recommend the use of the score chart to identify patients at risk for social inactivity. Such patients could be identified at admission to the rehabilitation center, to give them specific attention early in the process of patient care. Health care activities for stroke patients and their families should concentrate more on the recovery of social activity, especially among the group at risk. Further, outcome measures for social activity should be used more often in stroke research.

Appendix

Utrecht Communication Observation (UCO)

Communication level	Score
The patient is unable to communicate anything, not even if he understands what the research assistant means.	1
Some communication is possible; the patient responds to questions or expressions of the research assistant by, for example, indicating yes or no, pointing at something or by facial expressions.	2
Communication is possible; the patient makes his own contribution to the conversation by means of fragmentary non-verbal and verbal expressions; the research assistant can often ascertain what the patient means by guessing and questioning.	3
A conversation is possible on ordinary subjects; the patient cannot always express exactly what he means, but the patient and research assistant together keep the conversation going.	4
The patient can engage in a conversation on many subjects with very little help from the research assistant.	5

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5

Post-stroke fatigue: course and its relation to personal and stroke-related factors

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Abstract

Objectives To describe the course of fatigue during the first year post stroke and to determine the relation between fatigue at 1 year post stroke and personal characteristics, stroke characteristics, and post-stroke impairments.
Design Inception cohort.
Setting Rehabilitation center.
Participants Patients (N=167) with a first-ever supratentorial stroke admitted for inpatient rehabilitation.
Interventions Not applicable.
Main Outcome Measure The Fatigue Severity Scale measured the presence and impact of fatigue at admittance for inpatient rehabilitation, as well as at 6 months and 1 year post stroke.
Results At admission, 6 months and 1 year post stroke, fatigue was present in 51.5%, 64.1% and 69.5% of the patients respectively. Fatigue impact 1 year post stroke was greater among patients with more depressive symptoms, higher age, females and patients with a locus of control more directed to powerful others.
Conclusions Because fatigue impact is an increasing problem during the first year post stroke, it deserves more attention in clinical practice and scientific research. Locus of control and depression are related to post-stroke fatigue and might be important foci for future interventions.

Introduction

Fatigue is a common complaint in stroke patients[1,2] and can contribute to functional limitations[1,3], institutionalization and mortality[3]. Only a few articles have described the results of studies on self-reported fatigue in a population of stroke patients.
The percentage of stroke patients reporting fatigue problems ranges from 39 to 68%[1-4]. These estimates are based on studies with cross-sectional designs. There is little data available on the course of post-stroke fatigue. In cross-sectional studies[1,2,4], no association was found between the post-stroke time interval and fatigue. Longitudinal data have not yet been published.
Little evidence is available on factors associated with post-stroke fatigue. Depression is the only post-stroke impairment with an undeniable relation to post-stroke fatigue[5]. Nevertheless, it is important to realize that post-stroke fatigue can also develop independently of depression[1-4]. Other factors must therefore play a role in the development of post-stroke fatigue. Contradictory results have been found for the relation of personal factors, such as age and sex, to post-stroke fatigue[1,3,4]. Glader et al. found that patients who lived alone were more fatigued than patients who lived with a partner[3]. Moreover, they found that fatigue was more common in patients who were ADL dependent before their stroke[3], indicating that prestroke health condition and comorbidity could be of importance. Several authors[6,7] have suggested that fatigue could be the result of inadequate coping with the consequences of a stroke, and recommended to examine prestroke psychological factors in future studies. With respect to stroke-related variables, no relation has been found between post-stroke fatigue and type of stroke or hemisphere[1,3,4]. With respect to post-stroke impairments, cognitive disorders seem to play an important role in post-stroke fatigue on clinical grounds. Self-experienced neuropsychological problems showed some association to post-stroke fatigue in a study of van de Werf et al[2]. Sleeping problems have frequently been reported post stroke[8] and a relation with post-stroke fatigue seems likely.
We conclude that evidence on determinants of post-stroke fatigue is still limited. Results were not always unequivocal, and difficult to compare because of differences in the determinants studied and the post-stroke time interval between and within studies[1,2,4]. Like other authors[9,10] we conclude that more attention should be given to exploring the factors contributing to post-stroke fatigue, as this could lead to the development of treatment options.
Our study aimed: (1) to describe the course of fatigue during the first year post stroke and (2) to determine the relation between fatigue 1 year post stroke and personal characteristics, stroke characteristics, and post-stroke impairments.

Methods

Participants

Subjects were selected from stroke patients consecutively admitted to four Dutch rehabilitation centers according to the following inclusion criteria: (1) admittance for inpatient rehabilitation, (2) first-ever stroke, (3) unilateral supratentorial lesion, and (4) age above 18. Exclusion criteria were (1) disabling comorbidity (prestroke Barthel Index score below 18), (2) inability to speak Dutch and (3) aphasia. The medical ethical committees of University Medical Center Utrecht and the participating rehabilitation centers approved the study.

Procedure

At the start of inpatient rehabilitation, patients were invited by their rehabilitation physician to participate in the study. Informed consent was obtained from all patients. Personal and stroke characteristics were recorded at the first assessment, which took place as soon as possible after admission. Post-stroke impairments were assessed at 1 year post stroke. Fatigue was measured at the first assessment, and then 6 months and 1 year post stroke. All assessments were carried out by trained research assistants.

Measures

Fatigue. The Fatigue Severity Scale[4,11] (FSS) (Appendix) was used to evaluate post-stroke fatigue. It assesses the impact of fatigue on daily life. The FSS is a brief and simple instrument and therefore feasible for stroke patients. It consists of 9 statements about fatigue scored on a 7-point scale, ranging from 1 (strongly disagree) to 7 (strongly agree). The total score is the mean of the nine item scores. The higher the FSS score, the more impact fatigue has on daily life. The FSS was originally designed to evaluate the impact of fatigue in patients with multiple sclerosis[11], but it has also been used in the stroke population[4]. In the current study the internal consistency of the FSS, measured using the Cronbach α, was .89. Fatigue was scored as present if the FSS score was above 4[12]. A score above 4 indicates a moderate to high impact of fatigue on daily living.
Personal characteristics. Data on age, sex, marital status and comorbidity were obtained from medical records. Locus of control is a psychological characteristic defined as “the degree to which individuals perceive events in their lives as being the consequence of their own actions, and thereby controllable (internal control), or as being unrelated to their own behavior, and therefore beyond personal control (external control)”. The Multidimensional Health Locus of Control Scale[13] (MHLC) focuses on perceptions concerning the locus of control over health-related outcomes. The MHLC has three

subscales, each consisting of 6 items scored on a 6-point scale. The Internal subscale assesses the extent to which a person believes health is a function of his/her own behavior. The two other subscales assess the externally orientated beliefs. The Chance subscale assesses the degree to which a person believes his health is unpredictable, a matter of fate, luck or chance. The Powerful Others subscale assesses the extent to which a person believes that health is largely determined by the actions of physicians.

Stroke characteristics. Data on type of stroke and hemisphere were obtained from medical records. Type of stroke was classified as ischemic versus hemorrhagic (intracerebral hemorrhage and subarachnoid hemorrhage)

Post-stroke impairments. The Motricity Index[14,15] (MI) is a brief assessment method for motor impairment that scores the level of hemiparesis from 0 (paralysis) to 100 (normal strength). Cognitive functions were evaluated using two methods. First, the Mini Mental State Examination[16] (MMSE) is a widely used brief screening instrument. It tests orientation, memory, attention, calculation, language and construction functions. A subject who scored less than 24 on the MMSE was considered to have cognitive impairments. Second, the Trail Making Test part B[17] (TMT-B) indicates the level of executive functioning. It involves complex visual scanning, motor speed and attention. The participant has to connect 25 encircled numbers and letters, as quickly as possible, alternating between numbers and letters (1-a-2-b-3-c etc.). Both the time taken to complete the tests and the number of correct connections are recorded. We used the Center of Epidemiologic Studies Depression scale[18] (CES-D) to assess depression. It is a self-reporting questionnaire with 20 items and investigates mood over the past 7 days. A subject scoring above 16 was considered to be depressed[19]. One item of the Rehabilitation Activities Profile[20] was used to evaluate the presence of sleeping problems.

Statistical Analysis

We used descriptive statistics (means and standard deviations [SDs]; medians and interquartile ranges) to describe the baseline characteristics. A one-way repeated-measures analysis of variance was performed to compare FSS scores at admission, 6 months and 1 year post stroke. We used univariate analysis to examine the relations between the FSS scores and the independent variables (ie, personal characteristics, stroke characteristics and post-stroke impairments.) Variables with a significance level below 0.5 in the univariate analysis were selected for the multivariate regression analysis. Backward linear regression analysis was used until the remaining variables had a significance level below 0.1. This selection, with a more liberal significance level, increased the power for selection of true associated determinants and limited the bias in the regression coefficients[21].

Results

A total of 228 patients were included in the study. Eight patients died before 1-year follow-up, 15 had a recurrent stroke, 21 refused further participation and 17 patients had missing scores on 1 or more measures. Thus, data from 167 patients were available for analysis.
Patients were relatively young, and the majority lived with a partner (table 1). Infarctions were more frequent than hemorrhages. At 1 year post stroke 11.4% of the patients were considered cognitively impaired as indicated by the score on the MMSE. The CES-D score indicated a depression in 25.7% of patients.

Table 1. Descriptives of personal characteristics, stroke characteristics, and post-stroke impairments

Characteristic	Subjects (N=167)
Personal characteristics	
Mean age ± SD (y)	56.4 ± 11.4
Sex (% women)	41.3
Comorbidity (% present)	55.1
Marital status (% living with partner)	73.7
Mean MHLC ± SD	
Internal subscale	21.8 ± 5.0
Chance subscale	20.8 ± 5.4
Powerful others subscale	20.3 ± 5.4
Stroke characteristics	
Weeks post stroke (median, IQR)	6.0 (4.0)
Hemisphere (% right)	58.7
Type of stroke (% ischemic)	68.9
Impairments at 1 year post stroke	
Mean Motricity Index ± SD	70.7 ± 25.4
Mini Mental State Examination (median, IQR)	28.0 (3.0)
Trail Making Test part B	
Time (median, IQR) (s)	123.0 (87.0)
Number of correct connections (median, IQR)	24.0 (4.0)
Mean CES-D ± SD	10.7 ± 8.2
Sleeping problems (% present)	33.5

Abbreviations: SD, standard deviation; MHLC, Multidimensional Health Locus of Control scale; IQR, interquartile range; CES-D, Center of Epidemiologic Studies Depression scale

Course of post-stroke fatigue

Fatigue was present at admission, and at 6 months and 1 year post stroke in 51.5%, 64.1% and 69.5% of the patients respectively (table 2). In 37.7% of the patients, fatigue was present at all three assessments (fig 1); fatigue was only absent at all three assessments in 17.4% of the patients. A more variable course of fatigue during the first year post stroke was shown in the remaining 44.9% of the patients. Of the patients who reported fatigue at 1 year post stroke, 29.3% were also depressed. Table 2 presents means and SDs of FSS scores at the different post-stroke time intervals. There was a significant effect of time ($F_{2,165}$ = 10.95, P<.000.)

Table 2. Descriptive statistics for Fatigue Severity Scale (FSS) scores for admission to rehabilitation center, 6 months and 1 year post stroke (N=167)

Measurement period	% Fatigued	Mean FSS score ± SD
Admission	51.5	4.1 ± 1.3
6 months post stroke	64.1	4.5 ± 1.2
1 year post stroke	69.5	4.7 ± 1.3

Abbreviation: SD = standard deviation

Figure 1. Number (and proportion) of patients who reported fatigue at admission, 6 months and 1 year post stroke (N=167)

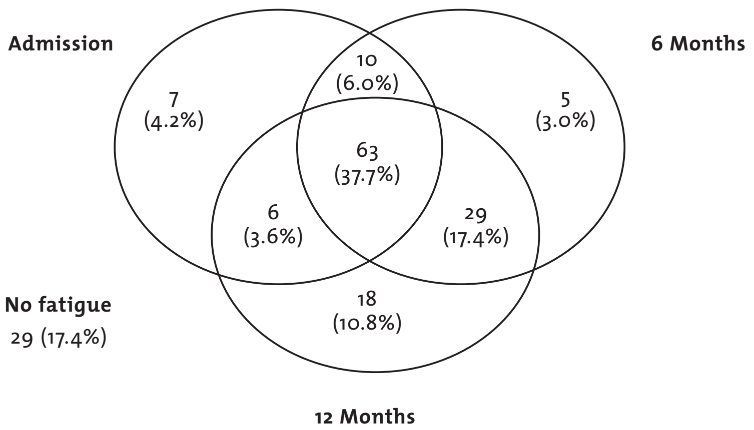

Table 3. Univariate and multivariate analyses between personal characteristics, stroke characteristics, and post-stroke impairments and the Fatigue Severity Score 1-year post stroke (N=167)

	Univariate analysis		Multivariate analysis	
Determinants	**Pearson r**	**P**	**ß**	**P**
Personal characteristics				
Age	.18	.02*†	.17	.02*
Sex (women)	.15	.06*†	.14	.06*
MHLC Internal subscale	-.07	.35†		NS
Chance subscale	.12	.12†		NS
Powerful Others subscale	.24	.002*†	.12	.09*
Comorbidity (present)	.04	.64		NA
Marital status (living with partner)	-.11	.18†		NS
Stroke characteristics				
Hemisphere (right)	.03	.73		NA
Type of stroke (ischemic)	.06	.41†		NS
Post-stroke impairments				
Motricity Index	-.05	.53		NA
Mini Mental State Examination	.03	.68		NA
TMT B Time	.03	.67		NA
Number of correct connections	-.03	.67		NA
CES-D	.39	<. 001*†	.34	<. 001*
Sleeping problems (present)	.12	.11†		NS

Abbreviations: MHLC = Multidimensional Health Locus of Control scale; TMT B = Trail Making Test Part B; CES-D = Center of Epidemiologic Studies Depression scale; NA = Not applicable; NS = Not significant

* P<0.1, † Determinants included in multivariate regression analysis

Regression analyses

Table 3 presents univariate correlation coefficients between FSS scores 1 year post stroke and the independent variables (ie, personal characteristics, stroke characteristics and post-stroke impairments.) The highest correlation coefficients were found for the CES-D, followed by the MHLC Powerful Others subscale and age. The variables included in the multivariate backward analysis were age, sex, all subscales of the MHLC, marital status, type of stroke, CES-D and sleeping problems. The multivariate model (see table 3) included age, sex, MHLC Powerful Others subscale and the CES-D, and explained 21% of the total variance (adjusted R^2 = .20) of FSS scores 1 year post stroke.

Discussion

The percentage of patients reporting fatigue increased over time: its prevalence increased from half of the patients at admission to two-thirds of the patients at 1 year post stroke. Fatigue impact scores increased significantly during the first year post stroke. Fatigue impact at 1 year post stroke was greater among patients with more depressive symptoms, higher age, female sex and patients with a locus of control more directed to powerful others. The prevalence of post-stroke fatigue was comparable to the estimates in the literature which range from 39 to 68%[1-4]. The relatively low percentage of 39% was found in a study that excluded patients who reported that they always felt depressed[3]. The impact of fatigue increased during the first year post stroke. This might be because in the first phase after their stroke, patients have to deal with many consequences. They could experience fatigue as a “minor” problem compared with their other impairments and functional limitations. At 1 year post stroke when most of the recovery has taken place, fatigue could remain as an important problem with disabling consequences for everyday life. The impact of fatigue could become more relevant as patients try to resume their work and social activities, and the demands of daily life increase.

In patient education, which is a first and important step in the management of fatigue problems, health care professionals must inform patients about the likelihood of experiencing fatigue after suffering a stroke, even long after the event. This will enable patients and their families to anticipate future problems and allows them to gain recognition for this problem. This may diminish distress and misunderstanding when fatigue problems occur[22].

Depression was an important determinant of fatigue impact in our study and this agrees with earlier findings[1-3]. Nevertheless, depression and fatigue must be seen as distinct post-stroke consequences[1-5] because three quarters of the patients with moderate to high fatigue impact were not depressed. Other factors were also related to post-stroke fatigue. The demographic variables age and sex were significantly related to post-stroke fatigue as was found by Glader et al[3]. Moreover our study investigated the health locus of control beliefs. The Powerful Others subscale, one of the externally orientated subscales, was found to be related to post-stroke fatigue. A higher belief of control directed to physicians was associated with higher levels of fatigue impact. Some others found associations between locus of control and health outcome. A high internal locus of control was associated with faster recovery from physical disability in stroke patients[23]. A low internal locus of control or high external locus of control was associated with more fatigue problems in patients with chronic fatigue syndrome[24] and with a chronic anxiety disorder[25]. A more favorable outcome was also shown to be related to high internal and low external control in other patient groups, i.e. patients with traumatic brain injury[26], spinal cord injury[27] and chronic low-back pain[28].

In clinical practice, stroke patients who have made a good physical recovery often have disabling fatigue problems. Patients with a lacunar infarction, who all had a maximum score on the Barthel Index, reported many emotional disturbances and fatigue problems[29]. Patients with good physical recovery seemed to be the most disabled by fatigue[6]. We did not find support for this idea, as motor impairment was not associated with fatigue impact. In our study population, patients with both good and poor motor recovery experienced fatigue problems.

Cognitive impairments were studied because on clinical grounds, it could be expected that these would be related to fatigue impact. Limited attentional capacity was found in patients with lacunar infarction who also reported fatigue[29]. As a result of cognitive problems many tasks cost more mental effort and it seems plausible that this would give rise to fatigue. However, we did not find a relation between fatigue impact and cognitive disorders. This might have been attributable to our assessment methods for cognitive impairments: the MMSE, which is only a global screening instrument, and one test for executive functioning (the TMT-B), were the instruments we used. To clarify the relation between cognitive impairments and post-stroke fatigue, additional research with more extensive neuropsychological assessments is needed.

The determinants depression, age, sex and locus of control explained one fifth of the variance of fatigue impact scores. Therefore, most fatigue impact remained unexplained. We expect that a number of factors we did not take into account might be associated with post-stroke fatigue. For example, the level of physical fitness[30,31] could be an important factor contributing to post-stroke fatigue. Fatigue could be the side effect of using certain medications[10]. Sleep apnea, which is commonly associated with stroke[8], might also be important[32]. Environmental factors and personal characteristics, such as coping strategies, might be relevant for post-stroke fatigue as well. Additional research is needed to clarify the impact of such factors on post-stroke fatigue.

We studied the factors potentially associated with post-stroke fatigue because exploring the underlying mechanism of post-stroke fatigue could support the development of intervention strategies. Depression is probably an important focus for interventions for post-stroke fatigue. It is known that depressive symptoms can improve with medication.

The preference is currently given to the selective serotonin reuptake inhibitors[5]. The question is whether administration of an antidepressant that alleviates the symptoms of depression could also reduce fatigue problems. There are indications that selective serotonin reuptake inhibitors sometimes reduce fatigue levels in patients with multiple sclerosis and cancer[10]. Additional research is needed to examine the effects of antidepressants on post-stroke fatigue in both depressed and non-depressed patients.
In addition to depression, locus of control could be an interesting focus for future interventions. Some consider locus of control to be a fairly stable psychological characteristic. However, it is far more likely that health locus of control beliefs can change over time. Changes in locus of control beliefs were found after dramatic illness-related experiences[33]. A multidisciplinary treatment program was shown to be effective in changing locus of control beliefs in chronic pain patients[34]. It would be interesting to investigate whether locus of control beliefs can be changed in stroke patients and whether these changes would have a positive effect on health outcome. Indications for this can be found in studies of other patient populations. In cancer patients, tailored counseling was shown to be effective with respect to locus of control and fatigue[35]. A mind-body wellness intervention for older adults with chronic illness led to a significant decrease in external locus of control and a decrease in sleeping problems, pain, anxiety and depression[36].

Conclusions

Fatigue is an important post-stroke impairment and its impact on every daily life increased during the first year post stroke. Depression, age, sex and health-related locus of control were related to post-stroke fatigue. Patient education on post-stroke fatigue should be routinely given to patients and their families. Depression and locus of control could become important foci for interventions. Future research should focus on a more detailed exploration of the determinants of post-stroke fatigue and on evaluating interventions for this.

Appendix

The Fatigue Severity Scale (FSS)

Statement
1. My motivation is lower when I am fatigued.
2. Exercise brings on my fatigue.
3. I am easily fatigued.
4. Fatigue interferes with my physical functioning.
5. Fatigue causes frequent problems for me.
6. My fatigue prevents sustained physical functioning.
7. Fatigue interferes with carrying out certain duties and responsibilities.
8. Fatigue is among my three most disabling symptoms.
9. Fatigue interferes with my work, family, or social life.

Patients are instructed to choose a number from 1 to 7 that indicates the degree of agreement with each statement where 1 indicates strongly disagree and 7 strongly agree.

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6

Functional recovery differs between ischemic and hemorrhagic stroke patients

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Submitted

Abstract

Background and Purpose Our study aimed to determine whether there is a difference between patients with a cerebral infarction (CI) and patients with an intracerebral hemorrhage (ICH) in a rehabilitation setting, in terms of the development of ADL independence over the first year post stroke.

Methods Patients with a first-ever stroke who were admitted to an inpatient rehabilitation program were included. The study had a longitudinal design and measurements took place at admission, 8, 10, 12, 26, and 52 weeks post stroke. The level of ADL independence was measured by the Barthel Index (BI). The relationship between the development of ADL independence over time and type of stroke was analyzed using Generalized Estimating Equations.

Results 229 CI patients and 45 ICH patients were included. From their admission to the rehabilitation center until 12 weeks post stroke, recovery tended to be more rapid for ICH patients than for CI patients. From 12 to 26 weeks post stroke, CI patients showed a significantly faster increase in BI scores. The time window for recovery of ADL independence was more restricted for ICH patients; a statistically significant increase in ADL was found until 10 weeks post stroke in ICH patients, whereas CI patients showed statistically significant recovery until 26 weeks post stroke.

Conclusions The differences in ADL recovery between CI patents and ICH patients should be taken into consideration in stroke management as regards selection for inpatient rehabilitation, prognosis of ADL recovery and differentiated planning of rehabilitation programs.

Introduction

Stroke is a major public health concern, being among the most common causes of death and disability in industrialized societies[1]. In general, strokes can be divided into those having an ischemic and those with a hemorrhagic origin. As the pathophysiological mechanism causing the brain damage is different for ischemic and hemorrhagic strokes, this distinction could be expected to have consequences for recovery and outcome. Differences between these two types of stroke are known for mortality, in that the mortality rate from hemorrhagic stroke is higher than that from ischemic stroke[2]. In the hospital population, hemorrhagic stroke patients generally have more severe neurological impairments during the acute phase than ischemic stroke patients[2]. From the perspective of rehabilitation medicine, it is more important to know what the differences are in terms of functional recovery. Detailed knowledge on the precise course of functional recovery, and the differences in this respect between ischemic and hemorrhagic strokes, would be of practical use to physicians, as it would enable them to develop a more differentiated prognosis and rehabilitation program.

Earlier studies[3-9] of functional recovery in the rehabilitation setting have assessed ADL scores, using the Functional Independence Measure or the Barthel Index (BI), at rehabilitation admission and discharge. The rate of recovery was then determined by dividing the gain in ADL scores by length of stay at the rehabilitation center. Some studies[5,6] showed that patients with an intracerebral hemorrhage (ICH) had a higher rate of recovery than patients with a cerebral infarction (CI), whereas other studies[3,7,9] found no differences in rate of recovery between the two types of stroke. Comparisons of the findings of these studies are complicated by the fact that they did not use fixed measurement times but the moments of admission and discharge, which can vary. Consequently, both the interval from stroke onset to admission, and the length of stay differed greatly between the studies, with periods of inpatient rehabilitation varying from on average the 2nd until the 7th week post stroke in the study by Ween et al[7], to on average the 10th until the 27th week post stroke in the study by Inouye et al[8]. Improving our understanding of the development of ADL independence over time thus requires longitudinal studies in the rehabilitation setting with serial assessments at fixed moments in time.

Our study aimed to determine whether there is a difference between CI patients and ICH patients in a rehabilitation setting regarding the development of ADL independence over the first year post stroke.

Methods

Participants

Subjects were selected from stroke patients consecutively admitted to four Dutch rehabilitation centers according to the following inclusion criteria: (1) admittance for inpatient rehabilitation, (2) a first-ever stroke due to CI or ICH, (3) a one-sided supratentorial lesion, and (4) age above 18 years. Exclusion criteria were (1) disabling comorbidity (prestroke BI score below 18) and (2) inability to speak Dutch. The medical ethics committees of University Medical Center Utrecht and the participating rehabilitation centers approved the study.

Procedure

At the start of inpatient rehabilitation, patients were asked by their rehabilitation physician whether they were willing to participate in the study. Informed consent was obtained from all patients. For patients with communication problems, both the patient and a proxy gave informed consent. The first assessment took place as soon as possible after admission. The scoring of ADL independence was repeated at 8, 10, 12, 26, and 52 weeks post stroke. All assessments were carried out by trained research assistants.

Measures

Type of stroke. Stroke was defined according to the World Health Organization criteria: rapidly developing clinical signs of focal disturbance of cerebral function, lasting more than 24 hours, with no apparent cause other than vascular origin. Patients were classified as having a CI or an ICH based on information from the referral letter from the hospital, including the imaging findings.

Baseline characteristics. Data on demographic variables were derived from medical charts. The Motricity Index (MI)[10,11] is a brief assessment method for motor impairment. The score for the level of hemiparesis varies from 0 (paralysis) to 100 (normal strength). Cognitive impairments were assessed by the Mini Mental State Examination (MMSE)[12], a widely used brief screening instrument. A score below 24 on the MMSE indicates the presence of cognitive impairments.

Outcome. The level of ADL independence was measured with the Barthel Index (BI)[13], with scores ranging from 0 to 20. The reliability and validity of the BI have been adequately established[13,14].

Statistical analyses

Independent samples T tests, Mann-Whitney U test, and Pearson chi-square tests were used to detect differences in baseline characteristics between the two stroke types.

The relationship between the development of ADL independence over time and the type of stroke was analyzed using Generalized Estimating Equations (GEE). GEE is a statistical technique for longitudinal data analysis, which takes into account that the repeated observations within one subject are not independent. A correction for these within-subject correlations was made by using an exchangeable working correlation structure in the GEE analysis. The advantage of using GEE instead of General Linear Models for repeated measurements is that all subjects are included in the analysis, regardless of missing values. Since we assumed that the development of ADL independence (i.e. the BI) over time was a non-linear function, time was added to the model as a categorical variable, modeling each time interval separately. For each time interval, we analyzed whether the ADL independence developed differently over time in the two types of stroke, by including interaction terms in the model. GEE analysis was carried out with STATA version 7[15].

Results

A total of 274 patients were included: 229 CI patients and 45 ICH patients. At one year post stroke, seven patients had died, 13 had suffered a recurrent stroke, and 20 were lost to follow-up.

Baseline characteristics (table 1) were not significantly different for CI and ICH patients, except for the time interval between stroke onset and admission to the inpatient rehabilitation program. The CI patients were admitted at a median of 6 weeks post stroke and the ICH patients at a median of 7 weeks post stroke ($p<0.05$).

The observed BI scores used to model the development of ADL independence over time are presented in Table 2. Figure 1 shows the modeled development of the BI over the first year post stroke for CI patients and ICH patients, based on the GEE analysis. No significant effect of group, (i.e. type of stroke) was found. A significant effect of time was found for both the CI and ICH patients (table 3). Among the CI patients, BI showed a significant increase over time until 26 weeks post stroke, whereas for the ICH patients, a significant increase in BI was found only until 10 weeks post stroke. The only significant effect of interaction between group and time was found between 12 and 26 weeks (figure 1). Over this interval, the BI of the CI patients increased more than that of the ICH patients. In the first three intervals shown in figure 1, the BI of the ICH group tended to increase more rapidly than that of the CI group, though these differences between the groups were not statistically significant.

Table 1. Comparison of baseline characteristics of patients with a cerebral infarction and patients with an intracerebral hemorrhage at admission to inpatient rehabilitation

	Cerebral infarction (N = 229)	Intracerebral hemorrhage (N=45)
Sex (% male)	65.1	64.4
Mean age ± SD (y)	57.5 ± 10.9	56.0 ± 10.5
Marital status (% living with partner)	72.0	73.3
Hemisphere (% right)	48.9	33.3
Mean Motricity Index ± SD	47.5 ± 28.7	53.6 ± 29.6
Mean Mini Mental State Examination ± SD	26.0 ± 2.7	26.3 ± 2.6
Mean Barthel Index ± SD	12.9 ± 4.5	13.7 ± 5.1
Weeks post stroke, median (range)*	6 (2-19)	7 (3-20)

Abbreviations: SD, standard deviation; y, years

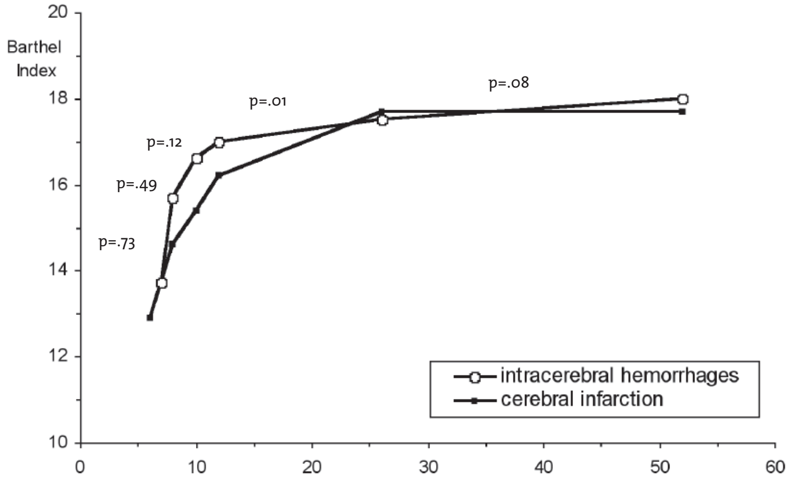
* $p < 0.05$

Table 2. Barthel Index (BI) of patients with a cerebral infarction and patients with an intracerebral hemorrhage, observed at baseline and 8, 10, 12, 26, and 52 weeks post stroke

	Cerebral infarction		Intracerebral hemorrhage	
Time post stroke	**N**	**Mean BI ± SD**	**N**	**Mean BI ± SD**
Baseline	229	12.9 ± 4.5	45	13.7 ± 5.1
8 weeks	182	14.8 ± 4.5	33	16.3 ± 4.9
10 weeks	201	15.5 ± 4.4	37	17.4 ± 4.0
12 weeks	207	16.2 ± 4.2	42	17.4 ± 4.0
26 weeks	213	17.6 ± 2.8	44	17.5 ± 4.0
52 weeks	193	17.7 ± 3.0	40	18.5 ± 2.5

Abbreviation: SD, standard deviation

Figure 1. Modeled development of the Barthel Index over the first year post stroke for patients with a cerebral infarction and patients with an intracerebral hemorrhage



P-values concern the difference between the two patient groups in development over a particular time period

Table 3. Changes in Barthel Index over the first year post stroke in patients with a cerebral infarction and patients with an intracerebral hemorrhage

	Cerebral Infarction			Intracerebral hemorrhage		
Time interval post stroke	**ß**	**SE**	**P**	**ß**	**SE**	**p**
Baseline – 8 weeks	1.72	0.19	0.00	1.92	0.55	0.00
8 – 10 weeks	0.74	0.16	0.00	0.99	0.32	0.00
10 – 12 weeks	0.79	0.14	0.00	0.35	0.26	0.17
12 – 26 weeks	1.54	0.20	0.00	0.48	0.36	0.19
26 – 52 weeks	0.002	0.14	0.99	0.62	0.33	0.06

Abbreviation: ß, regression coefficient for the effect of time; SE, Standard Error

Discussion

The development of ADL independence from the moment of admission for inpatient rehabilitation until 26 weeks post stroke differed between CI patents and ICH patients. During the period until 12 weeks post stroke, recovery tended to be more rapid for ICH patients than for CI patients, although the difference was not statistically significant. From 12 to 26 weeks post stroke, CI patients showed a statistically significantly faster increase in BI scores. The time window for recovery of ADL independence was more restricted for ICH patients; an increase in ADL independence was found until 10 weeks post stroke in ICH patients, whereas CI patients showed recovery until 26 weeks post stroke.
To our knowledge, this is the first longitudinal study to compare the development of ADL over time between CI and ICH patients. Although two other longitudinal studies[16,17] did examine the pattern of ADL recovery in stroke patients among a hospital population, they did not study the differences between the types of stroke. The Copenhagen Stroke Study[16] analyzed the development of ADL over time for all stroke patients, both CI and ICH, as one group. The study by Kwakkel et al.[17] only included stroke patients who had suffered a primary ischemic middle cerebral artery stroke.
Like Jorgensen et al.[16] and Kwakkel et al.[17], we found that the development of ADL over time shows a non-linear pattern. The cause of this non-linear pattern of recovery is insufficiently understood. Recent findings suggest that the pattern is mainly determined by 'spontaneous neurological recovery'[18] and much less by the type and level of therapy[19]. An examination of the pathophysiological processes in stroke, and especially the differences in these processes between CI and ICH, suggests a possible explanation for our findings of different recovery patterns in the two types of stroke. In ICH, the increase in intracranial pressure due to the space-occupying effect of the hematoma on the brain tissue plays a major role in the pathophysiological process[20]. As the hematoma resolves and edema diminishes in the acute phase, the brain tissue can be expected to partially or wholly restore its function. In clinical practice, a relatively sudden and rapid recovery of neurological signs and symptoms is seen in ICH patients. We also observed a somewhat faster recovery of ADL from rehabilitation admission up to 12 weeks post stroke in the ICH group. In CI, by contrast, the damage to the brain tissue itself, caused by the infarction, plays the main role in the pathophysiology. The lesioned area will partly recover as a result of tissue repair and recovery of penumbral tissues, but permanent damage will also be present as scar tissue is formed. We did indeed observe a more gradual and longer pattern of recovery in the CI group. Whereas the ICH patients reached the plateau phase at 10 weeks post stroke, the CI patients still showed ADL recovery up to 26 weeks post stroke.
In interpreting our results, several limitations of the study must be considered. First, functional recovery was assessed with the BI, which is a well-known and frequently used

measure to describe the functional status in stroke patents[21]. However, since the BI measures ADL independence, our study provides just a partial examination of the differences in functional recovery. Other areas of functioning still have to be examined to get a more comprehensive assessment of potential functional differences between CI and ICH. In addition, the BI is particularly suitable for use in the acute and subacute phases, whereas for later phases, one must consider the known ceiling effect of the BI, which causes the variation of BI scores to decrease over time (table 2). Second, the baseline variables were not assessed at a fixed time point, but at the moment of admission to the rehabilitation center, which can vary. As this time point was significantly different for CI and ICH patients (ICH patients being admitted an average of one week later than CI patients), this complicates the interpretation of the differences in ADL development during the first time interval. Thirdly, the number of ICH patients included was relatively small compared to the number of CI patients. As a result, potentially important differences between the two types of stroke could nevertheless be statistically non-significant.

Finally, our study was carried out in a selected stroke population, namely those in rehabilitation. The rehabilitation population has specific characteristics[22], in that the patients are relatively young and on average moderately disabled. Differences in neurological functions between CI and ICH patients which are found in the hospital population[2] were not found in our rehabilitation population. This is probably the result of the selection procedure for rehabilitation[23] at the hospital. Factors considered in this selection process include the severity of neurological impairments and the functional recovery, rather than the type of stroke. Our study provides no information on the period before inpatient rehabilitation, that is, the hospital stay, and it is likely that important differences in functional development between CI and ICH can also be found in this acute phase.

In the acute phase, the first step in stroke management is to differentiate between ischemic strokes and intracerebral hemorrhages[20]. Diagnosing the pathological type of stroke in the hospital phase is important, as this influences decisions about medical and surgical treatment. This contrasts with the rehabilitation phase, in which little attention is given to the differences between CI and ICH. The triage for rehabilitation does not take the pathological type of stroke into account, and after selection for inpatient rehabilitation, both patient groups generally follow a similar rehabilitation program. However, in view of the findings of this study, the pathological type of stroke must also be considered in the stroke management in the rehabilitation setting. Considering the small time window for ADL recovery in ICH patients, they should perhaps be selected for rehabilitation at an earlier stage than CI patients. Moreover, the planning of the rehabilitation program should differentiate more fully between ICH patients and CI patients, as the ICH patients mostly reach the plateau phase of ADL recovery within three months, compared to six months for the CI patients.

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7

General Discussion

This chapter recapitulates the main conclusions of the thesis. It discusses the strengths and limitations of the research project and considers the implications for stroke care and future research.

General conclusions

Clinimetrics

Our comparison of the responsiveness of a number of functional health status measures, namely the Barthel Index (BI), Functional Independence Measure (FIM), Frenchay Activities Index (FAI) and Stroke-Adapted Sickness Impact Profile 30 (SASIP30), had led to the following conclusions. The BI, FIM total and FIM motor score, FAI and SASIP30 were responsive measures. We recommend the BI in the subacute phase and the FAI and SASIP30 in the chronic phase, especially for the stroke rehabilitation population (Chapter 2). We also explored the relationship between the International Classification of Functioning, Disability and Health (ICF) model and outcome measures that are frequently used in stroke rehabilitation and focus on activities and participation. We compared the content of the Barthel Index (BI), Berg Balance Scale (BBS), Chedoke McMaster Stroke Assessment Scale (CMSA), Euroqol-5D (EQ5D), Functional Independence Measure (FIM), Frenchay Activities Index (FAI), Nottingham Health Profile (NHP), Rankin Scale (RS), Rivermead Motor Assessment (RMA), Rivermead Mobility Index (RMI), Stroke Adapted Sickness Impact Profile 30 (SASIP30), Medical Outcomes Study Short Form 36 (SF36), Stroke Impact Scale (SIS), Stroke Specific Quality of Life Scale (SSQOL) and the Timed Up and Go test (TUG) by linking them to the ICF. Most constructs of these functional outcome measures were covered by the ICF model, except those of the RS. Most linked constructs fitted into the activities and participation component, with mobility being the category most frequently covered in the instruments, followed by self-care. Although the outcome measures had been selected on the basis of their focus on activities and participation, a quarter of the constructs addressed the body functions categories. Approximately one tenth of the constructs could not be linked to the ICF. The RS, although widely used in stroke research, should only be viewed as a global functional health index and is therefore of limited value to rehabilitation. Clinicians and researchers who need to select an outcome measure have to be aware of the constructs covered by an instrument and the areas it fails to cover. Our content comparison enables them to choose the appropriate measure that best matches their area of interest (Chapter 3).

Determinants of outcome

We have developed an easy-to-use score chart to identify, at the start of inpatient rehabilitation, which patients are at risk for social inactivity one year post stroke. The chart includes the following prognostic determinants: sex, age, marital status, motor impairment as measured by the Motricity Index (MI), level of communication as measured by the Utrecht Communication Observation scale (UCO) and the level of ADL independence as measured by the BI. The chart proved to be well able to discriminate patients with poor social functioning from those with moderate to good social functioning. Identifying patients at risk enables health care professionals to focus on the social activity of this patient subgroup at an early stage in the care process (Chapter 4).

The percentage of stroke patients reporting fatigue was shown to increase over the first year post stroke: its prevalence rose from half of the patients at admission to two thirds at one year post stroke. The impact of fatigue at one year post stroke was greater among patients with more depressive symptoms, those of more advanced age, female patients and patients with a locus of control more directed towards powerful others. We concluded that information on post-stroke fatigue should be routinely given to patients and their families. Depression and locus of control could become important foci for future interventions and research on post-stroke fatigue (chapter 5).

Our study showed that the recovery of ADL independence differed between patients with a cerebral infarction (CI) and patients with an intracerebral hemorrhage (ICH). From their admission to inpatient rehabilitation until 12 weeks post stroke, recovery tended to be more rapid for ICH patients than for CI patients, although the difference was not statistically significant. From 12 to 26 weeks post stroke, CI patients showed a statistically significantly faster increase in BI scores. The time window for recovery of ADL independence was more restricted for ICH patients; an increase in ADL independence was found until 10 weeks post stroke in ICH patients, whereas CI patients showed recovery until 26 weeks post stroke. The final BI scores at one year post stroke were similar for both patient groups. In interpreting BI scores in the later post–stroke phases, the known ceiling effect must be taken into account. In the rehabilitation phase, little attention is usually given to the differences between CI and ICH, and both patient groups generally follow a similar rehabilitation programme. However, in view of the findings of this study, the pathological type of stroke must be considered in the rehabilitation setting. The planning of rehabilitation programmes should differentiate between ICH patients and CI patients, as most ICH patients reach the plateau phase of ADL independence within three months after stroke, compared to six months for the CI patients (chapter 6).

Strengths and considerations

Longitudinal design

The most important strength of the FuPro-stroke study is its longitudinal design. Longitudinal studies are defined as studies in which the outcome variable is repeatedly measured[1]. The baseline assessment took place at admission to inpatient rehabilitation. The second and third assessments were at fixed points in time, namely six months and one year post stroke. In addition, the BI was scored at three extra fixed time points, namely 8, 10 and 12 weeks post stroke.

The decision to use a longitudinal design was made for several reasons. First, the longitudinal design made it possible to answer prognostic questions. We identified six prognostic factors at the start of rehabilitation which were able to predict the level of social activity one year post stroke (chapter 4).

Second, the longitudinal design gave us the opportunity to examine the responsiveness of measurement instruments. Responsiveness can be seen as longitudinal validity and refers to an instrument's ability to detect relevant changes over time. The strength of our study was that various frequently used outcome measures were assessed simultaneously in the same study population. This design made it possible to compare the responsiveness of various instruments, i.e. to determine their relative responsiveness, as the estimates of responsiveness are likely to be affected by characteristics of the sample and by the methods for calculating responsiveness[2].

The third reason to design a longitudinal study was the possibility to examine the individual development of several characteristics over time. It allowed us to study the development of fatigue (chapter 5) and the development of ADL independence (chapter 6).

The statistical techniques used to explore this longitudinal development over time differed between the analysis of the development of fatigue and that of the development of ADL independence. The development of fatigue was analysed using MANOVA for repeated measurements, while the development of ADL over time was studied with Generalised Estimating Equations (GEE). In comparison with MANOVA for repeated measures, GEE is a relatively new and more sophisticated statistical technique for longitudinal data analysis. Both take into account that the repeated observations within one subject are not independent. However, one of the problems with MANOVA for repeated measures is that time periods are weighted equally. Hence, when the time periods are unequally spaced, the interpretation of the results of the MANOVA for repeated measures becomes problematic. Another advantage of GEE is that all subjects are included in the analysis, regardless of missing values. This is the reason why we decided to use GEE for the analysis of the development of ADL independence over time. For the analysis of the development of fatigue we decided to use the more well-known MANOVA for repeated measures as we had relatively few missing values in the fatigue data.

Some comments need to be made on the moment of assessment of baseline data. The reason for gathering the baseline data on admission to the rehabilitation center was that our stroke population of interest was the rehabilitation population, which was not clearly defined until rehabilitation admission. A consequence of this choice was that we had no information on patients' functioning in the early stages after stroke onset. Moreover, the baseline measurement was not a fixed point in time, but the variable moment of admission to the rehabilitation center, which has to be taken into account in the interpretation of the results. Across the total study population, the inclusion took place at a median of 4.2 weeks post stroke (range: 1.1 – 22.0 weeks). This is in contrast to the recommendation to include stroke patients in an inception cohort as soon as possible, preferably within two weeks from stroke onset[3], making it possible to include information on patients' functioning in the early stages after stroke onset in the analyses.

Rehabilitation population

We included stroke patients who were admitted for inpatient rehabilitation to Dutch rehabilitation centers, which reduces the generalisability of the results to the whole stroke population.

Almost every patient with a suspected stroke is admitted to hospital for rapid diagnosis and treatment. In the acute phase after stroke, a well-considered decision must be made on the optimal discharge destination. The decision about discharge destination is made by the rehabilitation physician and the multidisciplinary treatment team at the stroke unit. However, selection criteria for inpatient rehabilitation are not well-defined[4]. Recently, Meyer et al[5] (2005) developed the Stroke-unit Discharge Guideline, which provides a patient profile that could be used as a basis to establish a patient's prognosis and consequently for the decision on discharge destination. However, the Stroke-unit Discharge Guideline does not describe the specific selection criteria for inpatient rehabilitation either. Criteria derived from clinical practice that play a major role in this selection process are: (1) the patient cannot be discharged home, but is expected to return home in view of the prognosis and availability of caregivers; (2) the patient is able to learn and is sufficiently motivated; (3) the patient has sufficient vitality; (4) the rehabilitation goals are complex and need a multidisciplinary approach; (5) return to work may be possible; (6) a relatively high rate of rehabilitation is possible[6].

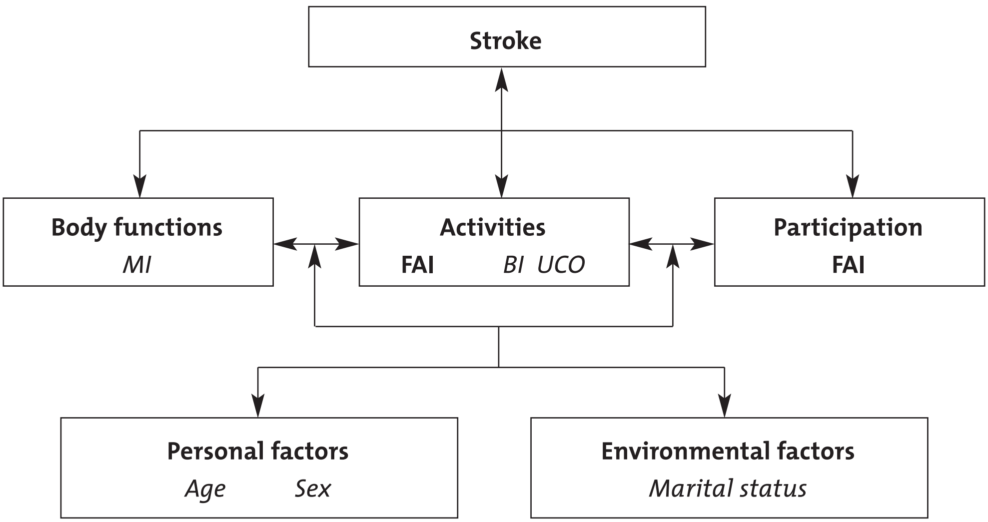
An examination of discharge destinations[7] showed that about 60% of the stroke patients who survived the hospital phase were eventually discharged home, while 26% were referred to a nursing home and only 14% were discharged to a rehabilitation center. Compared to patients who were discharged home, patients referred to a rehabilitation center were often younger and more frequently ADL-disabled at discharge. Most rehabilitation patients were eventually discharged home and survived up to 5 years post stroke[7]. The survival rate in the rehabilitation patients was comparable to that among the patients directly discharged home.
Although our study concerned a selected group of stroke patients, this group is very relevant for the rehabilitation setting, as one quarter of the rehabilitation center beds in the Netherlands are occupied by stroke patients[8]. An important aspect of our study was that we were able to assess the characteristics of stroke patients in rehabilitation in the Netherlands, which were relatively unknown. These patients were moderately disabled in terms of ADL (Table 1, chapter 4.) They were relatively young: on average 56 years of age, in contrast to the total population of hospitalised stroke patients in the Netherlands, who are on average 70 years of age[9]. Three quarters of the patients had a partner and almost half of them were employed before their stroke.
Patients with aphasia and communication problems form an important subgroup in the rehabilitation population. In contrast to many other stroke studies, our study did not exclude patients with aphasia in advance. In our population, about one third of the patients had aphasia or communication problems at baseline that meant that certain assessments (BI, FIM, FAI and SA-SIP 30) could not be done in these patients and proxy ratings had to be used. However, since some assessments of more subjective aspects could not be done in proxies either, data on depression and fatigue and on the cognitive tests were missing for this subgroup. There is no consensus on the use of proxy ratings in the literature[10,11]. However, considering the importance of the subgroup and the fact that the collection of information on these patients in clinical practice also depends on proxies, we decided to use proxy ratings rather than exclude these patients. Including patients with communication problems gave us the opportunity to describe the baseline characteristics, outcome and prognosis of the entire rehabilitation population.

ICF

The ICF[12], published in 2001, is a framework and classification system that was developed by the World Health Organization. Its predecessor, the International Classification of Impairments, Disabilities and Handicaps[13] (ICIDH), published in 1980, was developed to meet the need for information about non-fatal health outcomes. Health is a concept that concerns both how long one lives and how well one lives[14]. The latter refers to a

person's level of functioning and their self-perceived well-being. Many diseases do not kill but cause limitations in people's ability to function in everyday life. This is the focus of rehabilitation medicine, both in clinical practice and in research. The ICF is a framework that is highly suitable for use in rehabilitation medicine, as it classifies health components, i.e. body functions and structures, activities and participation, and also places them in the context of personal and environmental factors.
From our experience with the ICF, we conclude that it is highly useful, both in research and clinical practice. We applied the ICF as a framework to compare the contents of functional outcome measures, and proved it was possible to relate many constructs in the functional outcome measures to the ICF categories (chapter 3). The value of this framework can be further illustrated by putting two of the answers to our research questions into an ICF perspective. The first is the answer to the question how to predict patients' social activity (chapter 4), which we assessed using the FAI. Our study of the content of the FAI (chapter 3) showed that it addresses mobility, domestic and social life, and measures at the level of activities and participation (figure 1). Furthermore, the prediction model included the following prognostic determinants: the Motricity Index

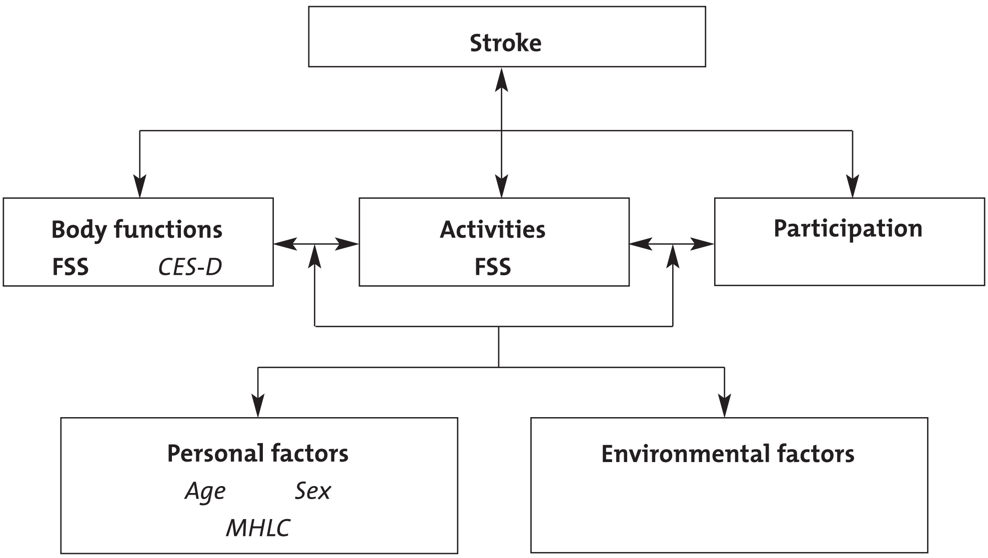
Figure 1. Prediction model for social activity as measured by the FAI in ICF perspective



Abbreviations: MI, Motricity Index; FAI, Frenchay Activities Index; BI, Barthel Index; UCO, Utrecht Communication Observation scale comes under the body function category; the Utrecht Communication Observation scale and most of the BI come under activities; age and sex are personal factors; and finally marital status falls under the environmental factors. Figure 1 shows how the outcome measure and determinants are related to each other in the ICF model. Figure 2 shows the determinants of post-stroke fatigue (chapter 5) from the ICF perspective. Fatigue was assessed with the Fatigue Severity Scale (FSS). Although in terms of the ICF categories, the construct of fatigue falls under body functions, many items of the FSS also involve constructs of activities and participation. The FSS actually examines the 'strength' of the relation between fatigue as a body function and a patient's level of activity and participation.

The above examples all show how the ICF can be used to structure research results. But the ICF can also be valuable in clinical practice. In team communication, which is a key process in rehabilitation[15], the ICF model is a workable instrument to obtain a good overview of a patient's situation[16]. An overview in ICF perspective facilitates the clinical analysis of a patient's problems. By relating activities and participation to important (modifiable) determinants, one can derive possible therapeutic targets[17].

Figure 2. Determinants of fatigue one year post stroke as measured by the FSS in ICF perspective



Abbreviations: FSS, Fatigue Severity Scale; CES-D, Center of Epidemiologic Studies Depression scale; MHLC, Mulidimensional Health Locus of Control scale

Implications for stroke care and future research

Clinimetrics

Clinimetrics is the field of developing, evaluating and applying measurement instruments. In recent years, there is a growing recognition that measurement instruments should be applied in stroke care. Some recent developments illustrate this trend in rehabilitation care. The stroke guidelines of the Netherlands Heart Foundation 'Rehabilitation after Stroke[6]' published in 2001, provide several recommendations on the use of measurement instruments in the care process. For example, recommendation no. 11 says: 'The opinion of the working group is that for every stroke patient, at least the BI should be used to record the basic physical disabilities.' The national stroke guidelines for physical therapy[18], published in 2004, recommend seven basic measurement instruments, including the MI, the Trunk Control Test and the BI. The Stroke Unit Discharge Guideline[5] (2005) recommends the use of various instruments in the hospital stroke unit to obtain a patient profile that could form the basis for a functional prognosis. The National ICT Institute in Care recently developed a digital application with which this guideline can be applied to electronic patient records.

Because of these developments, many professionals are nowadays increasingly inclined to apply measurement instruments in their daily routines. This could improve the quality of care for stroke patients. To further stimulate clinimetrics in stroke care, I would like to make some recommendations for the professionals:

- Professionals should be encouraged to use measurement instruments. The first step could be to fully implement all stroke guidelines regarding clinimetrics. This would greatly increase the practical experience with clinimetrics in care.
- Physicians and therapists should use the findings in the communication with patients and their families. For example, the use of a measurement instrument for fatigue (such as the FSS) in the consulting room could be very helpful to discuss a complex subject like fatigue. Goal-setting in the domain of social activities could be made easier by scoring the FAI and comparing the findings with the prestroke FAI. Measurement instruments which assess problems in different domains could be helpful in prioritising the problems to establish adequate therapy planning.
- Not only the scoring of the instruments itself is important in this respect, but even more so the clinical interpretation of the scores. In other words, much more attention must be given to the meaning of the findings obtained by the instruments for individual patients. Does a BI score of 14 mean that a patient can be discharged from the hospital to his home? Unfortunately, this step (translating the scores into what it means for a patient) has so far often been omitted, although it is an important step if clinimetrics is to provide added value in clinical practice. To help the users of measurement instruments with the interpretation of the findings of instruments

manuals and training courses on the application of measurement instrument should devote more attention to the clinical implications of scores.
- The scores on the various instruments applied by different therapists must be collected and studied in the total context of the patient, as the individual results only achieve their full value when they are studied in relation to each other. Rehabilitation physicians and their teams could employ the ICF model as a helpful framework. For example: with the BI score of 14, as mentioned above, the rehabilitation team can only advise whether or not to discharge home after evaluating other information e.g. on cognition and the environmental factors of the patient.

Moreover, some recommendations could be made for both professionals and researchers:
- Future research should give more insight in the purpose of measurement instruments. Instruments can generally have three purposes: to discriminate between individuals; to predict outcome; and to evaluate within-person change over time. In selecting and applying an instrument, it is important for professionals to realise for what purpose the instrument was developed[19].
- For the interpretation of change scores, professionals should realise that measurement error will be greater in clinical practice than in research. This greater measurement error hampers the ability to detect changes in individual patients[20]. More emphasis should be placed not only on changes beyond measurement error, but also on the clinical relevance of changes, in other words what change means a real difference in the lives of patients and their families. To encourage clinical interpretation of change scores, research reports on measurement instruments should show the minimal important difference, which is the smallest change that is considered to be worthwhile or important to a patient[21].

Determinants of outcome

Prognostic determinants

Most prognostic models are unattractive for use in clinical practice[22]. As we wanted to develop a prediction rule that would be easy to use in clinical practice, we chose determinants that can easily be collected, also in patients with aphasia, and we constructed a score chart from the prediction model. The use of this score chart is recommended in inpatient rehabilitation to identify the patients at risk for social inactivity. However, the eventual purpose of a prediction rule is not only to give a prognosis but also to suggest a diagnostic or therapeutic course of action. Before a clinical prediction rule can also be applied as a tool for clinical decision making, future research should evaluate its actual effect on patient care[23].

Furthermore, other easy to use models should be developed to predict functional outcome in other areas. The findings of the FuPro-stroke study could for example be used to develop a score chart for ADL dependence. For clinical practice it would be relevant to know at an early stage which patients will remain ADL-dependent in the long term, as one third of our stroke patients were still ADL-dependent (BI <19) one year post stroke.

Fatigue
We showed that fatigue is an important sequela even one year post stroke. Information on post-stroke fatigue should therefore be routinely given to patients and their families. For this purpose, a Dutch stroke patient association, called Samen Verder, has developed a brochure about post-stroke fatigue, in cooperation with some researchers of the FuPro-stroke study. Future research on fatigue should explore the relation between fatigue on the one hand and physical fitness and personal factors on the other. In addition, intervention studies should evaluate therapeutic strategies for post-stroke fatigue.

Personal and environmental factors: potentially important determinants
In rehabilitation medicine, there is growing attention for personal factors and the patient's environment[24,25]. The fact that the ICF model, unlike its predecessor the ICIDH, takes personal and environmental factors into account, is in my opinion also a major advantage. Future research should explore, however, how these contextual factors relate to patient functioning. It would be interesting to investigate whether therapies focusing on these factors have positive effects on patients' functioning.

- The influence of a partner on a patient's functioning needs to be investigated. We plan to use data of the FuPro-stroke study and the FuPro-stroke caregiver study to explore this relation.
- Locus of control, which is a psychological characteristic related to a patient's coping style, is a determinant of post-stroke fatigue. An interesting topic for future research would be whether locus of control beliefs and coping styles can be changed in stroke patients and whether these changes would have a positive effect on health outcomes.
- Self-management strategies focussing on problem-solving skills should be evaluated in stroke patients[26,27]. We increasingly believe that stroke is a chronic condition. Therefore, it is important to learn patients and their families how to manage their own problems on a day-to-day basis.

To make further progress in rehabilitation, I have the strong feeling that one of the most important challenges is to bridge the gap between research and clinical practice. A continuous interaction between professionals and researchers is needed. Together we should aim at common goals and a common language, to translate questions from care into research questions and to translate research findings into clinical practice.

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Summary

This thesis is based on findings of the FuPro-stroke study (Functional Prognostication and disability study on stroke). The FuPro-stroke study, started in 2000, had two main objectives: (1) to examine which outcome measures are most appropriate, and especially most responsive, for the assessment of functional outcome in stroke patients and (2) to study prognostic determinants of functional outcome and recovery after stroke. A total of 308 stroke patients were included. These patients were followed from admission to the rehabilitation center up to one year post stroke. The inclusion criteria were: (1) admittance for inpatient rehabilitation, (2) a first-ever stroke, (3) a one-sided supratentorial lesion and (4) age above 18.

In chapter 2 we compared the responsiveness of several functional outcome measures frequently used in stroke research, namely the Barthel Index (BI), Functional Independence Measure (FIM), Frenchay Activities Index (FAI) and Stroke-Adapted Sickness Impact Profile 30 (SASIP30). Ceiling effects and responsiveness, quantified by effect sizes, were studied for the periods between rehabilitation admission and 6 months post stroke (subacute phase) and between 6 months and 1 year post stroke (chronic phase). Effect sizes in the subacute phase were similar and were classified as large for the BI, FIM total and FIM motor score. The FIM cognitive score showed a considerable ceiling effect and had the smallest effect size in the subacute phase. In the chronic phase, the FAI and SASIP30 detected the most changes and had moderate effect sizes. We concluded that the BI, FIM total and FIM motor score, FAI and SASIP30 were responsive measures. We recommend the use of the BI in the subacute phase and the use of the FAI and SASIP30 in the chronic phase.

In chapter 3 we examined the content of outcome measures that are frequently used in stroke rehabilitation and focus on activities and participation, by linking them on item level to the categories of the International Classification of Functioning, Disability and Health (ICF). The ICF contains four components: body functions; activities and participation; environmental factors; and personal factors. The constructs within the items of the following instruments were linked to the ICF: Barthel Index (BI), Berg Balance Scale (BBS), Chedoke McMaster Stroke Assessment Scale (CMSA), Euroqol-5D (EQ5D), Functional Independence Measure (FIM), Frenchay Activities Index (FAI), Nottingham Health Profile (NHP), Rankin Scale (RS), Rivermead Motor Assessment (RMA), Rivermead Mobility Index (RMI), Stroke Adapted Sickness Impact Profile 30 (SASIP30), Medical Outcomes Study Short Form 36 (SF36), Stroke Impact Scale (SIS), Stroke Specific Quality of Life Scale (SSQOL) and Timed Up and Go test (TUG). It proved possible to link most constructs to the ICF. Most constructs fitted into the activities and participation component,

with mobility being the category most frequently covered in the instruments. Although instruments were selected on the basis of their focus on activities and participation, 27% of the constructs addressed categories of body functions. Approximately 10% of the constructs could not be linked, mostly because the constructs were too generally formulated. The conclusion is that the ICF is a useful tool to examine and compare contents of instruments in stroke rehabilitation. This content comparison should enable clinicians and researchers to choose the measure that best matches the area of their interest.

Chapter 4 reports on the development of an easy-to-use prediction rule for social activity 1 year post stroke that could identify, at the start of inpatient rehabilitation, patients at risk for social inactivity. Social activity was measured by the Frenchay Activities Index (FAI) at 1 year post stroke. Potential prognostic factors measured at admission were sex, age, marital status, prestroke employment status, educational level, type of stroke, hemisphere, motor impairment, trunk control, communication and activities of daily living (ADL) dependence. From the multivariate backward linear regression analysis was concluded that older patients, males, patients living with a partner, and patients with more problems with motor function, with communication and with ADL independence were more at risk for a worse FAI score 1 year post stroke. An easy-to-use score chart was constructed which could identify patients at risk for social inactivity. The score chart proved to be well able to discriminate poor social functioning from moderate to good social functioning. Identifying patients at risk allows health care professionals to focus on the social activity of this patient subgroup at an early stage in the care process.

Chapter 5 describes the course of fatigue during the first year post stroke and the relation between fatigue at 1 year post stroke and personal characteristics, stroke characteristics, and post-stroke impairments. The Fatigue Severity Scale measured the presence and impact of fatigue at admittance for inpatient rehabilitation, as well as at 6 months and 1 year post stroke. At admission, 6 months and 1 year post stroke, fatigue was present in 51%, 64% and 69% of the patients respectively. Fatigue impact 1 year post stroke was greater among patients with more depressive symptoms, higher age, females and patients with a locus of control more directed to powerful others. As fatigue impact is an increasing problem during the first year post stroke, it deserves more attention in clinical practice and scientific research. Depression and locus of control are related to post-stroke fatigue and might be important foci for future interventions.

In chapter 6 the difference was investigated between patients with a cerebral infarction (CI) and patients with an intracerebral hemorrhage (ICH) in a rehabilitation setting, in terms of the development of independence in Activities of Dailly Living (ADL) over the first year post stroke. A total of 229 CI patients and 45 ICH patients were included. Measurements took place at admission to the rehabilitation center, 8, 10, 12, 26, and 52 weeks post stroke. The level of ADL independence was measured by the Barthel Index (BI). From their admission to the rehabilitation center until 12 weeks post stroke, recovery tended to be more rapid for ICH patients than for CI patients. From 12 to 26 weeks post stroke, CI patients showed a significantly faster increase in BI scores. The time window for recovery of ADL independence was more restricted for ICH patients; a statistically significant increase in ADL was found until 10 weeks post stroke in ICH patients, whereas CI patients showed statistically significant recovery until 26 weeks post stroke. The differences in ADL recovery between CI patents and ICH patients should be taken into consideration in stroke management as regards selection for inpatient rehabilitation, prognosis of ADL recovery and differentiated planning of rehabilitation programs.

Chapter 7 contains the main conclusions, strengths and considerations to our study. The longitudinal design was considered as one of the main strengths. The choice for the stroke rehabilitation population as study base was discussed, as well as the usefulness of the ICF for research and clinical practice. Moreover, possible implications for stroke care and future research were discussed concerning (1) clinimetrics, (2) the score chart to predict social activity, (3) post stroke fatigue and (4) personal and environmental factors as determinants of outcome.

Samenvatting in Nederlands

Dit proefschrift is gebaseerd op gegevens verkregen uit het FuPro-CVA onderzoek (Functionele Prognose bij een cerebrovasculair accident (of beroerte)). In 2000 werd het FuPro-CVA onderzoek gestart met twee belangrijke doelstellingen welke in hoofdstuk 1 nader toegelicht worden. De eerste doelstelling was het bepalen welke uitkomstmaten het meest geschikt, en in het bijzonder het meest responsief, zijn om functionele uitkomsten te meten bij CVA patiënten. De tweede doelstelling was het bestuderen van prognostische factoren van functionele uitkomst en herstel 1 jaar na CVA. In totaal werden 308 CVA patiënten geïncludeerd voor dit onderzoek. Deze patiënten werden gevolgd in de periode van opname in het revalidatiecentrum tot 1 jaar na het CVA. De inclusie criteria waren: (1) opname voor klinische revalidatie, (2) een eerste CVA, (3) een eenzijdig, supratentorieel gelokaliseerde laesie en (4) leeftijd boven de 18 jaar.

In hoofdstuk 2 hebben we de responsiviteit (gevoeligheid voor verandering) vergeleken van verschillende functionele uitkomstmaten die vaak gebruikt worden in het CVA onderzoek, namelijk de Barthel Index (BI), Functional Independence Measure (FIM), Frenchay Activities Index (FAI) en Stroke-Adapted Sickness Impact Profile 30 (SASIP30). Plaffondeffecten en responsiviteit, uitgedrukt in effect sizes, werden bestudeerd voor de periode tussen opname en 6 maanden na CVA (subacute fase) en voor de periode tussen 6 maanden en 1 jaar na CVA (chronische fase). De responsiviteit van de BI, de totaal score van de FIM en de motorische score van de FIM waren vergelijkbaar in de subacute fase met grote effect sizes. De cognitieve score van de FIM liet een aanzienlijk plafond effect zien en had de kleinste effect size in de subacute fase. In de chronische fase waren de FAI en SASIP30 het meest gevoelig voor verandering met matige effect sizes. We concludeerden dat de BI, de totaal score van de FIM en de motorische score van de FIM, FAI en SASIP30 responsieve uitkomstmaten zijn. Het advies luidt om de BI in de subacute fase te gebruiken en de FAI en SASIP30 in de chronische fase.

In hoofdstuk 3 hebben we de inhoud onderzocht van verschillende uitkomstmaten, die vaak gebruikt worden in de CVA revalidatie en die zich richten op activiteiten en participatie. De inhoud hebben we bestudeerd aan de hand van de Internationale Classificatie van het menselijk Functioneren (ICF). De ICF bevat de componenten lichaamsfuncties, activiteiten en participatie, omgevingsfactoren en persoonlijke factoren. De afzonderlijke onderdelen van de items van de volgende uitkomstmaten werden gekoppeld aan de categorieën van de ICF: de Barthel Index (BI) , Berg Balance Scale (BBS), Chedoke McMaster Stroke Assessment Scale (CMSA), Euroqol-5D (EQ5D), Functional Independence Measure (FIM), Frenchay Activities Index (FAI), Nottingham Health Profile (NHP), Rankin Scale (RS), Rivermead Motor Assessment (RMA), Rivermead

Mobility Index (RMI), Stroke Adapted Sickness Impact Profile 30 (SASIP30), Medical Outcomes Study Short Form 36 (SF36), Stroke Impact Scale (SIS), Stroke Specific Quality of Life scale (SSQOL) en Timed Up and Go test (TUG). De meeste onderdelen konden gekoppeld worden aan de ICF en vielen onder de activiteiten en participatie component. Binnen deze component pasten de meeste onderdelen bij de categorie mobiliteit. Hoewel de uitkomstmaten waren geselecteerd op basis van hun focus op activiteiten en participatie, vielen nog 27% van de onderdelen in de categorieën van lichaamfuncties. Ongeveer 10% van de onderdelen konden niet worden gekoppeld aan de ICF, veelal omdat ze te algemeen geformuleerd waren. Geconcludeerd werd dat de ICF een bruikbaar kader is om de inhoud van meetinstrumenten uit de CVA revalidatie te onderzoeken en te vergelijken. De vergelijking van de inhoud van de hier beschreven meetinstrumenten, maakt het voor professionals en onderzoekers beter mogelijk om een instrument te kiezen dat past bij wat zij willen meten.

Hoofdstuk 4 beschrijft de ontwikkeling van een scorekaart waarmee bij opname in het revalidatiecentrum de mate van sociale activiteit 1 jaar na het CVA voorspeld kan worden. Patiënten die risico lopen op sociale inactiviteit kunnen hiermee worden opgespoord. Sociale activiteit werd gemeten met de Frenchay Activities Index (FAI) 1 jaar na CVA. De volgende, potentieel voorspellende, factoren werden gemeten bij opname: geslacht, leeftijd, burgerlijke staat, arbeidssituatie voor het CVA, opleidingsniveau, type CVA, hemisfeer, motorische stoornis, rompbalans, communicatie en zelfstandigheid voor de activiteiten van het dagelijkse leven (ADL). Een hogere leeftijd, het mannelijk geslacht, wonen met een partner, een ernstigere motorische stoornis, meer problemen met communicatie en met ADL zelfstandigheid, bleken meer risico te geven op een slechtere FAI score 1 jaar na CVA. We hebben een eenvoudig te gebruiken score kaart gemaakt waarmee patiënten kunnen worden geïdentificeerd die het risico lopen op sociale inactiviteit. Met de score kaart is men goed in staat om patiënten met een naar verwachting toekomstig laag sociaal activiteiten niveau, te onderscheiden van patiënten met een naar verwachting hoog sociaal activiteiten niveau. Het tijdig opsporen van de risicogroep maakt het voor de professionals mogelijk zich al in een vroege fase te richten op de sociale activiteiten van deze groep patiënten.

Hoofdstuk 5 behandelt het verloop van vermoeidheid gedurende het eerste jaar na CVA en beschrijft de relatie tussen vermoeidheid 1 jaar na CVA en persoonskenmerken, CVA karakteristieken en functiestoornissen. Met de Fatigue Severity Scale (FSS) werd de aanwezigheid van vermoeidheid vast gelegd, evenals de impact van vermoeidheid op het dagelijks leven. Bij respectievelijk 51%, 64% en 69% van de patiënten was bij opname in het revalidatiecentrum, 6 maanden en 1 jaar na CVA vermoeidheid aanwezig. De impact van de vermoeidheid op het dagelijkse leven nam in het eerste jaar na CVA toe. De impact was groter bij patiënten met meer depressieve kenmerken, een hogere leeftijd, het vrouwelijk geslacht en bij patiënten met een meer externe locus of control gericht op artsen. Gezien het belang van het probleem vermoeidheid bij CVA patiënten, verdient dit onderwerp meer aandacht te krijgen in de klinische praktijk en het onderzoek. Mogelijk belangrijke aangrijpingspunten van toekomstige interventies zijn depressie en locus of control (de wijze waarop de patiënt het gevoel heeft al of niet zelf controle te kunnen uitoefenen op zijn eigen gezondheid en functioneren).

In hoofdstuk 6 werden patiënten met een herseninfarct (HI) vergeleken met patiënten met een hersenbloeding (HB) in de revalidatie setting. Het verschil in herstel van zelfstandigheid van activiteiten van het dagelijks leven (ADL) werd bestudeerd gedurende het eerste jaar na CVA. In totaal werden 229 HI patiënten en 45 HB patiënten onderzocht. De mate van ADL zelfstandigheid werd gemeten met de Barthel Index (BI). Metingen werden verricht bij opname in het revalidatiecentrum, en bij 8, 10, 12, 26 en 52 weken na het CVA. De HB patiënten neigden tot sneller herstel dan de HI patiënten van opname in het revalidatiecentrum tot 12 weken na CVA. De HI patiënten lieten een statisch significant sneller herstel zien van 12 tot 26 weken na CVA. Het tijdsvenster voor herstel van ADL zelfstandigheid was korter voor de HB patiënten: zij lieten slechts statisch significant herstel zien tot 10 weken na CVA terwijl de HI patiënten herstelden tot 26 weken na CVA. Met de geconstateerde verschillen in herstel tussen HB en HI patiënten moet rekening gehouden worden in het revalidatie beleid. Hierbij valt te denken aan het beleid rondom de selectie voor klinische revalidatie na de ziekenhuisopname, prognosestelling en de planning van het revalidatie programma.

Hoofdstuk 7 bevat naast de belangrijkste bevindingen van het onderzoek, ook de discussie ten aanzien van de sterke en zwakke punten van deze studie. Het longitudinale karakter wordt beschouwd als een belangrijk sterk punt. Er komt aan de orde waarom bewust is gekozen voor de CVA revalidatie populatie als onderzoekspopulatie. Bovendien wordt besproken waarom de ICF goed bruikbaar is voor zowel het onderzoek als de klinische praktijk. Daarna worden de implicaties van het onderzoek voor de praktijk beschreven en suggesties gedaan voor toekomstig onderzoek. Dit betreft de klinimetrie, de score kaart om sociale activiteit te voorspellen, vermoeidheid na CVA en de persoonlijke en omgevingsfactoren als belangrijke factoren van uitkomst.

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Curriculum Vitae

Vera Schepers werd op 21 mei 1973 geboren te Roosendaal. In 1991 behaalde zij haar VWO diploma aan het Gertrudislyceum te Roosendaal. Zij startte met de studie Geneeskunde aan de Universiteit Utrecht en behaalde in 1998 het artsexamen. Zij werkte 1 jaar als arts-assistent in Revalidatiecentrum Blixembosch te Eindhoven. In 1999 begon zij met de opleiding tot revalidatiearts in het opleidingscircuit van Revalidatiecentrum De Hoogstraat en het Universitair Medisch Centrum Utrecht.

Zij volgde de AGIKO opleiding (Assistent Geneeskundige in Opleiding tot Klinisch Onderzoeker) waarbij de patiëntenzorg werd afgewisseld met perioden wetenschappelijk onderzoek. In 2000-2001 nam zij deel aan de opleiding wetenschappelijke vorming revalidatieonderzoek gefinancierd vanuit het Stimulering Programma Gezondheid-onderzoek (VRA-SGO).

In juli 2006 heeft zij de opleiding tot revalidatiearts afgerond. Per 1 december 2006 is zij werkzaam als revalidatiearts en onderzoeker in Revalidatiecentrum De Hoogstraat, met als aandachtsgebied CVA revalidatie.

Vera is sinds januari 2005 getrouwd met Hans Vercruijssen. In januari 2006 werd hun dochter geboren: Fleur.

Revalidatiecentrum
De Hoogstraat