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Leiden
The Netherlands

Comprehensive measurement of long-term outcomes and costs of rehabilitation in patients with stroke

Meijeren-Pont, W. van

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Chapter 1

General Introduction

Definition and epidemiology of stroke

Stroke, or cerebrovascular accident, is an acute neurological dysfunction caused by ischemia or haemorrhage in the brain, which persists more than 24 hours or until death¹. Ischemic stroke is caused by an interruption of the blood supply to a part of the brain, resulting in sudden loss of function (80% of stroke patients). Haemorrhagic stroke is caused by rupture of a blood vessel or an abnormal vascular structure in the brain (20% of stroke patients)².

In the Netherlands, in 2020 the incidence of stroke was approximately 38.300 (20.200 men and 18.100 women) and the estimated prevalence was 511.600³, whereas 8.890 people died because of stroke⁴. The prevalence of stroke in the Netherlands is expected to increase with 45% between 2018 and 2040, due to advances in treatment and the ageing society³.

Acute treatment after stroke

In the acute phase of stroke, patients are usually treated in the hospital⁵. After ischemic stroke acute treatment options are thrombolysis (i.e. drug treatment aiming to disperse the clot and return the blood supply to the brain) or endovascular thrombectomy (i.e. instrumental removal of the clot from the brain)^{6,7}. With the introduction of thrombolysis and thrombectomy the acute treatment of ischemic stroke has markedly improved, reducing death and functional dependency⁶. Acute treatment options of intracerebral haemorrhage consist of lowering the blood pressure, pressure release with a drain or with a neurosurgical intervention such as craniotomy, and specifically for subarachnoid haemorrhage coiling or clipping^{6,7}. In contrast with ischaemic stroke, functional outcomes of patients with haemorrhagic stroke did not clearly improve over the past 20 years, but the proportion of deaths did decrease⁸.

Care in the post-acute and chronic phase after stroke

In 2019, the average duration of hospital stay was 6.4 days⁵. The majority of stroke survivors (60%) is discharged home and 20% of stroke survivors are discharged to inpatient rehabilitation in a rehabilitation centre or to a geriatric rehabilitation setting⁹.

Multidisciplinary inpatient and/or outpatient rehabilitation in a multidisciplinary rehabilitation centre includes a combination of physical, cognitive, mental and/or speech-language treatment modalities. Treatment is provided by a multidisciplinary team, usually comprising a rehabilitation physician, nurse, physical therapist, occupational therapist, speech-language therapist, social worker and/or (clinical) psychologist¹⁰. Multidisciplinary rehabilitation in a multidisciplinary rehabilitation centre is delivered in accordance with national stroke rehabilitation guidelines^{9,11}.

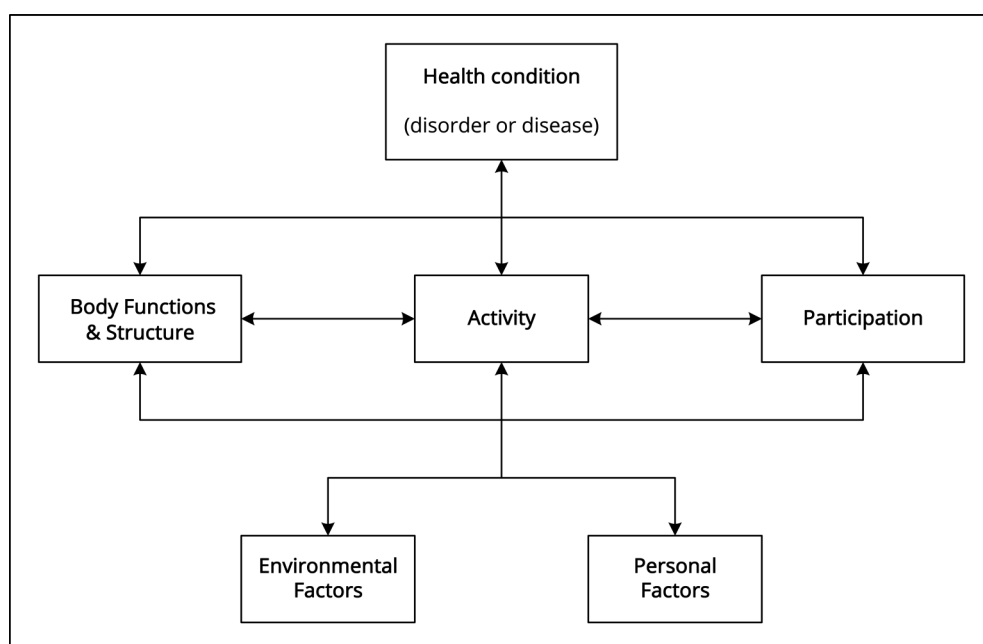
Of the patients who were discharged to their home, about two-thirds receive some form of rehabilitation treatment¹². This may consist of either outpatient multidisciplinary rehabilitation in a multidisciplinary rehabilitation centre or primary care treatment by e.g. a speech-language therapist, physical therapist, occupational therapist or psychologist¹³.

Like the situation in many countries, the costs associated with the (medical) treatment of stroke are substantial in the Netherlands and are expected to rise in the coming years¹⁴.

Measuring outcomes after stroke

Stroke can result in physical, cognitive, emotional, communicative, social, and functional limitations⁶. In order to describe, monitor and evaluate this complexity of outcomes after stroke a comprehensive framework for health status, either or not comprising stroke-specific outcome measures, is needed. A few of these frameworks or sets of outcome measures specifically for stroke will be described in more detail.

Figure 1. The ICF Model: Interaction between ICF components.



The International Classification of Functioning, Disability and Health (ICF) Core Set for Stroke

The ICF provides a standard language to categorize health outcomes at the level of body functions and body structures, activities and participation (Figure 1)¹⁵. The ICF consists of two parts. Part 1, dealing with Functioning and Disability, comprises the components Body functions and body structures, and Activities and Participation. Part 2 concerns Contextual Factors, including the components Environmental Factors and Personal Factors¹⁵. To make the ICF more applicable for clinical practice, 'ICF Core Sets' were developed¹⁶, comprising lists of essential categories that are relevant for specific health conditions and healthcare contexts¹⁶. ICF Core Sets are developed by following a scientific process based on preparatory studies and the involvement of a multidisciplinary group of experts, including health professionals and experts representing a broad range of disciplines and persons with the specific health condition¹⁷. In this way, the ICF Core Set for Stroke was developed, both in a comprehensive and a brief format¹⁶. The comprehensive ICF Core Set for Stroke contains 130 categories relevant for stroke patients¹⁶. The brief ICF Core Set for Stroke contains a selection of 18 of these categories, for example 'the structure of the upper extremity', 'attention function', 'walking', and 'health services, systems and policies'¹⁶. To facilitate the use of ICF Core Sets in clinical practice, electronic documentation forms (www.icf-core-sets.org) are available in various languages¹⁶. Concerning the timing of the measurements the ICF Core Sets do not provide a recommendation.

International Consortium of Health Outcome Measurement (ICHOM) Standard Set for Stroke

Building on the principles of value-based healthcare (VBHC), where the use of health outcomes data is promoted to improve outcomes important to patients and simultaneously reduce costs¹⁸, ICHOM has developed standard sets of outcome measures for various conditions, including stroke. This ICHOM Standard Set for Stroke was developed by an international expert panel comprising stroke patients, specialties from all phases of stroke care, major international professional societies, stroke registers, and centres and was published in 2016¹⁹. In accordance with the three-tiered model of VBHC¹⁸, this set comprises measures of survival and disease control, acute complications, and patient-reported outcomes and can be used in a variety of healthcare settings. Patient-reported outcomes include pain, mood, feeding, selfcare, mobility, communication, cognitive functioning, social participation, ability to return to usual activities and health-related quality of life. ICHOM recommends that baseline characteristics are recorded at admission to the hospital and that patient-reported outcome measures are recorded at discharge and at 90 days post stroke.

Minimal Data Set (MDS) Acquired Brain Injury (ABI)

ABI encompasses all types of damage to the brain that occur after birth and that are not related to progressive diseases. ABI includes, but is not limited to, stroke. A Dutch national dataset for adults with ABI was developed by 48 experts including psychologists, physicians and researchers in a three-round Delphi study and published in 2020²⁰. This set of standardised measures includes the minimum amount of data necessary for obtaining a global image of the patient across all healthcare sectors (primary, secondary and tertiary care) and disciplines in every stage (i.e. acute, subacute and chronic). Twelve domains were selected, namely demographics, injury characteristics, comorbidity, cognitive functioning, emotional functioning, energy, mobility, self-care, communication, participation, social support and quality of life. These outcomes should be measured with six existing measurement instruments, two screening questions and data from a registry of demographic and injury information. The six recommended measurement instruments include the Cumulative Illness Rating Scale (CIRS), Montreal Cognitive Assessment (MoCA), Hospital Anxiety and Depression Scale (HADS), Fatigue Severity Scale (FSS), Barthel Index (BI), and Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-P)²¹. The timing of the measurements is not defined.

The description of the three sets of outcomes for stroke patients makes it clear that there are a number of similarities, but also a few differences. The ICF Core Sets for stroke includes areas of functioning and contextual factors relevant for stroke patients rather than specific measurement instruments. However, electronic forms to score the presence and severity of impairments for every aspect included in the Core Sets are available¹⁶. The ICHOM Standard Set for Stroke does, apart from single questions, also comprise a few validated measurement instruments, in particular the Patient Reported Outcome Measurement Information System (PROMIS) Global Health (also called PROMIS-10)^{19,22}. Within the MDS-ABI²¹ a number of specific measurement instruments are specified, however no recommendations regarding the timing of their administration are provided. For all three abovementioned sets, clinical experience is limited with respect to their feasibility in and suitability to monitor, evaluate and improve the quality of care for stroke patients, in particular multidisciplinary rehabilitation setting.

The Stroke Cohort Outcomes of REhabilitation (SCORE) study

In 2013-2014, when the studies described in this thesis were designed, only the ICF Core Sets for stroke were available. Nevertheless, it was acknowledged at that time that, despite the availability of a few cohort studies, data on the long-term outcomes of stroke patients admitted for multidisciplinary rehabilitation were scarce. Furthermore, information on their healthcare usage and associated costs in the Netherlands were virtually absent.

For this reason, the SCORE study^{10,23,24} was designed and executed in two rehabilitation centres, Rijnlands Rehabilitation Centre Leiden and Sophia Rehabilitation Den Haag (currently: Basalt) with approval of the Medical Ethical Committee of the Leiden University Medical Centre (P13.249). The study was registered in the International Clinical Trial Registry Platform (<https://trialsearch.who.int/>: NTR4293). The design and execution of the study were done in close collaboration with a group of patient research partners²⁵, to ensure the relevance of the study for stroke patients and their caregivers.

This cohort study included all consecutive patients admitted for inpatient or outpatient multidisciplinary rehabilitation. The general aims of this study were: 1) to describe the structure and process of inpatient and outpatient stroke multidisciplinary rehabilitation, and the differences between the two centres, 2) to describe the functions, activities, participation, and quality of life of stroke patients on the short and long term, 3) to describe stroke-related costs for multidisciplinary rehabilitation, health care, and society; and 4) to determine which factors are associated with community participation of stroke patients on the long-term.

In line with these overarching aims, the study included measurements of outcomes and costs. For the selection of outcome measures the ICF served as a framework. Measurement instruments related to the ICF domains were chosen based on the literature and expert opinion. Expert opinion was derived throughout the course of the study in two ways: by means of advice and suggestions from patient research partners, a group of dedicated stroke patients (and their partners)²⁵, and from a steering group of scientists with background in neurology, geriatric rehabilitation, statistics, epidemiology and health economics. Based on the knowledge gaps they identified, a number of specific research questions and ensuing measurement instruments were (temporarily) added to the study protocol in the form of amendments during the conduct of the study.

The current thesis addresses six of the knowledge gaps. These gaps resulted in research questions, specifically focusing on the subgroup of stroke patients who were admitted to a multidisciplinary rehabilitation centre and, apart from the subacute (rehabilitation) phase, also on the chronic phase until 30 months after stroke. With this comprehensive description, the thesis is covering all components of the ICF, i.e. Upper extremity pain (Body functions and structures), Functional independence (Activities), Paid employment (Participation); Patient activation (Personal Factors), Caregiver Burden (Environmental factors) and Healthcare usage and costs (Environmental Factors).

Upper extremity pain

On the ICF level of Body functions and structures, pain is a common complication after stroke leading to diminished quality of life^{26,27}. However, pain after stroke is often underdiagnosed and undertreated in hospital-based populations^{28,29}. The upper extremity is the most common location of pain after stroke^{30,31}. Nevertheless, knowledge on the development and intensity of upper extremity pain during long-term follow-up was scarce and the results of current literature were contradictory with respect to the course of upper extremity pain. A study described that the frequency of upper extremity pain increased between three and six months after stroke³¹ while another study described a decrease in the frequency from four to 16 months after stroke³⁰.

Functional independence

In the ICF area of Activities, functional independence is an important outcome. Thus, functional independence is addressed in all outcome sets described above. Two frequently used outcome measures for functional independence are the Utrecht Scale for Evaluation of Rehabilitation (USER)^{32,33} and the Barthel Index³⁴. Relatively little was known on which of these outcome measures was most sensitive to change in a rehabilitation population of stroke patients and could best be used to assess functional independence.

Participation in stroke patients with paid employment

Outcomes on the Participation level are considered the most relevant and crucial outcomes of successful recovery after stroke^{35,36}. Participation is a multidimensional concept comprising social participation, community participation and (return to) work¹⁵. Previous research found that paid work might be more important than unpaid work for stroke patients³⁷. In addition, stroke patients who do not remain in paid employment reported more depressive feelings than those who are able to return to work^{38,39}. These findings underline the importance of addressing both paid and unpaid employment when studying participation in stroke patients over time. However, longitudinal studies on both participation and satisfaction with participation for working patients who do or do not return to paid employment have been relatively scarce.

Patient activation

One of the internal Personal factors having an impact on a patient's health is patient activation. This is defined as one's role in the care process and having the knowledge, skills, and confidence to manage one's health and healthcare⁴⁰. It is a prerequisite for effective self-management⁴¹ and in the literature better patient activation was associated with better health outcomes and better care experiences in patients with chronic conditions⁴². However, in stroke patients

research on patient activation is relatively scarce, and it has not been investigated whether and to what extent it changes over time.

Caregiver burden

As an important external Environmental factor according to the ICF model, the immediate family, including the caregiver of a stroke patient has an important impact on the patient's health. Due to long lasting impairments after stroke, 49% of patients were found to receive informal care from a caregiver with an average of 76.6 hours per week one year after stroke⁴³. Caregivers assist with therapy⁴⁴, they optimize recovery⁴⁵ and are important for a patient to remain active in the community⁴⁶. However, the role of caregiver may come with a burden and result in lower quality of life⁴⁷, depression^{48,49} and anxiety^{47,48} for the caregiver. The individual course of caregiver burden over time was relatively unknown and might be subject to change. Therefore, it is important to know this course in order to be able to monitor caregiver burden and provide support at the right time.

Healthcare usage and costs

Next to health outcomes, costs and healthcare usage are an important part of the equation in VBHC. Despite the importance of analysing costs in VBHC, not all measurement sets for stroke mention costs and/or healthcare usage and research on costs of stroke are scarce¹². In particular, the societal costs of stroke in the Netherlands, including costs for healthcare usage as well as for working hours lost, were understudied^{12,50}.

General aims and outline of this thesis

Given the abovementioned knowledge gaps, this thesis aims to comprehensively describe, in patients with stroke who were admitted in a multidisciplinary rehabilitation centre, the long-term course of pain, participation, patient activation, caregiver burden, healthcare usage and costs. Moreover, it aims to assess whether the USER or the Barthel Index can be used best to describe functional independence.

These aims are addressed in the following chapters (Figure 2):

Chapter 2 describes the course of the occurrence and severity of upper extremity pain in stroke patients at three, 18 and 30 months after the start of multidisciplinary rehabilitation.

Chapter 3 comprises a comparison of the responsiveness of the USER and the Barthel Index in stroke patients admitted for multidisciplinary rehabilitation.

Chapter 4 presents the long-term employment outcomes and participation of stroke patients who were in paid employment before stroke with comparisons of patients who do and do not return to work.

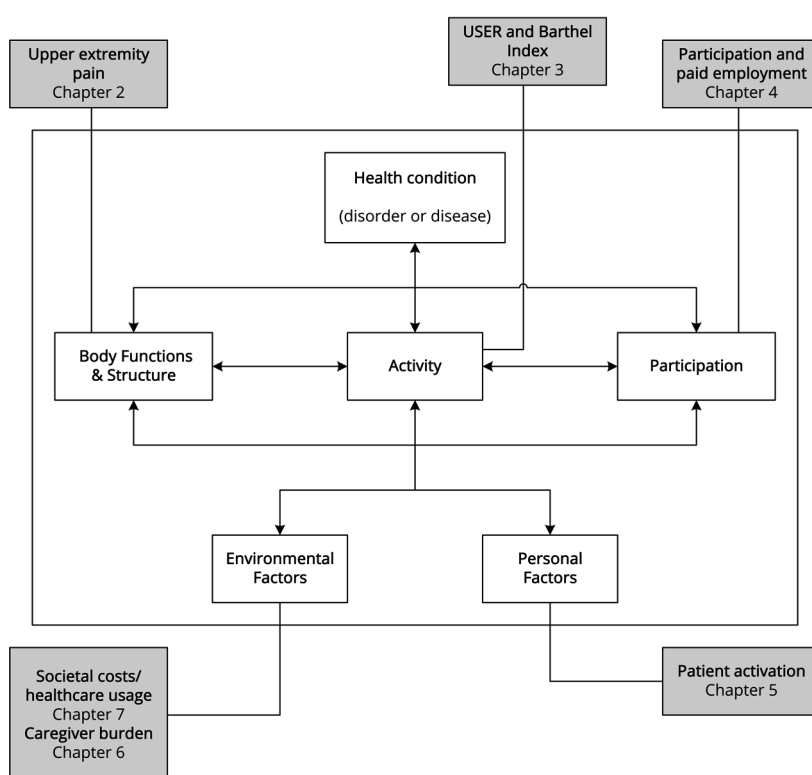
Chapter 5 describes patient activation at the start of multidisciplinary stroke rehabilitation and its course during six months follow-up.

Chapter 6 presents the course of burden for caregivers of stroke patients in the first year after the start of multidisciplinary rehabilitation.

Chapter 7 comprises an estimation of the societal costs from the start of the rehabilitation up to one year later in stroke patients who received multidisciplinary rehabilitation and an evaluation of their quality of life over time.

In *Chapter 8* the findings of the studies in this thesis are summarized and discussed.

Figure 2. Chapters of this thesis in relation to the ICF model.



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