The long term consequences of stroke

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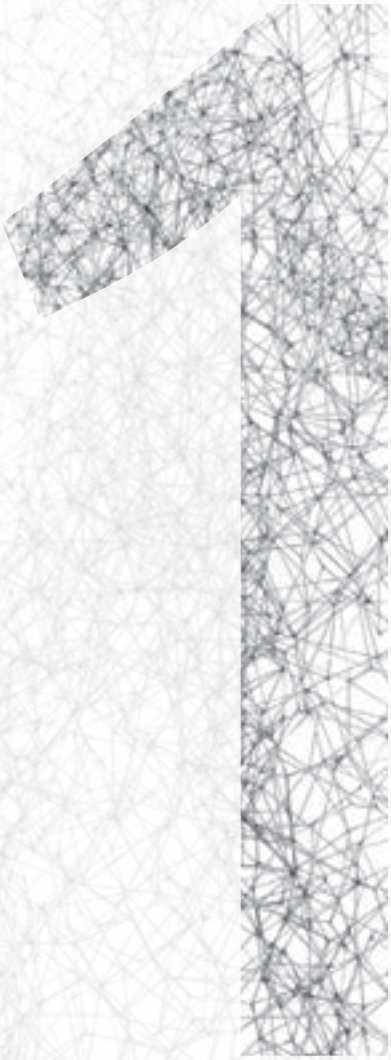

Chapter 1

Introduction

General introduction

Stroke, or a cerebrovascular accident, is a serious illness that can change one's health and future in an instant. A stroke is caused by the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot (67 - 80%).[1] This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. The consequences of a stroke depend on which part of the brain is injured and the severity of the tissue damage. In some cases there is only a brief interruption of blood supply leading to a transient loss of function without damage of brain tissue. This is described as a Transient Ischemic Attack (TIA) if full recovery is observed within 24 hours after onset.[2,3]

The most common symptoms of a stroke are sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include: confusion; difficulty speaking or understanding speech; difficulty seeing with one or both eyes; difficulty walking, dizziness, loss of balance or coordination; severe headache with no known cause; fainting or unconsciousness.[4] The clinical picture of stroke can be very diverse, varying from mild or no problems, to severe handicap or death.

In the acute phase, all patients should be cared for in a dedicated acute stroke unit, which in itself saves lives and significantly improves functional outcomes.[5] In the past decade, major advances have been made for the acute treatment of stroke. For acute ischemic stroke, the addition of endovascular thrombectomy of proximal large artery occlusion to intravenous alteplase increases functional independence for a further fifth of patients; for acute intracerebral haemorrhage, trials are ongoing to assess the effectiveness of acute blood pressure lowering, haemostatic therapy, minimally invasive surgery, anti-inflammation therapy, and neuroprotection methods.[6]

Patients with impairments after stroke may benefit from a rehabilitation treatment, tailored to the limitations perceived by the patient. These programs are focused on relearning old skills and learning new skills. They stretch out for several months, sometimes over 1 year. There is a growing body of knowledge on what works for whom in this phase, conveniently listed and summarized in national and international guidelines.[7,8,9] However, the endpoints are generally limited to 1 year post stroke.

Knowledge regarding the chronic phase after stroke is still relatively scarce. This thesis will therefore focus on the health condition of patients in the chronic phase after stroke.

Epidemiology

Estimates from the Global Burden of Diseases, Injuries, and Risk Factors Study ranked stroke as the second most common cause of death and the third most common cause of disability-adjusted life-years (DALY's) worldwide in 2010.[10] Stroke is the most common cause of long term adult disability in developed countries.[11] As stroke is predominately a vascular problem related to ageing, there is a gradual incline of the incidence in the western population. In the last two decades, increases took place in the absolute numbers of stroke survivors (84%), stroke-related deaths (26%), and DALYs (12%).[10] The prevalence of stroke is 3% of the adult population in the United States of America.[12] This number is rising because of the therapeutic options in the acute and subacute phase, leading to a better survival rate; high income countries mainly contributed to this trend.[13] In the Netherlands the incidence of stroke is estimated 38,800/year in 2017.[14] The year prevalence is 315,000 patients in the community based population. Nursing homes also accommodate stroke patients but their numbers are not precisely defined; 129,000 patients reside in nursing homes in the Netherlands.[15] Approximately one quarter of them suffer from of stroke related impairments, leading to 350,000 stroke patients in the Netherlands in total (prevalence of 2%).[16] Stroke is far more common than other chronic neurological illnesses, e.g. Multiple Sclerosis or parkinsonism (17,000 patients and 49,400 patients in the Netherlands in 2012 and 2011, respectively).[17,18]

Description of the consequences of stroke using the International Classification of Functioning, Disability and Health (ICF)

As a stroke can show a large variation in type and severity of neurologic impairments, international consensus is important to categorize and describe the consequences of a stroke. The ICF is a comprehensive framework and classification system to describe a health condition with its relevant components (Figure 1). It provides a universal language for the description of health and health-related states understood by health professionals, researchers, policymakers, patients and patient organizations:[19]

"ICF is a multipurpose classification intended for a wide range of uses in different sectors. It is a classification of health and health-related domains; domains that help us to describe changes in body function and structure, what a person with a health condition can do in a standard environment (their level of capacity), as well as what they actually do in their usual environment (their level of performance). These domains are classified from body, individual

and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. In ICF, the term functioning refers to all body functions, activities and participation, while disability is similarly an umbrella term for impairments, activity limitations and participation restrictions. ICF also lists personal and environmental factors that interact with all these components."

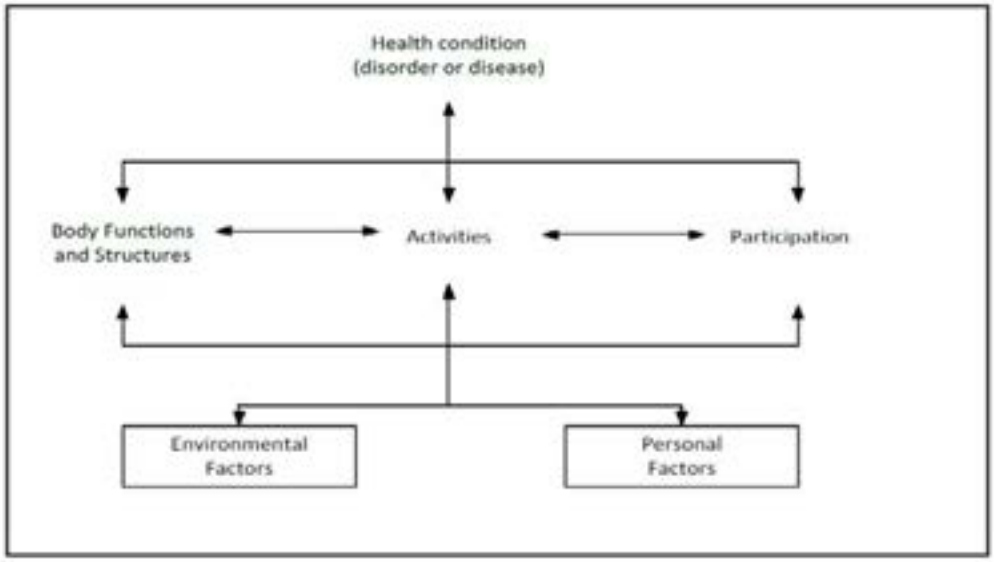

Figure 1. The ICF Model: Interaction between ICF components. Each ICF component consists of multiple domains, and each domain consists of categories that are the units of the classification.

To make the ICF more applicable for everyday use, the WHO (World Health Organisation) and the ICF Research Branch (www.icf-research-branch.org) created a process for developing core sets of ICF categories or "ICF Core Sets". ICF Core Sets facilitate the description of functioning, for example in clinical practice, by providing lists of essential categories that are relevant for specific health conditions and health care contexts (https://www.icf-core-sets.org/). The ICF Core Sets for Stroke shows the different categories of functions, activities and participation that can be hampered by a stroke.[20] The comprehensive core set for stroke comprises over 100 categories, including hand function (b710, b730, b760, d430, d440, d445, d510), mood (b152), work (d845, d850, d855, e352, e590) and health care systems (e580).[21] In this thesis we focused on these four categories.

Hand function after stroke

Hand function is impaired in two thirds of the patients directly after stroke.[22] In the long term the numbers vary, but approximately one third of the patients suffer from a permanently disturbed hand function to some extent.[23] Hand function is often assessed by instrumented hand function tests, such as the ARAT (Action Research Arm Test), Fugl Meyer Test, Frenchay Arm Test or the Nine Hole Peg Test. These tests are time consuming, necessitate face to face contact, skilled personnel and specific equipment. These requirements limit their use in larger patient groups and clinical practice. Questionnaires have an advantage in this respect. In a systematic review on hand function assessments, 6 hand questionnaires for stroke were evaluated (MAL – Motor Activity Log; COPM – Canadian Occupational Performance Measure; ABILHAND; GAS – Goal Attainment Scale; DHI – Duruoz Hand Index; HFS – Hand Function Survey).[24] The conclusion of this systematic review was that despite the available questionnaires, there is a need for instruments to measure hand function that are easy to administer, covering aspects of body functions as well as daily activities.

In order to fulfill this need the Michigan Hand outcome Questionnaire (MHQ) could be a relevant option.[25] This questionnaire is validated for several health conditions other than stroke, e.g. rheumatoid arthritis and carpal tunnel syndrome .[26,27] Evaluation of the MHQ in the stroke population is necessary prior to use it for hand function assessment after stroke.

Depression after stroke

At any time after stroke approximately one third of the patients have depressive complaints to a certain extent.[28] These depressive complaints may influence the extent and speed of influence in recovery after stroke and are inversely related to quality of life.[29] In the literature most outcome studies on depression in hospital based stroke populations are focused on the first year. A systematic review on this topic included 43 studies demonstrated that the prevalence of depression is stable across stroke populations at different time points in different areas of the world.[30] Validated scales were used in 29 studies. Major predictors of depression were: disability, depression pre-stroke, cognitive impairment, stroke severity and anxiety. Depression can also be considered as a predictor of a lower quality of life, higher mortality and disability after stroke.[30,31] Cause and effect are complex issues in this respect and are difficult to distinguish. Only two studies in the above mentioned review were based on a hospital population and had a follow up time of more than one year.[32,33] It

is important to recognize depressive complaints at any time after stroke because there are several treatment options, such as behavioral therapy, exercise and medication.[29,34,35]

Participation after stroke (work)

Work disability can be an important consequence of stroke, as classified in the ICF component Participation. Return to work rates can vary widely after stroke; return to work rates reported in four systematic reviews range from 11–85 %,[36] 19–73 %,[37] 22–53 %[38] and 0–100 %,[39] respectively. These wide ranges are explained by differences in study populations, in social security and health care systems, in follow up time and in the definition of work.

Most stroke patients are over 65 years and retired,[40] but there is a growing number of stroke patients in the working age with the pensionable age rising in many countries. Restoring working capacity is important for this subgroup from an economical point of view.[41,42] Furthermore, successful return to work is correlated to better outcomes in terms of quality of life.[43,44,45]

Due to legislation and formal procedures, it may take up to two years and sometimes even longer to accomplish return to work. Long term follow up is therefore essential to reveal the definitive results with respect to return to work.

Health care use and organization of care

Health care use by stroke patients in terms of which health care professionals are involved is to a large extent defined by the time since stroke. The hospitalization period after a stroke has dropped dramatically since 1995 in the Netherlands from 20-25 days to 7-8 days in the last years.[46] The majority of the surviving patients is discharged to their homes (60%), 10% follows an intensive rehabilitation, and 30% are referred to nursing homes for geriatric rehabilitation or long stay.[47] After 6 months 90% of the stroke survivors reside at their homes. The mortality is almost 10% in the hospital period, and 16% at 6 months.[47,48] There is little knowledge on which therapies stroke survivors still receive in the chronic phase to cover their needs.

Health care use as defined in economic terms is important from a societal perspective. The

treatment of stroke in the acute, subacute and chronic phase is responsible for €2.3 billion of the total health care budget in the Netherlands. This is a larger proportion than that for other chronic diseases such as Diabetics (€1.7 billion) or Chronic Pulmonary Obstructive Disease (€1.5 billion).[49] Hospital care takes care of a quarter of the stroke budget; this includes the subacute rehabilitation services in the Netherlands. Elderly care is responsible for two thirds, and community services (such as the General practitioner, the Physical Therapist, the Occupational Therapist) only 3%. Expenditures on medication, complementary therapies (such as homeopathy) and patient transportation account for 5%.

As the rehabilitation program terminates, the patient is usually referred to the general practitioner and other community services. As we know, more than one year after stroke, approximately one third of the stroke patients experience relevant limitations in daily activities and other domains of the ICF.[50,51] The general practitioner (GP) is supposed to act as a case manager, not only for the cardiovascular risk management but also to screen for relevant limitations as experienced by the patients with respect to their stroke, and act on that accordingly.[7] There is a lack of knowledge of the actual health care consumption, nor is information available on the determinants that are related to health care consumption. Evidence for continuation of physical therapy is scanty. As an example, the guideline for physical therapy is mainly based on expert opinion regarding the chronic phase after stroke.[8]

Besides evidence based care delivery, health care outcomes also depend on other areas such as the organization of health care delivery systems, especially when many health professions are involved in the care of people with a complex chronic condition as stroke.[52] There is in the Netherlands no agreement on the basic requirements of organization of a primary care network of health professionals, or on securing minimal quality standards.

Aims of this thesis

This thesis aims at providing detailed information from the patient's perspective on several aspects of functioning (hand function, mood), of activities and participation (work), and of environmental factors (health care consumption, organization of care) in stroke patients in the chronic phase. This information is essential to understand the patients' limitations and needs in the chronic phase after stroke, and can be helpful in developing evidence based treatment programs for stroke survivors.

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