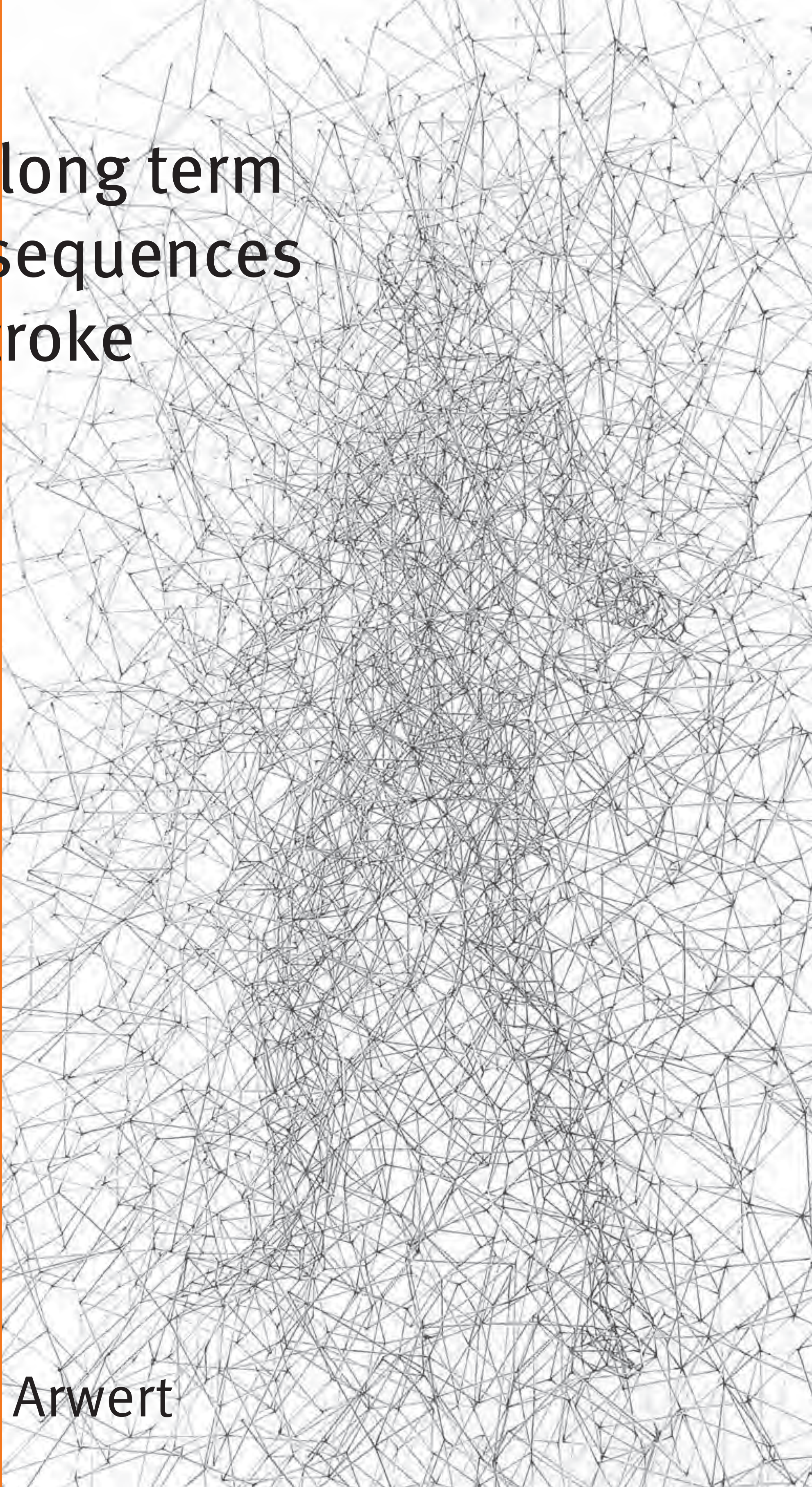
The long term consequences of stroke

Henk Arwert



The long term consequences of stroke

Colofon:

ISBN 978-90-9031315-3
Author: H.J. Arwert
Layout and design: Multicopy Maarssenbroek
Cover: Anthony Gormley, Mass (2006); Museum Voorlinden, Wassenaar; edited by N. Beckers
Print: Multicopy Maarssenbroek
Financial support was granted by RVO Praktijkleren and LIVIT

The long term consequences of stroke

Proefschrift
Ter verkrijging van
de graad van Doctor aan de Universiteit Leiden,
op gezag van de Rector Magnificus prof. mr. C.J.J.M. Stolker,
volgens besluit van het College voor Promoties
te verdedigen op dinsdag 4 december 2018
klokke 1345 uur

door
Hendrik Jaap Arwert
geboren te ‘s Gravenhage
in 1964

Promotor:

Prof. dr. T.P.M. Vliet Vlieland

Co-promotor:

Dr. J.J.L. Meesters

Leden promotiecommissie:

Prof. dr. M.J.H. Wermer
Prof. dr. C.A.M. van Bennekom, Vrije Universiteit, Amsterdam
Prof. dr. G. Kwakkel, Vrije Universiteit, Amsterdam

Contents

Chapter 1 9

Introduction

Chapter 2 23

Validity of the Michigan Hand Outcomes Questionnaire in Patients With Stroke

Arwert HJ, Keizer S, Kromme CH, Vliet Vlieland TP, Meesters JJ

Arch Phys Med Rehabil. 2016 Feb;97(2):238-44

Chapter 3 43

Patient reported outcomes of hand function three years after stroke

Arwert H, Schut S, Boiten J, Vliet Vlieland T, Meesters J

Top Stroke Rehabil. 2017 Oct 12:1-7

Chapter 4 65

Post stroke depression, a long term problem for stroke survivors

Arwert HJ, Meesters JJL, Boiten J, Balk F, Wolterbeek R, Vliet Vlieland TPM

Am J Phys Med Rehabil. 2018 Aug;97(8):565-571

Chapter 5 87

Return to Work 2–5 Years After Stroke: A Cross Sectional Study in a Hospital-Based Population

Arwert HJ, Schults M, Meesters JJL, Wolterbeek R, Boiten J, Vliet Vlieland T

J Occup Rehabil. 2017 Jun;27(2):239-246

Chapter 6 107

The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability, and Concurrent Validity in a Dutch Population.

Groeneveld IF, Arwert HJ, Goossens PH, Vliet Vlieland TPM

J Stroke Cerebrovasc Dis. 2018 Jan;27(1):267-275

Chapter 7 129

Health care use and its associated factors at 5 – 8 years after stroke.

Arwert HJ, Groeneveld IF, Vliet Vlieland TPM, Meesters JJL

Submitted in J Stroke Cerebrovasc

Chapter 8 147

Primary care networks for the management of stroke patients

Arwert HJ, Borcherts JHR, van Vree FM, Groeneveld IF, Meesters JJL, Vliet Vlieland TPM, Goossens PH

Submitted in Int J of Integrated Care

Chapter 9 169

Summary and general discussion

Appendices 185

- Nederlandse samenvatting
- List of publications
- Curriculum Vitae
- Dankwoord

1

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."

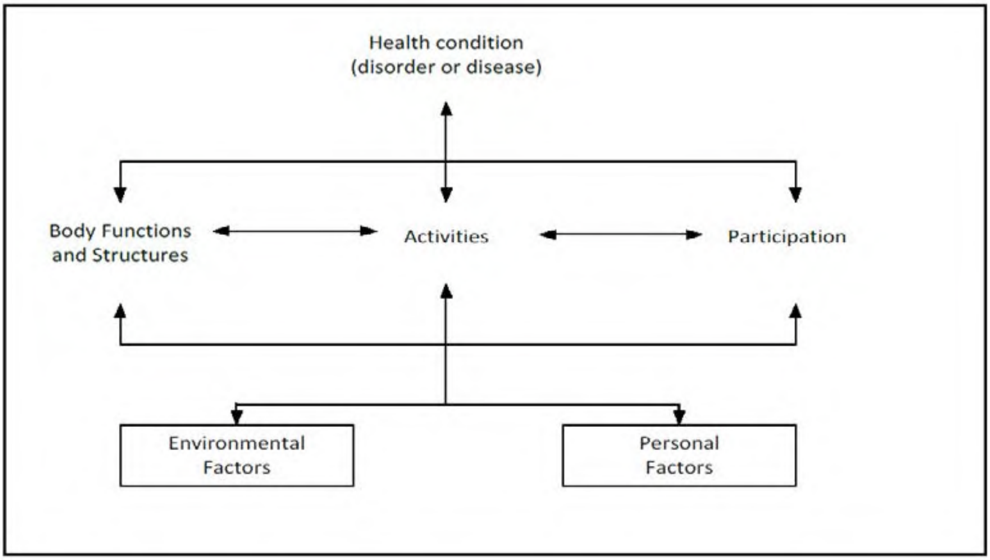


Figure 1. The ICF Model: Interaction between ICF components. Each ICF component consists of multiple domains, and each domain consists of categories that are the units of the classification.

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.

References

1. Feigin VL, Lawes CMM, Bennett DA, Anderson CS. Stroke epidemiology: a review of population-based studies of incidence, prevalence, and case-fatality in the late 20th century. Lancet Neurology 2003;2,43-53.
2. Hatano S. Experience from a multicenter stroke register: a preliminary report. Bulletin WHO 2010;54,541-553.
3. Easton JD, Saver JL, Albers GW, et al. Definition and evaluation of transient ischemic attack: a scientific statement for healthcare professionals from the American Heart Association/American Stroke Association Stroke Council; Council on Cardiovascular Surgery and Anesthesia; Council on Cardiovascular Radiology and Intervention; Council on Cardiovascular Nursing; and the Interdisciplinary Council on Peripheral Vascular Disease. Stroke 2009;40:2276-93.
4. WHO Stroke, Cerebrovascular disease; www.who.int/topics/cerebrovascular_accident/en/.
5. Asplund K, Berman P, Blomstrand C, et al. How do stroke units improve patient outcomes? A collaborative systematic review of the randomized trials. Stroke 1997;28:2139-2144.
6. Hankey GJ. Stroke. Lancet 2017;11;389(10069):641-654.
7. NHG: https://www.nhg.org/standaarden/volledig/nhg-standaard-beroerte.
8. KNGF: https://www.fysionet-evidencebased.nl/index.php/richtlijnen/richtlijnen/beroerte-2014.
9. NICE Stroke Guideline. https://www.nice.org.uk/guidance/cg162.
10. Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. Lancet 2014;383(9913):245–255.
11. Johnston SC, Mendis S, Mathers CD. Global variation in stroke burden and mortality: estimates from monitoring, surveillance, and modelling. Lancet Neurology 2009;8:345-54.
12. Roger VL, Go AS, Lloyd-Jones DM et al. Heart disease and stroke statistics--2011 update: a report from the American Heart Association. Circulation 2011 Feb 1; 123(4):e18-e209.
13. Benjamin EJ, Blaha MJ, Chiuve SE, et al. on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2017 update: a report from the American Heart Association. Circulation 2017;135:e229-e445.
14. RIVM(1): www.volksgezondheidenzorg.info/onderwerp/beroerte/cijfers-context/huidige-situatie.
15. Actiz: www.actiz.nl.
16. Achterberg WP, Gambassi G, Finne-Soveri H, Liperoti R, Noro A, Frijters DH, Cherubini A, Dell'aquila G, Ribbe MW. Pain in European long-term care facilities: cross-national study in

Finland, Italy and The Netherlands. Pain 2010;148(1):70-4.

17. https://www.volksgezondheidenzorg.info/onderwerp/ziekte-van-parkinson/cijfers-context/huidige-situatie#node-prevalentie-ziekte-van-parkinson-bevolkingsonderzoek.
18. MS Guideline 2012. https://richtlijnendatabase.nl/richtlijn/multipele_sclerose/multipele_sclerose_-_startpagina.html.
19. ICF1: http://www.who.int/classifications/icf/en/.
20. Geyh S, Cieza A, Schouten J, et al. ICF core sets for stroke. J Rehabil Med 2004;44(Suppl):135-41.
21. ICF2: https://icf-core-sets.org/en/page4.php
22. Nakayama H, Jørgensen HS, Raaschou HO, Olsen TS. Recovery of upper extremity function in stroke patients: the Copenhagen Stroke Study. Arch Phys Med Rehabil 1994;75:394–8.
23. Norlander A, Carlstedt E, Jönsson AC, et al. Long-term predictors of social and leisure activity 10 years after stroke. Plos One 2016;11(2):e0149395.
24. Lemmens RJ, Timmermans AA, Janssen-Potten YJ, Smeets RJ, Seelen HA. Valid and reliable instruments for arm-hand assessment at ICF activity level in persons with hemiplegia: a systematic review. BMC Neurol 2012;12:21.
25. Chung KC, Pillsbury MS, Walters MR, Hayward RA. Reliability and validity testing of the Michigan Hand Outcomes Questionnaire. J Hand Surg Am. 1998;23:575–587.
26. van der Giesen FJ, Nelissen RG, Arendzen JH, de Jong Z, Wolterbeek R, Vliet Vlieland TP. Responsiveness of the Michigan Hand Outcomes Questionnaire–Dutch language version in patients with rheumatoid arthritis. Arch Phys Med Rehabil 2008;89:1121–1126.
27. Ebrahimzadeh MH, Mashhadinejad H, Moradi A, Kachooei AR. Carpal tunnel release in diabetic and non-diabetic patients. Arch Bone Jt Surg 2013;1:23–27.
28. Kutlubaev MA, Hackett ML: Part II: predictors of depression after stroke and impact of depression on stroke outcome: an updated systematic review of observational studies. Int J Stroke 2014 Dec;9:1026-36.
29. Robinson RG, Jorge RE: Post-Stroke Depression: A Review. Am J Psychiatry 2016;173(3):221-31.
30. Ayerbe L, Ayis S, Wolfe CD, et al: Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. Br J Psychiatry 2013;202:14-21.
31. Kootker JA, van Mierlo ML, Hendriks JC, et al: Risk Factors for Symptoms of Depression and Anxiety One Year Poststroke: A Longitudinal Study. Arch Phys Med Rehabil 2016;97(6):919-28.
32. Robinson RG, Murata Y, Shimoda K: Dimensions of social impairment and their effect on depression and recovery following stroke. Int Psychogeriatr 1999;11(4):375-84.
33. Gesztelyi R, Fekete I, Kellermann M, et al: Screening for depressive symptoms among post-stroke outpatients in Eastern Hungary. J Geriatr Psychiatry Neurol 1999;12(4):194-9.

34. Adamson BC, Ensari I, Motl RW: Effect of exercise on depressive symptoms in adults with neurologic disorders: a systematic review and meta-analysis. Arch Phys Med Rehabil 2015;96(7):1329-38.

35. Ward SK, Turner A, Hambridge JA, et al: Group cognitive behavioural therapy for stroke survivors with depression and their carers. Top Stroke Rehabil 2016;17:1-8.

36. Wozniak MA, Kittner SJ. Return to work after ischemic stroke: a methodological review. Neuroepidemiology 2002;21(4):159–66.

37. Treger I, Shames J, Giaquinto S, Ring H. Return to work in stroke patients. Disabil Rehabil 2007;29(17):1397–403.

38. Wang YC, Kapellusch J, Garg A. Important factors influencing the return to work after stroke. Work 2014;47(4):553–9.

39. Daniel K, Wolfe CD, Busch MA, McKevitt C. What are the social consequences of stroke for working-aged adults? A systematic review. Stroke 2009;40(6):e431–40.

40. The Global Burden of Disease. 2008. Available from (http://www.who.int/healthinfo/global_burden_disease/GBD_report_200 4update_full.pdf).

41. Saka O, McGuire A, Wolfe C. Cost of stroke in the United Kingdom. Age Ageing. 2009;38(1):27–32.

42. Di Carlo A. Human and economic burden of stroke. Age Ageing 2009;38(1):4–5.

43. Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. J Rehabil Med 2003;35(3):127–31.

44. Roding J, Glader EL, Malm J, Lindstrom B. Life satisfaction in younger individuals after stroke: different predisposing factors among men and women. J Rehabil Med 2010;42(2):155–61.

45. Morris R. The psychology of stroke in young adults: the roles of service provision and return to work. Stroke Res Treat 2011;534812.

46. RIVM2: www.volksgezondheidenzorg.info/onderwerp/beroerte/preventie-zorg/zorg#node-opnameduur-voor-beroerte

47. Stroke guideline: www.zorginzicht.nl/bibliotheek/acute-beroertezorg/RegisterKwaliteitsstandaardenDocumenten/Conceptversie%20Richtlijn%20Herseninfarct%20en%20hersenbloeding.pdf.

48. Tuppin P, Samson S, Fagot-Campagna A, Woimant F. Care pathways and healthcare use of stroke survivors six months after admission to an acute-care hospital in France in 2012. Rev Neurol (Paris). 2016 Apr-May;172(4-5):295-306.

49. CBS (Cental Bureau for Statistics): www.statline.cbs.nl.

50. Singam A, Ytterberg C, Tham K, von Koch L. Participation in complex and social everyday activities six years after stroke: predictors for return to pre-stroke level. Plos One 2015;10(12):e144344
51. Crichton SL, Bray BD, McKevitt C, Rudd AG, Wolfe CD. Patient outcomes up to 15 years after stroke: survival, disability, quality of life, cognition and mental health. J Neurol Neurosurg Psychiatry 2016 Oct;87(10):1091-8.
52. Wagner EH, Bennett SM, Austin BT, Greene SM, Schaefer JK, Vonkorff M. Finding common ground: patient-centeredness and evidence-based chronic illness care. J Altern Complement Med 2005;11 Suppl 1:S7-15.

2

Chapter 2

Validity of the Michigan Hand Outcomes Questionnaire in Patients With Stroke

Arwert HJ, Keizer S, Kromme CH, Vliet Vlieland TP, Meesters JJ
Arch Phys Med Rehabil. 2016 Feb;97(2):238-44

List of abbreviations:

ARAT Action Research Arm Test
ICF International Classification of Functioning, Disability and Health
FAT Frenchay Arm Test
MCS mental component summary
MHQ Michigan Hand Outcomes Questionnaire MI Motricity Index
NHPT Nine Hole Peg Test
PCS physical component summary
SF-36 Medical Outcomes Study 36-Item Short-Form Health Survey

Abstract

Objective: To investigate the measurement properties of the Dutch version of the Michigan Hand Outcomes Questionnaire (MHQ) in patients with stroke.

Design: Validation study.

Setting: Outpatient rehabilitation clinic.

Participants: Consecutive patients with stroke (N=51; mean age, 60±11y; 16 women (31%)).

Interventions: Patients were asked to complete the MHQ (57 items) and Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36). Additional assessments included the Barthel Index and performance tests for hand function (Action Research Arm Test, Nine Hole Peg Test, Frenchay Arm Test, Motricity Index).

Main Outcome Measures: Associations between the MHQ and other outcome measures were determined using Spearman correlation coefficients and the internal consistency of the MHQ using Cronbach a. Floor or ceiling effects were present if >15% of the patients scored minimal or maximal scores, respectively. Test-retest reliability was established by the intraclass correlation coefficient.

Results: The mean MHQ total score was 70.0±22.4, with Cronbach α being .97. The MHQ total score correlated significantly with the physical component summary of the SF-36, the Barthel Index, and all hand function performance tests ($P<.01$). The MHQ total score showed no floor or ceiling effects. The test-retest intraclass correlation coefficient was .97.

Conclusions: This study provides preliminary evidence that the MHQ is an internally consistent, valid, and reliable hand function questionnaire in outpatients after stroke, although these results need to be further confirmed.

Introduction

Despite important advances in acute medical care, stroke accounts for ›6 million deaths per year worldwide and has a major impact on multiple areas of life in many of the survivors.[1] Regarding the consequences for upper extremity function, it was found that 69% of the patients experience hand function problems directly after stroke, leading to permanent limited function in half of them.[2] Moreover, the initial impairment of the upper extremity was found to be the strongest prognostic factor for the outcome of stroke.[3] The comprehensive International Classification of Functioning, Disability and Health (ICF) core set for patients with stroke comprises all aspects of health status that are important for patients with this condition,[4] including fine hand use as well as hand and arm use.

Until now, hand function problems in patients with stroke are usually identified and monitored by means of instrumented performance tests, such as the Nine Hole Peg Test (NHPT),[5] the Frenchay Arm Test (FAT),[6] or the Action Research Arm Test (ARAT).[7] Such instrumented tests are, however, time-consuming in terms of administration, preparation, and travel time for patients to attend face-to-face sessions and require specific equipment as well as trained clinicians. These requirements can form a barrier to assess poststroke hand function in a proper and timely manner in daily practice. Self-administered questionnaires have an important advantage in this respect, although questionnaires are subjective in their nature and some patients might not be able to complete a questionnaire without assistance. Self-reported outcome measures may cover information that is not obtained from the capacity outcome measures of upper limb function and vice versa.[8] In general, the aim and nature of a study will determine the type of the outcome measure to be chosen.

Ideally, a hand function questionnaire should include aspects of hand function not only in the ICF domains body functions and body structures but also in the domains activities and participation. Currently, there is no single valid and reliable outcome measure available to capture the full range of daily function in the hemiparetic upper limb.[9] This observation is in accordance with a systematic review on the topic of instruments for arm/ hand assessment,[10] concluding that 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. The Stroke Impact Scale[11] and the ABILHAND[12] are outcome questionnaires that comprise hand-related questions, but only with respect to some aspects of the ICF. The Stroke Impact Scale focuses on strength and daily activities and the ABILHAND on daily activities. The Michigan Hand

Outcomes Questionnaire (MHQ) covers the ICF core sets for stroke to a much larger extent than do the aforementioned questionnaires.

The MHQ[13] is a patient-reported outcome measure focusing on hand performance in daily life, but also takes such aspects into account as underlying impairments, work, and satisfaction. Apart from bimanual tasks, it includes an assessment of each hand separately. Its validity and responsiveness have been proven for various hand conditions, for example, in patients with rheumatoid arthritis, metacarpal phalangeal joint arthroplasty, carpal tunnel syndrome, hand injury, and distal radius fracture.[14-19] The MHQ was recently used in a study on the effect of botulinum toxin on spasticity in patients after acquired brain injury,[20] but is not validated for this patient group to date. Therefore, the present study aimed to investigate the measurement properties of the MHQ in patients with stroke receiving outpatient rehabilitation care.

Methods

Study design

This cross-sectional study was conducted from May 1, 2013 to February 1, 2014 in the Sophia Rehabilitation Center, The Hague. The study was judged to be nonmedical research by the Medical Ethics Review Committee of the Leiden University Medical Center. All participants gave written informed consent, and the study was conducted according to the Declaration of Helsinki.[21]

Patients

Consecutive adult patients with stroke who received multidisciplinary rehabilitation treatment in the Sophia Rehabilitation Center were selected using the following inclusion criteria: first stroke no longer than 5 years ago; 18 years or older; participating in an outpatient multidisciplinary rehabilitation program; being able to read and comprehend the Dutch language; being in a sufficient physical and emotional status to take part in assessments and to complete questionnaires. Potentially eligible patients were invited by their treating physician to participate.

Rehabilitation treatment

All patients received a regular stroke rehabilitation treatment, not necessarily focused on hand problems. This comprises a multidisciplinary, goal-oriented, individualized treatment program. National evidence-based guidelines were followed with respect to the type and intensity of individual treatment modalities.[22]

Assessment methods

Procedure

Stroke characteristics were collected from the medical record, including the nature of stroke (hemorrhagic/ischemic), time since stroke, and type of paresis (left/right).

Patients were invited to a 1-hour assessment on a regular treatment day. The assessment comprised the Barthel Index, a set of questionnaires (sociodemographic characteristics and the MHQ), and 4 instrumented tests. In case of bilateral involvement, the most affected site was tested. Patients whose treatment schedule allowed a retest 2 weeks after the first administration of the MHQ were asked to complete the MHQ for a second time (21 patients); they all complied. The clinical assessments and data extraction from the medical records were executed by a trained and experienced health professional (S.K.), who was not involved in the treatment of the patients.

Sociodemographic characteristics

Sociodemographic characteristics included age, sex, educational level (low: up to and including lower technical and vocational training; medium: up to and including secondary technical and vocational training; and high: up to and including higher technical and vocational training and university), and employment status (in patients younger than 65y).

The MHQ

The MHQ is a self-administered, 57-item questionnaire covering 6 domains: overall hand function, activities of daily living, pain, work performance, aesthetics, and patients' satisfaction with hand function.[13,23] It covers the relevant ICF categories to describe the effect of stroke on hand function.[4] The function of the left and right hand is recorded separately (except for the domains pain and work performance). Each item is scored on a 1 to 5 scale, with the domain scores ranging from 0 to 100. For every domain, a higher score indicates better hand function. The pain scale is reversed (100 - pain score) to obtain a range from worst (0) to best (100). The total score (the average of all domains) ranges from 0 to 100, with higher scores indicating better hand function.[13,23] This total score is obtained by summing the scores for all 6 scales and then dividing by 6. For scales with <50% missing items, the average of the existing scale items was imputed for the missing items. If 50% of the items are missing, the scale was not scored. The MHQ total score was not computed if scores for >2 scales were missing. The Dutch version of the MHQ was developed and validated in patients with rheumatoid arthritis.[24] Patients filled in the MHQ without further assistance. It takes 15 minutes to complete the questionnaire.[23]

Physical functioning

The Barthel Index is a structured interview to estimate a patient's performance in terms of activities of daily living. Scores range from 0 to 20, with 20 points indicating full independence in activities of daily living.[25]

Health-Related Quality of Life

The Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36) is a generic instrument with 36 items covering 8 domains: physical function, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health. From these, physical and mental component summary (PCS and MCS) of the SF36 can be computed, with both scales ranging from 0 to 100, with higher scores indicating better health status. Translation and validation of the Dutch version of the SF-36 was done by Aaronson et al.[26]

Instrumented tests

Hand function was measured using the following 4 instrumented tests, which were validated for patients with stroke:

The FAT assesses the functional capacity of the paretic upperextremity.[6] The test consists of 5 instrumented tasks, each scored binomially (0 or 1 point), with the maximum score being 5 points, with higher scores indicating better function.

The ARAT is an instrumented test to evaluate arm/hand function poststroke.[7] In this test, patients have to perform standardized tasks using 19 tools from a testing box. Dexterity and speed are scored on a 4-point scale (0-3). The maximum score is 57 points, with higher scores indicating good hand function.

The NHPT is an instrumented test specifically for hand function.[5] In this test, patients are asked to take 9 pegs from a box, stick them on a board, take them out again, and put them back in the box. Scores range from 0 to 18 points, with higher scores indicating better performance. Time is recorded, and the time limit is 50 seconds.

The Motricity Index (MI) measures muscle strength of the hemiplegic side in patients with stroke, arm and leg separately.[27] It takes into account the ability to perform voluntary movements and the maximal voluntary contraction. The score ranges from 0 to 100, with higher scores indicating more strength. In this study, the MI Arm was used.

Analysis

Descriptive analyses were used for disease characteristics, sociodemographic characteristics, instrumented tests, and outcomes on the questionnaires of patients participating in the study.

Then, the following measurement properties of the MHQ were determined.

Validity

In this study, the convergent validity, a subtype of construct validity, was used (how strongly a measure correlates with other related measures).[28] For this purpose, correlations between the MHQ total score and subscales on the one side and measures of physical and psychological functioning and overall quality of life on the other side were determined using Spearman correlation coefficients. We hypothesized that lower MHQ total scores would be associated with worse physical functioning and a lower quality of life. Furthermore, because the MHQ total score is a measure of hand function, we hypothesized that correlations with measures of mental functioning (MCS of the SF-36) would be the weakest whereas correlations with measures addressing hand function (instrumented tests) would be stronger.

Internal consistency

The internal consistency is related to the degree of interrelatedness of the MHQ total score and the 6 MHQ subscale scores. It was determined by calculating Cronbach α. The internal consistency is considered to be good when Cronbach α is between .70 and .95.[28]

Floor or ceiling effects

Possible floor or ceiling effects of the MHQ were determined by using the frequency distributions of the MHQ total and subscale scores at admission. Floor or ceiling effects were considered to be present if >15% of the respondents achieved the lowest or highest possible score, respectively.[28]

Test-retest reliability

Test-retest reliability was studied by computing the intraclass correlation of the total and subscale scores obtained at the assessment in the hospital and 2 weeks later in a subsample of 21 patients. Hand function was assumed to be stable in our population in a 2-week period, and exact recollection of the initial answers was not to be expected.

The validity and floor or ceiling effects were analyzed similarly in a subgroup of patients with limited hand function (MI Arm<100) to account for the fact that the patients in this study were not primarily included because of hand function problems.

All statistical analyses were performed using SPSS 22.0 for Windows.[a] A P value of <.05 was considered statistically significant. Tests were all 2-sided.

Results

In total, 51 patients agreed to participate in the study. Table 1 lists the sociodemographic and clinical characteristics of these patients.

Age, sex, and educational level were not significantly correlated to MHQ total scores (age: r=.02, P=.92; sex: r=.13, P=.39; educational level: r=.27, P=.06). The mean MHQ score was 70.0±22.4, with the best subscore for the domain pain (79.3±24.4) (table 2). The relatively high scores on the MHQ and instrumented tests were an indication for an overall mild impairment. A subgroup of patients with impaired hand function was identified using the MI Arm as a criterion; 37 patients scored <100 points. This subgroup had lower results on all outcome measures.

The ARAT and MHQ outcome scores of the patients with an MI Arm of 100 points were 56.4±1.3 and 92.1±9.1, respectively.

Table 3 presents the correlations between the MHQ scores of the affected hand and measures of physical functioning and quality of life. Significant correlations (2-tailed, P<.01) were found between the MHQ total score and outcome scores of the PCS of the SF-36, FAT, NHPT, MI Arm, and ARAT. The correlations indicated that lower MHQ scores were associated with worse physical functioning and lower quality of life. No significant correlation was found between the MHQ total score and score of the MCS of the SF-36. The subgroup of patients with impaired hand function (MI Arm score<100) yielded similar results. Table 4 presents the correlations between the MHQ subscales (all patients) and other outcome measures. The MHQ work subscale was significantly associated with the MCS of the SF-36, and the MHQ pain subscale was significantly associated with the PCS of the SF-36, NHPT time, and MI Arm.

With respect to the internal consistency of the MHQ, Cronbach α was .97 for the total score, .95 for the domain overall hand function, .97 for activities of daily living, .86 for pain, .97 for work performance, .90 for aesthetics, and .92 for patients' satisfaction with hand function.

Table 5 presents the number of patients with minimum and maximum scores (floor and ceiling effects). The MHQ total score showed no floor or ceiling effects. The MHQ subscores, however, did show ceiling effects. Floor or ceiling effects were also observed in the Barthel Index, FAT, ARAT, NHPT, and MI Arm. In the subgroup of patients with problems of arm/hand function (MI Arm<100), only the MHQ pain and aesthetics subscales showed a ceiling effect; the other MHQ subscales no longer showed it. The Barthel Index, FAT, ARAT, and NHPT still had large percentages in the minimum or maximum scores. The MI Arm no longer showed a ceiling effect because of the selection criterion of this subgroup (MI Arm<100).

Test-retest reliability was determined by means of the intraclass correlation coefficient computed in the 21 patients who filled in the MHQ twice. The intraclass correlation coefficient was .97 for the total score, .89 for the domain overall hand function, .84 for activities of daily living, .96 for pain, .90 for work performance, .78 for aesthetics, and .94 for patients' satisfaction with hand function.

Discussion

This study gives preliminary evidence that the MHQ is a consistent, valid, and reliable questionnaire to assess hand function in a population of 51 patients with stroke who were treated at an outpatient rehabilitation clinic. The MHQ comprises elements of the ICF domains body functions and structures, activities, and participation.

Our study population was not selected for problems in hand function specifically. This resulted in a relatively high MHQ total score compared with other studies. In previous studies of patients with rheumatic conditions and hand function problems, patients had average scores of 38.3[29] and 48.3[24] before treatment and 62.7 and 54.7 after treatment, respectively. In addition, patients with carpal tunnel syndrome had scores ranging from 47.6 to 52.9 before surgery and from 59.3 to 67.7 after surgery.[19] After selection of a subgroup of patients with hand function problems (MI Arm<100; n=37), the MHQ total score was 61.5 in our study, which is in line with other study populations.

The validity of the MHQ was accounted for by the significant correlations with the instrumented tests and PCS of the SF-36. As expected, lower MHQ total scores were related to unfavorable outcome scores, except for the MCS of the SF-36. We concluded that as far as emotional well-being is part of the MHQ construct, it does not correlate to mental aspects in general. In other populations such as those with rheumatoid arthritis, carpal tunnel syndrome, and distal radial fracture, the validity of the MHQ was established by relating the MHQ to instrumented hand tests or patient-reported improvement.[13,14,30]

The internal consistency of the MHQ was excellent for all subscales. In the study of Chung et al,[13] comparable values varying from .86 to .97 were found.

Floor or ceiling effects were prominent in the instrumented hand function tests and in the MHQ subscales. In the selected group of patients with hand function problems (MI Arm<100), the MHQ and 4 of the MHQ subscales showed no floor or ceiling effects; the MHQ subscales showed a ceiling effect for domains aesthetics and pain, as did the instrumented tests. The ceiling effect of the ARAT is a common problem, as demonstrated in another hospital-based population with stroke.[31] In the study of Shauver and Chung,[32] a ceiling effect was observed in the MHQ in patients with distal radial fracture 3 months postoperatively, in contrast to patients with rheumatoid arthritis or carpal tunnel syndrome. In our population with stroke, the MHQ can deal relatively well with floor and ceiling effects in the population with stroke, specifically in the subgroup with impaired hand function. Considering this, the MHQ is probably most suited for patients with stroke who actually experience hand function limitations.

The excellent reliability is in concordance with other studies of orthopedic patient groups such as those with rheumatoid arthritis and osteoarthritis; the intraclass correlation coefficient ranges from .85 to .96 for the total scores in these studies.[14]

Study limitations

This study is related to a population of patients with stroke taking part in an outpatient rehabilitation program in a specialized rehabilitation center. This population did not include the frail older population of patients with stroke who are referred to a nursing home after initial hospital admission, nor do the patients with very mild consequences who are directly discharged to their homes to receive treatment in primary care; therefore, the outcomes of this study cannot be applied to the population with stroke as a whole. Owing to the nature of a patient-reported outcome measure, patients with stroke and impaired cognitive functions may experience difficulties using the questionnaire. Another limitation of this study is the relatively small sample size, which prevented additional statistical analyses, such as confirmatory factor analysis. In contrast, the small sample size enabled the use of comprehensive hand function testing.

Conclusions

This study provides preliminary evidence that the MHQ is an internally consistent, valid, and reliable questionnaire with the ability to assess and describe hand function in patients with stroke admitted for outpatient rehabilitation; however, the results need to be confirmed in other populations with stroke. It may satisfy the need for a stroke-specific hand outcome measure that is easy to administer and covers the body functions and structures as well as the activities and participation domains of the ICF. Further research is needed to confirm responsiveness to treatment and to establish the minimal clinically important difference.

References

1. World Health Organization. Cardiovascular diseases. Available at: http://www.who.int/cardiovascular_diseases/en. Accessed October 22, 2015.
2. Nakayama H, Jørgensen HS, Raaschou HO, Olsen TS. Recovery of upper extremity function in stroke patients: the Copenhagen Stroke Study. Arch Phys Med Rehabil 1994;75:394-8.
3. Kwakkel G, Kollen BJ, van der Grond J, Prevo AJ. Probability of regaining dexterity in the flaccid upper limb: impact of severity of paresis and time since onset in acute stroke. Stroke 2003;34:2181-6.
4. Geyh S, Cieza A, Schouten J, et al. ICF core sets for stroke. J Rehabil Med 2004;44(Suppl):135-41.
5. Mathiowetz M, Weber K, Kashman N, Volland G. Adult norms for Nine Hole Peg Test of finger dexterity. Occup Ther J Res 1985;5: 24-38.
6. Heller A, Wade DT, Wood VA, Sunderland A, Hewer RL, Ward E. Arm function after stroke: measurement and recovery over the first three months. J Neurol Neurosurg Psychiatr 1987;50:714-9.
7. Lyle RC. A performance test for assessment of upper limb function in physical rehabilitation treatment and research. Int J Rehabil Res 1981; 4:483-92.
8. van Delden AL, Peper CL, Beek PJ, Kwakkel G. Match and mismatch between objective and subjective improvements in upper limb function after stroke. Disabil Rehabil 2013;35:1961-7.
9. Ashford S, Slade M, Malaprade F, Turner-Stokes L. Evaluation of functional outcome measures for the hemiparetic upper limb: a systematic review. J Rehabil Med 2008;40:787-95.
10. Lemmens RJ, Timmermans AA, Janssen-Potten YJ, Smeets RJ, Seelen HA. Valid and reliable instruments for arm-hand assessment at ICF activity level in persons with hemiplegia: a systematic review. BMC Neurol 2012;12:21.
11. Duncan PW, Wallace D, Lai SM, Johnson D, Embretson S, Laster LJ. The stroke impact scale version 2.0. Evaluation of reliability, validity, and sensitivity to change. Stroke 1999;30:2131-40.
12. Penta M, Thonnard JL, Tesio L. ABILHAND: a Rasch-built measure of manual ability. Arch Phys Med Rehabil 1998;79:1038-42.
13. Chung KC, Pillsbury MS, Walters MR, Hayward RA. Reliability and validity testing of the Michigan Hand Outcomes Questionnaire. J Hand Surg Am 1998;23:575-87.
14. Shauver MJ, Chung KC. The Michigan Hand Outcomes Questionnaire after 15 years of field trial. Plast Reconstr Surg 2013;131:779e-87e.
15. Horng YS, Lin MC, Feng CT, Huang CH, Wu HC, Wang JD.
Responsiveness of the Michigan Hand Outcomes Questionnaire and the Disabilities of the Arm, Shoulder, and Hand questionnaire in patients with hand injury. J Hand Surg Am 2010;35:430-6.

16. Kotsis SV, Lau FH, Chung KC. Responsiveness of the Michigan Hand Outcomes Questionnaire and physical measurements in outcome studies of distal radius fracture treatment. J Hand Surg Am 2007;32: 84-90.
17. Hoang-Kim A, Pegreffi F, Moroni A, Ladd A. Measuring wrist and hand function: common scales and checklists. Injury 2011;42:253-8.
18. Shauver MJ, Chang KW, Chung KC. Contribution of functional parameters to patient-rated outcomes after surgical treatment of distal radius fractures. J Hand Surg Am 2014;39:436-42.
19. Ebrahimzadeh MH, Mashhadinejad H, Moradi A, Kachooei AR. Carpal tunnel release in diabetic and non-diabetic patients. Arch Bone Jt Surg 2013;1:23-7.
20. Barden HL, Baguley IJ, Nott MT, Chapparo C. Measuring spasticity and fine motor control (pinch) change in the hand after botulinum toxin-A injection using dynamic computerized hand dynamometry. Arch Phys Med Rehabil 2014;95:2402-9.
21. World Medical Association. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. JAMA 2013;310:2191-4.
22. Dutch Society of Neurology. Stroke: diagnostics, therapy and careafter stroke [Dutch]. Available at: http://www.diliguide.nl/document/ 230/beroerte-diagnostiek-behandelingen-zorg-voor-patienten-met-eenberoerte.html. Accessed October 22, 2015.
23. University of Michigan. The Michigan Hand Outcomes Questionnaire(MHQ). Available at: http://mhq.lab.medicine.umich.edu/. Accessed October 22, 2015.
24. van der Giesen FJ, Nelissen RG, Arendzen JH, de Jong Z, Wolterbeek R, Vliet Vlieland TP. Responsiveness of the Michigan Hand Outcomes Questionnaire Dutch language version in patients with rheumatoid arthritis. Arch Phys Med Rehabil 2008;89:1121-6.
25. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud 1988;10:61-3.
26. Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol 1998; 51:1055-68.
27. Collin C, Wade D. Assessing motor impairment after stroke: a pilot reliability study. J Neurol Neurosurg Psychiatry 1990;53:576-9.
28. Terwee CB, Bot SD, de Boer MR, et al. Quality criteria were proposed for measurement properties of health status questionnaires. J Clin Epidemiol 2007;60:34-42.
29. Waljee JF, Chung KC, Kim HM, et al. Validity and responsiveness of the Michigan Hand Questionnaire in patients with rheumatoid arthritis: a multicenter, international study. Arthritis Care Res (Hoboken) 2010;62:1569-77.

30. Massy-Westropp N, Krishnan J, Ahern M. Comparing the AUSCAN Osteoarthritis Hand Index, Michigan Hand Outcomes Questionnaire, and Sequential Occupational Dexterity Assessment for patients with rheumatoid arthritis. J Rheumatol 2004; 31:1996-2001.
31. Lin JH, Hsu MJ, Sheu CF, et al. Psychometric comparisons of 4 measures for assessing upper-extremity function in people with stroke. Phys Ther 2009;89:840-50.
32. Shauver MJ, Chung KC. The minimal clinically important difference of the Michigan hand outcomes questionnaire. J Hand Surg Am 2009; 34:509-14.

Table 1. Baseline clinical and sociodemographic characteristics of 51 stroke patients receiving outpatient rehabilitation treatment.

Mean (min-max)	
Age, years	60 (39-87)
Time since stroke, months	8 (3-27)
Barthel Index	19 (12-20)
Number of patients; n (%)	
Female	16 (31)
Ischaemic stroke	39 (76)
Affected hand at time of study	
• Left	20 (39)
• Right	20 (39)
• Both	6 (12)
• None	5 (10)
Paid job before stroke [a]	30 (88)
Education level [b]	
• Low	14 (28)
• Medium	22 (44)
• High	14 (28)

[a] 30 out of 34 patients who had the workable age (≤65years before stroke)

[b] Low: up to and including lower technical and vocational training; medium: up to and including secondary technical and vocational training; and high: up to and including higher technical and vocational training and university.

Table 2. MHQ scores of the affected hand and measures of physical functioning and QoL of 51 stroke patients admitted for a general rehabilitation treatment, and in subgroup of 37 patients with hand function problems (Motricity Index Arm <100).

Hand Function Measure	N	Mean (SD) all patients	N	Mean (SD) subgroup MI<100
MHQ total score (worst-best; 0-100)	50	70.0 (22.4)	36	61.5 (20.1)
Subscales MHQ (worst-best; 0-100)				
Overall hand function	51	58.0 (27.3)	37	47.6 (22.2)
Activities of daily living	50	73.3 (26.6)	36	65.6 (27.1)
Pain	49	79.3 (24.4)	36	74.1 (25.9)
Work performance	45	63.4 (32.3)	33	53.3 (31.0)
Aesthetics	51	78.5 (29.4)	37	70.8 (31.2)
Satisfaction	51	63.7 (29.7)	37	53.9 (28.4)
Barthel index (worst-best, 0-20)	51	19.4 (1.4)	37	19.3 (1.6)
SF-36 PCS (worst-best; 0-100)	44	39.9 (11.2)	32	37.9 (10.7)
SF-36 MCS (worst-best; 0-100)	44	42.0 (13.8)	32	41.8 (13.5)
FAT (worst-best; 0-5)	51	4.2 (1.4)	37	3.7 (1.5)
ARAT (worst-best; 0-57)	51	49.0 (15.9)	37	46.2 (17.9)
NHPT performance (worst-best, 0-18)	51	14.5 (6.5)	37	13.2 (7.2)
NHPT time (best-worst, 0-50)	51	34.9 (10.6)	37	37.7 (10.7)
MI arm (worst-best, 0-100)	51	81.2 (18.4)	37	74.0 (16.7)

Table 3. Spearman rank correlation coefficients between the MHQ scores of the affected hand and measures of physical functioning and QoL of 51 stroke patients admitted for a general rehabilitation treatment, and in the subgroup of 37 patients with hand function problems (Motricity Index Arm <100).

Functional status	N	All patients Spearman	sign	N	Subgroup Spearman	MI<100 sign
Barthel index (worst-best, 0-20)	50	0.41	0.004	36	0.49	0.002
SF-36 PCS (worst-best; 0-100)	44	0.49	0.001	32	0.46	0.007
SF-36 MCS (worst-best; 0-100)	44	0.22	0.145	32	0.27	0.136
FAT (worst-best; 0-5)	50	0.45	0.001	36	0.39	0.020
ARAT (worst-best; 0-57)	50	0.64	0.000	36	0.60	0.000
NHPT performance (worst-best, 0-18)	50	0.56	0.000	36	0.52	0.001
NHPT time (best-worst, 0-50)	50	-0.64	0.000	36	-0.54	0.001
MI arm (worst-best, 0-100)	50	0.78	0.000	36	0.65	0.000

Table 4. Floor and ceiling effect of the MHQ scores of the affected hand and measures of physical functioning and QoL of 51 stroke patients admitted for a general rehabilitation treatment, and in the subgroup of 37 patients with hand function problems (Motricity Index Arm <100).

	Overall hand function	Activities of daily living	Pain	Work performance	Aesthetics	Satisfaction	MHQ total
Barthel index	.385**	.404**	.090	.162	.535**	.298*	.405**
SF-36 PCS	.404**	.492**	.354*	.407**	.487**	.435**	.493**
SF-36 MCS	.097	.224	.114	.338*	.220	.159	.223
FAT	.538**	.488**	.218	.206	.330*	.490**	.447**
ARAT	.715**	.624**	.242	.453**	.486**	.621**	.639**
NHPT perf	.598**	.631**	.145	.385**	.451**	.509**	.559**
NHPT time	-.696**	-.712**	-.303*	-.473**	-.421**	-.646**	-.640**
MI arm	.797**	.669**	.431**	.590**	.674**	.715**	.780**

**. *Correlation is significant at the 0.01 level (2-tailed).*

*. *Correlation is significant at the 0.05 level (2-tailed).*

3

Chapter 3

Patient reported outcomes of hand function three years after stroke

Arwert H, Schut S, Boiten J, Vliet Vlieland T, Meesters J
Top Stroke Rehabil. 2017 Oct 12:1-7

Abstract

Objective: To comprehensively describe hand function and associated factors among stroke survivors by means of the Michigan Hand Outcomes Questionnaire (MHQ; 6 domains; score 0–100, worst–best).

Methods: In this cross-sectional study, stroke patients were invited to complete a set of questionnaires on hand function, socio-demographic characteristics, mental functioning, daily activities, quality of life, and caregiver strain. Stroke characteristics were collected retrospectively from medical records. Multiple linear regression analysis adjusted for age, sex, and duration of follow-up was used to identify factors associated with MHQ score.

Results: 207 out of 576 eligible patients responded (36%); mean age 63.8 years (SD14.2), 125 males (60.4%). Mean time since stroke was 36.3 months (SD9.9). In 85% of the patients, the MHQ Total score was less than 100 points (median 79.9, IQR 63.0–95.8). The median scores of the domains were: overall hand function 75.0, daily activities 90.5, work 85.0, pain 100, appearance 93.8, and satisfaction with hand function 83.3. A lower MHQ Total score was significantly associated with a lower Barthel Index at hospital discharge, a lower level of education, a supratentorial stroke and with unfavorable outcomes regarding physical and mental functioning, quality of life, and caregiver strain.

Conclusion: Patients can perceive limitations on several domains with respect to hand function 2–5 years after stroke. Problems related to the appearance of the hand and satisfaction with hand function can be relevant and should be considered accordingly. Persistent hand problems after stroke are related to a more severe, supratentorial stroke in lower educated patients.

Introduction

Annually, 15 million people worldwide suffer a stroke. Of these, 5 million die and another 5 million are left permanently disabled, placing a burden on family and community.[1] These numbers are increasing, as is the overall global burden of stroke.[2]

Motor impairment, including hand function problems, after stroke affects about 80% of patients.[3] On hospital admission, more than two-thirds of the stroke patients have impairment of upper extremity function; after 3 months, 20% still have hand function problems, varying from mild to severe.[4] Of the patients with initially impaired motor function of upper and lower extremity some improvement in arm function was seen in 38%, [6] months after stroke.[5] In a study of Norlander et al., using a telephone interview in 145 patients, 35.4% mentioned limitations in upper extremity functioning 10 years post stroke.[6] In a selected population of 54 stroke patients with initial arm impairment, 50% had problems with arm function four years post stroke as measured with performance tests.[7] A remarkable finding in this latter study was that many patients, even those with moderate to good Fugl-Meyer motor scores, still reported the loss of function in an arm to be a major problem. The same observation was made in a study of 84 stroke patients deemed recovered after 3 months; stroke still affected their hand function significantly according to the Stroke Impact Score, compared to a control group of 246 community-dwelling elderly.[8] In a recent study, it was demonstrated that hand function was one of the domains with the highest perceived impact 6 years after stroke.[9]

According to the International Classification of Functioning, Disability and Health (ICF) problems after stroke reach out to several domains of health, including emotional aspects, sensory aspects, pain, activities of daily living, work, and leisure.[10] Hand function assessments used in the abovementioned studies addressed only some of these domains.[11] In addition, performance tests are generally costly and time consuming, requiring a trained professional and adequate equipment, whereas a self-reported questionnaire is relatively easy to administer in a larger population and provides important information about the perceived impact of stroke.[9]

The consequences of hand function problems after stroke are complex since many domains may be affected. Information on the prevalence of hand function problems and their resulting impact on all aspects of daily life in the chronic phase after stroke is essential to understand the needs of stroke patients in this respect, and may be important to explain health care usage.

However, research on this subject is scanty and inconsistent.[9] The Michigan Hand Outcomes Questionnaire (MHQ), a multidimensional questionnaire that was previously validated in stroke patients provides detailed information on several domains of hand function, e.g. pain, function, daily activities, satisfaction, and appearance.[12] The goal of our study was, therefore, to comprehensively describe the impact of hand function problems by means of the MHQ 2–5 years after stroke and to examine to what extent these are related to patient and stroke characteristics.

Methods

Design

This cross-sectional study was executed at the Haaglanden Medical Center (HMC), a large teaching hospital in The Hague, The Netherlands. This hospital has a comprehensive stroke center with vascular neurologists, neuro-interventionalists and vascular neurosurgeons.

Data were collected by means of a set of pen-and-paper questionnaires. Additional medical information was extracted retrospectively from the participants' medical records. The study was judged to fall outside the remit of the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee South West Netherlands, and a written exemption from ethical approval was obtained. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2013.[13] Informed consent was obtained from all patients for participation in the study.

Patients

All patients hospitalized for a stroke between January 2008 and December 2010 were identified from the HMC hospital registry. From patients who had been hospitalized for a stroke more than once during the study period, only the first hospitalization was taken into account. Of all potentially eligible patients, the hospital and town council registries were checked to identify any deceased patients. Then, a further selection was done using the following inclusion criteria: (a) first-ever ischemic or hemorrhagic stroke; (b) age 18 years or older at the time of hospitalization. Exclusion criteria were: (a) traumatic brain injury, cerebral neoplasms or transient ischemic attack (TIA); (b) medical condition not allowing participation (patients in a vegetative state).

Patients were invited by their treating physician to participate by means of a letter and an information leaflet. Participation concerned the completion of a questionnaire on paper about their current health status and of a questionnaire by their spouse or other caregiver, if applicable. They were asked to return the questionnaires and a signed informed consent form using a prestamped envelope. In case of no response, patients were contacted by telephone by a research nurse. Of the non-responders, the age, sex, and date of stroke were registered.

Hand function: the Michigan Hand Outcomes Questionnaire

The MHQ is a self-administered, 57-item questionnaire covering 6 domains: overall hand function, activities of daily living, pain, work performance, aesthetics, and patients' satisfaction with hand function (http://sitemaker.umich.edu/mhq/overview).[14] It has been validated for hand function problems in stroke patients, rheumatoid arthritis, metacarpal phalangeal joint arthroplasty, carpal tunnel syndrome, hand injury, and distal radius fractures.[12,14–19] The Dutch version of the MHQ was developed and validated in patients with rheumatoid arthritis.[20] In a previous study among stroke patients, the internal consistency of the MHQ was high (Cronbach's α 0.97); the MHQ total score correlated significantly with hand function performance tests ($p < 0.01$) as an indication of a good construct validity; the test–retest ICC was 0.97.[12] It covers several ICF categories to describe the effect of stroke on hand function.[10] The function of the left and right hand is recorded separately (except for the domains pain and work performance). Examples of questions of the 6 domains are: How was the strength in your left hand? (Overall hand function); How difficult was it for you to pick up a coin with your right hand? (activities of daily living); How often did you have to take it easy at your work because of problems with your hand(s)/ wrist(s)? (work performance); how often did the pain in your right hand(s)/ wrist(s) interfere with your sleep? (pain); the appearance (look) of my right hand sometimes made me uncomfortable in public (aesthetics); how is your satisfaction with the overall function of your left hand? (patients' satisfaction with hand function). Each item is scored on a 1–5 scale, with the domain scores ranging from 0 to 100, a higher score indicates better hand function. The pain scale is reversed (100 – pain score) to obtain a range from worst (0) to best (100). The total score (the average of all domains) ranges from 0 to 100, higher scores indicating better hand function. For domains with ≤ 50% missing items within an individual patient, the average of the existing scale items for the individual patient was imputed for the missing items. If > 50% of the items are missing, the domain was not scored. The MHQ total score was not computed if scores for > 2 domains were missing. Completing of the questionnaire takes 15 min.

Stroke-related characteristics

The following data were collected from the medical record: type of stroke (hemorrhagic/ischemic), lateralization (left hemisphere/right hemisphere/vertebrobasilar), receiving rt-PA thrombolysis or not, functioning after admission to the hospital and at discharge from hospital (Barthel Index – BI;[21] score range 0–20; higher score indicates less dependent in daily care) and duration of hospital stay (Length of Hospitalization – LOS; days).

Patient-related characteristics

The survey comprised questions on the following socio-demographic items: educational level (Low: up to and including lower technical and vocational training; medium: up to and including secondary technical and vocational training; and high: up to and including higher technical and vocational training and university), and living alone or not (social situation).

Physical and mental functioning

The FAI (Frenchay Activity Index) describes the level of activities and participation. This inventory scores 15 activities on a 4-point scale (range 0–3, never–frequently). The maximum score is 45 points and represents the highest level of functioning.[22,23]

Anxiety and depression were measured by means of a Dutch version of the Hospital Anxiety and Depression Scale (HADS) which contains two 7-item scales, one for anxiety and one for depression, both with a score range of 0–21.[24,25] A higher score means higher level of depression or anxiety. A HADS depression score of 8 points and above is an indicator of clinically relevant depressive symptoms.[24]

Health-related quality of life

The SF-36 is a generic instrument with 36 items covering eight domains (physical function, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health). The SF-36 subscale scores range from 0 to 100, with a higher score indicating better health status. From these, a physical and a mental summary scale can be computed. Scoring of the summary scales is undertaken by weighting and summing the original eight dimensions. These weights are gained from factor analysis of data from a general population. The SF-36 has been translated and validated by Aaronson et al. into a Dutch version.[26]

The EuroQol classification system (EQ5D) was administered, consisting of 5 questions on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.[27] From the

EQ5D classification system, the EQ5D utility index was calculated. The five 3-point Likert questions of the EQ5D yield a summary score ranging from –0.329 (no health) to 1 (full health).

Caregiver strain

Caregiver strain was measured using the caregiver strain index (CSI). Participants were instructed to ask their caregiver (partner, child, other family member or friend) to fill the CSI, if applicable. This questionnaire consists of 13 items (yes/no) to assess the subjective care load of the caregiver, the CSI total score ranges from 0 to 13; higher score means more caregiver strain.28 A score of seven or more indicates a high level of strain. The CSI was validated in a Dutch stroke population.[29]

Analysis

Descriptive statistics were used for the stroke-related and patient characteristics, the MHQ scores and the outcome measures (mean [SD] or median [inter quartile range; IQR]).

The unpaired T-test and chi-square test were used to analyze differences between the responders and non-responders with respect to age and sex.

Univariate linear regression analysis was used to determine which stroke characteristics, patient characteristics and health outcome measures (independent variables) were associated with hand function (MHQ total score; dependent variable). Adjustment was made for age, sex, and duration of follow-up as confounding factors. Results were reported as β with 95% Confidence Intervals (95%-CI) and corresponding p-values.

Patient and stroke-related characteristics that were significantly associated with hand function (univariate, $p < 0.05$) were entered in a multivariable linear regression model. In the first block confounding factors were entered (age, sex, and follow-up), in the second block the independent variables were entered. Subsequently, variables that did not contribute to the explained variance were removed from the equation by means of backward elimination. Results were reported as β with 95% Confidence Intervals (95%-CI) and corresponding p-values. Statistical analyses were performed using IBM SPSS statistics, version 22. For all analyses, $p < 0.05$ (2-tailed) is considered the criterion for statistical significance.

Results

A total of 576 patients met the inclusion criteria of the study, of whom 207 (36%) gave informed consent and completed the questionnaires (Figure 1). There were no significant differences between responders and non-responders with respect to sex ($p = 0.11$) and age ($p = 0.13$).

The general results are shown in Table 1. Mean age of the responders was 63.8 years (SD 14.2) at time of stroke, 60.4% were male. The median duration of hospital stay was 7 days (IQR 7). During admission, the median Barthel Index (BI) improved from 14 (IQR 11) to 19 (IQR 8) at discharge, with 77 of 174 (44.3%) having the maximal Barthel score (20 points). The majority of the patients was discharged to their homes (53.6%); others were transferred to another hospital, a rehabilitation clinic or a nursing home.

Most patients (181 of 207, 87.4%) had had an ischemic stroke. The stroke location was predominantly supratentorial (164 patients, 79.2%), 43 (20.8%) were cerebellar or brainstem lesions. One patient had bilateral cerebral lesions. The mean time of follow-up was 36.3 months (SD 9.9; range 21–57 months). At follow-up, most patients were living together (135 of 204 patients, 66.2%).

Of the patients, 38 (22.2%) had a FAI score lower than 15, indicating a serious level of dependence.[30] Clinically relevant depressive symptoms (HADS-D ≥ 8) were reported by 67 patients (34.2%).

Results of Michigan Hand Outcomes Questionnaire

The median score of the MHQ total was 79.9 (IQR 63.0–95.8, Figure 2). In 85% of the patients, the MHQ Total score was less than 100 points, indicating that a majority of the patients experienced hand problems to some extent. Patients with a Barthel Index < 20 points at discharge from the hospital had significantly lower scores on the MHQ Total compared to those with maximal Barthel Index (20 at discharge): 68.8 (SD 24.3) and 83.9 (SD 18.3), respectively (T-test, $p < 0.05$).

The domains that contributed to the MHQ total were all more or less relevant for the patients. Hand function as such was rated lower than limitations related to ADL or work. Appearance and satisfaction scored less than maximal in a majority of the patients (55 ± 6.9% and 63 ± 6.7%, respectively (95% CI). Pain was an issue in a minority of the patients, 43 ± 6.8% (95% CI).

The associations between the patient and stroke characteristics and measures of current health status on the one side and the MHQ scores on the other side are shown in Table 2, adjusted for age, sex, and follow-up. In a univariate regression analysis, lower education, longer hospitalization, lower Barthel Index after admission and at discharge, discharge to another institution and a supratentorial stroke were related to a worse outcome on the MHQ Total. Worse outcomes on daily activities, mood, anxiety and quality of life, and a higher caregiver strain were significantly associated with a lower MHQ Total score.

In order to understand the association of patients' and stroke characteristics with overall hand function as perceived by the patients, hierarchical multiple regression analysis was performed (based on complete data of 156 patients). Lower education (β 6.88, CI 3.00–10.77), a lower Barthel Index at discharge (β 1.62, CI 1.07–2.17), and a supratentorial location (β 9.72, CI 1.84–17.60) were related to a significantly lower MHQ Total score after 2–5 years, adjusted for age, sex, and follow-up (R^2 0.28).

Discussion

The MHQ is a validated, multidimensional tool that efficiently can describe outcome of hand function in larger stroke populations. In this cross-sectional hospital-based study 2 to 5 years after stroke, patients used the MHQ to report on hand function, ADL, work, pain, appearance, and satisfaction with hand function. A majority of the patients experienced at least some limitations; pain was less often mentioned as a problem compared to the other domains. The MHQ Total score was closely related to other health outcomes such as activity level, mood, quality of life, and caregiver strain. Patients with a more severe stroke, a lower education, and a supratentorial stroke location had significantly lower outcomes on the MHQ.

Patients in our study were included regardless of their initial impairment. This resulted in a relatively high MHQ Total compared to studies in patient populations with specific hand function problems as an inclusion criterion. In the present study, the MHQ Total of the subgroup with submaximal Barthel score at discharge (< 20) was 68.8 points (SD 24.3). This is in line with the results of other patient categories, such as rheumatoid patients[20,31] and patients with carpal tunnel syndrome.[19]

In literature, lower percentages of hand function problems are mentioned in unselected stroke cohorts.[4,6] This can be explained by the way hand function is defined and measured.[8] The Action Research Arm Test (ARAT) is frequently used; patients with mild hand function problems can be missed because of the ceiling effect of the ARAT.[11,32] Patients with seemingly good recovery could still experience relevant problems in hand function.[7,8] The MHQ seems to be able to discern the milder hand function problems stroke patients may perceive.

Stroke patients can suffer from complaints other than an impaired function with respect to the hand. The broad range of items that was included in the ICF Core set for stroke reflects the large variety of impairments, limitations, and restrictions of activities and participation involved, as well as the interactions with environmental factors.[10] Other validated assessment tools that comprise hand-related questions are the Stroke Impact scale (SIS) and the Abilhand.[33,34] The SIS focuses on strength and daily activities, the Abilhand on daily activities;[35] they cover a limited range of ICF items compared to the MHQ. In the present study, other domains were at least as important as pain. Of these domains, appearance of the hand and satisfaction with hand function have drawn little attention to date.

Our results indicate that a lower Barthel score at discharge, a lower educational level, and a supratentorial stroke contribute independently to a lower MHQ outcome 2–5 years after stroke. In line with our results, a higher Barthel score was related to a better hand function in a community-based stroke population.[36] The explanation of educational level as a contributor to the MHQ outcome is not unexpected. It is generally accepted that social inequality has effect on the outcome of chronic diseases, partly because of differences in exposure to behavioral risk factors.[37]

The relevance of stroke location for hand function is not fully understood yet. Several aspects could be of importance, e.g. cognition, sensibility, or compensation options for a loss of dexterity after a supratentorial stroke.[38,39] Schiemanck et al. found that at one year post-stroke lesions of the internal capsule were associated with a significantly lower probability of return of isolated hand motor function than lesions of the cortex, subcortex, and corona radiata; only patients with middle cerebral artery strokes were included.[40] Additional research is warranted to understand the influence of stroke location on hand function.

Limitations

Causal relations are difficult to infer due to the cross-sectional design of the study. A selection bias is imminent because not all patients responded to the questionnaire, especially if cognitive or language impairments are present; on the other hand, the non-responders were comparable with respect to age and sex, and the resultant study population was comparable to other hospital-based populations with respect to Barthel Index and health-related outcomes (depression, FAI, quality of life).[6,41,42,43]

Data regarding the volume and content of rehabilitation activities after stroke were not collected and therefore could not be used as a determinant for post-stroke hand function in this study. Objective measurements of hand function were not available, but from earlier research it is known that the MHQ is a valid method to assess post-stroke hand functioning compared with other objective and instrumented measurements.

Conclusions

By means of the MHQ, a multidimensional description of hand function and related aspects in a population of stroke survivors is provided. Apart from known items such as function, ADL, work, and pain, also items regarding appearance and satisfaction can be relevant for stroke patients and should be included in the evaluation of the effect of interventions. A more severe, supratentorial stroke and a lower level of education are associated with the risk of persistent impairments regarding the hand. Future research has to reveal whether interventions that aim to improve hand function in specific domains are effective.

Acknowledgments

We are indebted to A. Hanschke, research nurse at Landsteiner Institute, The Hague, for her assistance with the data collection and to C. Kromme, datamanager of Sophia Rehabilitation Center, the Hague, for his support with the database.

Funding

This work was supported by the Jacobus Foundation and the Research fund of Haaglanden Medical Center.

References

1. World Health Organisation. The global burden of stroke. Http://www.who.int/cardiovascular_diseases/en/cvd_atlas_15_burden_stroke. pdf?ua=1. Accessed August 31, 2017.
2. Feigin VL, Forouzanfar MH, Krishnamurthi R, et al. Global and regional burden of stroke during 1990–2010: findings from the Global Burden of Disease Study 2010. Lancet. 2014;383(9913):245–255.
3. Langhorne P, Coupar F, Pollock A. Motor recovery after stroke: a systematic review. Lancet Neurol. 2009;8(8):741–754.
4. Nakayama H, Jørgensen HS, Raaschou HO, Olsen TS. Recovery of upper extremity function in stroke patients: the Copenhagen stroke study. Arch Phys Med Rehabil. 1994;75:394–398.
5. Kwakkel G, Kollen BJ, van der Grond J, Prevo AJ. Probability of regaining dexterity in the flaccid upper limb: impact of severity of paresis and time since onset in acute stroke. Stroke. 2003;34:2181–2186.
6. Norlander A, Carlstedt E, Jönsson AC, et al. Long-term predictors of social and leisure activity 10 years after stroke. Plos One. 2016;11(2):e0149395.
7. Broeks JG, Lankhorst GJ, Rumping K, Prevo AJ. The long-term outcome of arm function after stroke: results of a follow-up study. Disabil Rehabil. 1999;21(8):357–364.
8. Lai SM, Studenski S, Duncan PW, Perera S. Persisting consequences of stroke measured by the stroke impact scale. Stroke. 2002;33(7):1840–1844.
9. Ytterberg C, Dybäck M, Bergström A, Guidetti S, Eriksson G. Perceived impact of stroke six years after onset, and changes in impact between one and six years [published online August 9 2017]. J Rehabil Med. 2017.
10. Geyh S, Cieza A, Schouten J, et al. ICF core sets for stroke. J Rehabil Med. 2004;36:135–141.
11. Santisteban L, Térémetz M, Bleton JP, Baron JC, Maier MA, Lindberg PG. Upper limb outcome measures used in stroke rehabilitation studies: a systematic literature review. Plos One. 2016;11(5):e0154792.
12. Arwert HJ, Keizer S, Kromme CH, Vliet Vlieland TP, Meesters JJ. Validity of the Michigan Hand Outcomes Questionnaire in patients with stroke. Arch Phys Med Rehabil. 2016;97(2):238–244.
13. World Medical Association. Declaration of helsinki – ethical principles for medical research involving human subjects. Https://www.wma. net/policies-post/wma-declaration-of-helsinki-ethical-principles-formedical-research-involving-human-subjects/. Accessed August 31, 2017)
14. Chung KC, Pillsbury MS, Walters MR, Hayward RA. Reliability and validity testing of the Michigan Hand Outcomes Questionnaire. J Hand Surg Am. 1998;23:575–587.
15. Shauver MJ, Chang KW, Chung KC. Contribution of functional parameters to patient-rated

outcomes after surgical treatment of distal radius fractures. J Hand Surg Am. 2014;39:436–442.

16. Horng YS, Lin MC, Feng CT, Huang CH, Wu HC, Wang JD. Responsiveness of the Michigan Hand Outcomes Questionnaire and the disabilities of the arm, shoulder, and hand questionnaire in patients with hand injury. J Hand Surg Am. 2010;35:430–436.
17. Kotsis SV, Lau FH, Chung KC. Responsiveness of the Michigan Hand Outcomes Questionnaire and physical measurements in outcome studies of distal radius fracture treatment. J Hand Surg Am. 2007;32:84–90.
18. Hoang-Kim A, Pegreffi F, Moroni A, Ladd A. Measuring wrist and hand function: common scales and checklists. Injury. 2011;42:253–258.
19. Ebrahimzadeh MH, Mashhadinejad H, Moradi A, Kachooei AR. Carpal tunnel release in diabetic and non-diabetic patients. Arch Bone Jt Surg. 2013;1:23–27.
20. van der Giesen FJ, Nelissen RG, Arendzen JH, de Jong Z, Wolterbeek R, Vliet Vlieland TP. Responsiveness of the Michigan Hand Outcomes Questionnaire–Dutch language version in patients with rheumatoid arthritis. Arch Phys Med Rehabil. 2008;89:1121–1126.
21. Collin C, Wade DT, Davies S, et al. The barthel ADL index: a reliability study. Int Disabil Stud. 1988;10:61–63.
22. Wade DT, Legh-Smith J, Langton HR. Social activities after stroke: measurement and natural history using the Frenchay Activities Index. Int Rehabil Med. 1985;7(4):176–181.
23. Post MW, de Witte LP. Good inter-rater reliability of the Frenchay Activities Index in stroke patients. Clin Rehabil. 2003;17(5):548–552.
24. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. Acta Psychiatr Scand. 1983;67:361–370.
25. Spinhoven P, Ormel J, Sloekers PP, et al. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. Psychol Med. 1997;27(2):363–370.
26. Aaronson NK, Muller M, Cohen PD, et al. Translation, validation, and norming of the Dutch language version of the SF-36 health survey in community and chronic disease populations. J Clin Epidemiol. 1998;51(11):1055–1068.
27. EuroQol Group. EuroQol–a new facility for the measurement of health-related quality of life. Health Policy. 1990;16(3):199–208.
28. Robinson BC. Validation of a Caregiver Strain Index. J Gerontol. 1983;38(3):344–348.
29. van Exel NJ, Scholte op Reimer WJ, Brouwer WB, et al. Instruments for assessing the burden of informal care giving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. Clin Rehabil. 2004;18(2):203–214.

30. Singam A, Ytterberg C, Tham K, vonKoch L. Participation in complex and social everyday activities six years after stroke: predictors for return to pre-stroke level. Plos One. 2015;10(12):e144344.
31. Waljee JF, Chung KC, Kim HM, et al. Validity and responsiveness of the Michigan Hand Questionnaire in patients with rheumatoid arthritis: a multicenter, international study. Arthritis Care Res (Hoboken). 2010;62(11):1569–1577.
32. Lin JH, Hsu MJ, Sheu CF, et al. Psychometric comparisons of 4 measures for assessing upper-extremity function in people with stroke. Phys Ther. 2009;89:840–850.
33. Duncan P, Wallace D, Lai S, Johnson D, Embretson S, Jacobs LL. The stroke impact scale version 2.0: evaluation of reliability, validity, and sensitivity to change. Stroke. 1999;30:2131–2140.
34. Penta M, Thonnard JL, Tesio L. ABILHAND: a rasch-built measure of manual ability. Arch Phys Med Rehabil. 1998;79(9):1038–1042.
35. Lemmens RJ, Timmermans AA, Janssen-Potten YJ, Smeets RJ, Seelen HA. Valid and reliable instruments for arm-hand assessment at ICF activity level in persons with hemiplegia: a systematic review. BMC Neurol. 2012;12:563.
36. Pang MY, Harris JE, Eng JJ. A community-based upper-extremity group exercise program improves motor function and performance of functional activities in chronic stroke: a randomized controlled trial. Arch Phys Med Rehabil. 2006;87(1):1–9.
37. Nordahl H. Social inequality in chronic disease outcomes. Dan Med J. 2014;61(11):B4943.
38. Ward NS, Brown MM, Thompson AJ, Frackowiak RS. The influence of time after stroke on brain activations during a motor task. Ann Neurol. 2004;55(6):829–834.
39. Rossiter HE, Eaves C, Davis E, et al. Changes in the location of cortico-muscular coherence following stroke. Neuroimage Clin. 2012;13(2):50–55.
40. Schiemanck SK, Kwakkel G, Post MW, Kappelle LJ, Prevo AJ. Impact of internal capsule lesions on outcome of motor hand function at one year post-stroke. J Rehabil Med. 2008;40(2):96–101.
41. Kootker JA, van Mierlo ML, Hendriks JC, et al. Risk factors for symptoms of depression and anxiety one year poststroke: a longitudinal study. Arch Phys Med Rehabil. 2016;97(6):919–928.
42. Gadidi V, Katz-Leurer M, Carmeli E, Bornstein NM. Long-term outcome poststroke: predictors of activity limitation and participation restriction. Arch Phys Med Rehabil. 2011;92(11):1802–1808.
43. Ayerbe L, Ayis S, Crichton S, Wolfe CD, Rudd AG. The long-term outcomes of depression up to 10 years after stroke; the South London stroke register. J Neurol Neurosurg Psychiatry. 2014;85(5):514–521.

Figure 1. Characteristics of responders and non responders.

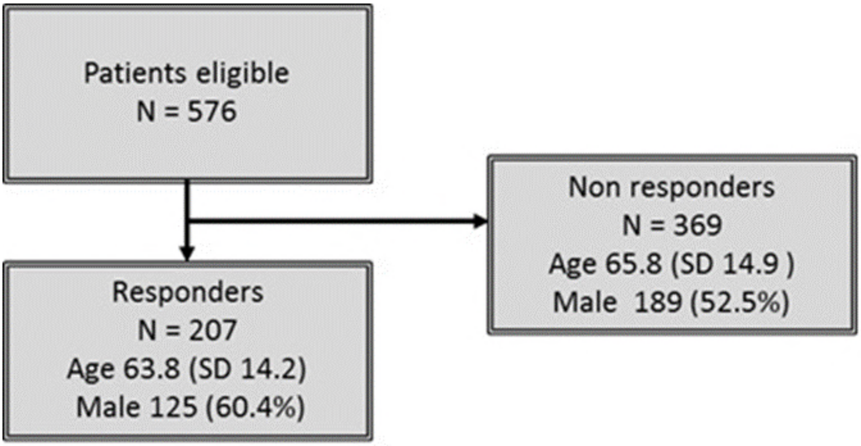


Figure 2. Median scores and IQR of the MHQ Total and the MHQ domains.

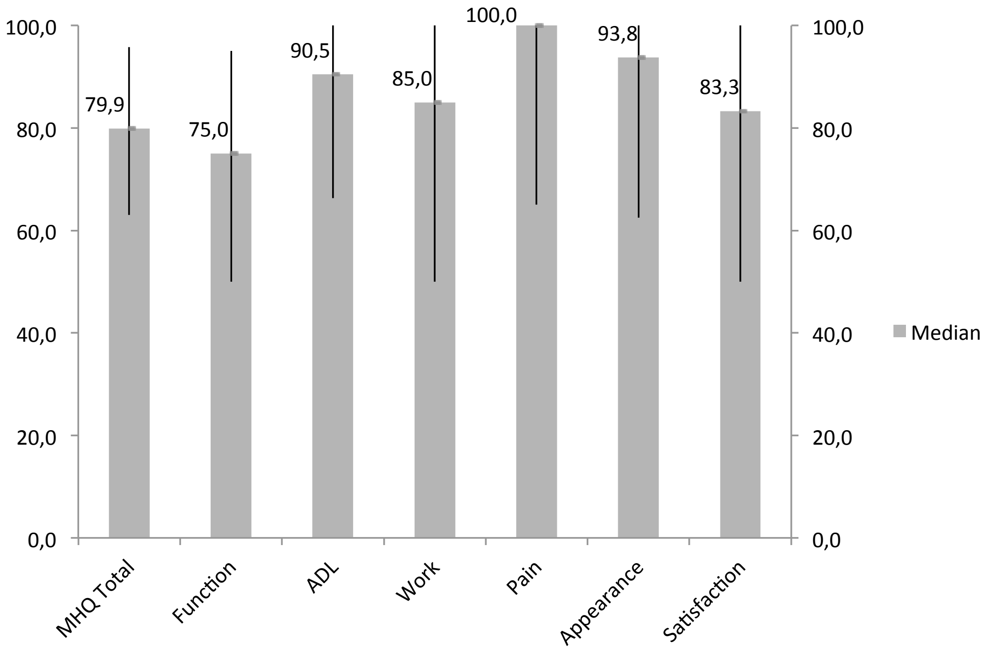


Table 1. Patients' characteristics and stroke characteristics; current health status.

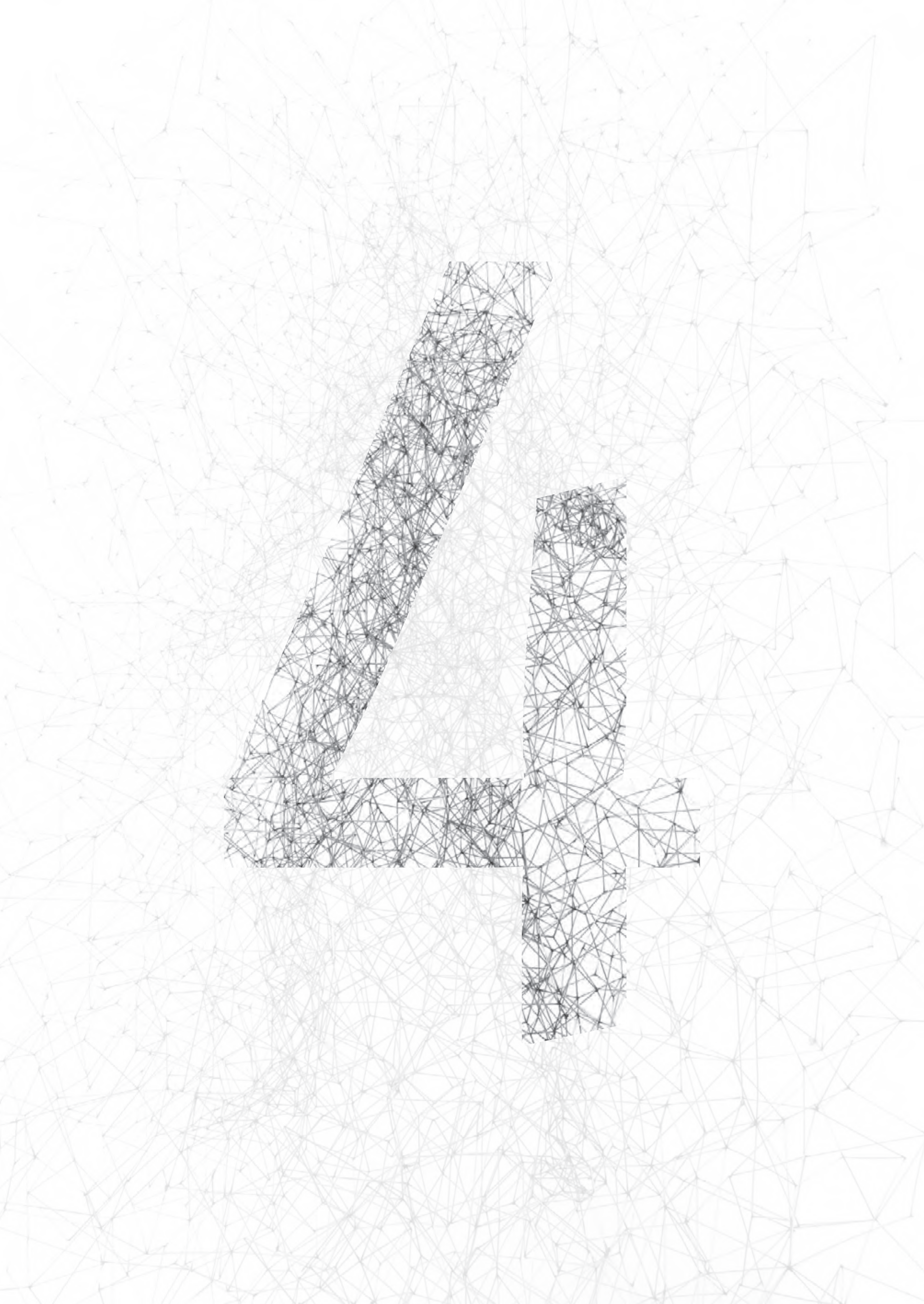
Patients' characteristics		**N total**	
Mean age at stroke, years (SD)		207	63.8 (14.2)
Sex:	- male N (%)	207	125 (60.4)
	- female N (%)		82 (39.6)
Mean duration of follow-up; Months (SD)		207	36.3 (9.9)
Educational level, number:	- Low N (%)	207	72 (36.2)
	- Middle N (%)		72 (36.2)
	- High N (%)		55 (27.6)
Social situation:	- living together N (%)	204	135 (66)
	- living alone N (%)		69 (34)
Stroke characteristics		N total	
Type of stroke:	- ischemic N (%)	207	181 (87.4)
	- haemorragic N (%)		26 (12.6)
Lesion; Number N (%)			
	- Supratentorial	207	164 (79.2)
	- left		97 (46.9)
	- right		66 (31.9)
	- bilateral		1 (0.5)
	- Vertebrobasilar		43 (20.8)
Thrombolysis:	- Yes N (%)	204	49 (23.7)
	- No N (%)		156 (76.3)
Length of hospital stay, days; median (IQR)		207	7 (7)
Barthel Index (0-20; worst – best); Median (IQR)			
	- at admission	174	14 (11)
	- at discharge	174	19 (8)
Discharge:			
	- home N (%)	178	98 (56.3)
	- other institution N (%)		80 (46.4)
Current health status		N total	Mean (SD)
FAI total (Score 0-45; worst-best)		171	23.19 (10.82)
HADS			
	- Anxiety (Score 0-21; best-worst)	195	5.41 (4.71)
	- Depression (Score 0-21; best-worst)	196	5.57 (4.93)
SF 36			
	- PCS (Score 0-100; worst-best)	186	41.49 (13.57)
	- MCS (Score 0-100; worst-best)	186	46.44 (12.53)
EQ5D (Score -0.321-1; worst-best)		195	0.73 (0.25)
CSI (Score 0-13; best-worst)		133	4.46 (3.71)

Abbreviations:, SD = standard deviation, IQR = interquartile range, Abbreviations: SD = standard deviation, IQR = interquartile range, FAI = Frenchay Activity Index, HADS = Hospital Anxiety and Depression scale, EQ5D = EuroQol, CSI = caregiver strain index

Table 2. Patient characteristics, stroke characteristics and outcomes of current health status of stroke patients in relation to the MHQ total (univariate regression analysis, corrected for age, sex and follow-up).

Patients' characteristics	**mean MHQ total**	**N total**	**β (95% CI)**	**p level**
Educational level:		191	6.87 (2.83 – 10.92)	0.001
- Low	69.9			
- Medium	75.3			
- high	83.3			
Social situation:		195	-0.46 (-7.19 – 7.10)	0.990
- living together	75.5			
- living alone	75.7			
Stroke characteristics		N total		
Type of stroke:		196	-0.78 (-10.52 – 8.95)	0.874
- ischemic	75.8			
- haemorragic	74.4			
Stroke lesion		196	12.73 (4.80 – 20.65)	0.002
- Supratentorial	73.1			
- Vertebrobasilar	85.3			
Thrombolysis		194	3.59 (-3.59 –10.77)	0.325
-Yes	74.5			
-No	76.2			
Length of hospital stay		196	-0.69 (-1.07 – -0.31)	<0.001
Barthel Index				
- at admission		165	1.33 (0.83 – 1.84)	<0.001
- at discharge		165	1.74 (1.17 – 2.30)	<0.001
Discharge destination:		175	11.25 (4.51 – 18.00)	0.001
- Home	81.0			
- other institution	69.5			
Current health status		N total		
FAI total (Score 0-45; worst-best)		166	1.55 (1.30 – 1.80)	<0.001
HADS				
- Anxiety (Score 0-21; best-worst)		188	-2.27 (-2.92 – -1.61)	<0.001
- Depression (Score 0-21; best-worst)		189	-2.64 (-3.22 – -2.06)	<0.001
SF 36:				
- PCS		180	1.23 (1.05 – 1.42)	<0.001
- MCS		180	0.77 (0.51 – 1.04)	<0.001
EQ5D* (Score -0.321-1; worst-best)		188	6.18 (5.21 – 7.14)	<0.001
CSI (Score 0-13; best-worst)		129	-3.77 (-4.73 – -2.82)	<0.001

** EQ5D data were multiplied by 10 in this analysis; the B and CI are based on the decile score of the EQ5D which is more comprehensible to interpret*


4

Chapter 4

Post stroke depression, a long term problem for stroke survivors

Arwert HJ, Meesters JJL, Boiten J, Balk F, Wolterbeek R, Vliet Vlieland TPM

Am J Phys Med Rehabil. 2018 Aug;97(8):565-571

Erratum:

In the Abstract, the Results, and the Discussion sections of this article, it was stated that "Male sex and being born abroad was statistically significantly associated with a high HADS depression score, adjusted for age, sex and stroke severity." This phrase contains a seemingly contradictory statement. The authors suggest rephrasing this statement in those sections as follows to avoid confusion:

Abstract:

Male sex and being born abroad was statistically significantly associated with a high HADS depression score, adjusted for age, sex and stroke severity (where appropriate).

Results:

A HADS depression score ≥ 8 at follow up was associated with male sex (0.46; CI 0.22 – 0.93; adjusted for age and Barthel Index at discharge) and with being born abroad (OR 2.70; CI 1.31 – 5.53; adjusted for age, sex and Barthel Index at discharge); less patients in the depression group drank alcohol (Table 3)

Table 3:

Asterix at age, sex and Barthel at discharge indicating:

* with adjustment for the other two confounding factors

Abstract

Objectives: To ascertain the prevalence of depressive mood and its determinants in the chronic phase after stroke.

Design: 576 consecutive patients were invited to participate 2-5 years after hospitalization for a first-ever stroke. Stroke characteristics at hospitalization were collected retrospectively from medical records. Patients and their caregivers completed questionnaires on depression (Hospital Anxiety and Depression Scale; HADS), socio-demographic characteristics, healthcare usage, daily activities, Quality of Life and caregiver strain. Patients with HADS depression scores <8 were compared to patients with HADS depression scores ≥8 by means of univariate logistic regression analyses, adjusted for age, sex and Barthel Index at discharge.

Results: 207 patients (36%) returned the questionnaires. After a mean follow-up of 36.3 months, 67 patients (34%) had a HADS depression score ≥8. Male sex and being born abroad was statistically significantly associated with a high HADS depression score, adjusted for age, sex and stroke severity. Depressed patients had higher anxiety levels, a more avoidant coping style, less daily activities and a lower Quality of Life; their caregivers experienced a higher burden.

Conclusion: In the chronic phase after stroke, a considerable proportion of patients has depressive symptoms. This appears to be related to sex, country of origin, anxiety, coping style, daily activities, Quality of Life and caregivers' strain. Future research should focus on causal relationships, and opportunities for treatment.

Keywords: stroke; depression; outcome assessment; humans; disability evaluation; social participation.

Introduction

Post stroke depression (PSD) is a common sequel of stroke, warranting the need for appropriate identification, education and treatment not only in the acute hospital phase but also in later stages. However, research on the longer term after stroke in a hospital based population is scanty.

A recent systematic review on depression post stroke including 23 studies showed that approximately one-third of survivors at any time up to five years after stroke are affected;[1] in this systematic review physical disability in the acute and later phases of stroke and stroke severity were consistently associated with depression. The follow up period of the hospital based studies in this review was only up to one year post stroke.

Another systematic review on this topic demonstrated that the prevalence of depression is stable across studies assessing patients at different time points in different areas of the world.[2] Across 43 studies, 29 studies used validated scales, 2 studies used a validated question as a definition of PSD, and 12 studies used DSM IV criteria; However, only two studies were based on a hospital population and had a follow up time of more than one year.[3, 4] Major predictors of depression were found to be: disability, depression pre-stroke, cognitive impairment, stroke severity and anxiety; On the other hand, depression was also found to be a predictor of lower quality of life, higher mortality and disability after stroke.

Depressive symptoms in the acute or subacute phase after stroke are associated with persistence of depression after 12 months.[5, 6, 7] To what extent socio-demographic factors (age, sex, educational level) contribute to PSD risk on the longer term is still out for debate.[6]

Depression is often poorly recognized and receives suboptimal treatment in primary care.[8] This is important, as chronic stroke patients usually do not receive intensive therapy anymore one year after stroke.

Several interventions have been reported to be effective in PSD. In an uncontrolled study cognitive behavioral therapy led to lower depression scores, compared with baseline.[9] A meta-analysis in stroke patients provided evidence for the positive effects of exercise on depression.[10] In addition, antidepressive medication seems to have an effect on PSD superior to placebo.[11]

Given the large impact of depression in patients after stroke, and the opportunities for treatment, identification of patients at risk, even in the later phases, is important. As literature on PSD in the chronic phase of hospital based populations is scarce, the aim of this study was to determine the prevalence of depressive mood in this specific population. Secondly, it aimed to determine which patient and stroke characteristics and measures of their current health status are associated with depressive mood. These results can guide professionals in order to identify and advise patients adequately along the line of therapy, and to make evidence-based decisions in treatment options.

Methods

Study design

This study was executed in 2012 at the Haaglanden Medical Center (HMC), a large teaching hospital in The Hague, The Netherlands. It has a comprehensive stroke department with vascular neurologists, neuro-interventionalists and vascular neurosurgeons.

Data were collected by means of patient reported outcome measures. Additional medical information was extracted retrospectively from the participants' medical records. The study was judged to fall outside the remit of the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee South West Netherlands, and a written exemption from ethical approval was obtained. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2013 (https://www.wma.net/what-we-do/medical-ethics/declaration-of-helsinki/); accessed April 7, 2017). Written informed consent was obtained from all patients participating in the study. This study conforms to all STROBE guidelines and reports the required information accordingly (see Supplementary Checklist).

Patients

All patients hospitalized for a stroke between January 2008 and December 2010 were identified from the hospital registries. From patients who had been hospitalized for a stroke more than once during the study period, only the first admission was taken into account. The following inclusion criteria were used: a. first ever ischaemic or haemorrhagic stroke; b. age

18 years or older at the time of hospitalization. Exclusion criteria were: a. other diagnosis such as traumatic brain injury, cerebral neoplasms or transient ischaemic attack (TIA); b. medical condition not allowing participation (patients in a vegetative state); c. insufficient Dutch language skills.

Subsequently, of all potentially eligible patients the hospital and town council registries were checked to identify any deceased patients.

Patients were invited by the treating physician to participate by means of a letter and an information leaflet. Participation concerned the completion of a questionnaire about their current health status and of a questionnaire by their spouse or other caregiver, if applicable. They were asked to return the questionnaires and a signed informed consent form using a pre-stamped envelope. Patients were instructed to take their time, and were encouraged to complete the questionnaires. In case of no response patients were contacted by telephone by a research nurse.

Assessment methods

Stroke-related determinants

Of all patients who agreed to participate in the present study, data were collected from the medical records about the type of stroke (hemorrhagic/ischaemic), lateralization (left hemisphere / right hemisphere / vertebrobasilar), thrombolysis treatment (rtPA), functioning after admission to and at discharge from hospital (Barthel Index;[12] score range 0 to 20) and duration of hospital stay (Length of Hospitalization – LOS).

Socio-demographic determinants

The survey comprised questions on the following socio-demographic determinants: life style characteristics (smoking Y/N, alcohol Y/N), educational level (Low: up to and including lower technical and vocational training; medium: up to and including secondary technical and vocational training; and high: up to and including higher technical and vocational training and university), living alone or not (social situation), and being born in the Netherlands or not (ethnicity).

Measures of current health status

The outcomes with respect to psychological and physical functioning concerned the following aspects:

- Anxiety and depression were measured by means of a Dutch version of the Hospital Anxiety and Depression Scale (HADS) which contains two 7-item scales, one for anxiety and one for depression, both with a score range of 0–21.[13] A higher score means higher level of depression or anxiety. A HADS-D score of 8 points or higher is used as a cut off point for clinically relevant depressive symptoms.[13]

- Coping was measured using the CopeEasy (Coping Orientations to Problems Experienced), a self-reported questionnaire comprising 32 items, with an ordinal scale from 1 to 4.[14, 15] It describes the extent to which three different types of coping strategies are used by patients to deal with their situation: Active, Avoiding and Seeking Support. Higher scores mean the patient uses this coping strategy more.

- The FAI (Frenchay Activity Index) describes the level of activities and participation. This inventory scores the frequency of 15 activities on a 4 point scale (range 0-3, never – frequently). The maximum score is 45 points and represents the highest level of functioning.[16]

- Caregiver strain was measured using the Caregiver strain index (CSI): This questionnaire consists of 13 items to assess the subjective care load of the caregiver, range from 0 to 13; higher means more caregiver strain. A score of seven or more indicates a high level of strain. [17, 18]

Healthcare usage was estimated by the number and type of physicians visited in the last six months (none or 1 physician; 2 or more physicians).

Health related quality of life

The SF-36 is a generic instrument with 36 items covering eight domains (physical function, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health). The SF-36 subscale scores range from 0 to 100, with a higher score indicating better health status. From these, a physical and a mental summary scale can be computed.

Scoring of the summary scales is undertaken by weighting and summing the original eight dimensions. These weights are gained from factor analysis of data from a general population. The SF-36 has been translated and validated by Aaronson et al into a Dutch version.[19]

Patients described their general health status using the EuroQol classification system (EQ5D), consisting of 5 questions on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.[20] From the EQ5D classification system, the EQ5D utility index was calculated. The five 3-point Likert questions of the EQ5D yield a summary score ranging from –0.329 (no health) to 1 (full health).

Analysis

A missing or incomplete answer on a question was considered as a missing value. If an individual patient did not meet the questionnaire-specific rules regarding the maximum number of missing values to calculate the total or subscale scores, the total numbers do not add up to 207 subjects.

Comparisons of age, sex, Barthel Index on admission, Barthel at discharge and discharge destination between patients who completed the questionnaires versus those who were eligible but did not participate were done by unpaired T-tests or Chi-Square tests.

Descriptive statistics were used for the stroke-related and patient characteristics, the measures of current health status and caregiver strain (mean (SD) or median (inter quartile range; IQR) dependent on their distribution).

We dichotomized the population according to their score on the HADS depression (HADS $<$ 8, or HADS $\geq$ 8).[13] The group with higher depression scores was compared with the group with lower depression scores by means of univariate logistic regression analysis, with adjustment for age, sex and Barthel at discharge as confounders. Independent variables were categorized into patient characteristics (educational level, social situation, ethnicity), stroke characteristics (type and localization of stroke, length of hospitalization, Barthel Index at admission and discharge, discharge destination) and measures of current health status and caregiver strain (HADS-Anxiety, CopeEasy, FAI, SF-36, EQ5D, CSI and healthcare usage). Results were reported as odds ratios (OR) with 95 % confidence interval (CI). For the EQ5D we multiplied the outcome by 10 in this analysis (EQ5D-decile), to have a meaningful OR of a raise of 0.1 point in the EQ5D. Analysis of interaction effects was conducted for sex and age in relation to patient characteristics, stroke characteristics and patient reported outcomes by means of additional logistic regression analysis.

Statistical analyses were performed using IBM SPSS Statistics, version 22. For all analyses, $p \leq 0.05$ (2-tailed) was considered the criterion for statistical significance.

Results

A total of 576 patients met the inclusion criteria of the study, of whom 207 (36%) gave informed consent and returned the questionnaires. There were no significant differences between responders and non-responders with respect to sex, age, Barthel Index on admission or discharge destination (Figure 1). The Barthel Index at discharge was higher for the responders compared to the non-responders (T-test, p = 0.01). The difference is less than 1.85 which is considered as the Minimal Clinically Important Difference (http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=916).

Patient and stroke-related determinants (Table 1)

The mean age of the responders was 63.8 years (SD 14.2) at time of stroke, 60.4% were male. The median duration of hospital stay was 7 days (IQR 7). During admission the median Barthel Index improved from 14 (IQR 11) to 19 (IQR 8) at discharge, with 77 of 174 (44.3%) reaching the maximal Barthel score (20 points) at discharge. The majority of the patients was discharged to their homes (53.6%); others were transferred to another hospital, a rehabilitation clinic or a nursing home. 161 of 204 patients were born in the Netherlands (78.9%). Of the 43 patients born abroad 4 were European of origin, the others were born in Africa, Middle East or Indonesia.

181 patients (87.4%) had had an ischaemic stroke. The stroke location was predominantly supratentorial (164 patients, 79.2%), whereas 43 (20.8%) were cerebellar- or stem lesions. One patient had bilateral cerebral lesions.

The mean time of follow up was 36.3 months (SD 9.9; range 21 to 57 months). At follow up 29 of 205 patients (14.1%) were currently smoking and 90 of 205 patients (43.9%) used alcohol. Most patients were living with a partner (135 of 204 patients, 66.2%).

58 patients (29.4%) had seen 2 or more physicians in the last 6 months.

Current health status

In Table 2 the results of the measures concerning the patients' current health status and the caregiver strain are presented. Of the patients 38 (22.2%) had a FAI score lower than 15, indicating a serious level of dependence.

Risk of depression

Of 196 patients who completed the HADS, 67 (34.2%) had a score of 8 or higher on the depression scale of the HADS, which is an indication of clinically relevant depressive symptoms. In both groups 9 patients had visited a psychiatrist in the last 6 months. Male sex (0.46; CI 0.22 – 0.93) and being born abroad (OR 2.70; CI 1.31 – 5.53) was associated with a HADS depression score ≥ 8 at follow up, adjusted for age, sex and Barthel Index at discharge; less patients in the depression group drank alcohol (Table 3).

In Table 4 the current health status of patients and their caregiver strain in relation to depression are presented. The subgroup with depression score ≥ 8 were compared to patients with depression score ‹ 8, adjusted for age, sex and Barthel Index at discharge. Patients with higher depression scores showed higher anxiety scores and lower outcomes on daily activities (FAI, OR 0.90; CI 0.87 – 0.94). They were significantly more avoidant in their coping (OR 8.26; CI 3.92 – 17.41). The Quality of Life was substantially lower (EQ5D-decile, OR 0.38; CI 0.28-0.51; PCS, OR 0.91; CI 0.88 – 0.94; MCS, OR 0.85; CI 0.81 – 0.89). Their caregivers showed higher strain levels (OR 1.28; CI 1.14 – 1.43).

According to the interaction analysis of age and sex on outcome measures no interaction was observed except for two relations: the relation between the FAI and depression was influenced by age; the relation between the EQ5D and depression was influenced by sex.

Discussion

In this hospital-based cohort of 207 subjects 2-5 years after stroke, one third was at risk for a depression. This subgroup showed a lower level of activities, was more avoidant in their coping, and had a lower quality of life; their caregivers experienced more strain. Being born abroad and male sex were related to higher depression scores.

The stroke severity in this cohort was comparable to other hospital based studies as can be concluded from the Barthel Index on admission to the hospital (median 14 points), and at discharge (Barthel Index of 19 or above in 50%). At follow up 22.2% were seriously limited in their activities (FAI < 15 points). These determinants are in line with other hospital based stroke studies.[7, 21]

In a meta-analysis the prevalence of PSD was 29% after follow up of more than 1 year, and 30% in hospital based studies.[2] Two hospital based studies had a follow up of more than 1 year, they used different instruments to identify PSD. Robinson et al used the DSM IV, resulting in 42% of the patients with a minor or major depression.[3] Gesztelyi et al used the Becks Depression Inventory;[4] 26% scored 10 point or more as an indicator of a mild depression or worse. In a recent prospective study with follow up of 1 year 27% of the stroke patients scored ≥ 8 on the depression scale of the HADS.[7]

In recent literature the risk of depression was found to be related to the initial severity of the stroke.[1, 2, 6, 7] In the present study the Barthel Index at discharge, as a proxy variable for stroke severity, was used as a covariate in the logistic regression in order to evaluate the risk of depression irrespective of the neurological deficit.

Male participants scored significantly higher on the HADS depression subscale in this study. In the literature, the relation between sex and depression in stroke patients is not consistent. Being female was a negative predictor for the EQ5D in one study.[22] In another study, male gender was an additional predictor for post-stroke depressive symptoms 3 years after stroke.[23] Kootker et al found no influence of gender on depression.[7] Age and gender did not predict depression in six out of the seven studies in a meta-analysis.[2]

The results show that ethnicity is a predictive factor for the development of depressive symptoms, being born abroad is related to higher depression scores on the HADS. Other studies consistently report an elevated burden of stroke in some race/ethnic groups, e.g. Hispanics and Blacks compared with Whites.[24] Latino stroke survivors have a significantly higher prevalence of depression compared to their non-Latino counterparts.[25] The reason for the influence of ethnicity is unknown; social, environmental and genetic factors can be involved.

Stroke localization was not related to depression in this study. In a systematic review only 1 study reported a significant association between PSD and stroke location;[6] subcortical and ACA lesions were independent risk factors for PSD. The study of Kootker et al suggested a small contribution of a lesion in the PCA as a risk factor for PSD. [7] In another recently published study, PSD was not related to lesion location.[26]

Inactivity, defined as a low score on the FAI, and depression are closely related in literature.[27] We confirmed the close relationship between lower outcomes on the FAI and mood disturbances (HADS-D ≥ 8). This relation was not influenced by the initial stroke severity, age or sex, as these factors were used as covariates in the analysis.

An avoidant coping strategy was related to higher depression scores in this study. In a hospital based study, avoidance was the independent factor most closely related to post stroke depression 3 months after stroke.[26] Avoidant responses may be more effective for managing short-term threats, but for long-term threats problem-solving coping may manage stress more effectively.[28] Stroke patients who prefer an accommodative coping strategy, accepting the consequences of an event, show fewer symptoms of depression;[29] this accommodative coping strategy corresponds largely to a less avoidant coping style.

The burden of caregivers was comparable to the results of previous studies on this subject, although the follow up was shorter, 6 months and 12 months respectively.[21, 30] As expected from this literature, the CSI was strongly related to depressive symptoms of the patients.

Due to the cross sectional design causal relations cannot be inferred. Another limitation of the study was that data on comorbidity, on the current treatment of depression and on cognitive deficits were not available. Furthermore, survey studies may be subject to response bias, therefore interpretation of the results must be done with care. Nevertheless, responders and non-responders were comparable with respect to age, sex, Barthel on admission and discharge destination. Notably, the characteristics of responders in the current study population were comparable with other stroke populations.

In conclusion, the present study found that depression is a relatively common problem even in the chronic phase after stroke, and is strongly related to coping style, Quality of Life, activities in daily life and participation. Caregivers of depressed patients experience a large burden. A higher risk of a depression in the chronic phase after stroke is observed in male patients and in patients from abroad.

The cross-sectional design of the study does not allow conclusions on potential targets for interventions, as it is not possible to make causal inferences. Research on causal relationships is essential, however for that purpose a prospective study design is needed.

Acknowledgments

We are indebted to A. Hanschke, research nurse Landsteiner Institute, The Hague for her assistance with the data collection and to C. Kromme, data manager of Sophia Rehabilitation Center, for his support with the database.

References

1. Kutlubaev MA, Hackett ML: Part II: predictors of depression after stroke and impact of depression on stroke outcome: an updated systematic review of observational studies. Int J Stroke 2014 Dec;9:1026-36.
2. Ayerbe L, Ayis S, Wolfe CD, et al: Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. Br J Psychiatry 2013;202:14-21.
3. Robinson RG, Murata Y, Shimoda K: Dimensions of social impairment and their effect on depression and recovery following stroke. Int Psychogeriatr 1999;11(4):375-84.
4. Gesztelyi R, Fekete I, Kellermann M, et al: Screening for depressive symptoms among post-stroke outpatients in Eastern Hungary. J Geriatr Psychiatry Neurol 1999;12(4):194-9.
5. Kouwenhoven SE, Kirkevold M, Engedal K, et al: Depression in acute stroke: prevalence, dominant symptoms and associated factors. A systematic literature review. Disabil Rehabil 2011;33(7):539-56.
6. De Ryck A, Brouns R, Geurden M, et al: Risk factors for poststroke depression: identification of inconsistencies based on a systematic review. J Geriatr Psychiatry Neurol 2014;27(3):147-58.
7. Kootker JA, van Mierlo ML, Hendriks JC, et al: Risk Factors for Symptoms of Depression and Anxiety One Year Poststroke: A Longitudinal Study. Arch Phys Med Rehabil 2016;97(6):919-28.
8. Ho CSh, Feng L, Fam J, et al: Coexisting medical comorbidity and depression: multiplicative effects on health outcomes in older adults. Int Psychogeriatr 2014;26(7):1221-9.
9. Ward SK, Turner A, Hambridge JA, et al: Group cognitive behavioural therapy for stroke survivors with depression and their carers. Top Stroke Rehabil 2016;17:1-8.
10. Adamson BC, Ensari I, Motl RW: Effect of exercise on depressive symptoms in adults with neurologic disorders: a systematic review and meta-analysis. Arch Phys Med Rehabil 2015;96(7):1329-38.
11. Robinson RG, Jorge RE: Post-Stroke Depression: A Review. Am J Psychiatry 2016;173(3):221-31.
12. Collin C, Wade DT, Davies S, et al: The Barthel ADL Index: a reliability study. Int Disabil Stud 1988;10:61–3
13. Zigmond AS, Snaith RP: The hospital anxiety and depression scale. Acta Psychiatr Scand 1983;67:361-70
14. Carver CS, Scheier MF, Weintraub JK: Assessing coping strategies: a theoretically based approach. J Pers Soc Psychol 1989;56(2):267-83.
15. Kleijn WC, van Heck GL, van Waning A: Ervaringen met een Nederlandse bewerking van de COPE copingvragenlijst. De COPE-Easy. Gedrag en Gezondheid 2000;28:213-26
16. Wade DT, Legh-Smith J, Langton Hewer R: Social activities after stroke: measurement and

natural history using the Frenchay Activities Index. Int Rehabil Med 1985;7(4):176-81.
17. Robinson BC: Validation of a Caregiver Strain Index. J Gerontol 1983;38(3):344-8
18. van Exel NJ, Scholte op Reimer WJ, Brouwer WB, et al: Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. Clin Rehabil 2004;18(2):203-14
19. Aaronson NK, Muller M, Cohen PD, et al: Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol 1998;51(11):1055-68.
20. EuroQol Group: EuroQol--a new facility for the measurement of health-related quality of life. Health Policy 1990;16(3):199-208.
21. Norlander A, Carlstedt E, Jönsson AC, et al: Long-Term Predictors of Social and Leisure Activity 10 Years after Stroke. PLoS One 2016;11(2):e0149395.
22. Luengo-Fernandez R, Gray AM, Bull L, et al: Quality of life after TIA and stroke: ten-year results of the Oxford Vascular Study. Neurology 2013;81(18):1588-95.
23. Schepers V, Post M, Visser-Meily A, et al: Prediction of depressive symptoms up to three years post-stroke. J Rehabil Med 2009;41(11):930-5.
24. Goldmann E, Roberts ET, Parikh NS, Lord AS, Boden-Albala B. Race/ethnic Differences in Post-stroke Depression (PSD): Findings from the Stroke Warning Information and Faster Treatment (SWIFT) Study. Ethn Dis 2016 21;26(1):1-8.
25. Fei K, Benn EKT, Negron R, Arniella G, Tuhrim S, Horowitz CR. Prevalence of Depression among Stroke Survivors: Racial-Ethnic Differences. Stroke 2016;47(2):512-5.
26. Wei C, Zhang F, Chen L, et al: Factors associated with post-stroke depression and fatigue: lesion location and coping styles. J Neurol 2016;263(2):269-76.
27. Mutai H, Furukawa T, Araki K, et al: Long-term outcome in stroke survivors after discharge from a convalescent rehabilitation ward. Psychiatry Clin Neurosci 2013;67(6):434-40.
28. Donnellan C, Hevey D, Hickey A, et al: Defining and quantifying coping strategies after stroke: a review. J Neurol Neurosurg Psychiatry 2006;77(11):1208-18.
29. Visser MM, Aben L, Heijenbrok-Kal MH, et al: The relative effect of coping strategy and depression on health-related quality of life in patients in the chronic phase after stroke. J Rehabil Med 2014;46(6):514-9.
30. Kruithof WJ, Post MW, van Mierlo ML, et al: Caregiver burden and emotional problems in partners of stroke patients at two months and one year post-stroke: Determinants and prediction. Patient Educ Couns 2016;11.pii: S0738-3991(16)30159-8.

Figure 1. Characteristics of responders and non-responders.

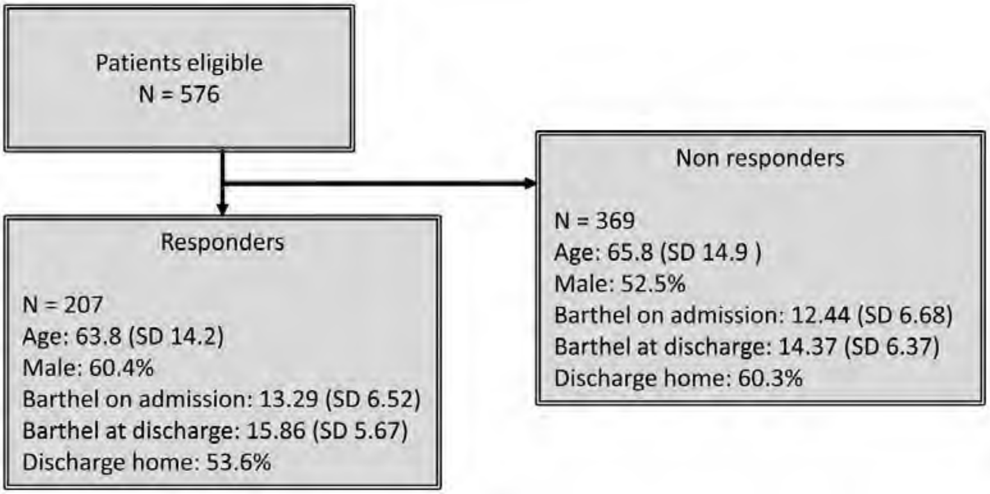


Table 1. Patient characteristics and stroke characteristics.

		Responders, N = 207
Patients' characteristics		
Mean age at stroke, years (SD)		63.8 (14.2)
Sex (%) Male/ Female		125 (60.4) / 82 (39.6)
Follow up		
	- 2-3 years (%)	93 (45)
	- 3-4 years (%)	63 (30)
	- 4-5 years (%)	51 (25)
Mean duration of follow-up; Months (SD)		36.3 (9.9)
Educational level, number (%):	- Low	72 (36.2)
	- Middle	72 (36.2)
	- High	55 (27.6)
Social situation, living together (%)		
Yes / No		135 (66.2) / 69 (33.8)
Born in the Netherlands (%)		
Yes / No		161 (79) / 43 (21)
Smoking (%)		
Yes / No		28 (14) / 168 (86)
Alcohol (%)		
Yes / No		87 (44) / 109 (56)
Stroke Characteristics		
Type of stroke:	- ischaemic number (%)	181 (87.4)
	- hemorrhagic (%)	26 (12.6)
Lesion; Number (%)		
	- Left hemisphere	97 (46.9)
	- Right hemisphere	66 (31.9)
	- Bilateral	1 (0.5)
	- Vertebrobasilar	43 (20.8)
Thrombolysis (%)		49 (23.7) / 156 (76.3)
Yes / No		
Length of hospital stay, days; median (IQR)		7 (7)
Barthel Index (0-20; worst – best); Median (IQR)		
Admission / Discharge		14 (11) / 19 (8)
Discharge (%):		
Home / other institution		98 (53.6) / 85 (46.4)

Abbreviations: SD = standard deviation, IQR = interquartile range

Table 2. Current health status of stroke patients and caregiver strain.

Outcome	Mean (SD)
HADS	
Score 0-21; best-worst	
- Anxiety	5.41 (4.71)
- Depression	5.57 (4.93)
Cope Easy	
Score 1-4; less-more	
- Active coping	2.01 (0.75)
- Avoidant coping	1.67 (0.59)
- Seeking support	1.87 (0.66)
FAI	
Score 0-45: worst-best	23.19 (10.82)
SF 36	
- PCS	41.49 (13.57)
- MCS	46.44 (12.53)
EQ5D	0.73 (0.25)
CSI total score	
Score 0-13; worst-best	4.46 (3.71)
Healthcare usage:	
- 0 or 1 physician (%)	139 (70.6)
- 2 or more physicians (%)	58 (29.4)

Abbreviations: SD = standard deviation, HADS = Hospital Anxiety and Depression Questionnaire, FAI = Frenchay Activity Index, SF-36 = Short Form 36 Health Survey, PCS = physical component summery scale, MCS = mental component summery scale, EQ5D = EuroQol, CSI = caregiver strain index

Table 3. Depression in relation to patient and stroke related characteristics. Univariate logistic regression (OR (95% CI)), adjusted for Barthel at discharge, age and sex.

Patient characteristics	N	HADS-d ‹ 8	N	HADS-d ≥8	OR (95% CI)	p level
Mean age at stroke, years	129	64.7	67	61.9	0.99 (0.96 – 1.01)	0.253
Sex, Male/Female	129	72/57	67	47/20	0.46 (0.22 – 0.93)	0.032
Educational level low/middle/ high	125	42/45/38	66	27/24/15	*	0.076
Social situation living together/alone	128	82/46	67	47/20	1.17 (0.56 – 2.47)	0.673
Born Netherlands/abroad	128	109/19	67	45/22	2.86 (1.29 – 6.31)	0.010
Smoking Yes/No	129	15/114	67	13/54	0.68 (0.27 – 1.72)	0.412
Alcohol Yes/No	129	65/64	67	22/45	2.31 (1.12 – 4.74)	0.023
Stroke characteristics						
Stroke location Left/Right/vertebrobasilar	128	58/41/29	67	31/23/13	*	0.693
Stroke type Ischaemic/hemorrhagic	129	114/15	67	56/11	1.14 (0.43 – 3.04)	0.789
Thrombolysis Yes/No	128	33/95	67	14/53	2.19 (0.91 – 5.26)	0.079
Barthel on admission mean (SD)	112	13.6 (6.5)	53	12.4 (6.7)	0.98 (0.91 – 1.06)	0.579
Barthel at discharge mean (SD)	112	16.2 (5.7)	53	15.0 (5.9)	0.96 (0.91 – 1.02)	0.174
Length of hospital stay mean (SD)	129	7.8 (5.9)	67	10.5 (11.3)	1.05 (0.99 – 1.10)	0.102
Discharge destination Home/other	114	64/50	60	29/31	0.86 (0.35 – 2.15)	0.754

*Abbreviations: SD = standard deviation. * in these 3-category variable the OR value is less informative.*

Table 4. Depression in relation to measures of health status and caregiver strain, adjusted for Barthel (discharge), age and sex; univariate logistic regression (OR (CI 95%)).

	N	HADS-d ‹ 8	N	HADS-d ≥8	OR (95%)	p level
HADS anxiety						
Score 0-21; best-worst	195	3.1		9.9	1.82 (1.50 – 2.20)	‹0.001
Cope Easy (SD)						
Score 1-4; less-more						
- Active coping	165	2.0 (0.8)		2.1 (0.7)	1.13 (0.68 – 1.89)	0.653
- Avoidant coping	172	1.5 (0.5)		2.1 (0.6)	8.33 (3.66 – 18,93)	‹0.001
- Seeking support	176	1.8 (0.7)		2.0 (0.6)	1.38 (0.76 – 2.52)	0.294
FAI (SD)						
Score 0-45: worst-best	171	26.5 (9.1)		17.6 (11.6)	0.90 (0.86 – 0.95)	‹0.001
SF 36 (SD)						
- PCS	186	46.3 (12.9)		33.1 (10.8)	0.91 (0.87 – 0.94)	‹0.001
- MCS	186	52.8 (7.9)		35.6 (11.0)	0.86 (0.82 – 0.90)	‹0.001
EQ5D (SD)	195	0.85 (0.14)		0.52 (0.27)	0.33 (0.23 – 0.48) ‡	‹0.001
CSI total score (SD)						
Score 0-13; worst-best	133	3.2 (3.1)		6.3 (3.8)	1.30 (1.13 – 1.49)	‹0.001
Health care usage	123		65		2.20 (1.14 – 4.25)	0.062
- 0 or 1 physician		94		39		
- 2 or more physicians		29		26		

Abbreviations: SD = standard deviation, OR = Odd's Ratio, HADS = Hospital Anxiety and Depression Questionnaire, FAI = Frenchay Activity Index, SF-36 = Short Form 36 Health Survey, PCS = physical component summery scale, MCS = mental component summery scale, EQ5D = EuroQol, CSI = caregiver strain index.

‡ The OR of the EQ5D refers to a change in a decile of the score (0.1 points)

5

Chapter 5

Return to Work 2–5 Years After Stroke: A Cross Sectional Study in a Hospital-Based Population

Arwert HJ, Schults M, Meesters JJL, Wolterbeek R, Boiten J, Vliet Vlieland T

J Occup Rehabil. 2017 Jun;27(2):239-246

Abstract

Purpose: To describe factors associated with RTW in patients 2–5 years after stroke.

Methods: Cross sectional study, including patients 2–5 years after hospitalization for a first-ever stroke, who were ‹65 years and had been gainfully employed before stroke. Patients completed a set of questionnaires on working status and educational level, physical functioning (Frenchay Activities Index, FAI), mental functioning (Hospital Anxiety and Depression Scale, HADS), Coping Orientations to Problems Experienced, (COPE easy) and quality of life (Short-Form(SF)36 and EQ(Euroqol)-5D). Caregivers completed the Caregiver Strain Index (CSI). Baseline stroke characteristics were gathered retrospectively. Baseline characteristics and current health status were compared between patients who did and did not RTW by means of logistic regression analysis with odds ratios (OR) and 95 % confidence intervals (CI), adjusted for age and gender.

Results: Forty-six patients were included, mean age of 47.7 years (SD 9.7), mean time since stroke of 36 months (SD 11.4); 18 (39 %) had RTW. After adjusting for age and gender a shorter length of hospitalization was associated with RTW (OR 0.87; CI 0.77–0.99). Of the current health status, a lower HADS depression score (0.76; 0.63–0.92), a less avoidant coping style (1.99; 0.80–5.00), better scores on the FAI (1.13; 1.03–1.25), the mental component summary score of the SF36 (1.07; 1.01–1.13), the EQ5D (349; 3.33–36687) and the CSI (0.68; 0.50–0.92) were associated with the chance of RTW.

Conclusions: A minority of working patients RTW after stroke; a shorter duration of the initial hospitalization was associated with a favorable work outcome. The significant association between work status and activities, mental aspects and quality of life underlines the need to develop effective interventions supporting RTW.

Introduction

According to data from the World Health Organization, 9.0 million people experience a first-ever stroke each year; the estimated prevalence of moderate and severe disability due to stroke worldwide, concerns the age group 0–60 years in 43 %, as compared to the age group of 60 years and older.[1] Despite important improvements in the treatment of stroke including thrombolysis, its impact on patients' lives is often considerable in different domains of functioning, due to significant cognitive, emotional and/or physical impairments in many patients.[2-5] Work disability is a major consequence of stroke at the participation level. In four systematic reviews, return to work rates after stroke reported in clinical studies varied between 11–85 %,[6] 19–73 %,[7] 22–53 %[8] and 0–100 %,[9] respectively. This variation is explained by differences among the study populations, the definitions of work, and the duration of follow-up.

Work disability resulting from stroke may have considerable negative consequences for quality of life and self-esteem in individual patients.[10-12] In addition, loss of gainful work and productivity has an important impact on the societal level, contributing substantially to the economic burden of stroke.[13,14] Therefore, it is important to examine which factors are associated with return to work, some of which may be modifiable.

Several health outcome factors were found to be related to the chance of return to work including fatigue,[15] physical disability,[8,16] independence in activities of daily life (ADL)[6,17] and depression.[6,7] Furthermore, pre-stroke characteristics such as socioeconomic status,[18] educational level,[7] and work characteristics such as factory size[19] were of influence. Study populations in literature consist of patients admitted to a hospital,[15-17] of patients who successfully resumed work after stroke[18] or were population based.[19,20] Mean follow up period in the hospital based studies was less than 2 years, which is relatively short considering the procedures that can be involved in the process of resuming work.

Little is known about the chances of returning to work on the longer term. The objective of this study was to determine factors associated with sustained return to work 2–5 years after stroke in a hospital based population in the Netherlands.

Methods

Study Design

The present study on return to work was part of a larger, cross sectional study on the long-term outcomes of stroke, executed at the Medical Centre Haaglanden (MCH), a large teaching hospital in The Hague, The Netherlands. This hospital has a specialized neurovascular department.

Data about the actual situation of patients at time of the study were collected by means of a questionnaire. Additional medical information was extracted retrospectively from the participants' medical records. As the study concerned the completion of a survey once-only, and patients were free to respond or not, the study was judged to fall outside the remit of the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee South West Netherlands, and a written exemption from ethical approval was obtained. All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000.[21] Informed consent was obtained from all patients for being included in the study.

Patients

For the larger cross sectional study, all patients hospitalized for a stroke in the hospital between January 2008 and December 2010 were identified from the hospital registries. From patients who had been hospitalized for a stroke more than once during the study period, only the first hospital-ization was taken into account. Then, a further selection was done using the following inclusion criteria: a. first ever ischemic or haemorrhagic stroke; b. age 18–65 years at the time of hospitalization; c. having a paid job at the time of hospitalization. Exclusion criteria were: a) traumatic brain injury, cerebral neoplasms or transient ischemic attack (TIA); b) medical condition not allowing participation (patients in a vegetative state); c) insufficient Dutch lan-guage skills; and d) age retired at time of the study. Subsequently, of all potentially eligible patients the hospital and town council registries were checked to identify any deceased patients.

The patients who were subsequently considered eligible were invited by the treating physician to participate by means of a letter and an information leaflet. Participation included a questionnaire about their current health status and the completion of one questionnaire by their spouse or other caregiver, if applicable. They were asked to return the questionnaire and a signed informed consent form using a pre-stamped envelope. In case of no response after 4 weeks patients were contacted by telephone by a research nurse.

Assessment Methods

Stroke Characteristics

Data about the type of stroke (hemorrhagic/ischemic), lateralization (left hemisphere/right hemisphere/vertebrobasilar), impairment at stroke onset and at discharge from hospital (Barthel Index; score range 0–20),[22] and duration of hospitalization were collected retrospectively from the medical records of the hospital.

Sociodemographic Characteristics

The survey comprised questions on the following sociodemographic characteristics: age, sex, and educational level (Low: up to and including lower technical and vocational training; Medium: up to and including secondary technical and vocational training; and High: up to and including higher technical and vocational training and university).

Work Status Before Stroke and at Present

Work status (working yes/no) before stroke was extracted from the medical records. Patients were asked to fill in the Work Productivity and Activity Impairment Questionnaire General Health (WPAI).[23] The WPAI was created as a patient-reported quantitative assessment of the amount of absenteeism (absent from work due to health problems), presenteeism (present at work) and daily activity impairment attributable to general health (Dutch version: http://www.reillyassociates.net/WPAI_Translations.html; accessed October 23, 2015). The questionnaire has 6 questions: Q1 = currently employed; Q2 = hours missed due to health problems; Q3 = hours missed due to other reasons; Q4 = hours actually worked; Q5 = degree health affected productivity while working (0 = no effect, 10 = work not possible); and Q6 = degree health affected regular activi-ties other than work (0 = no effect, 10 = daily activities not possible). Patients without paid employment answered only the first question and the last question of the WPAI.

Psychological and Physical Functioning

Anxiety and depression were measured by means of a Dutch version of the Hospital Anxiety and Depression Questionnaire (HADS[24] Dutch version[25]) which contains two 7-item scales, one for anxiety and one for depression, both with a score range of 0–21. A higher score means higher level of depression or anxiety. For screening purposes on depression in stroke patients a cut off >7 is recommended.[26]

Coping was measured using the CopeEasy (Coping Orientations to Problems Experienced), a self-reported questionnaire of 32 items, in an ordinal scale from 1 to 4.[27,28] It describes the extent to which three different types of coping strategies are used by patients to deal with their situation: Active, Avoiding and Seeking Support. Higher scores mean the patient uses this coping strategy more.

Physical functioning was measured using the FAI (Frenchay Activity Index).[29,30] This inventory scores the frequency of 15 activities on a 4 point scale (range 0-3, never-frequently). The maximum score is 45 points and represents the highest level of functioning.

Health Related Quality of Life

The SF-36 is a generic instrument with 36 items covering eight domains (physical function, role physical, bodily pain, general health, vitality, social function, role emotional, and mental health). The SF-36 subscale scores range from 0 to 100, with a higher score indicating better health status. From these, a physical and a mental summary scale can be computed. Scoring of the summary scales is undertaken by weighting and summing the original eight dimensions. These weights are gained from factor analysis of data from a general population. The SF-36 has been translated and validated by Aaronson et al. into a Dutch version.[31]

Patients described their general health status using the EuroQol classification system (EQ5D), consisting of 5 questions on mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.[32] From the EQ5D classification system, the EQ5D utility index was calculated. The five 3-point Likert questions of the EQ-5D yield a summary score ranging from -0.329 (no health) to 1 (full health).

Caregiver Strain

Caregiver strain was measured using the Caregiver strain index (CSI): This questionnaire consists of 13 items to assess the subjective care load of the caregiver,[33] range from 0 to 13; higher means more caregiver strain. A score of seven or more indicates a high level of strain. The CSI was validated in a Dutch stroke population.[34]

Analysis

Descriptive statistics were used for the sociodemographic and stroke characteristics, work status, measures of functioning and quality of life, and caregiver strain [mean (SD) or median (inter quartile range; IQR)]. Differences among working (RTW group) and non-working (non-RTW group) stroke patients at 2–5 year follow-up were analyzed by means of logistic regression analyses. Analyses were done by univariate logistic regression (crude OR) and again per variable by multivariable logistic regression to adjust for potential confounders (age, gender). Independent variables were categorized into characteristics of stroke at baseline (type of stroke, localization, length of hospitalization, and Barthel Index at admission and discharge) and into measures of the patient’s current health status and caregiver strain (HADS, CopeEasy, FAI, SF-36, EQ5D, and CSI). Results were reported as odds ratios (OR) with the 95 % confidence interval (CI).

Statistical analyses were performed using IBM SPSS Statistics, version 22 (Leiden, the Netherlands, 2015).

Results

The flow of participants in this study is shown in Fig. 1. Out of 576 subjects who were considered eligible and were invited to participate in the larger study, 207 (36 %) responded. Of those, 102 (49 %) were under 65 years at the time of stroke, of whom 57 (56 %) were gainfully employed at that time. At follow up 11 were retired (age related), so 46 patients met the inclusion criteria and were eligible for the present analysis.

Baseline Characteristics and Chance of Return to Work

The baseline characteristics of the 46 patients are presented in Table 1. Mean age was 47.7 years (SD 9.7, range 20–90 years) and the mean time since stroke was 36.0 months (SD 11.4). Logistic regression showed a significant difference in the length of stay in the hospital;

the RTW group was hospitalized shorter than the non-RTW group (median 6.5 days (IQR 6) vs. 10 days (9); OR 0.87, CI 0.77–0.99). No significant differences were found with respect to age, gender, educational level, and type and localisation of the lesion. After adjustment for age and gender the results did not change in general. Only the Barthel Index at discharge showed a trend towards group difference, the RTW group had better scores but this was not significant ($p < 0.10$).

Current Health Status and Chance of Return to Work

The RTW group scored better on most outcome measures 2–5 years after stroke compared to the non-RTW group (Table 2). RTW patients scored lower than the non-RWT group on depression and anxiety (HADS; depression [mean 3.3 (SD 3.1) vs. 8.6 (5.4); anxiety 4.9 (3.4) vs. 8.7 (5.7)] and were less avoidant in their coping [Cope Easy 1.6 (0.6) vs 2.1 (0.6)]. The RTW patients performed better in daily life activities [FAI 30.6 (7.3) vs 22.6 (9.9)] and had a better quality of life [MCS of the SF-36 48.8 (10.3) vs. 37.3 (15.4); EQ5D 0.86 (0.12) vs. 0.64 (0.28)]. Their caregivers showed a lesser burden [CSI 2.4 (2.3) vs. 6.3 (3.8)]. These differences remained unaltered after correcting for age and gender, except for anxiety (OR 0.85, CI 0.73–1.00).

Work Status and Work Productivity

Eighteen of the 46 patients (39 %) returned to work. Table 3 shows the amount of absenteeism, presenteeism and daily activity among these patients as measured with the WPAI. On average patients worked 29.6 h a week. Only one patient missed working hours in the week before follow up due to health problems and one due to other factors. Patients reported only a mild effect of health problems on productivity while working. Question 6 of the WPAI was answered by all patients (degree health affected regular activities other than work, 0 = no effect - 10 = daily activities not possible). The RTW group scored significantly better on this aspect compared to the non-RTW group (median 1 (IQR 4) versus 6 (IQR 5); OR 0.68 (CI 0.53–0.87).

Discussion and Conclusions

This cross sectional study among 46 premorbidly employed stroke patients showed that after a follow up of 2–5 years, 39 % was able to return to work. The patients that returned to work scored better on the Hospital Anxiety and Depression Scale, were less avoidant in their coping, and showed a higher quality of life and a higher level of daily activities.

Previous studies reported varying RTW rates. Daniel et al. reported in a review of 70 studies (8810 patients) an average RTW rate of 44 % (range 0–100 %). These studies were performed in different countries all over the world and in a large timeframe (1962–2008); study populations were hospital based, population based or originated from rehabilitation centres.[9] In hospital based populations return to work varied from 55 to 75 %.[15-17] Our data, showing a lower RTW rate (i.e. 39 %), were collected in a period of economic decline and higher unemployment rates in the Netherlands which may be of influence; the unemployment rate doubled from 2008 to 2013.[35] Furthermore, social security in the Netherlands offers a sufficient allowance for those who cannot return to work; this can also influence the RTW rate. In accordance with our results are the results of a study in an urban population using data from the South London Stroke Register, which reported a RTW rate of 35 % at 1 year post-stroke.[36]

Current literature mentions severity of stroke as an important negative predictor of return to work. The length of hospitalization is mentioned previously as a relevant indicator for RTW in stroke, as could be confirmed in our results.[8] A strong association was found between RTW and regular daily activities, as measured by the FAI. The actual score on the FAI, a measure of daily activities, reflects the impact of stroke at the time of follow up. The FAI seems stable in the chronic phase of stroke (>1 year after stroke) and appears to be a good indicator of social activity, e.g., work, in the long term.[37]

Quality of life as assessed by the SF-36 MCS was also lower in the non-RTW group, while the physical component score of the SF-36 did not differ significantly. High scores for depression on the HADS were found in the non-RTW group. This could reflect the importance of mental factors in the process of returning to work and may lead to consequences in terms of treatment strategies. Depression after stroke is associated with lower RTW rates at a later stage.[6,7,38] On the other hand, unemployment probably has a negative influence on mental health.[10-12]

A clinical cut off was provided for the HADS (>7) by Zigmond et al..[24] Based on this cut off a majority of the patients in the non-RTW group (15 patients, 54 %) was at risk of a clinical relevant depression. Three patients in the non-RTW group consulted a psychiatrist in the last 6 months; in the RTW group no patient did.

Failure to return to work is correlated to a higher strain for their caregivers. The common factor could be the HADS which is in our results closely related to RTW as well as to the CSI. This is in line with results of Smeets et al. where the HADS and the CSI were correlated 1 year after acquired brain injury.[39]

There are limitations that have to be considered. Due to the cross sectional design of this study causal relations cannot be inferred. Moreover, the study population of 46 patients is relatively small. Detailed information about work prior to stroke was not available, nor the moment patients were able to resume their work. It is possible that patients were not able to return to work for other reasons. The longer the follow up period is, the more influence will be seen from other factors such as comorbidity. A larger prospective study can shed more light on factors that are of influence in the process of returning to work, but still will have limitations to which extent relations can be accounted for as causal.

In conclusion, the chance of return to work after stroke relates positively to less initial stroke severity and better outcomes with respect to activities, mental aspects and quality of life. The inability to return to work is related to a high caregiver strain. These results may give guidance to the rehabilitation goals of patients. In the patient group that did not RTW in the chronic phase after stroke, extra attention should be paid to mood disturbances and to the caregivers.

Acknowledgments

We are indebted to Anne Hanschke, research nurse Landsteiner Institute, The Hague for her assistance with the data collection and to Cedric Kromme, data manager of Sophia Rehabilitation Centre, for his support with the electronic database.

Funding

This study was financially supported by the Research fund Medical Center Haaglanden, the Netherlands.

References

1. The Global Burden of Disease. 2008. Available from (http://www.who.int/healthinfo/global_burden_disease/GBD_report_200 4update_full.pdf).
2. Nakayama H, Jørgensen HS, Raaschou HO, Olsen TS. Recovery of upper extremity function in stroke patients: the Copenhagen Stroke Study. Arch Phys Med Rehabil. 1994;75:394–8.
3. Jang SH. The recovery of walking in stroke patients: a review. Int J Rehabil Res. 2010;33(4):285–9.
4. Kwakkel G, Kollen BJ. Predicting activities after stroke: what is clinically relevant? Int J Stroke. 2013;8(1):25–32.
5. D'Aniello GE, Scarpina F, Mauro A, Mori I, Castelnuovo G, Bigoni M, et al. Characteristics of anxiety and psychological well-being in chronic post-stroke patients. J Neurol Sci. 2014;338(1–2):191–6.
6. Wozniak MA, Kittner SJ. Return to work after ischemic stroke: a methodological review. Neuroepidemiology. 2002;21(4):159–66.
7. Treger I, Shames J, Giaquinto S, Ring H. Return to work in stroke patients. Disabil Rehabil. 2007;29(17):1397–403.
8. Wang YC, Kapellusch J, Garg A. Important factors influencing the return to work after stroke. Work. 2014;47(4):553–9.
9. Daniel K, Wolfe CD, Busch MA, McKevitt C. What are the social consequences of stroke for working-aged adults? A systematic review. Stroke. 2009;40(6):e431–40.
10. Vestling M, Tufvesson B, Iwarsson S. Indicators for return to work after stroke and the importance of work for subjective well-being and life satisfaction. J Rehabil Med. 2003;35(3):127–31.
11. Roding J, Glader EL, Malm J, Lindstrom B. Life satisfaction in younger individuals after stroke: different predisposing factors among men and women. J Rehabil Med. 2010;42(2):155–61.
12. Morris R. The psychology of stroke in young adults: the roles of service provision and return to work. Stroke Res Treat. 2011;534812.
13. Saka O, McGuire A, Wolfe C. Cost of stroke in the United Kingdom. Age Ageing. 2009;38(1):27–32.
14. Di Carlo A. Human and economic burden of stroke. Age Ageing. 2009;38(1):4–5.
15. Andersen G, Christensen D, Kirkevold M, Johnsen SP. Post-stroke fatigue and return to work: a 2-year follow-up. Acta Neurol Scand. 2012;125(4):248–53.
16. Saeki S, Toyonaga T. Determinants of early return to work after first stroke in Japan. J Rehabil Med. 2010;42(3):254–8.
17. Hackett ML, Glozier N, Jan S, Lindley R. Returning to paid employment after stroke: the

Psychosocial Outcomes In StrokE (POISE) cohort study. PLoS ONE. 2012;7(7):e41795.

18. Brey JK, Wolf TJ. Socioeconomic disparities in work performance following mild stroke. Disabil Rehabil. 2015;37(2):106–12.
19. Hannerz H, Ferm L, Poulsen OM, Pedersen BH, Andersen LL. Enterprise size and return to work after stroke. J Occup Rehabil. 2012;22(4):456–61.
20. Walsh ME, Galvin R, Loughnane C, Macey C, Horgan NF. Community re-integration and long-term need in the first 5 years after stroke: results from a national survey. Disabil Rehabil. 2014;13:1–5.
21. http://www.wma.net/en/30publications/10policies/b3. Accessed 23 Oct 2015.
22. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud. 1988;10:61–3.
23. Reilly MC, Zbrozek AS, Dukes EM. The validity and repro-ducibility of a work productivity and activity impairment instrument. PharmacoEconomics. 1993;4(5):353–65.
24. Zigmond AS, Snaith RP. The hospital anxiety and depression scale. Acta Psychiatry Scand. 1983;67:361–70.
25. Spinhoven P, Ormel J, Sloekers PP, Kempen GI, Speckens AE, Van Hemert AM. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. Psychol Med. 1997;27(2):363–70.
26. Turner A, Hambridge J, White J, Carter G, Clover K, Nelson L, Hackett M. Depression screening in stroke: a comparison of alternative measures with the structured diagnostic interview for the diagnostic and statistical manual of mental disorders, fourth edition (major depressive episode) as criterion standard. Stroke. 2012;43(4):1000–5.
27. Carver CS, Scheier MF, Weintraub JK. Assessing coping strategies: a theoretically based approach. J Pers Soc Psychol. 1989;56(2): 267–83.
28. Kleijn WC, Heck GLv, Waning Av. Ervaringen met een Neder-landse bewerking van de COPE copingvragenlijst [Use of the Dutch version of the COPE questionnaire]. De COPE_Easy. Gedrag en Gezondheid. 2000;28:213–26.
29. Wade DT, Legh-Smith J, Langton Hewer R. Social activities after stroke: measurement and natural history using the Frenchay Activities Index. Int Rehabil Med. 1985;7(4):176–81.
30. Post MW, de Witte LP. Good inter-rater reliability of the Fren-chay Activities Index in stroke patients. Clin Rehabil. 2003; 17(5):548–52.
31. Aaronson NK, Muller M, Cohen PD, Essink-Bot ML, Fekkes M, Sanderman R, et al. Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol. 1998;51(11):1055–68.

32. EuroQol Group. EuroQol-a new facility for the measurement of health-related quality of life. Health Policy. 1990;16(3):199–208.
33. Robinson BC. Validation of a Caregiver Strain Index. J Gerontol. 1983;38(3):344–8.
34. van Exel NJ, Scholte op Reimer WJ, Brouwer WB, van den Berg B, Koopmanschap MA, van den Bos GA. Instruments for assessing the burden of informal caregiving for stroke patients in clinical practice: a comparison of CSI, CRA, SCQ and self-rated burden. Clin Rehabil. 2004;18(2):203–14.
35. http://www.cbs.nl/nl-NL/menu/themas/arbeid-sociale-zekerheid/ publicaties/arbeidsmarkt-vogelvlucht/default.htm. Accessed 16 Jan 2016.
36. Busch MA, Coshall C, Heuschmann PU, McKevitt C, Wolfe CD. Sociodemographic differences in return to work after stroke: the South London Stroke Register (SLSR). J Neurol Neurosurg Psychiatry. 2009;80(8):888–93.
37. Jansen HE, Schepers VP, Visser-Meily JM, Post MW. Social activity one and three years post-stroke. J Rehabil Med. 2012;44(1):47–50.
38. Glozier N, Hackett ML, Parag V, Anderson CS. The influence of psychiatric morbidity on return to paid work after stroke in younger adults: the Auckland Regional Community Stroke (ARCOS) Study, 2002 to 2003. Stroke. 2008;39(5):1526–32.
39. Smeets SM, van Heugten CM, Geboers JF, Visser-Meily JM, Schepers VP. Respite care after acquired brain injury: the well-being of caregivers and patients. Arch Phys Med Rehabil. 2012;93(5):834–41.

Figure 1 . Flowchart of participants through the study

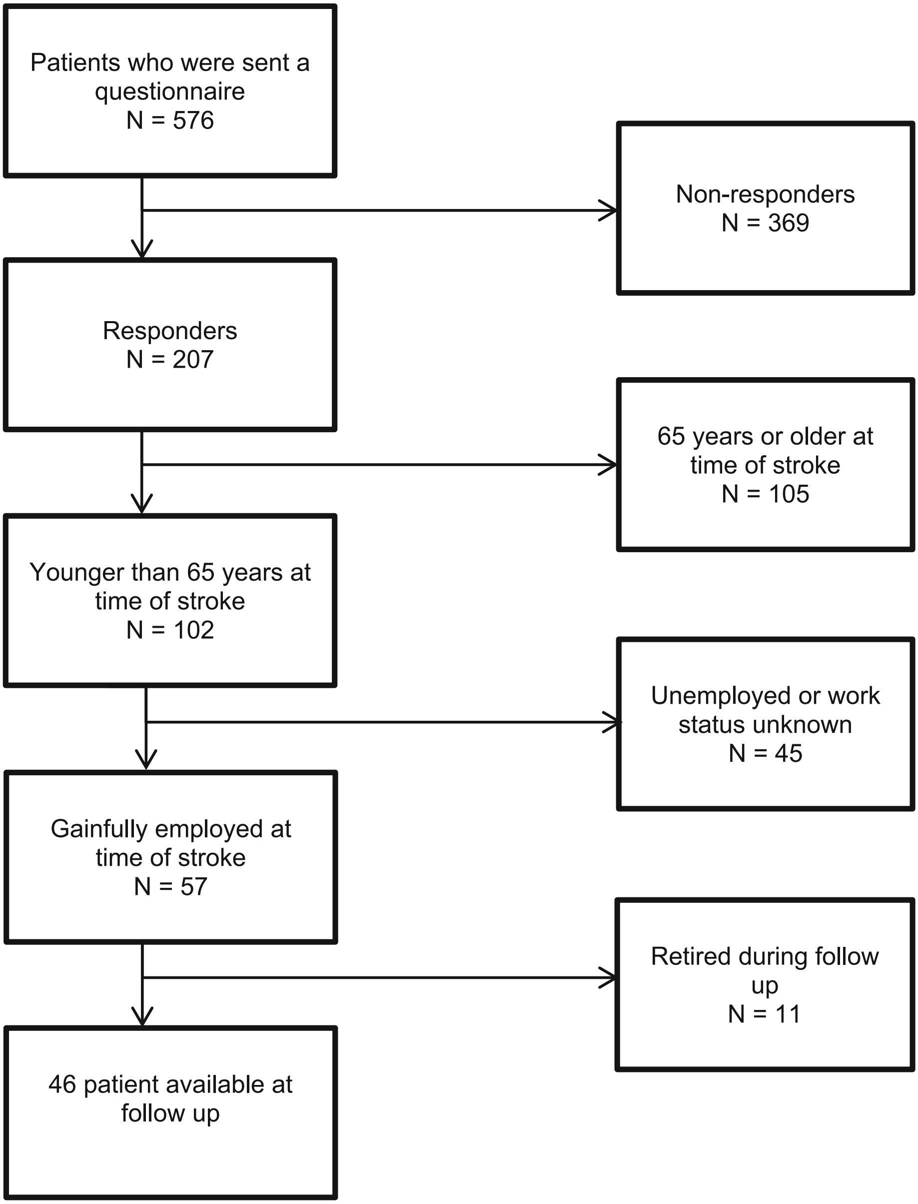


Table 1 . Baseline characteristics of patients who responded to a cross-sectional questionnaire survey that returned to work (RTW; n = 18) or did not return to work (non-RTW; n = 28) after stroke. Crude odds ratios are presented, as well as odds ratios after adjustment for age and gender.

	All (n = 46)	RTW (n = 18)	Non-RTW (n = 28)	OR (95 % CI) crude	OR (95 % CI) corrected
Mean age at follow-up					
Years (SD)	47.7 (9.7)	48.5 (9.5)	47.1 (9.9)	1.02 (0.95–1.08)	1.03 (0.96–1.11)
Gender; male					
Number (%)	29 (63)	10 (56)	19 (68)	0.59 (0.17–2.01)	0.47 (0.12–1.82)
Mean duration of follow-up					
Months (SD)	36.0 (11.4)	36.6 (12.5)	35.6 (10.9)	1.00 (0.96–1.06)	1.03 (0.97–1.09)
Educational level, Number					
Low (%)	13 (28)	5 (28)	8 (29)	1.31 (0.61–2.79)	1.29 (0.60–2.79)
Middle (%)	17 (37)	5 (28)	12 (43)		
High (%)	16 (35)	8 (44)	8 (29)		
Type of stroke					
Number ischemic (%)	38 (83)	16 (89)	22 (79)	0.46 (0.08–2.57)	0.36 (0.057–2.24)
Lesion; number					
Left hemisphere (%)	23 (50)	8 (44)	15 (54)	1.55 (0.74–3.28)	1.63 (0.74–3.60)
Right hemisphere (%)	13 (28)	4 (22)	9 (32)		
Vertebrobasilar (%)	10 (22)	6 (33)	4 (14)		
Length of hospital stay					
Days; median (IQR)	9.2 (5.9)	6.5 (6)	10.5 (9)	0.87 (0.77–0.99)*	0.87 (0.77–0.99)*
Barthel Index (0–20; worst–best); Median (IQR)					
At admission	13.5 (14)	17 (9)	12 (16)	1.08 (0.98–1.20)	1.08 (0.97–1.20)
At discharge	20 (6)	20 (1)	19 (8)	1.16 (0.96–1.41)	1.19 (0.98–1.43)

** Sign* $p < 0.05$

OR odds ratio, CI confidence Interval, RTW return to work, SD standard deviation, IQR interquartile range

Table 2. Current health status of patients who responded to a cross-sectional questionnaire survey that returned to work (RTW; n = 18) or did not return to work (non-RTW; n = 28) after stroke. Crude odds ratios are presented, as well as odds ratios after adjustment for age and gender

	N	All	RTW N = 18	Non-RTW N = 28	OR (95 % CI) crude	OR (95 % CI) corrected
Mean HADS (SD)						
Score 0–21; best-worst						
Anxiety	45	7.1 (5.2)	4.9 (3.4)	8.5 (5.7)	0.84 (0.72–0.99)*	0.85 (0.73–1.00)
Depression	45	6.3 (5.3)	3.3 (3.1)	8.6 (5.4)	0.76 (0.63–0.91)*	0.76 (0.63–0.92)*
Cope Easy (SD)						
Score 1–4; less-more						
Active coping	42	2.3 (0.75)	2.5 (0.8)	2.2 (0.7)	1.98 (0.80–4.94)	1.99 (0.80–5.00)
Avoidant coping	42	1.9 (0.67)	1.6 (0.6)	2.1 (0.6)	0.21 (0.059–0.74)*	0.204 (0.053–0.78)*
Seeking support	45	2.1 (0.70)	2.0 (0.8)	2.2 (0.7)	0.69 (0.28–1.69)	0.561 (0.203–1.550)
FAI (SD)	45	25.8 (9.7)	30.6 (7.3)	22.6 (9.9)	1.13 (1.03–1.24)*	1.13 (1.03–1.25)*
Score 0–45: worst-best						
SF 36 (SD)						
PCS	44	43.6 (12.9)	46.9 (12.3)	41.5 (13.1)	1.04 (0.98–1.09)	1.04 (0.98–1.09)
MCS	44	41.7 (14.7)	48.8 (10.3)	37.3 (15.4)	1.07 (1.01–1.12)*	1.07 (1.01–1.13)*
Equation5D (SD)**	46	0.73 (0.25)	0.86 (0.12)	0.64 (0.28)	1.89 (1.17–3.04)*	1.80 (1.13–2.86)*
CSI total score (SD)	33	4.5 (3.7)	2.4 (2.3)	6.3 (3.8)	0.67 (0.50–0.90)*	0.68 (0.50–0.92)*
Score 0–13; worst-best						

* *Sign* $p < 0.05$

** *The OR of the EQ5D refers to a change in a decile of the score (0.1 points)*

OR odds ratio, RTW return to work, SD standard deviation, IQR interquartile range, HADS Hospital Anxiety and Depression Questionnaire, FAI Frenchay Activity Index, EQ5D EuroQol, CSI caregiver strain index

Table 3. Work productivity as measured with the Work Productivity and Activity Impairment Questionnaire General Health (WPAI) in working stroke patients (n = 46) 2–5 years after stroke.

WPAI question		Median (IQR)
2	Health related absenteeism last 7 days (h)	0 (0)
3	Non-health related absenteeism last 7 days (h)	0 (0)
4	Worked hours last 7 days (h)	31 (16)
5	Influence of health on work productivity 0 = no effect; 10 = work not possible	1.0 (3.0)
6	Influence of health on other activities 0 = no effect; 10 = work not possible	1.0 (4.0)


6

Chapter 6

The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability, and Concurrent Validity in a Dutch Population

Groeneveld IF, Arwert HJ, Goossens PH, Vliet Vlieland TPM

J Stroke Cerebrovasc Dis. 2018 Jan;27(1):267-275

Abstract

Background: Unmet needs are common after stroke. We aimed to translate the 22-item Longer-term Unmet Needs after Stroke (LUNS) Questionnaire and validate it in a Dutch stroke population. Methods: The LUNS was translated and cross culturally adapted according to international guidelines. After field testing, the Dutch version was administered twice to a hospital-based cohort 5 - 8 years after stroke. Participants were also asked to complete the Frenchay Activity Index (FAI) and Short Form (SF)-12. To explore acceptability, the response and completion rates as well as number of missing items were computed. For concurrent validity, the differences in health status (FAI, SF-12) between groups who did and did not report an unmet need were calculated per item. To determine the 14-day test-retest reliability, the percentage of agreement between the first and the second administration was calculated for each item.

Results: Seventy-eight of 145 patients (53.8%) returned the initial Dutch LUNS (average age 68.3 [standard deviation 14.0] years, 59.0% male); 66 of these patients (84.6%) fully completed it. Of all items, 3.3% were missing. Among completers, the median number of unmet needs was 3.5 (2.0-5.0; 1.0-14.0). For 15 of 22 items, there was a significant association with the FAI or SF-12 Mental or Physical Component Summary scales. The percentage of agreement ranged from 69.8% to 98.1% per item.

Conclusions: Among the 53.8% who completed the survey, the LUNS was concluded to be feasible, reliable, and valid; two-thirds of its items were related to activities and quality of life. Its usefulness and acceptability when administered in routine practice require further study.

Introduction

Worldwide, stroke is one of the leading causes of death and disability.[1] Despite recent advances in stroke treatment, stroke can result in impairments in body functions, limitations in activities, and restrictions in participation[2] that often persist years after stroke.[3] As a result, patients may still have specific needs for a long term after stroke, such as care needs and information needs. Care needs include the need for a consultation with a health professional or the need for aids or adaptations. Information needs include the need for information on stroke, on available health-care services, or on dealing with difficulties in household tasks or traveling.[3]

If expressed needs are not satisfied by their current service provision, they are classified as unmet.[4] Unmet needs are relevant because they are associated with reduced quality of life for both patients[5] and caregivers.[6] In a cross-sectional Australian survey among 765 stroke survivors 2 years after stroke, 96% reported needs regarding the domains of health, everyday living, work, leisure, social support, and finances. Of these patients, 84% had 1 or more needs that were not fully met.[7] In the literature, the most frequently reported unmet need concerns information on the causes and prevention of stroke.[3,8] Other areas in which unmet needs are frequently reported include fatigue, memory, and emotion.[9-11] Regarding the unmet needs of Dutch stroke survivors, a multicenter study on the quality of care showed that 31% (N = 120) of non-institutionalized patients had at least 1 unmet need 6 months after stroke. Although most of these needs were resolved after 5 years, 20% of patients had the same or new unmet needs at follow-up.[12]

Until recently, no comprehensive and validated instrument existed to assess stroke survivors' unmet needs in the longer term. Therefore, the Longer-Term Stroke care (LoTS care) study team developed the Longer-term Unmet Needs after Stroke (LUNS) monitoring tool, a 22-item questionnaire concerning needs on information as well as the physical, social, and emotional consequences of stroke.[13]

Its content was based on a literature review and semi-structured interviews with stroke survivors.[14] Its purpose was to detect unmet needs in stroke individuals and populations. In a previous validation study among 850 British stroke survivors 3-6 months after stroke, the LUNS was found to be acceptable (on average completed in 6 minutes; 3.5% of items missing), showed moderate to good agreement (kappa .45-.67) in test-retest analysis, and was found to be valid based on the identification of unmet needs that were consistently related to poorer (mental) health according to the Short Form 12 (SF-12).[13]

As no translated version of the LUNS was available in the Netherlands, the objective of the present study was to translate the LUNS into Dutch and examine its psychometric properties in a hospital-based stroke population 5-8 years after stroke.

Methods

Study Design

The study consisted of 2 parts: (1) translation and cross-cultural adaptation of the LUNS and (2) determination of the psychometric properties of the Dutch language version by testing it among stroke survivors 5-8 years after stroke. The second part of the study was conducted as an extension of a cross-sectional study of the Haaglanden Medical Center that took place 3 years previously. This concerned a study on the functioning, activities, participation, coping, health-care use, and quality of life 2-5 years after stroke in patients ≥18 years who had been admitted to the hospital for their first-ever stroke. That study was described in greater detail in a previous publication.[15]

As both the previous cross-sectional study and the present study concerned a questionnaire study in which the invitees were not obliged to participate, the study was judged to fall outside the purview of the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee South West Netherlands. Informed consent for study inclusion was obtained from all patients. All study procedures were executed in accordance with the Helsinki Declaration of 1975, as revised in 2013.[16] The validation process of the LUNS was conducted in accordance with the COnsensus-based Standards for the selection of health Measurement Instruments criteria.[17]

Translation and Cross-Cultural Adaptation

Forward and Backward Translation

The process of translation and cross-cultural adaptation was based on the guidelines proposed by Beaton et al.[18] First, the questionnaire was translated into Dutch independently by a physiotherapist and physician in stroke rehabilitation (BS, PG) as well as 1 lay person (FH). For each item, they recorded their ambiguities, uncertainties, challenging phrases, and other comments. After the translation process, the principal investigator (IG) proposed a synthesis of the translations. This translated version was then translated back into English by 2 translators whose mother tongue was English, independent of the forward translators. One of them had a background in rehabilitation medicine (FM) and the other was uninformed on the topic (MG). They also recorded their comments. All of the translators strived for semantic, idiomatic, and experiential equivalence.[19]

Expert Revision

An expert committee consisting of a methodologist (TVV), clinical linguist (LB), translators, and principal investigator carefully read all of the translations and synthesized versions of the questionnaire. In a 2-hour meeting, they discussed the items 1 by 1 until a consensus questionnaire.

Field Testing

For the field test, a group of 20 stroke survivors with a heterogeneous composition regarding sex, age, disability type, and time since rehabilitation were invited by the principal investigator on behalf of the rehabilitation physician (PG) to fill out and comment on the prefinal version of the Dutch LUNS. First, in an open-ended question, they were asked to comment on the clarity of the questions, per item. Then, they were asked to give their opinion regarding the potential presence of overlap, contradictions, inappropriateness, or incompleteness, using closed-ended questions (yes or no). If they answered yes, they were asked to fill out the item numbers, or topics, of concern. Third, they were asked for their overall opinion on the clarity of instructions (yes or no), difficulty completing the list (not at all-a little-very), time to complete the list (minutes), and appropriateness of the font and size of letters (yes or no). Lastly, they were given the opportunity to make general remarks about the questionnaire.

If more than 1 of the patients had difficulties with an item, the expert committee would consider adapting the item. Based on the respondents' comments in the field testing phase, a final version of the questionnaire was made.

Determination of Psychometric Properties

Study Population

The study population was derived from a cross-sectional study that had taken place 3 years previously. For the present study, only the 145 patients who had agreed to be invited in case of an evolving follow-up study and who were still alive at the start of the current study were considered eligible.

Recruitment and Timing of Assessments

Eligible patients were invited by regular mail by means of an invitation letter from the principal investigator of the cross-sectional study, who is a rehabilitation physician in the Haaglanden Medical Center (HA). An information leaflet, an informed consent form, and a questionnaire were enclosed. Patients who returned both the signed informed consent form and questionnaire were considered participants. Those who did not return the questionnaire within 2 weeks were contacted by phone.

Patients who returned the first questionnaire received a second questionnaire 2 weeks later. For the second questionnaire, no reminders were sent. If a questionnaire was not fully completed, patients were not contacted to acquire the missing information.

Assessments

The LUNS was used to identify longer term unmet needs in the areas of information, services, social and emotional consequences, health problems, and related areas. The LUNS includes 22 statements that express a need for information or advice (“I would like advice on employment after stroke”); need for assistance or aids (“I need additional aids or adaptations inside the home”); or worries or complaints (“I am worried that I might fall [again] and this is stopping me from doing usual things”).13 Each item has a “yes or no” response, with the “no” option applying to either no need or fulfilment of a need. Based on Rasch and factor analysis in previous research, the original developers of the LUNS considered the scale neither suitable for calculation of a total score, nor for division into domains.[20]

The SF-12 version 1 was used to describe health related quality of life. It was adapted from the Short Form 36 and contains 12 items with 2 (yes or no) to 5 (always - never) outcome categories. The SF-12 is divided into a Mental Component Summary (MCS) scale (6 items) and a Physical Component Summary (PCS) scale (6 items).

Indicator variables of each item were weighted using regression coefficients from the general US population. The scales range from 0 to 100, where a zero score indicates the worst possible health state and a 100 score indicates the best possible health state.[21] In the general US population, the scales have a mean of 50 and a standard deviation of 10.

The Frenchay Activities Index (FAI) was applied to evaluate household, work or leisure, and outdoor activities in the last 3 months (10 items) or 6 months (5 items), using 4 answering categories for each item: never (0) to most of the time (3).[3] The scale provides a sum score of 0 (least active) to 45 (most active). It has good construct validity and high test-retest reliability.[22] The Dutch version, as translated by Schuling et al, showed good reliability (Cronbach α for the total scale .88) and convergent validity with the Barthel Index, an indicator of performance in activities of daily living (Pearson r = .66).[23]

Sociodemographic, clinical, and treatment-related characteristics were derived from the hospitals' administration as part of the larger cross-sectional study. These included age at time of stroke, sex, level of education (low - intermediate - high), stroke type (hemorrhagic or ischemic), lateralization (left hemisphere or right hemisphere or vertebrobasilar), performance in activities of daily living 4 days after hospital admission (Barthel Index; score range 0-20), treatment with thrombolysis (yes or no), duration of hospitalization (days), and discharge destination after hospital stay (nursing home versus home).

Analyses

First, the sociodemographic, clinical, and treatment related characteristics were described for invited and noninvited patients as well as for responders and non-responders using means (standard deviation [SD]) and percentages. Differences between eligible and non-eligible patients and responders and non-responders were analyzed using chi-square tests for dichotomous and ordinal variables, and Mann-Whitney U tests were used to analyze continuous variables.

The overall response rate to the initial administration of the questionnaire was recorded. The number (%) of respondents who completed all of the items of the LUNS was calculated as well as the completion rates per item and number (%) of missing values. The number (%) of respondents who had 1 or more unmet needs was calculated, and the median number (interquartile range [IQR: 25th-75th percentile]; min-max) of unmet needs was reported for the respondents who completed the LUNS as a whole.

The median (IQR, min-max) scores on the FAI, SF-12 MCS, and SF-12 PCS were calculated for patients with and without unmet needs, per item. The Mann-Whitney U test was applied to detect the statistical significance of the difference in FAI and SF-12 MCS and SF-12 PCS scores between those with and without unmet needs. For each item, the proportion of observed agreement between the first and the second administration of the LUNS was calculated. As the questionnaire is used to distinguish between no unmet needs and unmet needs at the patient level instead of the population level, we did not use a reliability measure, such as Cohen kappa.[24]

Results

Translation and Cross-Cultural Adaptation

Translation and Expert Revision

All of the translators completed their translations. In the expert meeting, several items were discussed that appeared challenging to translate literally or that raised ambiguity. After discussion, "diet" (item 12) was translated as "eetpatroon"; "home library" (item 21) was omitted; "feeling low" (item 20) was translated as "somber"; and "physical relationship" was translated as "intieme relatie."

Field Testing

Twelve of the 15 (80%) patients who were invited to take part in the field test returned the postal questionnaire. The average duration of completion was 8 minutes. All respondents indicated that the instructions were clear and that the questionnaire was easy to fill out. None of them encountered contradictions or inappropriate questions. Three respondents noted an overlap between questions, that is, items 1 ("information on stroke"), 3 ("having pain"), 4 ("difficulties moving"), and 5 ("fear of falling"), as well as items 13 ("managing money") and 14 ("applying for benefits"). One respondent suggested that the item on intimacy (item 18) could be changed to "sexual relationship." One respondent noted that a question on "additional rehabilitation services" was lacking. All remarks were made by only 1 respondent. Therefore, no further discussion took place within the expert group, and no adjustments were made. The LUNS was concluded feasible for use in the target population.

Determination of Psychometric Properties

Population Characteristics

In Figure 1, a flowchart is presented. Of the original research population in the cross-sectional study (N = 207), 145 (70.0%) were alive and indicated a willingness to be invited for a future study. Compared with the 62 patients of the previous study who were not invited, the eligible 145 patients of the current study were somewhat younger (age at time of stroke: 62.7 versus 66.2, P = .10), but were otherwise comparable. Of the 145 eligible patients, 78 (53.8%) returned the set of questionnaires and informed consent form. In Table 1, the baseline characteristics of responders (N = 78) and non-responders (N = 67) to the LUNS questionnaire and differences between groups are presented. Overall, there were no significant differences between the 2 groups, except for educational level, with the proportion of higher educated patients being higher among responders (38.7%) than among nonresponders (20.3%; P = .026). Among responders, the average age at questionnaire completion was 68.5 (SD 14.0). Sixteen (21.1%) respondents lived alone.

Missing Items

In total, 66 participants (84.6%) completed all of the items of the LUNS at its initial administration. Ten respondents had 1-5 missing items, and 2 respondents had 19 or more missing items. Of all 78 × 22 items, 57 (3.3%) were missing. The percentages of missing values per item ranged from 1.3% (“information on stroke” and “information on public transport”) to 7.7% (“having pain”).

Prevalence of Unmet Needs

Of all 78 respondents who had filled out 1 or more items of the LUNS, 53 (67.9%) indicated having 1 or more unmet needs. Of the LUNS completers, 44 respondents (66.6% of 66) reported having 1 or more unmet needs, and the median number of unmet needs in this group was 3.5 (IQR 2.0-5.0; min 1.0, max 14.0). The unmet need for information on stroke was indicated most frequently (N = 36; 46.2%). The unmet need for information on driving and need for aids or adaptations outside was reported least frequently, by 2 (2.6%) participants.

Test-Retest Reliability

Of all 78 participants, 54 (69.2%) completed the second questionnaire (T2). On average, the interval between completion of T1 and T2 was 15.4 days (SD 4.7). As presented in Table 2, the percentage agreement ranged from 69.8 (“information on stroke”) to 98.1 (“need for aids or adaptations outside”). In Figure 2, the percentage of respondents who indicated having an unmet need was presented for each item, for completers at T1 and T2.

Concurrent Validity

In Table 3, the results of the concurrent validity analyses are shown. For the FAI, SF-12 MCS, and SF-12 PCS, significant differences between those with and without unmet needs were found in 11, 11, and 9 items of the LUNS, respectively. In total, 15 items (68.2%) had an association with the FAI or the SF-12 MCS or the SF-12 PCS. Participants with unmet needs regarding walking, fear of falling, household tasks, bladder or bowel problems, concentration or memory, mood, and daily occupations had significantly lower scores on all 3 instruments than participants with no unmet needs on these items. Respondents with unmet needs regarding pain, public transport, money, benefits, occupation, personal care, and physical relationship did not show lower scores on any of the 3 instruments.

Discussion

In this study, we translated and cross-culturally adapted the LUNS into Dutch and assessed its psychometric properties in a heterogeneous population of stroke survivors between 5 and 8 years after stroke. Field testing yielded a comprehensive and feasible questionnaire. In a larger group, it showed high agreement between the test and the retest measurements and yielded few missing items. For 15 out of 22 items, those with unmet needs had significantly worse scores on 1 or more instruments for activities and quality of life, substantiating its validity.

The test-retest reliability of the LUNS, time needed for completion, and proportion of missing values (3.3%) appeared to be comparable with the original validation study of the LoTS care LUNS study team. Regarding the concurrent validity, in their study, 21 items were significantly associated with lower scores on the FAI or the SF-12, whereas in our study, only 15 items were.[13]

The difference in concurrent validity between the 2 studies could be related to the small size of our population combined with the small percentage of unmet time frame; 6 years after stroke, activities and quality of life can be affected by other factors than unmet needs related to stroke.

The median number of unmet needs was 3.5, and the prevalence of each unmet need ranged from 3% to 47%. Various other studies in populations 3-36 months after stroke also reported medians of 3[9,10] or 4[7,13] unmet needs. Interestingly, from our study, this number of unmet needs was observed much later, that is, 5-8 years after stroke.

Consistent with other studies, the prevailing need for information on stroke ("what is it, why did it happen to me, how to prevent recurrence")[8] was most frequently mentioned, followed by unmet needs regarding fatigue, memory or concentration, and mood.[7,8,11] Thus, the Dutch translation of the LUNS captures unmet needs years after stroke; the amount is comparable with previous studies.

In the Netherlands, the majority of stroke patients are monitored within the healthcare system for up to 1 or 2 years after stroke. After that, they drop out of sight of health professionals. From our study, it appears that it is important to continue to assess unmet needs for a longer period of time. Identifying unmet needs at the individual level will guide the provision of personalized care and information. Murray et al investigated a primary care based model. Of the 190 problems identified in 68 stroke patients and their caregivers 4-18 months post stroke onset, 75% was solved within 3 months.[25] Moreover, measuring unmet needs at the population level can facilitate the development and evaluation of services regarding care and information after stroke. Eventually, insight into unmet needs in the long term after stroke can be used to adapt initial stroke rehabilitation to prevent those unmet needs in future patients.

A comment that should be made regarding the content of the LUNS is that some items explicitly express the need for advice or help (e.g., "I would like outside help to get jobs done in my home"), whereas others merely express a problem (e.g., "I am worried that I might fall [again] and this is stopping me from doing my usual things"). Respondents possibly do not have a need regarding the latter issues but nevertheless have worries. Thus, the phrase "unmet needs" should be used with caution. Another remark is that an item on unmet rehabilitation needs is lacking, although this need was reported in other studies.[26] In future use, this item could be added to a questionnaire in addition to the LUNS. Still, the LUNS is highly informative for health professionals as it provides a comprehensive picture of all areas in which there is a desire for improvement after stroke.

The main limitation of our study is the relatively low number of respondents. For the concurrent validity analyses, this may have affected the chance of finding significant differences between groups in the FAI or SF-12 MCS or SF-12 PCS and can also explain the deviating values in some of the items. For example, the median FAI score of patients with an unmet need regarding driving (N = 2) was 7.5 (2.0-13.0), as opposed to a score of 28.0 (20.0-34.0) for patients without an unmet need. Another issue is that the responsiveness of the LUNS, for example, to patient education interventions needs further exploration.

Conclusion

Among the 53.8% who completed the survey, the LUNS was concluded to be feasible, reliable, and valid; two thirds of its items are related to activities and quality of life. Even 5-8 years after stroke, two-thirds of stroke survivors appeared to have 1 or more unmet needs. Its usefulness and acceptability when administered in routine practice require further study.

Acknowledgments: We acknowledge the Haaglanden Medical Center for funding the study. We thank Bart Steens, van Markus-Doornbosch, Floris Hekster, Maggie Goossens, and Liesbeth Boyce for their contribution to the translation process. We are grateful to Anne Hanschke of the Haaglanden Medical Center for screening the initial study population, Floor Arwert for carrying out telephone reminders during the study, and Gerard Volker for his advice in the statistical analyses.

References

1. World Health Organization. In: Mendis S, Puska P, Norrving B, eds. Global atlas on cardiovascular disease prevention and control. Geneva: WHO, 2011.
2. Geyh S, Cieza A, Schouten J, et al. ICF Core Sets for stroke. J Rehabil Med 2004;(44 Suppl):135-141.
3. Murray J, Ashworth R, Forster A, et al. Developing a primary care-based stroke service: a review of the qualitative literature. Br J Gen Pract 2003;53:137-142.
4. Heinemann AW, Sokol K, Garvin L, et al. Measuring unmet needs and services among persons with traumatic brain injury. Arch Phys Med Rehabil 2002;83:1052-1059.
5. Andrew NE, Kilkenny MF, Lannin NA, et al. Is healthrelated quality of life between 90 and 180 days following stroke associated with long-term unmet needs? Qual Life Res 2016;25:2053-2062.
6. Andrew NE, Kilkenny MF, Naylor R, et al. The relationship between caregiver impacts and the unmet needs of survivors of stroke. Patient Prefer Adherence 2015;9:1065-1073.
7. Andrew NE, Kilkenny M, Naylor R, et al. Understanding long-term unmet needs in Australian survivors of stroke. National Stroke Foundation. Int J Stroke 2014; 9(SupplA100):106-112.
8. Hafsteinsdóttir TB, Vergunst M, Lindeman E, et al. Educational needs of patients with a stroke and their caregivers: a systematic review of the literature. Patient Educ Couns 2011;85:14-25.
9. Walsh ME, Galvin R, Loughnane C, et al. Community re-integration and long-term need in the first five years after stroke: results from a national survey. Disabil Rehabil 2015;37:1834-1838.
10. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. Stroke 2011;42:1398-1403.
11. Rothwell K, Boaden R, Bamford D, et al. Feasibility of assessing the needs of stroke patients after six months using the GM-SAT. Clin Rehabil 2013;27:264-271.
12. Op Reimer WJ, Scholte de Haan RJ, Rijnders PT, et al. Unmet care demands as perceived by stroke patients: deficits in health care? Qual Health Care 1999;8:30-35.
13. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. Clin Rehabil 2013;27:1020-1028.
14. Murray J, Young J, Forster A, et al. Developing a primary care-based stroke model: the prevalence of longer-term problems experienced by patients and carers. Br J Gen Pract 2003;53:803-807.
15. Arwert HJ, Schults M, Meesters JJ, et al. Return to work 2-5 years after stroke: a cross sectional study in a hospital-based population. J Occup Rehabil 2017;27:239-246.
16. World Medical Association Declaration of Helsinki. Ethical principles for medical research involving human subjects. JAMA 2013;310:2191-2194.

17. Mokkink LB, Terwee CB, Patrick DL, et al. Cosmin Cecklist Manual. Amsterdam, Cosmin, Jan 2012. Available at: http://www.cosmin.nl/images/upload/files/COSMIN%20checklist%20 manual%20v9.pdf. Accessed February 09, 2016.
18. Beaton DE, Bombardier C, Guillemin F, et al. Guidelines for the process of cross-cultural adaptation of self-report measures. Spine 2000;25:3186-3191.
19. Guillemin F, Bombardier C, Beaton D. Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. J Clin Epidemiol 1993;46:1417-1432.
20. Forster A, Mellish K, Farrin A, et al. Project 3: Longer-term Unmet Needs after Stroke study. P77-95. In: Development and evaluation of tools and an intervention to improve patient- and carer-centred outcomes in Longer-Term Stroke care and exploration of adjustment post stroke: the LoTS care research programme. National Institute for Health Research, 2014:2-6 [Chapter 4], Programme grants for applied research.
21. Ware JE, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: construction of scales and preliminary tests of reliability and validity. Med Care 1996;34:220-233.
22. Turnbull JC, Kersten P, Habib M, et al. Validation of the Frenchay Activities Index in a general population aged 16 years and older. Arch Phys Med Rehabil 2000;81:1034-1038.
23. Schuling J, de Haan R, Limburg M, et al. The Frenchay Activities Index. Assessment of functional status in stroke patients. Stroke 1993;24:1173-1177.
24. de Vet HC, Mokkink LB, Terwee CB, et al. Clinicians are right not to like Cohen's κ. BMJ 2013;346:f2125.
25. Murray J, Young J, Forster A, et al. Feasibility study of a primary care-based model for stroke aftercare. Br J Gen Pract 2006;56:775-780.
26. Ullberg T, Zia E, Petersson J, et al. Perceived unmet rehabilitation needs 1 year after stroke: an observational study from the Swedish stroke register. Stroke 2016;47:539-541.

Figure 1. Study flow chart of a study on the cross-cultural adaptation and validation of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire in a Dutch population 5-8 years after stroke.

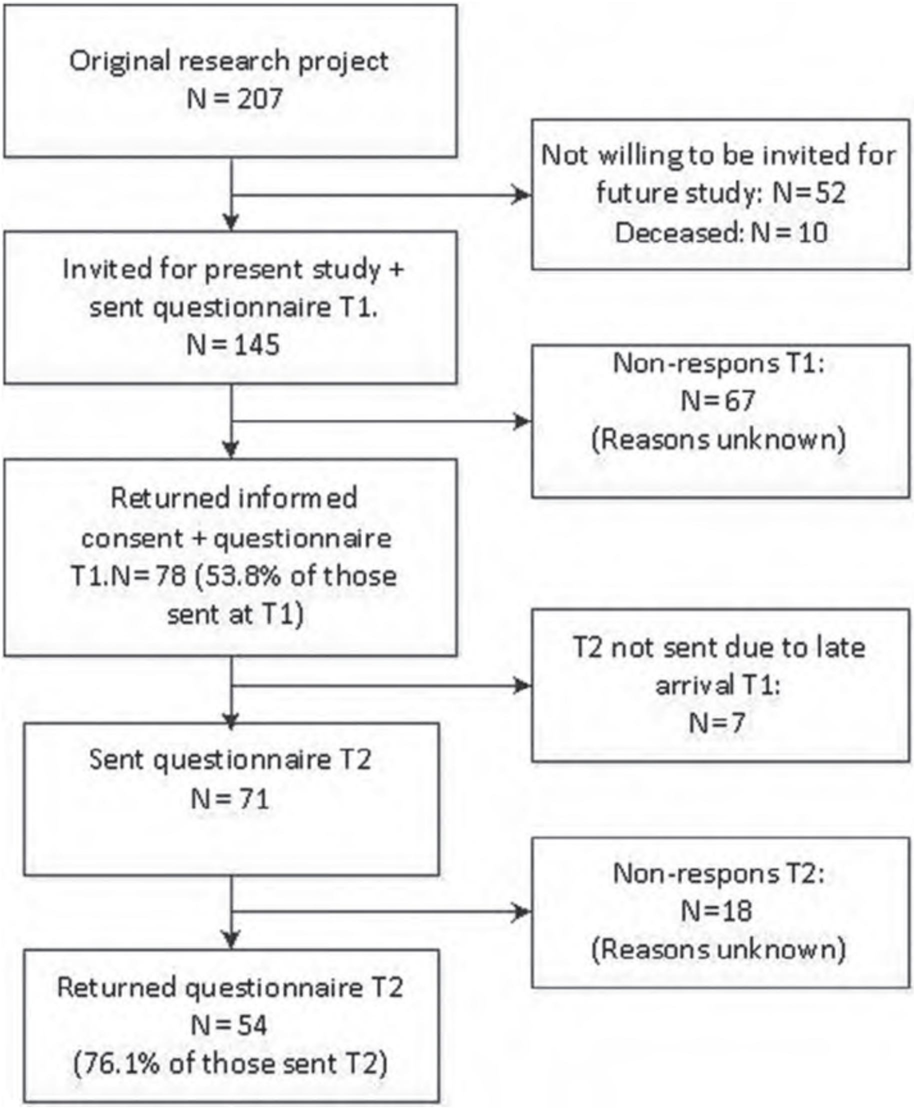


Figure 2. Percentages of stroke survivors 5-8 years after stroke (y-axis) reporting unmet needs for each of the 22 items of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire, at the first assessment (T1) and the assessment 2 weeks later (T2).

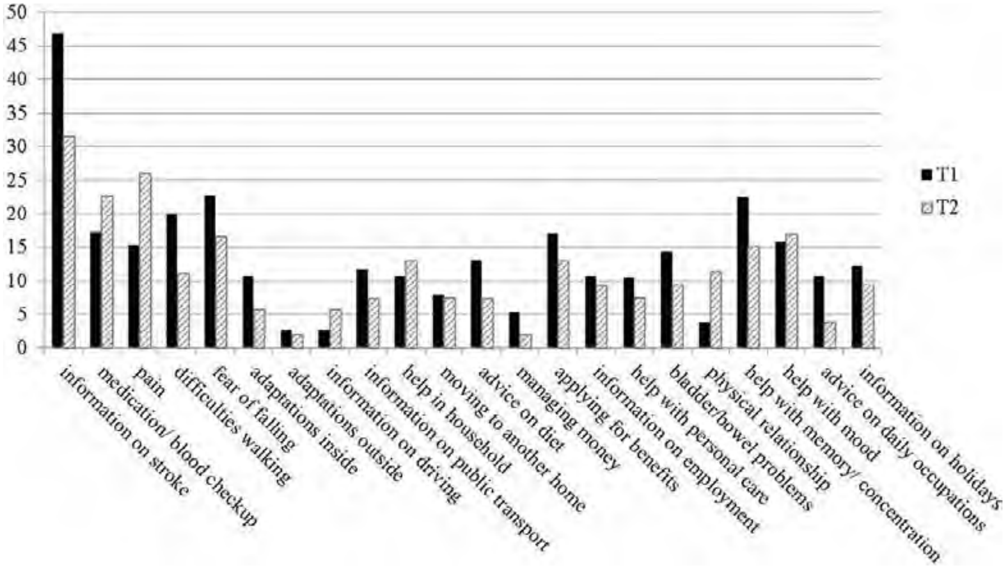


Table 1. Baseline characteristics and differences between responders and non-responders in a study on the cross-cultural adaptation and validation of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire among Dutch stroke survivors 5-8 years after stroke.

	Responders (N=78)	Non-responders (N=67)	P-value*
Sex (male; N (%)	46 (59.0)	44 (65.7)	0.493
Education (N; %)			0.056 for overall comparison. p=0.026 for high vs. other
- Low	22 (29.3)	27 (42.2)	
- Intermediate	24 (32.0)	24 (37.5)	
- High	29 (38.7)	13 (20.3)	
Age at time of stroke (mean; SD)	61.7 (13.8)	63.8 (14.5)	0.438
Type of stroke (ischemic; N, %)	71 (91.0)	60 (89.6)	0.785
Received thrombolysis (N; %)	22 (28.2)	15 (25.9)	0.846
Barthel Index at day 4 after stroke (mean; SD)	13.6 (6.5)	12.7 (6.4)	0.398
Discharge destination (home; N, %)	48 (63.2)	26 (46.4)	0.076
SF-12 Mental Component Summary score (mean; SD) N=65	50.0 (12.0)	NA	
SF-12 Physical Component Summary score (mean SD) N=65	43.0 (10.0)	NA	
FAI (mean; SD) N=71	25.5 (11.0)	NA	

Table 2. The prevalence of unmet needs, the acceptability of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire, and the test-retest reliability expressed as the percentage agreement between the first (T1) and the second (T2) assessment, among stroke survivors 5-8 years after stroke

	Prevalence	Missing items	Test-retest reliability
	T1.	T1.	T2-T1.
	N=78	N=78	N=54
	N (%) of respondents who indicated an unmet need	N (%) of respondents who left the item blank	Percentage agreement
Information on stroke	36 (46.2)	1 (1.3)	69.8
Medication/blood checkup	13 (16.7)	3 (3.8)	88.2
Pain	11 (14.1)	6 (7.7)	88.0
Difficulties walking	15 (19.2)	3 (3.8)	82.7
Fear of falling	17 (21.8)	3 (3.8)	86.5
Need for aids/ adaptations inside	8 (10.3)	3 (3.8)	88.7
Need for aids/ adaptations outside	2 (2.6)	3 (3.8)	98.1
Information on driving	2 (2.6)	3 (3.8)	96.2
Information on public transport	9 (11.5)	1 (1.3)	96.3
Help in household	8 (10.3)	3 (3.8)	88.7
Information on moving to another home	6 (7.7)	3 (3.8)	96.2
Advice on diet	10 (12.8)	2 (2.6)	92.5
Help with managing money	4 (5.1)	2 (2.6)	94.3
Help with applying for benefits	13 (16.7)	2 (2.6)	90.6
Information on employment	8 (10.3)	3 (3.8)	94.2
Help with personal care	8 (10.3)	2 (2.6)	92.3
Help with bladder/ bowel problems	11 (14.1)	1 (1.3)	90.6
Advice on physical relationship	3 (3.8)	2 (2.6)	92.3
Help with concentration/ memory	17 (21.8)	2 (2.6)	86.5
Help with mood	12 (15.4)	2 (2.6)	92.3
Advice on daily occupations	8 (10.3)	3 (3.8)	94.2
Information on holidays	9 (11.5)	4 (5.1)	98.0

Table 3. Concurrent validity of the Longer-term Unmet Needs after Stroke (LUNS) questionnaire among stroke survivors 5-8 years after stroke, using the SF-12 MCS, SF-12PCS and the FAI.

	SF-12 MCS scale 0-100; no unmet need- unmet need (median; IQR)	SF-12 PCS scale 0-100; no unmet need- unmet need (median; IQR)	FAI range: 0-45; no unmet need- unmet need (median; IQR)
Information on stroke	46.8 (37.6-53.9)	55.1 (49.8-59.8)	30.0 (26.0-35.0)*
	41.3 (34.0-46.8)	51.7 (40.0-56.9)	26.0 (12.5-30.5)
Medication/blood checkup	45.5 (37.7-52.5)	55.0 (48.9-59.1)*	29.0 (21.0-35.0)
	38.2 (32.2-45.9)	50.6 (32.6-51.9)	23.0 (16.0-30.0)
Pain	45.5 (37.6-53.6)	52.6 (47.8-57.9)	28.0 (19.0-33.0)
	38.0 (28.9-44.7)	53.4 (33.2-59.4)	29.5 (21.0-35.0)
Difficulties walking	45.9 (37.7-53,6)**	55.0 (50.2-59.1)**	29.0 (23.0-35.0)**
	36.4 (27.3-38.8)	33.3 (26.5-47.8)	18.0 (4.0-26.0)
Fear of falling	45.2 (37.6-53.6)*	54.8 (49.8-58.8)*	30.0 (25.0-35.0)**
	38.6 (27.8-46.2)	42.0 (29.5-54.5)	12.5 (2.0-25.0)
Need for aids/ adaptations inside	45.3 (35.8-53.1)*	53.5 (47.8-58.7)	28.0 (19.0-33.0)
	38.8 (27.3-43.9)	48.9 (26.5-56.9)	29.0 (14.5-33.5)
Need for aids/ adaptations outside	44.4 (35.8-52.1)	52.7 (47.6-58.3)	28.0 (20.0-34.0)*
	38.4 (38.4-38.4)	19.5 (19.5-19.5)	3.0 (2.0-4.0)
Information on driving	44.9 (35.8-52.5)	52.8 (47.8-58.7)*	28.0 (20.0-34.0)*
	36.7 (34.9-38.4)	29.2 (19.5-38.9)	7.5 (2.0-13.0)
Information on public transport	43.8 (35.8-52.1)	53.5 (48.2-58.3)	28.0 (19.0-33.0)
	45.5 (38.8-48.3)	47.8 (30.4-52.3)	26.5 (15.0-32.5)
Help in household	45.2 (37.6-53.1)*	54.8 (47.8-58.8)*	29.0 (21.0-35.0)*
	35.4 (27.3-38.4)	45.3 (34.8-51.9)	17.5 (8.5-25.5)
Information on moving to another home	45.5 (38.4-53.1)**	54.8 (48.9-58.8)**	29.0 (19.5-34.5)
	32.2 (27.9-35.4)	37.5 (28.5-51.6)	23.0 (18.0-26.0)
Advice on diet	43.9 (35.8-52.5)	52.8 (47.4-58.7)	29.0 (23.0-35.0)**
	41.7 (35.8-47.0)	51.9 (39.4-57.4)	18.0 (6.5-24.5)
Help with managing money	44.4 (35.8-52.5)	52.7 (47.4-58.7)	28.0 (19.0-34.0)
	38.8 (27.3-47.0)	51.6 (30.4-57.4)	26.0 (25.0-29.0)
Help with applying for benefits	45.2 (35.8-52.5)	54.3 (47.8-58.7)	28.5 (20.0-35.0)
	39.1 (32.4-43.9)	51.4 (28.5-54.8)	26.0 (17.0-31.0)
Information on employment	44.9 (35.8-53.1)	54.3 (47.4-57.9)	28.0 (20.0-33.0)
	39.3 (35.8-48.3)	49.6 (19.5-51.9)	28.0 (2.0-34.0)
Help with personal care	45.1 (37.5-53.1)	53.5 (47.4-58.8)	28.0 (21.0-34.0)
	40.7 (27.0-46.6)	51.3 (34.8-56.4)	19.0 (10.0-31.0)
Help with bladder/ bowel problems	45.9 (37.6-53.1)**	54.8 (49.6-58.8)**	29.0 (21.0-34.0)*
	37.1 (26.7-39.7)	32.6 (26.6-51.6)	19.0 (4.0-29.0)
Advice on physical relationship	44.4 (35.8-51.7)	53.5 (47.4-58.7)	28.0 (19.0-33.0)
	37.5 (27.3-52.5)	49.6 (24.9-51.6)	26.0 (17.0-40.0)
Help with concentration/ memory	46.8 (37.7-53.8)**	55.0 (50.2-58.7)**	29.0 (24.0-35.0)**
	38.0 (35.4-41.9)	35.5 (24.9-51.9)	18.5 (16.0-25.0)
Help with mood	45.9 (37.7-53.1)**	55.0 (50.2-58.8)**	29.0 (22.5-35.0)**
	37.5 (31.9-38.6)	26.7 (22.1-32.6)	17.0 (5.0-23.0)
Advice on daily occupations	45.7 (37.6-53.1)*	54.9 (47.8-58.8)*	29.0 (21.0-35.0)*
	36.7 (29.4-38.4)	41.0 (24.9-51.9)	19.0 (4.0-26.0)
Information on holidays	46.2 (37.5-53.4)*	54.9 (49.3-58.8)*	28.5 (20.5-34.5)
	38.4 (27.3-39.3)	38.9 (26.5-52.5)	25.0 (4.0-32.0)

*P< 0.05; **P<0.01


7

Chapter 7

Health care use and its associated factors at 5 – 8 years after stroke

Arwert HJ, Groeneveld IF, Vliet Vlieland TPM, Meesters JJL

Submitted in J Stroke Cerebrovasc

Abstract

Objectives: To describe health care use and its associated factors in the chronic phase after stroke.

Methods: Patients completed a questionnaire on health care use, 5-8 years after hospital admission for stroke. It comprised the number of physicians visited (P-Use; Low ≤1 or High ≥2) and other health care professionals (HCP-Use; Low 0 or High ≥1) over the past 6 months. Moreover, the Longer-term Unmet Needs after Stroke (LUNS); Frenchay Activity Index (FAI) and the Short Form 12, from which the Physical and Mental Component Summary Scales (PCS and MCS) scores were computed, were administered. The associations between health status (FAI, PCS, MCS) and LUNS on the one side and health care use (high, low) were determined by means of logistic regression analysis, adjusted for sex and age.

Results: Of 145 eligible patients, 78 (54%) returned the questionnaires; mean time-since-stroke was 80.3 months (SD10.2), age-at-stroke 61.7 years (SD13.8), and 46 (59%) were male. Physician contacts concerned mainly the general practitioner (58;79.5%), cardiologist (10;13,5%), neurologist (8; 10.8%) and ophthalmologist (8; 10.8%). Forty-one patients (52.6%) visited ≥2 physicians; thirty-seven patients (47.4%) visited ≥1 other HCP (mainly physical therapist). Forty-four (67%) patients had one or more unmet need, mostly in non-physical domains. Higher P-Use and HCP-Use were significantly associated with worse PCS scores (OR 0.931; 95%CI 0.877-0.987 and OR 0.941; 95%CI 0.891-0.993, respectively), but not with the FAI, MCS or LUNS.

Conclusions: Health care use after stroke is substantial and is related to physical aspects of QoL, but not to mental aspects, activities or unmet needs.

Introduction

Stroke is a relatively common condition, with its outcomes ranging from full remission to severe disability and death. In many patients the personal, familial and social burden is significant and long-lasting. Long-term stroke studies have shown that five to ten years after stroke at least 30% of the patients experience a reduced level of participation in complex and social everyday activities.[1-3] Given the sustained, significant impact on many patients' health, the question arises to what extent their problems are adequately addressed by means of health care services. Regarding the latter, it has been found that stroke survivors and caregivers may feel abandoned because they have become marginalized by services.[4] Nevertheless, before the quality of health services can be improved, it is important to have insight into the actual health care use of stroke survivors.

Research into health care use in the chronic phase after stroke is however scanty. In a French observational study on stroke management, more than 60.000 stroke patients were followed regarding their health care use during the first three months after hospitalization for stroke. The health care providers that were most often visited in this period were the general practitioner (93.1%), nurse (47.3% and the physical therapist (29.6%).[5] A register-based study from Sweden, including more than 47.000 stroke patients, reported 5 visits to primary care centers for therapy in the second year after stroke.[6] In a Dutch study 232 of 352 stroke patients who were discharged from hospital to their homes (66%) visited one or more allied health professionals (i.e. physical therapists or social workers), in the first year after stroke, with a median number of visits being 20.[7] Whereas two of these studies focused only on the first year after stroke,[5,7] and two did not provide detailed data on the use of specific health professionals,[6,7] little is known about the use of specific health care providers on the longer term after stroke.

Regarding factors associated with health care use, it was found in the abovementioned Swedish study that primary health care use in the second year after stroke was not related to functioning as measured with the modified Rankin Scale at 12 months (stratified for age and level of functional disability).[6] In a study on determinants of health care use in stroke patients in the (sub)acute phase, patients with a comprehensive health insurance were more likely to have speech therapy.[8]

The large variation in the methodology and few available studies clearly indicate that a more detailed insight in, and understanding of the health care use of stroke survivors on the longer term is needed. Furthermore, it is relevant to understand to what extent the patients' needs are adequately covered by the provided care.

The primary purpose of this study was therefore to describe health care use of community-based stroke survivors on the longer term after stroke. Secondly, the relationship of health care use with functioning, health related quality of life and unmet needs was studied.

Methods

Study design

The study was conducted at Haaglanden Medical Centre, The Hague, as an extension of a cross-sectional study on the functioning, activities, participation, coping, depression and quality of life two to five years after stroke, in patients ≥ 18 years who had been admitted to the hospital for their first-ever stroke.[9,10]

The study was judged to fall outside the Medical Research Involving Human Subjects Act by the Medical Ethics Review Committee South West Netherlands. Informed consent for study inclusion was obtained from all patients. All study procedures were executed in accordance with the Helsinki Declaration of 1975, as revised in 2013.[11]

Study population and recruitment

For the present study, the patients from the initial cohort study who had agreed to be invited to a follow-up study and who were still alive at the start of the current study were considered eligible. In 2016 (i.e. 3 years after the initial cross-sectional study) patients were invited by means of an invitation letter from the principal investigator (HA). An information leaflet, an informed consent form, and a questionnaire were enclosed. Patients who returned both the signed informed consent form and questionnaire were considered participants in the current study. Those who did not return the questionnaire within two weeks were contacted by telephone as a reminder.

Sociodemographic, clinical, and treatment-related characteristics

In the original cross-sectional study, sociodemographic, clinical, and treatment-related characteristics were derived from the hospitals' administration. These included: age at time of stroke, sex, level of education (low-intermediate-high), stroke type (hemorrhagic/

ischemic), lateralization (left hemisphere/right hemisphere/vertebro-basilar), performance in activities of daily living four days after hospital admission (Barthel Index; score range 0–20),[12] treatment with thrombolysis (yes/no), duration of hospitalization (days), and discharge destination after hospital stay (inpatient rehabilitation facility / nursing home/ versus home).

Health care use

Health care use in the last six months (contact with physicians or with other health care professionals) was assessed by means of an adapted version of a questionnaire that had been used in previous research with rheumatic diseases.[13] Patients were asked which physicians (P) they had seen in the last six months (general practitioner, neurologist, rehabilitation physician, psychiatrist, occupational physician, or other medical specialist). Furthermore, patients were asked which other primary health care professionals (HCP) were contacted in the last six months (physical therapist, occupational therapist, speech therapist, social worker, psychologist, complementary medicine/therapist, nurse, household professional, or other).

Unmet needs

The Longer-term Unmet Needs after Stroke (LUNS) questionnaire was used to identify longer-term unmet needs (UN) in the areas of information, services, social and emotional consequences, health problems, and related areas. The LUNS includes 22 statements that express a need for information or advice (“I would like advice on employment after stroke”); need for assistance or aids (“I need additional aids or adaptations inside the home”); or worries or complaints (“I am worried that I might fall [again] and this is stopping me from doing usual things”). Each item has a ‘yes/no’ response, with the ‘no’ option applying to either no need or fulfilment of a need.[14] Two-thirds of its items are being related to activities and quality of life. The LUNS was recently recently cross-culturally adapted and validated in Dutch, and was found to be acceptable, reliable and valid.[15]

Health related quality of life

The Short Form 12 (SF-12) version 1 was used to describe health related quality of life. It was adapted from the Short Form 36 (SF-36) and contains 12 items with two (yes/no) to five (always-never) outcome categories. The SF-12 is divided into a Mental Component Summary (MCS) scale (6 items) and a Physical Component Summary (PCS) scale (6 items).[16] The summary scales range from 0 to 100, where a zero score indicates the worst possible health state and a 100 score indicates the best possible health state. The SF-12 is translated and validated into the Dutch language.[17]

Activities

The Frenchay Activities Index (FAI) was applied to evaluate household, work/leisure, and outdoor activities in the last three months (10 items) or six months (5 items), using four answering categories for each item: never (0) to most of the time (3), resulting in a total score ranging from 0 (least active) to 45 (most active). It proved to have a good construct validity and high test-retest reliability in stroke patients.[18] The Dutch version showed good reliability (Cronbach's α for the total scale 0.88) and convergent validity with the Barthel Index, an indicator of performance in activities of daily living (Pearson's r = 0.66).[19]

Data analyses

First, the sociodemographic, clinical, and stroke-related characteristics were compared between non-responders and responders by x2 tests for dichotomous and ordinal variables, and Mann-Whitney-U tests or unpaired t-tests for continuous variables, where appropriate.

Descriptive statistics (mean, SD; median, IQR; number, %) were used for health care use, unmet needs, health related quality of life and activities of the participating patients.

Health care use was dichotomized by the median number of contacts, separately for the contacts with physicians (≤1 physician visit versus ≥2; low P-Use versus high P-Use) and with other health care professionals (0 visits versus ≥1; low HCP-Use versus high HCP-Use).

Subsequently, the association between low vs high health care use (either P-Use or HCP-Use) as a dependent variable, and health status (FAI, SF12 PCS, SF12 MCS) and the total number of unmet needs (UN) as independent variables were tested by means of multivariable logistic regression analyses, adjusted for sex and age. Odds ratios (OR) and 95% confidence intervals (95%-CI) were reported.

Statistical analyses were performed using IBM SPSS Statistics, version 24.

Results

Of the 207 patients of the original study in 2013, 10 patients were deceased at follow-up and 52 patients had previously indicated not to be available for follow-up, resulting in 145 patients who were eligible for the current study. Of these patients, 78 (54%) returned the questionnaire and provided informed consent.

Table 1 shows the characteristics of the eligible patients who did and did not participate in the present study. The mean time since stroke was 80.3 months (SD 10.2, range 65 to 100). Participants and non-participants were comparable with respect to age, sex, type of stroke, Barthel Index on admission, educational level and discharge destination (p-values › 0.05).

In Table 2 the health care use of the participants in the previous six months is presented. Most of the 74 patients had visited the general practitioner in the last six months (79.5%), 41 patients (N = 58, 52.6%) visited two or more physicians (general practitioner and/or medical specialist). A small number of patients contacted a neurologist or a rehabilitation physician, eight (10.8%) and three (4.1%) respectively. Of the other medical specialists, the cardiologist and the ophthalmologist were mentioned most frequently (10, 13.5%; 8, 10.8%).

Regarding the HCP, one third of the stroke patients received treatment by a physical therapist (PT). Household professionals covering the needs with respect to household maintenance for medical reasons were ranked secondly (14.9%). Other HCP were involved less frequently (‹10%).

Most of the patients had one or more stroke-related unmet needs (N = 44, 67%). The three most common unmet needs in this study concerned: information regarding the stroke (N = 36, 46.2%); problems with memory and concentration (N = 17, 21.8%); and fear of falling (N = 17, 21.8%) (Table 3).

In Table 4 the results of the multivariable logistic regression analyses regarding health care use are presented, adjusted for age and sex. Higher scores on the SF12 PCS were associated with lower health care use (P-Use OR 0.931, 95% CI 0.877-0.987; HCP-Use OR 0.941, 95% CI 0.891-0.993). The SF12 MCS and the FAI scores as well as the number of unmet needs were not related to health care use.

Discussion

In this cross-sectional study in a hospital-based chronic stroke population (N = 74), 41 patients (52.6%) visited two or more physicians (P), and 37 patients (47.4%) visited one or more other health care professional (HCP) in the previous six months. The most frequently visited health professionals included the general practitioner (n = 58, 79.5%) and the physical therapist (n = 25, 33.8%). Less than 10% of the patients had contacted the neurologist or rehabilitation physician. Two-thirds of the patients reported one or more stroke-related needs. Health care use was related to the Physical Component Summary Score of the SF12 (PCS), but not to the Mental Component Summary Score (MCS), activities or the number of stroke-related unmet needs.

Regarding the use of specific physicians or health professionals, our results can best be compared with the study by Tuppin et al., although that study was confined to health care use in the first 6 months after stroke.[5] With respect to visits to physicians, the rates for the general practitioners, physical therapists and neurologists were comparable, whereas the proportions of patients visiting the psychiatrist or nurse were lower in the present study than in the study by Tuppin et al.

In our study 80% visited their general practitioner in the last six months, whereas less than 10% visited physicians directly related to stroke (neurologist, rehabilitation physician). Therefore, we conclude that most stroke patients were transferred to primary care, in line with the general practitioners' guideline for stroke.[20] In comparison with the study of Tuppin et al.,[5] the proportions of patients who visited the physical therapist were in the same range, the numbers of patients who visited the speech therapist were lower and the nurse much lower in the present study. Comparisons with other studies are difficult to make as they did not report the results per health care provider.[6,7]

To what extent health care systems and health insurance play a role in the present study remains unclear, as we did not assess how patients were insured. In the Netherlands, visits to physical therapist are covered by health insurance depending on additional health insurance conditions, which may have influenced our results. Observed differences in health care use in the USA may also be attributed to differences in health care systems.[8] As another example it is unusual that patients in Italy with chronic stroke are offered any form of rehabilitation.[21]

With respect to determinants of health care use, in our study a relationship with physical functioning as measured with the SF-12, but not with FAI was found. Comparably, in the study by Lekander, no association between the modified Ranking scale and primary health care use was observed.[6]

These findings suggest that factors other than physical functioning are important in health care use. Papers from different countries and health care systems describe it as difficult for stroke patients to gain access to advice and services once discharged into the community, probably reflecting a mismatch between what patients need and what is delivered.[22]

A study by McKevitt et al reported that unmet needs of stroke survivors mainly concerned areas not typically addressed by current services.[23] On the other hand, Olaiya et al observed one or more unmet needs in over 80% of patients 2 years after stroke, and found that the number of unmet needs was positively related to the use of more community services.[24]

Relevant in this respect was the result of a systematic review of Pindus et al. demonstrating that stroke survivors and caregivers feel abandoned because they have become marginalized by services and they do not have the knowledge or skills to re-engage.[4]

In line with literature on this subject, our results show that the relations between health condition after stroke, health care needs and health care use are of a complicated nature. A variety of factors may contribute to the observed variance in health care use of stroke patient in the chronic phase such as health condition and outcome after stroke, coverage, accessibility, a lack of knowledge and coping skills in patients and carers, cultural aspects and a lack of evidence regarding therapeutical options.

The limitations of this study are related to its cross-sectional design, so causal relations cannot be established. The population was relatively small and selection bias is imminent; however, the participants in this study were comparable to the non-participants on relevant determinants. Furthermore, health care use years after stroke can result from other conditions than stroke. The strengths of this study on the other hand, are the detailed information on health care use in a hospital based population, and the relation to other outcomes on the longer term after stroke.

In conclusion, health care use among stroke patients in the Netherlands is related to physical aspects of health related quality of life, not to mental aspects or daily activities. The observation that health care use is not related to unmet needs may lead to the conclusion that more attention should be given to the perceived needs of stroke survivors in the long term. Further research is warranted to understand which strategy enables stroke survivors to cope with their health care needs more effectively.

References

1. Jönsson AC, Delavaran H, Iwarsson S, Ståhl A, Norrving B, Lindgren A. Functional status and patient-reported outcome 10 years after stroke: the Lund Stroke Register. Stroke. 2014 Jun;45(6):1784-90.
2. Singam A, Ytterberg C, Tham K, von Koch L. Participation in complex and social everyday activities six years after stroke: predictors for return to pre-stroke level. Plos One 2015;10(12):e144344.
3. Benjamin EJ, Blaha MJ, Chiuve SE, et al. on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2017 update: a report from the American Heart Association. Circulation 2017;135:e229-e445.
4. Pindus DM, Mullis R, Lim L, Wellwood I, Rundell AV, Abd Aziz NA, Mant J. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. PLoS One 2018 Feb 21;13(2):e0192533.
5. Tuppin P, Samson S, Fagot-Campagna A, Woimant F. Care pathways and healthcare use of stroke survivors six months after admission to an acute-care hospital in France in 2012. Rev Neurol (Paris) 2016 Apr-May;172(4-5):295-306.
6. Lekander I, Willers C, von Euler M, Lilja M, Sunnerhagen KS, Pessah-Rasmussen H, Borgström F. Relationship between functional disability and costs one and two years post stroke. PLoS One. 2017 Apr 6;12(4):e0174861.
7. van Eeden M, van Heugten C, van Mastrigt GA, van Mierlo M, Visser-Meily JM, Evers SM. The burden of stroke in the Netherlands: estimating quality of life and costs for 1 year poststroke. BMJ Open 2015 Nov 27;5(11):e008220.
8. Ostwald SK, Godwin KM, Cheong H, Cron SG. Predictors of resuming therapy within four weeks after discharge from inpatient rehabilitation. Top Stroke Rehabil 2009 Jan-Feb;16(1):80-91.
9. Arwert H, Schut S, Boiten J, Vliet Vlieland T, Meesters J. Patient reported outcomes of hand function three years after stroke. Top Stroke Rehabil 2017;12:1-7.
10. Arwert HJ, Meesters JJL, Boiten J, Balk F, Wolterbeek R, Vliet Vlieland TPM. Post stroke depression, a long term problem for stroke survivors. Am J Phys Med Rehabil 2018 Mar 5. Epub ahead of print
11. World Medical Association, 2013; http://www.health.uct.ac.za/sites/default/files/image_tool/images/116/Helsinki%202013.pdf. Accessed December 10th, 2017.
12. Collin C, Wade DT, Davies S, Horne V. The Barthel ADL Index: a reliability study. Int Disabil Stud. 1988;10:61–3.
13. Zirkzee EJ, Steup-Beekman GM, Schouffoer AA, Henquet SM, Caljouw MA, Huizinga TW, Vlieland

TP. Health care usage in Dutch systemic lupus erythematosus patients. Lupus. 2011;20(11):1147-54.

14. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. Clin Rehabil. 2013;27(11):1020-8.
15. Groeneveld IF, Arwert HJ, Goossens PH, Vliet Vlieland TPM. The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability, and Concurrent Validity in a Dutch Population. J Stroke Cerebrovasc Dis. 2018;27(1):267-275.
16. Ware J, Kosinski M, Keller SD. A 12-Item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. Med. Care 1996, 34, 220–233
17. Aaronson NK, Muller M, Cohen PD, et al: Translation, validation, and norming of the Dutch language version of the SF-36 Health Survey in community and chronic disease populations. J Clin Epidemiol. 1998;51(11):1055-68.
18. Wade DT, Legh-Smith J, Langton Hewer R. Social activities after stroke: measurement and natural history using the Frenchay Activities Index. Int Rehabil Med. 1985;7(4):176-81.
19. Schuling J, de Haan R, Limburg M, et al. The Frenchay Activities Index. Assessment of functional status in stroke patients. Stroke 1993;24:1173-1177.
20. NHG: https://www.nhg.org/standaarden/volledig/nhg-standaard-beroerte.
21. Ferrarello F, Baccini M, Rinaldi LA, Cavallini MC, Mossello E, Masotti G, Marchionni N, Di Bari M. Efficacy of physiotherapy interventions late after stroke: a meta-analysis. J Neurol Neurosurg Psychiatry 2011 Feb;82(2):136-43.
22. Gallacher K, Morrison D, Jani B, Macdonald S, May CR, Montori VM, Erwin PJ, Batty GD, Eton DT, Langhorne P, Mair FS. Uncovering treatment burden as a key concept for stroke care: a systematic review of qualitative research. PLoS Med 2013;10(6):e1001473.
23. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. Stroke 2011 May;42(5):1398-403.
24. Olaiya MT, Cadilhac DA, Kim J, Nelson MR, Srikanth VK, Andrew NE, Bladin CF, Gerraty RP, Fitzgerald SM, Phan T, Frayne J, Thrift AG; STANDFIRM (Shared Team Approach Between Nurses and Doctors for Improved Risk Factor Management) Investigators. Long-term unmet needs and associated factors in stroke or TIA survivors: An observational study. Neurology 2017 Jul 4;89(1):68-75.

Table 1. Characteristics of participants and non-participants in a follow-up study on health care use 5 to 8 years after stroke.

	Participants in follow-up study (N = 78)	Non-Participants# (N = 67)	P value*
Age at time of stroke (mean; SD)	61.7 (13.8)	63.8 (14.5)	.438
Gender (male; N, %)	46 (59.0)	44 (65.7)	.493
Mean duration of follow-up; Months (SD)	80.3 (10.2)	NA	
Educational level (N, %)			.056
- Low	22 (29.3)	27 (42.2)	
- Middle	24 (32.0)	24 (37.5)	
- High	29 (38.7)	13 (20.3)	
Type of stroke;			
(ischemic; N, %)	71 (91.0)	60 (89.6)	.785
Barthel Index (admission; 0-20; mean, SD)	13.6 (6.5)	12.7 (6.4)	.398
Discharge destination (home; N, %)	48 (63.2)	26 (46.4)	.076
SF-12 MCS (mean; SD) N = 65	50.0 (12.0)	NA	
SF-12 PCS (mean; SD) N = 65	43.0 (10.0)	NA	
FAI total score (mean; SD) N = 71	25.5 (11.0)	NA	
LUNS (median; IQR)	2 (4.25)	NA	

FAI, Frenchay Activities Index; SF-12, Short Form 12; MCS, Mental Component Summary score; PCS, Physical Component Summary score.

**P value of Mann-Whitney U test or chi-square test, where appropriate.*

#Non-participant= deceased or not responding to invitation

Table 2. Health care use of stroke patients; number of patients contacted a physician or a health care professional in the last 6 months.

Contact in the last 6 months with physicians:	N total	N Yes (%)
General practitioner	73	58 (79.5)
Cardiologist	74	10 (13.5)
Ophthalmologist	74	8 (10.8)
Neurologist	74	8 (10.8)
Rehabilitation physician	74	3 (4.1)
Occupational physician	74	2 (2.7)
Psychiatrist	74	4 (5.4)
Other physicians	74	22 (29.7)
- Visited no physician	78	14 (17.9)
- Visited 1 physician	78	23 (29.5)
- Visited 2 or more physicians	78	41 (52.6)
Contact in the last 6 months with health professionals:		
Physical therapist	74	25 (33.8)
Occupational therapist	74	3 (4.1)
Speech therapist	78	4 (5.1)
Psychologist	74	2 (2.7)
Social worker	73	2 (2.7)
Complementary medicine/therapist	73	3 (4.1)
Nurse	72	6 (8.3)
Household professional	74	11 (14.9)
Other type of care	74	7 (9.5)
- Visited no health care professional	78	41 (52.6)
- Visited 1 health care professional	78	17 (21.8)
- Visited 2 or more health professionals	78	20 (25.6)

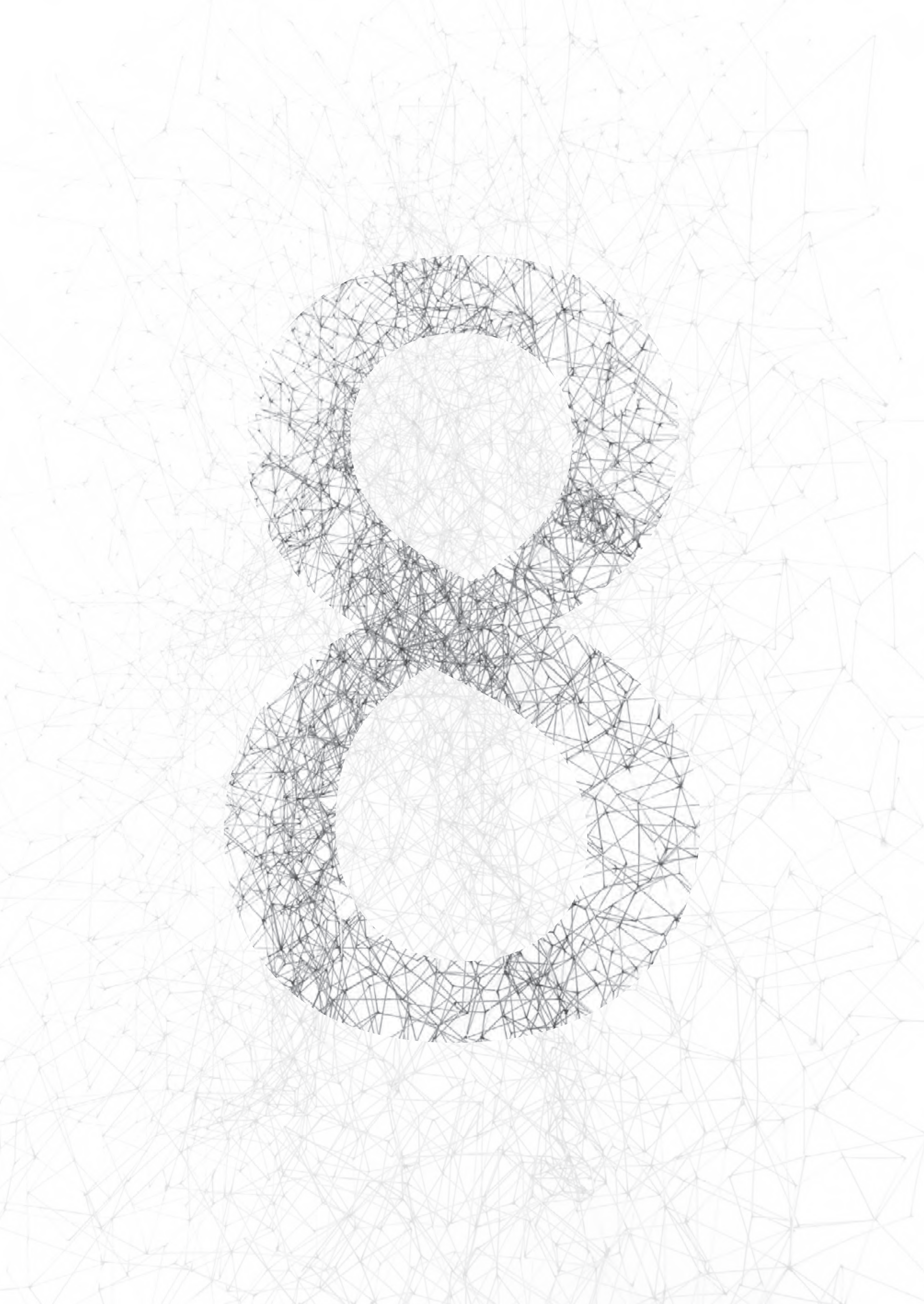
Table 3. Stroke related unmet needs 5 – 8 years after stroke, previously published in Groeneveld et al.[15]

Unmet need	N (%) of participants
Information on stroke	36 (46.2)
Fear of falling	17 (21.8)
Help with concentration/ memory	17 (21.8)
Difficulties walking	15 (19.2)
Help with applying for benefits	13 (16.7)
Medication/blood checkup	13 (16.7)
Help with mood	12 (15.4)
Pain	11 (14.1)
Help with bladder/ bowel problems	11 (14.1)
Advice on diet	10 (12.8)
Information on holidays	9 (11.5)
Information on public transport	9 (11.5)
Help in household	8 (10.3)
Need for aids/ adaptations inside	8 (10.3)
Help with personal care	8 (10.3)
Advice on daily occupations	8 (10.3)
Information on moving to another home	6 (7.7)
Help with managing money	4 (5.1)
Advice on physical relationship	3 (3.8)
Need for aids/ adaptations outside	2 (2.6)
Information on driving	2 (2.6)

Table 4. Relation between health care use (contacts with physician; contacts with health care professionals and outcome after stroke (SF12; FAI; LUNS); logistic regression, crude and adjusted for age and sex.

	Physician ≤1 (SD)	Physician ≥ 2 (SD)	OR (raw)	95% CI	p	OR (corr)	95% CI	p
SF 12 PCS; n=65	46.29 (9.22)	40.33 (9.93)	0.936	0.885 – 0.990	0.020	0.931	0.877 – 0.987	0.017
SF12 MCS; n=65	52.08 (10.91)	48.31 (12.73)	0.972	0.931 – 1.016	0.213	0.970	0.927 – 1.014	0.176
FAI; n=71	26.41 (12.10)	24.71 (10.11)	0.986	0.944 – 1.030	0.518	0.995	0.951 – 1.042	0.845
LUNS Total needs; n=66	2.39 (2.68)	3.11 (3.68)	1.075	0.919 – 1.258	0.365	1.088	0.923 – 1.283	0.317
	HCP 0 (SD)	HCP ≥ 1 (SD)	OR (raw)	95% CI	p	OR (corr)	95% CI	p
SF 12 PCS; n=65	45.36 (9.72)	40.05 (9.72)	0.945	0.896 – 0.997	0.037	0.941	0.891 – 0.993	0.028
SF12 MCS; n=65	51.07 (10.73)	48.66 (13.51)	0.983	0.943 – 1.025	0.420	0.985	0.944 – 1.027	0.469
FAI; n=71	26.65 (10.09)	24.37 (11.91)	0.982	0.940 – 1.025	0.402	0.979	0.936 – 1.024	0.360
LUNS Total needs; n=66	2.64 (3.36)	2.93 (3.15)	1.029	0.885 – 1.196	0.712	1.027	0.883 – 1.194	0.732

HCP: health care professional. OR: Odd's Ratio. CI: confidence interval. SF12 PCS: Physical Component Summery Scales of the Short Form 12. SF12 MCS: Mental Component Summery Scales of the Short Form 12. FAI: Frenchay Activity Index. LUNS: Longer-term Unmet Needs after Stroke.


8

Chapter 8

Primary care networks for the management of stroke patients

Arwert HJ, Borcherts JHR, van Vree FM, Groeneveld IF, Meesters JJL, Vliet Vlieland TPM, Goossens PH

Submitted in Int J of Integrated Care

Abstract

Aim: Most stroke patients are in need of care after initial hospitalization. Primary care stroke networks (PCSN) are set up to ensure the quality and accessibility of a continuum of health services. This study aimed to describe the structure and processes of PCSN in the Netherlands and formulate recommendations for their optimal organization and further development.

Methods: PCSN were defined as collaborations of primary health care providers with formal agreements on cooperation and/or the content of care for stroke patients. By searching the internet, contacting health care institutions, professional organizations and opinion leaders in stroke care, PCSN in the Netherlands were identified. By means of structured telephone interviews and online questionnaires information on the structure and processes of the PCSN was systematically gathered from their coordinators and members. During an invitational conference with relevant stakeholders, results were discussed, and recommendations were formulated.

Results: Fifteen PCSN met the definition, with their size varying from 4-140 members. Most members were physical therapists; 12 networks were multidisciplinary. 14 networks had membership entry criteria and 8 imposed a membership fee. Collaborations were reported with hospital and/or rehabilitation centers (n=14); the regional coordinator of a stroke chain of care (n=10); patients or patient association (n=8); and/or the general practitioner (n=7). Standardized treatment programs and/or measurements were used by 9 PCSN. 139 network members (response 25,5%) from 15 networks completed the online survey. Last year, 60 of 126 (48%) had had postgraduate education on stroke, 87 of 97 (90%) had taken part in network meetings and 71 of 91 (78%) had seen more than 5 stroke patients. Time and money were most frequently mentioned as barriers for continuation. Mutual trust, commitment and direct lines of communication were mentioned as success factors. During an invitational conference, a set of recommendations for the future organization and development of PCSN were formulated; the need for a national, centralized approach being a consistent advice.

Conclusion: Large variation was observed in the structure and processes of 15 PCSN in the Netherlands. A national, centralized approach towards their organization and further development was advocated.

Introduction

Every year around 45.000 people in the Netherlands suffer from a first cerebrovascular accident or stroke.[1] The prevalence of stroke patients in the community is 315.000 in the Netherlands (2% of the population).[2] The death rate with respect to stroke is decreasing considerably, which leads to an increasing prevalence.[3] In the United States of America, 56% of stroke patients were discharged to their homes after hospitalization in 2011; 44% were discharged to inpatient rehabilitation or skilled nursing facilities of whom a majority returned to their homes as well after rehabilitation.[3] This pattern is comparable to the Netherlands.[4]

Recent literature shows that community dwelling stroke survivors do not always receive an optimal amount and type of care,[5] which may lead to unmet needs[6,7] and unnecessary restrictions in activities and participation.[8] These problems could be overcome by implementing well-organized networks of health professionals in primary care, with the common goal of improving the quality and continuity of care and enhancing communication between primary health care providers.[9] Working in networks may lead to better implementation of guideline recommendations, fewer healthcare costs, a higher treatment volume and better multidisciplinary collaboration around the patient.[10] On the other hand, a Cochrane review showed there is not sufficient evidence to draw clear conclusions on the effects of interprofessional collaboration interventions.[11] In a systematic review, nine randomized controlled trials on interventions by stroke support workers, care coordinators or case managers were identified. The methodological quality of the studies was variable. Patients and caregivers receiving formal primary care-based follow-up did not show gains in physical function, mood, or quality of life when compared with those who did not. Patients and caregivers receiving follow-up were generally more satisfied with aspects of communication, and had a greater knowledge of stroke.[12] A randomized controlled trial in the UK concerning a new post-discharge system of care comprising a structured assessment covering longer-term problems experienced by patients with stroke and their carers, demonstrated no benefit in clinical or cost-effectiveness outcomes associated with the new system of care compared with usual practice.[13]

Knowledge in this respect is still developing. Currently, a review is being carried out to construct hypotheses for the development of a primary care model which aims to provide sustainable long-term support for stroke survivors and informal carers in the community.[14] Another systematic review protocol has been developed regarding the impact of quality improvement strategies on quality of life as well as physical and psychological well-being of individuals with stroke.[15]

In the Netherlands, primary care networks have been established for several other chronic conditions such as rheumatic and musculoskeletal conditions, Parkinson's disease or peripheral arterial disease resulting in increasing expertise, better communication and higher patient satisfaction.[16-20] Over the past years, primary care stroke networks (PCSN) have also been formed in several regions in the Netherlands. However, insight into their number and organizational features is lacking.

The aim of this project is to obtain an overview of the PCSN in the Netherlands and describe the structure and processes. Moreover, an inventory of barriers and facilitators for their continuation is made, and recommendations for their optimal organization and further development are formulated.

Methods

This study was carried out between June 2016 and September 2017. It concerned an online survey among network coordinators and members, and an invitational conference with relevant stakeholders. Because patient data were not involved the study fell outside the remit of the Medical Research Involving Human Subjects Act. All data of coordinators and members were processed anonymously.

The triad of structure, process, and outcome was used to evaluate the quality of PCNS.[21] In this concept "structure" is defined as the settings, qualifications of providers, and administrative systems through which care takes place; "process" as the components of care delivered; and "outcome" as recovery, restoration of function, and survival. These concepts remain the foundation of quality assessment and are used to describe the characteristics of a PCN in a formal way.[22]

Identification of existing networks

The following definition of a network was used: "Any collaboration of health care providers (either or not with the same professional background and not only comprising general practitioners and / or home care) in primary health care, with formal agreements about cooperation and / or the content of care provision to people with stroke." The network could be focused on other patient groups as well (e.g. brain injury) but their dedication to stroke had to be explicitly formulated.

Networks were identified and approached between June 2016 and September 2017, using various methods. First, information was obtained from the Knowledge Network for Stroke (www.CVAkennisnetwerk.nl), of the Working group for Stroke the Netherlands (WCN, part of Netherlands Society of Rehabilitation Medicine), the Dutch Society for Neurology and the snowball method among all involved in the project. In addition, a call inviting PCSN to participate in the project was made using various media relevant for healthcare providers involved in the treatment of people with stroke (e.g. websites of local, regional and national stroke patients' associations, the Rehabilitation Knowledge Network, Quality Network Rehabilitation Centers, professional associations of physical therapy, occupational therapy and speech therapy. Furthermore, the internet and the social media were searched for messages and as well as reports from relevant care networks (search terms (in Dutch) 'network', 'organization', 'healthcare', 'definition', 'integrated care' and 'interprofessional'). Finally, during the research, presentations were held at various symposia, after which networks could register to participate in the study.

Questionnaire network coordinators

By means of an online questionnaire among the coordinators of the identified stroke networks, followed by a telephone interview if data were unclear or incomplete, the characteristics of the networks were recorded. The questions concerned the following: the number of professionals and their background (physical therapists, occupational therapists, psychologists, speech therapists, nurses, social workers, dietitians, general practitioners), quality of care (goals set, goals evaluated and reset, exchange of patient data, shared patient record, combined treatment program, case management, requirements for membership yes/no), requirements (education, minimum number of stroke patients treated, registration in quality register of professional body), objectives of the network (improve quality of care, implement guidelines, offer specific expertise, improve communication, improve coordination, share knowledge and information, improve organizational aspects of care, improve efficiency of care, offer care in local community, care, uniform treatment protocols, prevent undertreatment, visibility) and future perspectives (need for uniformity, need for certification, need for nationwide support of content and organization of networks). Two open questions about success factors and barriers were added (what is in your opinion the reason for success of this network? what barriers are relevant in your opinion regarding this network?).

Questionnaire network members

The network coordinators were asked to invite the network members to fill in an online survey based on questionnaires used to describe the organization and outcomes of primary care networks for other chronic conditions (Fyranet network[16] and the ParkinsonNet network[23]).

The survey for members comprised questions regarding: profession, tasks and responsibilities in the network, costs and revenues being a member, requirements to become and stay a member of the network, number of years working as a professional and specifically regarding stroke patients, postgraduate courses or congresses, use of guidelines for stroke, use of a uniform treatment protocol within the network, outcome measures (patient level and aggregated at group level), the use of outcomes to adapt treatment program, the role of a case manager, way of communication between members concerning patients, familiarity with expertise of colleague members, procedures to refer patients to other members, contacts with professionals outside the network, contacts with general practitioner or hospital organizations, organization of network meetings, attendance of network meetings, participation in intervision, number of stroke patient treated last year, number of patients referred to other members and to professionals outside the network, audits being organized, satisfaction (with the network; the network meetings; the number of referred patients; the publicity of the network for patients, colleagues and referrers; the communication between network members), the need for uniformity in stroke networks, the need for nationwide or centralized support for networks, expectations over 5 years, the need for support to be successful as a network member. The following questions about success factors and barriers were added: What is in your opinion the reason for success of this network? What barriers are relevant in your opinion regarding this network?

Invitational Conference

In order to formulate recommendations based on the results of the inventory, an invitational conference with stakeholders was organized: local scientific advisory board of patients, PCSN health providers, stroke network coordinators, national patients' associations, national professionals' associations (physical therapists, physical medicine and rehabilitation, neurology, general practitioner), national stroke knowledge network (CVA Kennisnetwerk), health insurance companies, The Netherlands Organisation for Health Research and Development (ZonMW; Zorg Onderzoek Nederland Medische Wetenschappen) and the Quality Fund for Medical Specialists (SKMS; stichting Kwaliteitsgelden Medisch Specialismen). Subsequently, the following topics were discussed in smaller groups: the requirements regarding quality of the networks and individual members, communication and cooperation, finance, and standardization.

Results

PCSN: network coordinators' perception

Fifteen stroke networks met the definition. Their geographical distribution over The Netherlands is shown in Figure 1. All 15 coordinators of these networks were willing to collaborate and completed the online survey. In 5 cases additional contact by telephone was necessary.

The median number of members per network was 27, range 4-140. Table 1 presents the professional background of network members and organizational aspects.

Three networks had been instituted in the past 24 months; of the other 12 networks 6 had been instituted before 2010. Three networks did not only focus on stroke but on neurological disorders in a broader sense.

Requirements for membership were imposed on network members in 14 networks. These could concern requirements for admission to the network and/or for continuation of membership. The extent to which admission and continuation requirements were set, operationalized and described varied among networks. In the 11 networks that had set requirements for a minimum number of stroke patients, the minimum number varied from 5 to 14 patients per year.

Concerning the required registrations in professional bodies, coordinators referred to the guidelines and quality registers of the professional groups. Educational requirements for network members were found to differ among professional groups, with reference to the professional group's guideline and to various training courses in the field of stroke.

Some of the network coordinators appointed additional requirements, such as signing a covenant, financial contribution, ‘interest, motivation and passion’, willingness to collaborate and location of the practice. For continuation of the membership, apart from the aforementioned requirements, the presence at network meetings and / or reference evenings was also required by various networks.

All 15 networks had formulated goals, including quality, coordination, efficiency and publicity (Table 2). Regarding quality of care, aspects that were mentioned concerned the application of national frameworks and guidelines, the provision of high-quality, evidence-based care, to enhance the skills of professionals and the coordination in the chain of care of the organizations involved. For this purpose, they focused on sharing knowledge, education and expertise promotion and some perform structured intervision. From the networks’ perspective, the needs of the individual patient should be leading in stroke care.

Six networks had a formalized structure and formed an association or partnership. Two of these networks had a statute and / or regulations. In the other networks, the cooperation structure was less formally established but based on agreements, shaped by informal coordinators or by periodic consultation between the members. Tasks and responsibilities of the network members were described in 8 networks.

The networks were funded in various ways, according to the coordinators’ answers. Eight networks were (partly) financed by a contribution from the network members, 5 networks received funds from affiliated centers, hospitals or intramural partners, 1 network received financial support by a health insurer and 1 network indicated that they were not being financed at all.

All coordinators indicated that network meetings were organized. For most of the networks, quality aspects had been elaborated, such as the exchange of patient data, a shared treatment protocol and uniform measurements of the results.

Regarding barriers and facilitators for the continuation of the networks, the coordinators often mentioned a lack of time and money as the most important impeding factors. Furthermore, achieving a minimum number of treatment patients was not always guaranteed. The ‘short lines’ and interprofessional contacts were mentioned as an important facilitating factor.

People experienced trust, involvement and know each other personally. In addition, the ‘bottom-up’ formation and organization of the networks was mentioned as a success factor.

Structure and process of PCSN: network members

Table 3 shows the characteristics of the 139 responding network members (response 25.5%). Most of the respondents (83%) worked in the field of stroke patients more than 5 years. Almost half of them had participated in stroke-oriented postgraduate courses or training one or more times during the past year and almost all network members participated in network meetings in the past year.

Communication about patients took place by e-mail (48%), personal contact (45%), telephone (44%), via team meetings (32%) or in writing (24%). To a much lesser extent, communication took place by fax (6%) or a joint electronic patient file (4%).

In general, network members were satisfied with the number and content of network meetings. Almost half of the responding network members were satisfied with the communication within the network, a similar proportion experienced an improvement in quality of care since being part of the stroke network (46%). Two thirds of the network members were unsatisfied with the publicity of the stroke network among colleagues, general practitioners, referring institutions and patients.

The available (inter)national profession-specific guidelines were followed by most practitioners, however, guidelines were not available for every discipline. Just over a third of the responding network members reported to have an interdisciplinary treatment program, about half of them measured progress and outcomes of the treatment of stroke.

Network members mentioned a lack of time and the lack of compensation for network activities as barriers. The volume requirements were in some cases difficult to meet. Few members also mentioned the risk of competition for production as an impeding issue. The above mentioned ‘short lines’ were considered as a facilitator. Knowing each other’s skills and learning from each other was enhanced by working in networks, specifically in networks with less members.

A formal instrument for certification of quality is required according to 41% of the responding network members. Approximately 60% of network members saw a central or national financial support as a prerequisite to stimulate standardization in the content and organization of the stroke networks. A small proportion of respondents, ranging from 6% to 17%, believed that more uniformity, central support or quality certification was not required.

Recommendations for future development: Invitational conference

The participants (n = 43) in the invitational conference were representing local scientific advisory board of patients, PCSN health providers, stroke network coordinators, national patients' associations, national professionals' associations (physical therapists, physical medicine and rehabilitation, neurology, general practitioner), national stroke knowledge network (CVA Kennisnetwerk), health insurance companies, The Netherlands Organisation for Health Research and Development (ZonMW) and the Quality Fund for Medical Specialists (SKMS).

The results of the conference, in terms of recommendations, are summarized in Table 4. The participants agreed upon a multidisciplinary network being preferred over a monodisciplinary network. Network meetings were important in meeting other members and for sharing knowledge. Responsibility for the organization and activities of the network must be assigned to a network coordinator. A shared vision on treatment and outcome measures promotes the quality of care.

Minimal requirements for admission and continuation as a PCSN member should comprise postgraduate education, minimal years of experience with and volume of stroke patients, registration in quality registries if applicable, participation in network meetings and intervision.

To improve the quality of care for stroke patients, it was necessary according to the participants in the conference that agreements with referring institutions about content and moment of information transfer were established. Other primary care providers such as GP's (general practitioners) and community nurses and should also be involved in the networks. Effective publicity and accessibility were considered important for the success of the PCSN.

Members contributed financially to the network, but additional funding is needed for both the start and continuation of the network. Participants argued for a central, national support for stroke networks to promote uniformity in the organization of the networks. This central support should facilitate the development of regional networks and their visibility for referrers as well as for patients, formulation of requirements for education and quality management, and exchange of knowledge within networks. Participants also argued for a national certification.

Discussion

With a considerable proportion of patients having some limitations in functioning after initial hospitalization and/or inpatient or outpatient rehabilitation for stroke, there is a need for integrated care provided in primary care. Networks of primary care professionals may guarantee the quality and accessibility of care but research in this area is scanty. This study identified 15 primary care networks, with a large variety in their structure and processes. Time and money were most frequently mentioned as barriers for continuation, whereas mutual trust, commitment and direct lines of communication were mentioned as success factors. During an invitational conference, a set of recommendations for the future organization and development of PCSN was formulated; the need for a national, centralized approach being a consistent advice.

In most countries some form of network organization regarding stroke patients is pursued. The structure and objectives of these networks may differ. In the Canadian Stroke Network best practices were advocated in the acute, subacute and chronic stroke care and a central registry was developed to collect necessary information on stroke risk factors, symptoms, treatment and hospital management to inform research and to identify gaps in care. [http://canadianstrokenetwork.ca/en/] The Kompetenznetz Schlaganfall in Germany is primarily focused on research efforts and implementation of its results. [http://www.kompetenznetz-schlaganfall.de/89.0.html]. The NHS in the United Kingdom established in 2013 the Strategic Clinical Networks that serve in key areas of major health and wellbeing challenges such as stroke. Each of the five NHS region teams may develop other Strategic Clinical Networks depending on local need. As an example, the South East Coast Strategic Clinical Networks issued the ‘Life After Stroke Commissioning Guidance’. The empowerment of stroke survivors and their carers to manage their care, with the help of appropriately skilled staff, is a key theme of this guidance, offering evidence-based guidelines on care for stroke survivors. [https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2017/07/life-after-stroke.pdf]

The evidence for the effectiveness of primary care networks is gradually growing. Enhanced expertise and coordination of teams in a variety of patient groups showed a limited effect on patient outcomes.[9] In a recent Cochrane study the impact of practice-based interventions designed to improve interprofessional collaboration amongst health and social care professionals was compared to usual care or to an alternative intervention. Strategies to improve interprofessional collaboration between health and social care professionals may slightly improve patient functional status, professionals' adherence to recommended practices, and the use of healthcare resources.[11] Further research is indicated to understand the efficacy of PCNS in stroke populations.

Our results indicate that sufficient financial resources are essential to keep an interprofessional stroke network running. These may consist of a contribution from members, possibly supplemented with funding from other parties (municipality, hospitals, health insurance). The quality of the network can be guaranteed by setting up a quality system for the treatment of stroke patients in which, among other things, performance indicators can be recorded. Process aspects should focus on collaboration, quality of care and visibility of the network. Agreements with referring physicians on sharing information and on shared opinions about treatment protocol is important. Sharing information from patients within the network must be done with due regard to the laws and regulations on privacy. Outcome measures at the level of the individual patient, care provider and the network need to be established. The network should be brought to the attention of local and regional health institutions and practices (hospitals, rehabilitation facilities, nursing homes, general practitioners and community nurses).

This study has some limitation relevant to be mentioned. Probably not all primary care stroke networks were found that met the criteria, although extensive efforts have been made to identify stroke networks in the Netherlands. A relatively large number of network members did not respond to the invitation of the questionnaire. Strengths of this study are the fact that all coordinators of the included networks did participate, and that a set of recommendations for further development of PCSN was discussed and formulated at an invitational conference.

In conclusion, there is no uniformity regarding the structure and process among 15 regional PCSN in the Netherlands. Recommendations are proposed for the organization of PCSN, based on structured response from network coordinators, network members and stakeholders. Centralized coordination and support is advocated. Further research is necessary to establish the beneficial effects of coordinated interprofessional care for stroke patients in primary care networks.

References

1. RIVM 2016; Rijksinstituut voor Volksgezondheid en Milieu. https://www.volksgezondheidenzorg.info/onderwerp/beroerte
2. CBS 2016; Central Bureau for Statistics. https://dspace.library.uu.nl/bitstream/handle/1874/333890/hart_en_vaatziekten_in_Nederland_2015.pdf?sequence=1
3. Benjamin EJ, Blaha MJ, Chiuve SE, Cushman M, Das SR, Deo R, de Ferranti SD, Floyd J, Fornage M, Gillespie C, Isasi CR, Jiménez MC, Jordan LC, Judd SE, Lackland D, Lichtman JH, Lisabeth L, Liu S, Longenecker CT, Mackey RH, Matsushita K, Mozaffarian D, Mussolino ME, Nasir K, Neumar RW, Palaniappan L, Pandey DK, Thiagarajan RR, Reeves MJ, Ritchey M, Rodriguez CJ, Roth GA, Rosamond WD, Sasson C, Towfighi A, Tsao CW, Turner MB, Virani SS, Voeks JH, Willey JZ, Wilkins JT, Wu JH, Alger HM, Wong SS, Muntner P; American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart Disease and Stroke Statistics-2017 Update: A Report From the American Heart Association. Circulation 2017 Mar 7;135(10):e146-e603.
4. National Stroke Guideline 2017. https://www.zorginzicht.nl/bibliotheek/acute-beroertezorg/KwaliteitsstandaardenDocumenten/Richtlijn%20herseninfarct%20en%20hersenbloeding.pdf.
5. Taule T, Strand LI, Skouen JS, Råheim M. Striving for a life worth living: stroke survivors' experiences of home rehabilitation. Scand J Caring Sci 2015 Dec;29(4):651-61.
6. Groeneveld IF, Arwert HJ, Goossens PH, Vliet Vlieland TPM. The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability, and Concurrent Validity in a Dutch Population. J Stroke Cerebrovasc Dis 2018;27(1):267-275.
7. LoTS care LUNS study team. Validation of the longer-term unmet needs after stroke (LUNS) monitoring tool: a multicentre study. Clin Rehabil 2013;27(11):1020-8.
8. Clark ML, Gropen T Advances in the stroke system of care. Curr Treat Options Cardiovasc Med 2015 Jan;17(1):355.
9. Bosch M, Faber MJ, Cruijsberg J, Voerman GE, Leatherman S, Grol RP, et al. Review article: Effectiveness of patient care teams and the role of clinical expertise and coordination: a literature review. Med Care Res Rev 2009;66(6 Suppl):5S-35S.
10. De Stampa M, et al. Fostering participation of general practitioners in integrated health services networks: incentives, barriers, and guidelines, BMC Health Serv 2009;17(9):48.
11. Reeves S, Pelone F, Harrison R, Goldman J, Zwarenstein M. Interprofessional collaboration to improve professional practice and healthcare outcomes. Cochrane Database Syst Rev 2017 Jun 22;6:CD000072.
12. Allison R, Shelling L, Dennett R, Ayers T, Evans PH, Campbell JL. The effectiveness of various models of primary care-based follow-up after stroke: a systematic review. Prim Health Care Res Dev 2011 Jul;12(3):214-22.

13. Forster A, Young J, Chapman K, Nixon J, Patel A, Holloway I, Mellish K, Anwar S, Breen R, Knapp M, Murray J, Farrin A. Cluster Randomized Controlled Trial: Clinical and Cost-Effectiveness of a System of Longer-Term Stroke Care. Stroke 2015 Aug;46(8):2212-9.
14. Aziz NA, Pindus DM, Mullis R, Walter FM, Mant J. Understanding stroke survivors' and informal carers' experiences of and need for primary care and community health services--a systematic review of the qualitative literature: protocol. BMJ Open 2016 Jan 6;6(1):e009244.
15. Munce SEP, Perrier L, Shin S, Adhihetty C, Pitzul K, Nelson MLA, Bayley MT. Strategies to improve the quality of life of persons post-stroke: protocol of a systematic review. Syst Rev 2017 Sep 7;6(1):184.
16. Verhoef J, Oosterveld FG, Hoekman R, Munneke M, Boonman DC, Bakker M, Otten W, Rasker JJ, de Vries-Vander Zwan HM, Vliet Vlieland TP. A system of networks and continuing education for physical therapists in rheumatology: a feasibility study. Int J Integr Care 2004;4:e19.
17. Van der Marck MA, Bloem BR, Borm GF, Overeem S, Munneke M, Guttman M. Effectiveness of multidisciplinary care for Parkinson's disease: a randomized, controlled trial. Mov Disord 2013 May;28(5):605-11
18. Ypinga JHL, de Vries NM, Boonen LHHM, Koolman X, Munneke M, Zwinderman AH, Bloem BR. Effectiveness and costs of specialised physiotherapy given via ParkinsonNet: a retrospective analysis of medical claims data. Lancet Neurol 2018; 17: 153–61
19. Hageman D, van den Houten MM, Spruijt S, Gommans LN, Scheltinga MR, Teijink JA. Supervised exercise therapy: it does work, but how to set up a program? J Cardiovasc Surg (Torino) 2017 Apr;58(2):305-312.
20. Klokkerud M, Hagen KB, Kjeken I, Bremander A, Hørslev-Petersen K, Vliet Vlieland TP, Grotle M. Development of a framework identifying domains and elements of importance for arthritis rehabilitation. J Rehabil Med 2012;44:406-13.
21. Donabedian A. Evaluating the quality of medical care. Milbank Mem Fund Q 1966;44:Suppl:166-206
22. Ayanian JZ, Markel H. Donabedian's Lasting Framework for Health Care Quality. N Engl J Med 2016 Jul 21;375(3):205-7.
23. Wensing M, van der Eijk M, Koetsenruijter J, Bloem B, Munneke M, Faber M. Connectedness of healthcare providers involved in the treatment of patients with Parkinson's disease: a social networks study. Implement Sci 2011;6:67.

Figure 1. Geographical distribution of fifteen stroke networks that were identified in The Netherlands.

Legenda

CVA network = stroke network; eerstelijn = primary care; zorgketen = chain of care.

Table 1. Health professionals, quality of care aspects, and requirements for membership in primary care networks, and the number of networks in which these (professionals, aspects and requirements) are represented.

Representation of professions:	Number of Networks
Physical therapists	15
Monodisciplinary (only physical therapists)	3
Occupational therapists	12
Psychologists	11
Speech therapists	8
Nurse	7
Social workers	5
Dietitians	5
GP	5
Quality aspects:	
Goals set	13
Goals evaluated and reset	13
Exchange of patient data	12
Shared patient record	1
Combined treatment program	9
Case management	6
Requirements for membership yes/no	14/1
If available, requirements concerned:	
Education	12/14
Minimum number of stroke patients treated	11/14
Registration in quality register of professional body	6/14

PCSN: primary care stroke network; GP: general practitioner.

Table 2. Objectives of PCSN (Primary Care Stroke Networks) as reported by the network coordinators (n = 15).

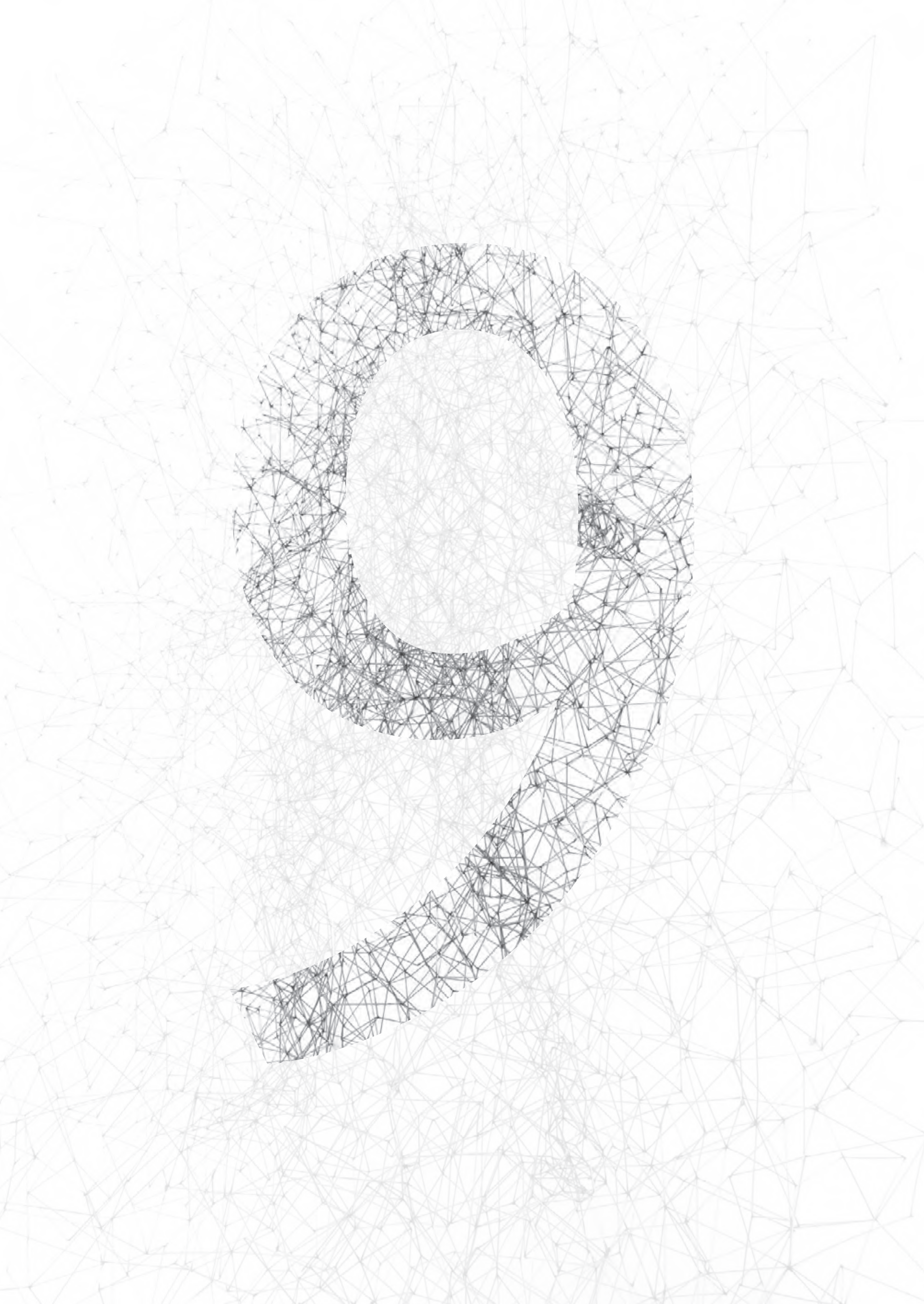
Improve quality of care	7
Implement guidelines	5
Offer specific expertise	6
Improve communication	5
Improve coordination	5
Share knowledge and information	4
Improve organizational aspects of care	4
Improve efficiency of care	3
Offer care in local community	3
Care	2
Uniform treatment protocols	2
Prevent undertreatment	2
Visibility/publicity	1

Table 3. Results from a survey among members of 15 PCSN (N = 139; answer categories Yes or No)

Experience and education	N	%
Took part in ≥ 1 network meeting last year	87/97	90%
Treats stroke patients > 5 years	102/123	83%
> 5 stroke patients last year	71/91	78%
Followed symposium or congress on stroke < 5 yrs	89/125	71%
Follows education on stroke > 1 per year	60/126	48%
Intervision in network	37/101	37%
Quality of care		
Following guidelines for stroke	100/125	80%
Evaluations of goals during treatment	55/106	52%
Structured outcome measurements	52/108	48%
Using uniform treatment protocol	42/122	34%
Adjustment of goals during treatment	23/81	28%
Being case manager for stroke patient	22/108	20%

Table 4. Recommendations for the organization and future development of PCSN as formulated at an invitational conference.

Structure	
	Formulate a shared vision on the treatment of stroke patients, based on existing guidelines, and a collaborative approach regarding measurable, concrete goals.
	Develop a multidisciplinary network: physical therapy, occupational therapy, speech therapy, supplemented when available with disciplines such as psychology, dietetics and nursing
	Involve Other stakeholders in the network: GP, hospital organizations, rehabilitation facilities and (regional) patient associations
	Tasks and responsibilities of network members must be formulated
	Consider a broader target group with similar neurological problems, for example 'patients with non-progressive central neurological disorders' or 'patients with acquired brain disorders'
	Organize network meetings at least once a year to ensure the coherence within a network and the quality of the care provided.
	Ensure funding for network coordination
	Set up a quality system for the treatment of stroke patients in which performance indicators can be recorded
	Consider a legal status for the network
Process	
	Establish agreements with referring institutions about content and timing of information transfer
	Make arrangements on internal and external lines of communication of the PCSN
	Formulate requirements for entry and continuation of membership
	Ensure publicity and visibility of the PCSN


9

Chapter 9

Summary and general discussion

Summary

A stroke is a common medical condition in which blood flow to the brain is obstructed. There are two main types of stroke: ischemic, due a vascular blood clot (thrombus), and hemorrhagic, due to an intracranial bleeding. As a result, a part of the brain does not function properly, temporarily or permanently. In approximately one third of the patients this leads to permanent disability, varying from mild to severe.

Chapter 1 gives an overview of the epidemiology of stroke and the challenges for stroke survivors. In the Netherlands the incidence of stroke is estimated 42,300/year in 2016. The prevalence of stroke is increasing due to ageing of the population and recent advances in therapeutic options. Following stroke, patients can experience impairments, limitations or restrictions in several domains of health status according to the ICF (International Classification of Functioning, Disability and Health). The consequences may pertain to body functions (e.g. motor functions, sensory functions, cognition, or mood), activities (e.g. reaching, dexterity, walking) and participation (e.g. engagement in paid employment or leisure activities). The nature and extent of disability depends on contextual factors, i.e. environmental and personal factors.

In the weeks and months after the initial stroke patients recover to some extent from their neurological deficits, most often supported by rehabilitation. Most of the patients return to their homes, directly after discharge from the hospital or after a rehabilitation period in a rehabilitation facility. Approximately one third of all stroke survivors experience limitations in activities and participation on the long term. In this chronic phase, most stroke patients are dependent on health care providers in primary care, to cover the needs they experience because of their stroke. Both in research and in daily clinical practice, it is found that there is room for improvement with respect to the delivery of stroke care in the chronic phase.

Currently, most research in stroke is focused on the initial medical treatment and the post-acute phase, either or not organized in the form of stroke services. More research in patients in the chronic phase after stroke is however needed, as it appears that the proportion of patients with disability on the longer term and ensuing health care needs is substantial. Therefore, the aim of this thesis was to describe the long-term consequences of stroke according to the different domains of the ICF. The second aim was to describe the health care use of community dwelling stroke patients, how this relates to their health condition and unmet needs, as well as the organization of primary care stroke networks.

Hand function after stroke

In Chapter 2 the measurement properties of the Dutch version of the Michigan Hand Outcome Questionnaire (MHQ) are evaluated in patients with stroke. The MHQ describes hand function in 6 domains: function, daily activities, pain, work, appearance and satisfaction (score 0–100, worst–best).

Fifty-one consecutive patients with stroke (mean age 60 ± 11 years; 16 women) were asked to complete the MHQ (57 items) and the 36-Item Short-Form Health Survey (SF-36), of which the Physical and Mental Component Summary Scales (PCS and MCS) scores were calculated. Additional assessments included the Barthel Index and performance tests for hand function (Action Research Arm Test, Nine Hole Peg Test, Frenchay Arm Test, Motricity Index).

The mean MHQ total score was 70.0 (SD 22.4), with Cronbach's α being .97. The MHQ total score correlated significantly with the PCS of the SF-36, the Barthel Index, and all hand function performance tests ($P < .01$). The MHQ total score showed no floor or ceiling effects and had no cut off level between normal and affected hand function. The test-retest intraclass correlation coefficient was .97.

This study provided preliminary evidence that the MHQ is an internally consistent, valid and reliable hand function questionnaire in outpatients after stroke, although these results need to be further confirmed.

Chapter 3 concerns hand function as measured with the MHQ in a large population of stroke survivors in the chronic phase. In this cross-sectional study, a hospital based stroke population was invited to complete a set of questionnaires on hand function, socio-demographic characteristics, mental functioning, daily activities, quality of life, and caregiver strain. Of 576 eligible patients 207 responded (36%); mean age 63.8 years (SD 14.2), 125 males (60.4%). Mean time since stroke was 36.3 months (SD 9.9). In 85% of the patients, the MHQ total score was less than 100 points (median 79.9, IQR 63.0–95.8). The median scores of the domains were: overall hand function 75.0, daily activities 90.5, work 85.0, pain 100, appearance 93.8, and satisfaction with hand function 83.3. A lower MHQ Total score was significantly associated with a lower Barthel Index at hospital discharge, a lower level of education, a supratentorial stroke and with unfavorable outcomes regarding physical and mental functioning, quality of life, and caregiver strain. A majority of the patients perceived limitations on one or more domains with respect to hand function. Problems related to the appearance of the hand and satisfaction with hand function can be relevant for patients and should be considered accordingly. A more severe stroke, a supratentorial stroke and a lower education were related to lower scores on hand function.

Depressive complaints after stroke

Chapter 4 describes the prevalence of depressive complaints and its determinants in the same hospital based stroke population 2 – 5 years after stroke. Patients and their caregivers completed questionnaires on depression (Hospital Anxiety and Depression Scale; HADS), socio-demographic characteristics, healthcare use, daily activities, Quality of Life and caregiver strain. A depression score of 8 or is an indication of clinically relevant depressive symptoms. Patients with HADS depression scores <8 were compared to patients with HADS depression scores ≥ 8 by means of univariate logistic regression analysis.

After a mean follow-up of 36.3 months, 67 of 207 responders (34%) had a HADS depression score ≥ 8. A higher HADS depression score was statistically significantly associated with male sex (adjusted for age and stroke severity), and with being born abroad (adjusted for age, sex and stroke severity). Patients with higher depression scores had higher anxiety levels, a more avoidant coping style, less daily activities and a lower Quality of Life; their caregivers experienced a higher burden.

Participation after stroke (work)

In Chapter 5, Return to Work (RTW) was evaluated in patients 2–5 years after stroke. For this purpose, a subgroup of the stroke patients in the previously described cohort was selected (below pensionable age and having a paid job prior to stroke). Forty-six patients were included, with a mean age of 47.7 years (SD 9.7), and a mean time since stroke of 36 months (SD 11.4); 18 patients (39 %) had succeeded in returning to work. After adjusting for age and gender, a shorter length of hospitalization was associated with RTW. Of the current health status, a lower HADS depression score, a less avoidant coping style, better scores on the FAI (Frenchay Activity Index), the MCS of the SF-36, the EQ5D (EuroQol classification system) and the CSI (Caregiver Strain Index) were associated with the chance of RTW. In the literature on hospital-based stroke populations the percentages of successful return to work are in general higher, warranting the need for further research. The significant association between work status and activities, mental aspects and quality of life may guide the development of effective interventions supporting RTW.

Longer-term unmet needs after stroke

In Chapter 6, a Dutch version of the 22-item Longer-term Unmet Needs after Stroke (LUNS) Questionnaire was developed and its measurement properties were examined in a Dutch stroke population. First, the LUNS was translated and cross-culturally adapted according to international guidelines. After field testing, the Dutch version was administered twice (2 weeks in between) to a hospital-based cohort of stroke patients 5 - 8 years after stroke. Participants were also asked to complete the FAI and SF-12. Seventy-eight of 145 patients (53.8%) returned the Dutch LUNS (mean age 68.3 years, SD 14.0; 59.0% male); questionnaires in the first assessment were fully completed by 66 patients.

In the first assessment, 3.3% of all items were missing. The median number of unmet needs was 3.5 (IQR 2.0-5.0). For 15 of 22 items, there was a significant association with the FAI or SF-12 Mental or Physical Component Summary scales.

The percentage of agreement between first and second assessment, as a measure of test-retest reliability, ranged from 69.8% to 98.1% per item.

The LUNS was concluded to be feasible, reliable, and valid; two-thirds of its items were related to activities and quality of life. Its use in daily practice requires further research.

Health care use and organization of care after stroke

Chapter 7 describes health care use and its associated factors in the chronic phase after stroke. Patients completed a questionnaire on health care use: the number of physicians visited (P-Use; Low ≤1 or High ≥2) and other health care professionals (HCP-Use; Low 0 or High ≥1) over the past 6 months. The LUNS, FAI and the SF-12, from which the PCS and MCS were calculated, were administered. The associations between health status (FAI, PCS, MCS) and LUNS on the one side and health care use (high, low) on the other were determined by means of logistic regression analysis, adjusted for age and sex.

Of 145 eligible patients, 78 (54%) returned the questionnaires; mean time-since-stroke was 80.3 months (SD10.2), age-at-stroke 61.7 years (SD 13.8), and 46 (59%) were male. Physician contacts in the past 6 months concerned mainly the general practitioner (58; 79.5%), cardiologist (10; 13.5%), neurologist (8; 10.8%) and ophthalmologist (8; 10.8%). Forty-one patients (52.6%) visited ≥2 physicians; thirty-seven patients (47.4%) visited ≥1 other HCP (mainly physical therapist). Forty-four (67%) patients had one or more unmet needs, mostly in non-physical domains. Higher P-Use and HCP-Use were significantly associated with worse PCS scores, but not with the FAI, MCS or LUNS.

Networks for stroke

Primary care stroke networks (PCSN) are set up to ensure the quality and accessibility of a continuum of health services. Chapter 8 describes the structure and processes of PCSN in the Netherlands and recommendations for their optimal organization and further development are formulated.

PCSN were defined as collaborations of primary health care providers with formal agreements on cooperation and/or the content of care for stroke patients. By searching the internet, contacting health care institutions, professional organizations and opinion leaders in stroke care, PCSN in the Netherlands were identified. Information on the structure and processes of the PCSN was systematically gathered from their coordinators as well as from their individual members by an online survey. During an invitational conference with stakeholders, results were discussed, and recommendations were formulated.

Fifteen PCSN met the definition, with their size varying from 4-140 members. Most members were physical therapists; 12 networks were multidisciplinary. 14 networks had membership entry criteria and 8 imposed a membership fee. Collaborations were reported with hospital and/or rehabilitation centers (n=14); the regional coordinator of a stroke chain of care (n=10); patients or patient association (n=8); and/or the general practitioner (n=7). Standardized treatment programs and/or measurements were used by 9 PCSN.

139 network members from 15 networks completed the online survey. 48% had had postgraduate education on stroke, 90% had taken part in network meetings and 78% had seen more than 5 stroke patients in the past 12 months. Time and money were the most frequently mentioned barriers for continuation of PCSN. Mutual trust, commitment and direct lines of communication were most often mentioned as success factors.

During an invitational conference, a set of recommendations for the future organization and development of PCSN were formulated; the need for a national, centralized approach being a consistent advice.

General discussion

Stroke is a relatively common disease, prevalences of 2% to 3% in the adult population are reported, and rates are expected to increase in the future.[1] Stroke can have a high impact on both physical, emotional and cognitive functioning as well as on societal participation on the short and long term and is thereby considered to be the most important contributor to complex disability in the developed world.[2,3] Patients often need comprehensive rehabilitation in the hospital or rehabilitation center and/or treatment by health care professionals in primary care.

Despite many improvements in the acute and post-acute treatment of stroke in recent years, research regarding the long term impact of stroke on functioning, the needs of stroke patients and the organization of the health delivery system in the chronic phase is relatively scanty. This thesis addressed these aspects in patients 2 – 8 years after stroke, with the aims being: to describe specific aspects of health condition in chronic stroke patients, the health care use of these patients and the unmet needs they experience. Subsequently the associations between health condition, health care use and unmet needs were evaluated and primary care stroke networks were described.

Health status in the chronic phase after stroke

In general, in the literature it is reported that a third of stroke survivors may experience a reduced level of functioning, activities and participation.[1,2,4,5] The results of the studies described in this thesis showed comparable outcomes to a large extent regarding hand function, depressive complaints and return to work.

Hand function after stroke

In our study, the MHQ proved to be an internally consistent, valid, and reliable hand function questionnaire in stroke survivors at least 8 months after rehabilitation (range 2 - 27 months). The need for a comprehensive hand function questionnaire that is easy to administer, covering aspects of body functions as well as daily activities as formulated by Lemmens et al.[6] can thus probably be addressed by the MHQ. Most of the stroke patients in our study showed sub maximal outcomes with respect to hand function. In contrast to other measurements of hand function, such as the ARAT and the motricity Index, the MHQ showed no ceiling effect.

Currently, a clear cut off point for impairment of hand function is not available. Interestingly, by using the MHQ, it was demonstrated that stroke patients may experience limitations other than the familiar domains such as hand function, work and pain; in our study, a considerable proportion of the patients perceived limitations regarding the appearance of the hand. Moreover, satisfaction with hand function was found to be limited in relatively many patients, an aspect that is not always taken into account. In order to identify to what extent the MHQ covers all areas of hand function that are relevant for patients after stroke, probably more qualitative research, in stroke patients with different nature and extent of hand function impairment in different phases of the disease, is needed.

Depressive complaints after stroke

Research on depressive complaints in a hospital based population of stroke survivors is limited and relatively old.[7,8] Clinically relevant depressive symptoms by means of the HADS were reported by 34% of the patients (hospital based, 2-5 years post-stroke) in our study, with a large impact on quality of life and caregiver burden. These numbers were in line with other stroke populations.[4]

With the interpretation of the findings, it is important to consider the prevalence of depressive complaints in the general population. Overall, the point prevalence of depression in the community in 19 European studies was considerably lower than in our population (11.9% in pooled data from 79503 subjects); in the Unites States the point prevalence was 13.4% (11 studies, 295279 subjects).[9] However, comparisons must be done with caution. The prevalence for studies using self-report instruments was higher (17.3%, 95% CI: 15.0–19.9%) than that of studies using interview-based assessment tools (8.5%, 95% CI: 6.5–11.0%).[9] Nevertheless, the findings of our study and similar studies in other countries, suggest that depression is a relevant problem in stroke survivors on the longer term.

There are several treatment options, such as behavioral therapy, exercise and medication.[10-12] Given the negative relations of depression with other outcomes after stroke on activities and participation, it is important to explore depressive complaints routinely in community based stroke survivors. This monitoring should be part of a system of routine assessment of the many other areas where stroke survivors may experience problems on the longer term.

Participation after stroke (work)

To evaluate Return to Work (RTW) and its sustainment, a long follow up is necessary, because the procedures concerned with the formalization of work disability may take two years and even longer in many countries. In our study, 39% of the stroke patients were able to RTW, which is lower than rates reported in other studies. In other hospital-based populations described in the literature, RTW varied from 55 to 75 %.[13-15] Our data were collected in a period of economic decline, the unemployment rate doubled from 2008 to 2013 in the Netherlands. Furthermore, social security in the Netherlands offers a sufficient allowance for those who cannot return to work for medical reasons. These factors may explain the differences compared to other studies, with a stroke comparable population. The observations in our population that patients successfully returning to work experienced a higher quality of life and less depressive complaints, and their caregivers experienced less strain, support the importance of work as a goal in rehabilitation. Patients at risk for problems in returning to their work should be identified early in the process of rehabilitation. Interventions directed at RTW comprise a comprehensive work analysis, early contact with employer and occupational health physician, specific training of working skills and guidance in the process of increasing working hours and content.

Health care use, health care needs and the organization of care after stroke

In the Netherlands, the overall health consumption (in financial terms) of stroke patients is larger than diseases such as chronic obstructive pulmonary disease, coronary heart disease or diabetes (http://statline.cbs.nl/Statweb/). In our study, health care for stroke survivors in the community was provided mainly by primary care professionals such as the general practitioner, physical therapist or a practice nurse. The transition from hospital based care or subacute rehabilitation facilities to primary care is in line with national guidelines. Remarkably, there is a lack of knowledge of the actual health care consumption of stroke patients, nor is information available on the determinants that are related to health care consumption. As a consequence, it is unknown to what extent stroke survivors overuse or underuse medical care. Furthermore, limited research is available regarding the needs stroke patients may experience in the chronic phase, which is also important in this respect. Stroke patients should have access to therapeutic options that are evidence based and take into account their actual needs.

The relation between health condition, health care use and unmet needs is of a complicated nature. Health care use in our population was related to the Physical Component Summary score of the SF12, not to the Mental Component Summary score of the SF12. This is also reflected by the unmet needs patients reported in our study; the unmet needs were predominantly oriented on psycho-social domains. The fact that one third of chronic stroke patients had depressive complaints was not reflected by health care use of professionals in this area (psychologist, psychiatrist). Community based stroke patients in our study seem to know how to access the health care system regarding their physical needs, in contrast to needs of social, mental of cognitive nature. This view is supported by the observation of McKevitt et al. that unmet needs in stroke patients concerned areas not specifically addressed by health care services.[16] In a recent systematic review, stroke patients reported feeling abandoned and marginalized by health care, lacking the skills to re-engage; a solution to this may come from a more proactive role of health care services regarding follow up and focusing on improvement of self-management skills.[17] This may ask for awareness in primary health care that chronic stroke patients may suffer from chronic complaints on several domains of the ICF that have to be addressed.

In other chronic illnesses, the development of primary care networks is regarded as an effective tool to improve the quality of care. Examples in this area are networks for M Parkinson, rheumatic and musculoskeletal conditions, and peripheral arterial disease.[18-22] Supportive structures and processes for the primary care networks can be helpful to enhance expertise of network members and improve communication and patient satisfaction. Regarding stroke, there is in the Netherlands no agreement on the basic requirements of the organization of a primary care network of health professionals, nor on securing minimal quality standards. A set of recommendations regarding the development networks for stroke was proposed, based on best practices of 15 local networks in the Netherlands (http://cvanetwerken.rrc.nl/). These recommendations were discussed and accepted by stakeholders in stroke care, particularly advocating a centralized approach in support for stroke networks.

Future research

Future research should focus on themes addressed above, concerning a better understanding of the health condition and the needs of stroke survivors, evaluating the effectiveness of care in the chronic phase, and the best way to get this organized in the primary care setting.

These aspects could be covered by means of a large prospective cohort of hospital based stroke patients, so that better information can be gathered systematically to study relations between the initial neurological deficit in the context of the health status of the individual as a whole, including contextual factors, the intervention by means of rehabilitation and the outcomes on the long term. New treatment concepts such as blended care, combining regular rehabilitation care with e-health components can be evaluated in such a cohort. Furthermore, this gives the opportunity to understand and highlight preventive measures, for instance to reduce the risk of a new stroke or the risk of complications and deterioration. Large numbers of participants are important to establish robust results, therefore a larger regional or national stroke register, using the same outcome measures, will be necessary. Technology is available and should be recruited to ensure a complete follow up and to support database management.

The experience of the SCORE study, in which a growing cohort of stroke patients admitted for rehabilitation in The Hague and Leiden is included, will be helpful.[23] Patient Reported Outcome Measures are imperative in these cohort studies. Choosing wisely among the large variety of questionnaires is a challenge, leading to lack of standardization in their use, hindering comparisons across studies and populations. The National Institute of Health's (NIH) Patient Reported Outcomes Measurement Information System (PROMIS) has introduced a number of static short-form patient reported outcome measures, which probably offer a uniform, efficient and cost-effective alternative to a wide array of time consuming questionnaires.[24,25] These are in line with the ICHOM standard set for Stroke, developed by an international consortium (www.ichom.org/medical-conditions/stroke/). ICHOM urges all providers to measure outcomes that matter most to stroke patients: mood, cognition, pain, fatigue, mobility, feeding, self-care, communication, returning to activities and participation. The use of PROMIS Global Health is mentioned by ICHOM as a relevant tool. In a prospective cohort of stroke patients the value of PROMIS could be evaluated.

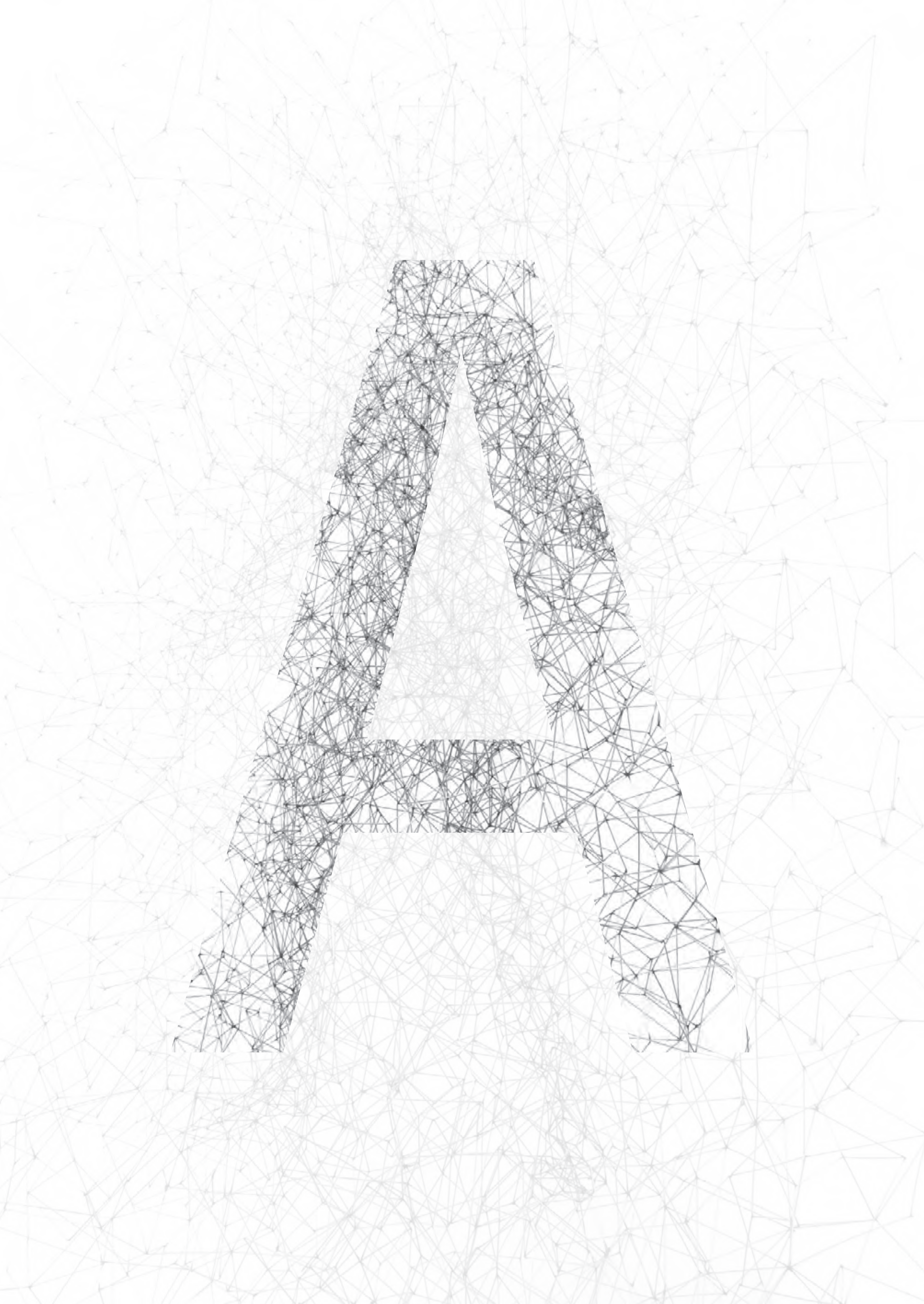
Unmet needs in the chronic phase after stroke should give guidance to research questions, but the concept of unmet needs itself needs further development. It will be important to cooperate with primary care professionals designing research protocols, as that is the area where the issues of chronic stroke patients have to be tackled. Rehabilitation facilities should participate in research as well, as implementation and evaluation of rehabilitation programs focusing on longer term goals are needed. Furthermore, the involvement of patients and their caregivers as research partners is important in formulating and prioritizing of research questions.[26] Apart from patient related interventions it will also be important to structurally document the results of a better coordination and organization of stroke care in the chronic phase.

In summary: consensus have to be reached regarding the outcomes measures, the timing of assessments, the financial constraints, the lines of communication and the responsibility for the coordination, between stakeholders such as stroke units, subacute care facilities, nursing homes, primary health care professionals and patient organizations. Considering the complexity of this, a shared responsibility by a group of dedicated health providers, supported by their professionals' associations, will be essential. A first step is the development of multidisciplinary stroke networks, according to the SKMS recommendations for their optimal organization and further development (http://cvanetwerken.rrc.nl/).

References:

1. Benjamin EJ, Blaha MJ, Chiuve SE, et al. on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2017 update: a report from the American Heart Association. Circulation 2017;135:e229-e445.
2. Johnston SC, Mendis S, Mathers CD. Global variation in stroke burden and mortality: estimates from monitoring, surveillance, and modelling. Lancet Neurology 2009;8:345-54.
3. Rothwell PM. The high cost of not funding stroke research: a comparison with heart disease and cancer. Lancet 2001;357:1612-6.
4. Ayerbe L, Ayis S, Wolfe CD, et al: Natural history, predictors and outcomes of depression after stroke: systematic review and meta-analysis. Br J Psychiatry 2013;202:14-21.
5. Singam A, Ytterberg C, Tham K, von Koch L. Participation in complex and social everyday activities six years after stroke: predictors for return to pre-stroke level. Plos One 2015;10(12):e144344.
6. Lemmens RJ, Timmermans AA, Janssen-Potten YJ, Smeets RJ, Seelen HA. Valid and reliable instruments for arm-hand assessment at ICF activity level in persons with hemiplegia: a systematic review. BMC Neurol 2012;12:21.
7. Robinson RG, Murata Y, Shimoda K: Dimensions of social impairment and their effect on depression and recovery following stroke. Int Psychogeriatr 1999;11(4):375-84.
8. Gesztelyi R, Fekete I, Kellermann M, et al: Screening for depressive symptoms among post-stroke outpatients in Eastern Hungary. J Geriatr Psychiatry Neurol 1999;12(4):194-9.
9. Lim GY, Tam WW, Lu Y, Ho CS, Zhang MW, Ho RC. Prevalence of Depression in the Community from 30 Countries between 1994 and 2014. Sci Rep 2018 Feb 12;8(1):2861.
10. Adamson BC, Ensari I, Motl RW: Effect of exercise on depressive symptoms in adults with neurologic disorders: a systematic review and meta-analysis. Arch Phys Med Rehabil 2015;96(7):1329-38.
11. Ward SK, Turner A, Hambridge JA, et al: Group cognitive behavioural therapy for stroke survivors with depression and their carers. Top Stroke Rehabil 2016;17:1-8.
12. Robinson RG, Jorge RE: Post-Stroke Depression: A Review. Am J Psychiatry 2016;173(3):221-31.
13. Andersen G, Christensen D, Kirkevold M, Johnsen SP. Post-stroke fatigue and return to work: a 2-year follow-up. Acta Neurol Scand. 2012;125(4):248–53.
14. Saeki S, Toyonaga T. Determinants of early return to work after first stroke in Japan. J Rehabil Med. 2010;42(3):254–8.
15. Hackett ML, Glozier N, Jan S, Lindley R. Returning to paid employment after stroke: the Psychosocial Outcomes In StrokE (POISE) cohort study. PLoS ONE. 2012;7(7):e41795.

16. McKevitt C, Fudge N, Redfern J, et al. Self-reported long-term needs after stroke. Stroke 2011;42:1398-1403.
17. Pindus DM, Mullis R, Lim L, Wellwood I, Rundell AV, Abd Aziz NA, Mant J. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. PLoS One 2018 Feb 21;13(2):e0192533.
18. Verhoef J, Oosterveld FG, Hoekman R, Munneke M, Boonman DC, Bakker M, Otten W, Rasker JJ, de Vries-Vander Zwan HM, Vliet Vlieland TP. A system of networks and continuing education for physical therapists in rheumatology: a feasibility study. Int J Integr Care 2004;4:e19.
19. Van der Marck MA, Bloem BR, Borm GF, Overeem S, Munneke M, Guttman M. Effectiveness of multidisciplinary care for Parkinson's disease: a randomized, controlled trial. Mov Disord 2013 May;28(5):605-11
20. Ypinga JHL, de Vries NM, Boonen LHHM, Koolman X, Munneke M, Zwinderman AH, Bloem BR. Effectiveness and costs of specialised physiotherapy given via ParkinsonNet: a retrospective analysis of medical claims data. Lancet Neurol 2018; 17: 153–61
21. Hageman D, van den Houten MM, Spruijt S, Gommans LN, Scheltinga MR, Teijink JA. Supervised exercise therapy: it does work, but how to set up a program? J Cardiovasc Surg (Torino) 2017 Apr;58(2):305-312.
22. Klokkerud M, Hagen KB, Kjeken I, Bremander A, Hørslev-Petersen K, Vliet Vlieland TP, Grotle M. Development of a framework identifying domains and elements of importance for arthritis rehabilitation. J Rehabil Med 2012;44:406-13.
23. Groeneveld IF, Goossens PH, van Braak I, van der Pas S, Meesters JJL, Rambaran Mishre RD, Arwert HJ, Vliet Vlieland TPM; SCORE-study group. Patients' outcome expectations and their fulfilment in multidisciplinary stroke rehabilitation. Ann Phys Rehabil Med. 2018 Jul 24. pii: S1877-0657(18)31426-X.
24. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, Amtmann D, Bode R, Buysse D, Choi S, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005–2008. J Clin Epidemiol 2010;63:1179–94.
25. Salinas J, Sprinkhuizen SM, Ackerson T, Bernhardt J, Davie C, George MG, Gething S, Kelly AG, Lindsay P, Liu L, Martins SC, Morgan L, Norrving B, Ribbers GM, Silver FL, Smith EE, Williams LS, Schwamm LH. An International Standard Set of Patient-Centered Outcome Measures After Stroke. Stroke 2016 Jan;47(1):180-6.
26. Van Vree FM, Meesters JJL, Vliet Vlieland TPM, Groeneveld IF, Goossens PH. Onderzoekspartners in het revalidatieonderzoek. Nederlands Tijdschrift voor Revalidatiegeneeskunde 2014;2:90-91.



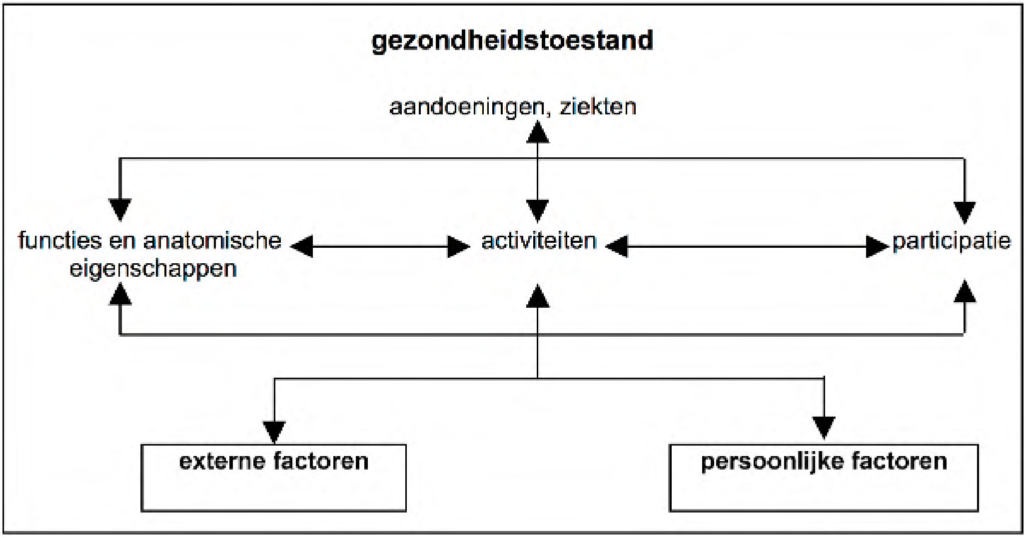
Appendices

- Nederlandse samenvatting
- List of publications
- Curriculum Vitae
- Dankwoord

Samenvatting

Een cerebrovasculair accident (CVA) is een veel voorkomende medische aandoening waarbij de bloedtoevoer naar de hersenen wordt belemmerd. Dit kan veroorzaakt worden door een verstopping in een bloedvat naar de hersenen, of door een bloeding. In Nederland krijgen jaarlijks meer dan 38.800 mensen een CVA (incidentie 2017, https://www.volksgezondheidenzorg.info/onderwerp/beroerte/cijfers-context/huidige-situatie#node-prevalentie-en-nieuwe-gevallen-van-beroerte). De prevalentie in westerse landen wordt geschat op 2 tot 3 procent, en zal naar verwachting toenemen toe als gevolg van de vergrijzing van de bevolking en de recente vooruitgang in de behandelmogelijkheden in de acute fase, waaronder trombolyse.[1,2]

Na een CVA kunnen patiënten gevolgen ondervinden in verschillende domeinen van hun functioneren. De International Classification of Functioning, Disability and Health (ICF) wordt veel gebruikt om deze gevolgen te ordenen en structureren (zie figuur). De gevolgen kunnen betrekking hebben op lichaamsfuncties (zoals motoriek, zintuiglijke functies, cognitie, gemoedstoestand), activiteiten (zoals reiken, lopen) en participatie (zoals werk, gezinsrol, vrijetijdsactiviteiten). De aard en omvang van de beperkingen hangt verder af van contextuele factoren (externe en persoonlijke).



Patiënten kunnen (deels) herstellen van hun neurologische uitval. Dit herstel kan ondersteund worden met behulp van revalidatiebehandeling. De meeste patiënten kunnen na het CVA weer thuis functioneren, ofwel direct na de ziekenhuisfase ofwel na een klinische revalidatieperiode. Ongeveer een derde ervaart beperkingen in activiteiten en deelname aan het sociaal-maatschappelijk leven op de lange termijn. In deze fase zijn patiënten voor hun behandeling doorgaans aangewezen op zorgverleners in de eerste lijn.

Het wetenschappelijk onderzoek op het gebied van CVA richt zich hoofdzakelijk op de initiële medische behandeling en op de revalidatiefase. Meer onderzoek bij patiënten in de chronische fase (vanaf 6 maanden na een CVA) is relevant, vanwege het grote aantal patiënten en het brede palet aan klachten en beperkingen met bijbehorend zorggebruik. Het is niet bekend hoe de samenhang is tussen deze klachten, beperkingen, de zorgbehoefte en het zorggebruik. Daarnaast is er nog onvoldoende kennis over de optimale organisatie van de zorg om klachten en beperkingen die mensen met een CVA in de chronische fase kunnen ervaren te verminderen. Eerstelijns CVA-netwerken kunnen een middel zijn om de kwaliteit en toegankelijkheid van de zorg voor mensen met een CVA te borgen en verbeteren.

Het doel van dit proefschrift is het uitgebreid en systematisch beschrijven van het functioneren (handfunctie, stemming), de activiteiten en participatie (werk) en de omgevingsfactoren (zorgconsumptie, organisatie van zorg) van en bij CVA patiënten in de chronische fase. Deze informatie is essentieel om de beperkingen en behoeften van de patiënt in de chronische fase na een CVA te begrijpen en te herkennen en de zorg te optimaliseren.

Handfunctie na een CVA

In hoofdstuk 2 worden de resultaten van de Michigan Hand Outcome Questionnaire (MHQ) bij mensen met een CVA geëvalueerd. De MHQ beschrijft de handfunctie in 6 domeinen: functie, dagelijkse activiteiten, pijn, werk, uiterlijk en tevredenheid (score 0-100, slecht - goed).

Aan 51 patiënten met een CVA die revalidatiebehandeling gekregen hadden (gemiddelde leeftijd 60 jaar, 16 vrouwen (31%), 8 maanden na CVA) werd gevraagd om de MHQ (57 items) in te vullen, evenals de SF-36 (Short Form 36), waaruit de PCS en MCS (Physical en Mental Component summary score) scores werden berekend. Verder werden de Barthel Index en geïnstrumenteerde handfunctie tests afgenomen (Action Research Arm Test, Nine Hole Peg Test, Frenchay Arm Test, Motricity Index). De totale score van de MHQ correleerde significant met de PCS van de SF-36, de Barthel Index en alle handfunctietests (P <0.01). De MHQ-totaalscore vertoonde geen vloer- of plafondeffect. De MHQ leek een intern consistente, valide en betrouwbare handfunctie-vragenlijst te zijn voor poliklinische patiënten na een beroerte.

In hoofdstuk 3 is in een populatie mensen met een CVA beschreven hoe de handfunctie ervaren werd in de chronische fase. Het betrof een cross-sectioneel onderzoek bij patiënten die tussen 2008 en 2010 opgenomen waren geweest in het Haaglanden Medisch Centrum (HMC) vanwege een eerste CVA. Deze HMC populatie werd gevraagd vragenlijsten in te vullen over handfunctie, sociaal-demografische kenmerken, mentaal functioneren, dagelijkse activiteiten, kwaliteit van leven en belasting van de mantelzorger. Van 576 in aanmerking komende patiënten reageerden er 207 (36%); gemiddelde leeftijd 64 jaar, 82 vrouwen (39,6%). Gemiddelde tijd sinds CVA was 36,3 maanden. Bij 85% van de deelnemende patiënten was de MHQ-totaalscore minder dan 100 punten (mediaan 79.9). De mediane scores van de domeinen waren: algemene handfunctie 75.0, dagelijkse activiteiten 90.5, werk 85.0, pijn 100.0, uiterlijk 93.8 en tevredenheid met handfunctie 83.3.

Een meerderheid van de patiënten ervoer beperkingen op een of meer domeinen met betrekking tot de handfunctie. Het blijkt daarnaast relevant om ook te vragen naar het uiterlijk van de hand en de tevredenheid met de handfunctie. De meerderheid gaf aan geen pijnklachten te hebben. Een ernstiger CVA, een supratentoriële beroerte en een lagere opleiding waren gerelateerd aan slechtere scores qua handfunctie.

Stemmingsklachten na een CVA

Hoofdstuk 4 beschrijft de prevalentie van depressieve klachten en de determinanten in de eerder beschreven CVA-populatie. Patiënten vulden vragenlijsten in over depressie (Hospital Anxiety and Depression Scale; HADS 0 - 21, geen – ernstig; een depressiescore van 8 of meer is een aanwijzing voor klinisch relevante depressieve symptomen), sociaal-demografische kenmerken, gezondheidszorg gebruik, copingstijl, dagelijkse activiteiten en kwaliteit van leven. Mantelzorgers werd gevraagd naar hun ervaren belasting. Patiënten met HADS-depressiescores <8 werden vergeleken met patiënten met HADS-depressiescores ≥ 8 door middel van een univariate logistische regressieanalyse.

Na een gemiddelde follow-up van 36 maanden hadden 67 van de 207 deelnemers (34%) een HADS-depressiescore ≥ 8. Een relatief hogere HADS-depressie score werd gezien bij mannelijke CVA patiënten in vergelijking met vrouwelijke patiënten (gecorrigeerd voor leeftijd en ernst van het CVA), en bij patiënten die in het buitenland geboren waren in vergelijking met in Nederland geboren patiënten (gecorrigeerd voor leeftijd, geslacht en ernst van de beroerte). Patiënten met hogere depressie scores hadden relatief hogere HADS-angstscores, hogere scores op vermijdende coping-stijl, meer beperkingen bij dagelijkse activiteiten (FAI) en een lagere kwaliteit van leven (PCS en MCS van de SF-12); hun mantelzorgers ervoeren een hogere belasting.

Terugkeer naar werk na een CVA

In hoofdstuk 5 wordt een studie beschreven waarin de kans op werkhervatting (Return to Work; RTW) werd onderzocht bij patiënten 2 tot 5 jaar na een CVA. Voor dit doel werd een subgroep van de CVA-patiënten uit de eerder beschreven populatie geïncludeerd die nog niet pensioengerechtigd was en betaald werk had voorafgaand aan het CVA. In totaal voldeden 46 patiënten aan deze criteria, met een gemiddelde leeftijd van 48 jaar. Uiteindelijk waren na gemiddeld 36 maanden na het CVA 18 patiënten (39%) erin geslaagd om weer aan het werk te gaan. Na correctie voor leeftijd en geslacht, bleek een kortere opnameduur in het ziekenhuis na het CVA geassocieerd te zijn met werkhervatting. Een lagere HADS-depressie score, een minder vermijdende coping-stijl, betere scores op het activiteiten niveau (Frenchay Activity Index, FAI), een betere kwaliteit van leven (EQ5D (EuroQol-classificatiesysteem; MCS van de SF 36) en een lagere belasting voor mantelzorgers (Caregiver Strain Index) waren gerelateerd aan werkhervatting. Dit pleit voor het opnemen van werkhervatting als doelstelling van de revalidatiebehandeling voor CVA-patiënten in de werkgerechtigde leeftijd.

Onvervulde zorgbehoefte na een CVA

Hoofdstuk 6 beschrijft een onderzoek waarin de Longer Term Unmet Needs After Stroke (LUNS; onvervulde zorgbehoefte na CVA) vragenlijst werd vertaald in het Nederlands en gevalideerd in een CVA populatie in de chronische fase. Deze vragenlijst bestaat uit 22 items die met ja of nee beantwoord worden. De patiënten uit de eerder beschreven HMC populatie werden ruim 3 jaar na het eerste onderzoek benaderd om te participeren in deze LUNS-studie. De patiënten werd gevraagd tweemaal de vragenlijst in te vullen met een tussentijd van 2 weken (t1 en t2). Aan de deelnemers werd, naast de LUNS, ook gevraagd om de FAI en SF-12 in te vullen. Van de 145 patiënten stuurden 78 (54%) de vragenlijst terug (gemiddelde leeftijd 68,3 jaar, 59% man, gemiddelde tijd sinds CVA 80,3 maanden); de LUNS werd door 66 patiënten volledig ingevuld.

Het mediane aantal onvervulde behoeften op t1 was 3,5 (interkwartiel range 2,0-5,0). Voor 15 van de 22 items was er een significante associatie met de FAI, de PCS of de MCS. Het percentage overeenstemming tussen t1 en t2, als maatstaf voor de test-hertest betrouwbaarheid, varieerde van 69.8% tot 98.1% per item.

De conclusie was dat de LUNS een betrouwbare en valide meetinstrument is voor deze doelgroep; twee derde van de aangegeven items over onvervulde zorgbehoefte had betrekking op activiteiten en kwaliteit van leven. Het gebruik van het concept zorgbehoefte in de dagelijkse praktijk vereist verder onderzoek.

Zorggebruik in de chronische fase na een CVA

Hoofdstuk 7 beschrijft het zorggebruik van patiënten in de LUNS studie in samenhang met hun zorgbehoefte en gezondheidstoestand. Patiënten vulden een vragenlijst in over het contact met verschillende zorgverleners in de gezondheidszorg: het aantal bezochte artsen (arts: laag ≤1 of hoog ≥ 2) en andere zorgverleners (andere zorgverlener: laag 0 of hoog ≥ 1) in de afgelopen 6 maanden. De LUNS, FAI en de SF-12 (PCS, MCS) werden ingevuld. De associaties tussen gezondheidsstatus (FAI, PCS, MCS) en LUNS enerzijds en zorggebruik (hoog, laag) anderzijds, werden bepaald door middel van logistische regressieanalyse, gecorrigeerd voor leeftijd en geslacht.

Van 145 patiënten stuurden 78 (54%) de vragenlijsten terug. De contacten met een arts in de laatste 6 maanden betroffen vooral de huisarts (58; 79.5%), cardioloog (10; 13.5%), de neuroloog (8; 10,8%) en de oogarts (8; 10.8%). Eenenveertig patiënten (52.6%) bezochten ≥ 2 artsen; 37 patiënten (47.4%) bezochten ≥ 1 andere zorgverlener (voornamelijk de fysiotherapeut). Vierenveertig (67%) patiënten hadden één of meer onvervulde zorgbehoeften, zoals behoefte aan informatie over het CVA, problemen met concentratie en geheugen en angst om te vallen. Een hoger aantal bezochte artsen en/of andere zorgverleners hing samen met slechtere uitkomsten van de fysieke aspecten van kwaliteit van leven, maar niet met uitkomsten betreffende activiteiten of mentale aspecten van kwaliteit van leven. Ook was er geen relatie tussen zorggebruik en mate van onvervulde zorgbehoefte.

Eerstelijns netwerken CVA

Hoofdstuk 8 beschrijft de structuur en processen van eerstelijns CVA-netwerken in Nederland, en aanbevelingen voor het ondersteunen en uitbreiden van CVA-netwerken in Nederland. Een CVA-netwerk werd gedefinieerd als samenwerkingsverbanden van eerstelijns behandelaars met formele afspraken over samenwerking en/of de inhoud van zorg voor patiënten met een CVA. Via internet en door rechtstreeks navraag te doen bij zorginstellingen, professionele organisaties in de CVA-zorg en patiëntenverenigingen, werd een overzicht gemaakt van de CVA-netwerken in Nederland. Informatie over de structuur en de processen van het CVA-netwerk werd systematisch verzameld middels een (online) enquête bij zowel de netwerkcoördinatoren als onder de individuele leden.

Vijftien CVA netwerken voldeden aan de definitie, in omvang variërend van 4 tot 140 leden. De meeste leden waren fysiotherapeuten; twaalf netwerken waren multidisciplinair. Veertien netwerken hadden toegangscriteria voor lidmaatschap, acht vroegen contributie. Gestandaardiseerde behandelprogramma's en / of uitkomstmetingen werden toegepast door negen CVA netwerken.

Het online onderzoek werd door 139 leden ingevuld. De helft (48%) had een vervolgopleiding gevolgd gericht op CVA zorg, 90% had deelgenomen aan netwerkbijeenkomsten en 78% had minimaal 5 CVA patiënten gezien in de afgelopen 12 maanden. Tijd en geld waren de meest genoemde barrières voor de voortzetting van het netwerk. Wederzijds vertrouwen, betrokkenheid en directe communicatielijnen werden het vaakst genoemd als succesfactoren. Tijdens een conferentie met coördinatoren en leden van CVA-netwerken en overige stakeholders werden de resultaten besproken en werden aanbevelingen geformuleerd. De behoefte aan een landelijke, gecentraliseerde ondersteuning van eerstelijns-CVA netwerken werd onderschreven. De conclusies zijn vervat in een SKMS rapport (Stichting Kwaliteitsgelden Medisch Specialisten; zie http://cvanetwerken.rrc.nl/).

Discussie

Ondanks sterke verbeteringen in de acute en post-acute behandeling van een CVA in de afgelopen jaren, is onderzoek naar de lange termijn gevolgen van een CVA op het functioneren, de behoeften van patiënten, hun zorggebruik en de organisatie daarvan nog steeds van belang. Dit proefschrift richt zich hierop en heeft als doel: het beschrijven van de gezondheidstoestand bij chronische CVA-patiënten op verschillende ICF domeinen, het zorggebruik van deze patiënten en de zorgbehoeften die zij ervaren. Vervolgens is de samenhang tussen gezondheidstoestand, zorggebruik en zorgbehoeften geëvalueerd; Als voorbeeld van mogelijkheden om de zorg in de chronische fase te optimaliseren zijn eerstelijns CVA netwerken in Nederland beschreven en wensen voor hun toekomstige organisatie geïnventariseerd, leidend tot adviezen voor verdere implementatie.

Ervaren gezondheidstoestand in de chronische fase na een CVA

De MHQ bleek een valide en betrouwbare handfunctie vragenlijst te zijn bij mensen met een CVA in de chronische fase. De MHQ kan voorzien in de bestaande behoefte aan een uitgebreide handfunctie-vragenlijst die CVA patiënten zelf kunnen invullen en die verschillende domeinen van de ICF bestrijkt. De MHQ maakt het mogelijk om bij grote groepen patiënten een beeld te krijgen van de handfunctie na CVA. Verder bleek dat patiënten met een beroerte niet alleen beperkingen ervaren op bekende domeinen zoals functie en pijn; in onze studie ervoer een aanzienlijk deel van de patiënten beperkingen met betrekking tot het uiterlijk van de hand. Bovendien bleek de tevredenheid over de handfunctie bij relatief veel patiënten beperkt, een aspect dat niet altijd wordt meegenomen.

In onze studie werden depressieve klachten gerapporteerd door 34% van de CVA patiënten, 2 tot 5 jaar na hun CVA. Het hebben van depressieve klachten bleek gerelateerd te zijn aan een verminderde kwaliteit van leven, verminderd activiteiten niveau en grotere ervaren last door de mantelzorger. Bij de interpretatie van deze bevindingen is het belangrijk om de prevalentie van depressieve klachten in de algemene bevolking te kennen. De prevalentie van depressieve klachten in de algemene populatie in 19 Europese onderzoeken is 11.9% in gepoolde gegevens van 79503 mensen); in de Verenigde Staten was de prevalentie 13.4% (11 studies, 295279 mensen).[3] Echter de wijze waarop stemmingsklachten worden gemeten heeft invloed op de uitkomst en daarom zijn vergelijkingen moeilijk te maken. Met zelfrapportage instrumenten (zoals de HADS) was de prevalentie hoger (17.3%) dan bij instrumenten die gebaseerd zijn op interviews (8.5%). Gezien de samenhang van depressieve klachten met andere uitkomsten na een CVA, zoals activiteiten, participatie en belasting voor mantelzorgers, is het van belang om bij follow up routinematig na te vragen in hoeverre stemmingsklachten ervaren worden.

Om de werkhervatting te evalueren, is een lange follow-up noodzakelijk. De procedures voor de reïntegratie kunnen in veel landen twee jaar en soms zelfs langer beslaan. In onze studie was het 39% van de CVA-patiënten gelukt het werk te hervatten, hetgeen lager is dan de cijfers in andere onderzoeken. Hierbij moet er rekening mee gehouden worden dat onze gegevens werden verzameld in een periode van economische achteruitgang, de werkloosheid verdubbelde van 2008 tot 2013 in Nederland. Verder biedt het sociale stelsel in Nederland een goed vangnet voor mensen die om medische redenen niet meer kunnen werken. Deze factoren zouden de verschillen kunnen verklaren. De observatie dat patiënten die met succes naar hun werk terugkeren, een hogere kwaliteit van leven en minder depressieve klachten ervaren en dat hun mantelzorgers minder last ervaren, ondersteunen het belang van werk als een doel in revalidatie. Patiënten met een risico op problemen bij werkhervatting moeten vroeg in het revalidatieproces worden geïdentificeerd. Interventies gericht op terugkeer naar werk kunnen bestaan uit een uitgebreide werkanalyse, vroeg contact met de werkgever en de bedrijfsarts, specifieke training van arbeidsvaardigheden en begeleiding bij het uitbreiden van het werk.

Zorggebruik, zorgbehoefte en de organisatie van zorg na een CVA

In Nederland is de totale zorgconsumptie (in financiële termen) van patiënten met een CVA groter dan die bij aandoeningen zoals chronische obstructieve longziekte, coronaire hartziekten of diabetes (http://statline.cbs.nl/Statweb/). De zorg voor CVA patiënten in de algemene populatie wordt voornamelijk geleverd door professionals in de eerstelijns gezondheidszorg, zoals de huisarts, de fysiotherapeut of de praktijkondersteuner. De waargenomen overgang van de ziekenhuis- en revalidatiefase naar de eerstelijnszorg is in overeenstemming met nationale richtlijnen.

Opmerkelijk is dat er weinig bekend is over het type zorggebruik en zorgbehoefte van patiënten met een CVA en dat er ook weinig kennis is over de determinanten die hier verband mee houden. Het zorggebruik was gerelateerd aan de fysieke, maar niet aan de mentale kwaliteit van leven. Onvervulde zorgbehoeften waren voornamelijk gericht op psychosociale domeinen. Het feit dat een derde van onze populatie depressieve klachten had, kwam niet tot uiting in het bezoek van professionals op dit gebied (psycholoog, psychiater). Dit kan er mogelijk op wijzen dat mensen met een CVA makkelijker toegang hebben tot zorg met betrekking tot hun fysieke behoeften dan tot hun zorgbehoeften van sociale, mentale of cognitieve aard.

Uit een recente systematische review blijkt dat patiënten met een CVA in de eerste lijn zich soms verlaten en gemarginaliseerd voelen door de gezondheidszorg. Het ontbrak hen aan vaardigheden om hun zorgvragen te adresseren; een oplossing hiervoor kan een meer actieve follow up zijn van de patiënten in de chronische fase, gericht op herkennen van de late gevolgen van een CVA en daarnaast een focus op verbetering van zelfmanagementvaardigheden in de voorafgaande revalidatiefase.[4]

Bij andere chronische ziekten wordt de ontwikkeling van eerstelijns zorgnetwerken gezien als een effectief hulpmiddel om de kwaliteit van zorg te verbeteren. Wat CVA-netwerken betreft, is er in Nederland geen overeenstemming over de basisvereisten voor de organisatie van een eerstelijns netwerk, noch over het waarborgen van minimale kwaliteitsnormen. Een aantal aanbevelingen voor de ontwikkeling van CVA netwerken werd voorgesteld op basis van de ervaringen van 15 lokale netwerken in Nederland (http://cvanetwerken.rrc.nl/). Deze aanbevelingen werden besproken en vastgesteld tijdens een conferentie met CVA netwerkleden en andere stakeholders, waarbij een gecentraliseerde aanpak ter ondersteuning en coördinatie van CVA netwerken als een van de belangrijkste voorwaarden genoemd werd.

Toekomstig onderzoek

Toekomstig onderzoek moet zich richten op de hierboven behandelde thema's: een beter begrip van de gezondheidstoestand en de zorgbehoeften in de chronische fase van patiënten met een CVA, het evalueren van de effectiviteit van zorg in de chronische fase en de beste manier om dit te organiseren in de eerste lijn.

Hiervoor is een groot prospectief cohort van patiënten na een CVA noodzakelijk, waarbij systematisch informatie kan worden verzameld om de relaties te bestuderen tussen de initiële neurologische uitval, de toegepaste interventies en de resultaten op de lange termijn ten aanzien van het functioneren van de patiënt in brede zin. Nieuwe behandelconcepten zoals blended care, de combinatie van reguliere revalidatiezorg met e-health componenten, kunnen in een dergelijk cohort worden geëvalueerd. Er zullen grote aantallen deelnemers nodig zijn om tot valide uitspraken te kunnen komen. Daarom is een groter regionaal of nationaal systeem voor monitoring van CVA patiënten zinvol, waarbij transmurale afstemming over de te gebruiken uitkomstmaten noodzakelijk is. Informatietechnologie kan ondersteunen bij de follow up en het database beheer, bijvoorbeeld door gebruik te maken van een slimme database in combinatie met een interface die voor de patiënt goed toegankelijk is. Uiteraard binnen de geldende kader voor privacy en data veiligheid.

De Stroke Cohort Outcomes of REhabilitation (SCORE) studie, een groeiend cohort van CVA patiënten van de revalidatiecentra in Den Haag, Delft en Leiden, is hiervan een goed voorbeeld.[5] In deze prospectieve studie worden CVA patiënten op gestructureerde momenten gevolgd in de tijd na hun revalidatieperiode gericht op een breed scala aan uitkomstmaten (follow up 3 jaar). Het kiezen tussen de grote verscheidenheid aan uitkomstmaten is hierbij een uitdaging gebleken; er is weinig standaardisatie waardoor vergelijkbaarheid met andere studies en populaties wordt bemoeilijkt. Het PROMIS (Patient Reported Outcomes Measurement Information System) van het National Institute of Health heeft een aantal uitkomstmaten geïntroduceerd, die mogelijk een uniform, efficiënt en kosteneffectief alternatief bieden voor een breed scala aan tijdrovende vragenlijstonderzoeken. Deze zijn voor CVA populaties uitgewerkt door een internationaal consortium (www.ichom.org/medical-conditions/stroke/). ICHOM adviseert met betrekking tot CVA patiënten de volgende domeinen aandacht te geven: stemming, cognitie, pijn, vermoeidheid, mobiliteit, voeding, zelfzorg, communicatie, terugkeer naar activiteiten en participatie. In een prospectief cohort van patiënten met een CVA kan de waarde van PROMIS worden geëvalueerd.

Onvervulde zorgbehoeften in de chronische fase na een CVA kunnen ook richting geven aan nieuwe onderzoeksvragen. Het gegeven dat een meerderheid van de patiënten na jaren nog steeds onvervulde zorgbehoeften hebben gerelateerd aan hun CVA vraagt uitwerking en verdieping.

Daarnaast is het belangrijk om eerstelijns professionals te betrekken bij het uitwerken van onderzoeksvragen, omdat de lange termijn gevolgen na een CVA zich vooral afspelen in de eerste lijn. Revalidatie instellingen zullen ook kunnen bijdragen aan onderzoek gericht op de chronische fase na CVA, bijvoorbeeld gericht op implementatie en evaluatie van revalidatieprogramma's gericht op lange termijn doelen. Verder is de betrokkenheid van patiënten en hun mantelzorgers als onderzoekspartners (patiënten die als gelijkwaardige partner betrokken zijn bij onderzoeksprojecten) van meerwaarde bij het formuleren en prioriteren van onderzoeksvragen.

Naast patiëntgebonden interventies zal het ook noodzakelijk zijn om de resultaten van een betere coördinatie en organisatie van de eerstelijns CVA zorg structureel te documenteren. Er zal consensus moeten worden bereikt over de gezamenlijke onderzoeksvragen, de benodigde uitkomstmaten, de financiële borging en de verantwoordelijkheid voor de coördinatie tussen belanghebbenden zoals stroke units, revalidatie instellingen, verpleeghuizen, eerstelijns behandelaars en patiëntenorganisaties.

Referenties

1. Benjamin EJ, Blaha MJ, Chiuve SE, et al. on behalf of the American Heart Association Statistics Committee and Stroke Statistics Subcommittee. Heart disease and stroke statistics—2017 update: a report from the American Heart Association. Circulation 2017;135:e229-e445.
2. Johnston SC, Mendis S, Mathers CD. Global variation in stroke burden and mortality: estimates from monitoring, surveillance, and modelling. Lancet Neurology 2009;8:345-54.
3. Lim GY, Tam WW, Lu Y, Ho CS, Zhang MW, Ho RC. Prevalence of Depression in the Community from 30 Countries between 1994 and 2014. Sci Rep 2018 Feb 12;8(1):2861.
4. Pindus DM, Mullis R, Lim L, Wellwood I, Rundell AV, Abd Aziz NA, Mant J. Stroke survivors' and informal caregivers' experiences of primary care and community healthcare services - A systematic review and meta-ethnography. PLoS One 2018 Feb 21;13(2):e0192533.
5. Groeneveld IF, Goossens PH, van Braak I, van der Pas S, Meesters JJL, Rambaran Mishre RD, Arwert HJ, Vliet Vlieland TPM; SCORE-study group. Patients' outcome expectations and their fulfilment in multidisciplinary stroke rehabilitation. Ann Phys Rehabil Med. 2018 Jul 24. pii: S1877-0657(18)31426-X.

List of publications

Related to the Thesis (The long term consequences of stroke):

Arwert HJ, Meesters JJL, Boiten J, Balk F, Wolterbeek R, Vliet Vlieland TPM. Post stroke depression, a long term problem for stroke survivors. Am J Phys Med Rehabil. 2018 Mar 5 (e-pub).

Arwert H, Schut S, Boiten J, Vliet Vlieland T, Meesters J. Patient reported outcomes of hand function three years after stroke. Top Stroke Rehabil. 2018 Jan;25(1):13-19.

Groeneveld IF, Arwert HJ, Goossens PH, Vliet Vlieland TPM. The Longer-term Unmet Needs after Stroke Questionnaire: Cross-Cultural Adaptation, Reliability, and Concurrent Validity in a Dutch Population. J Stroke Cerebrovasc Dis. 2018 Jan;27(1):267-275.

Arwert HJ, Schults M, Meesters JJL, Wolterbeek R, Boiten J, Vliet Vlieland T. Return to Work 2-5 Years After Stroke: A Cross Sectional Study in a Hospital-Based Population. J Occup Rehabil. 2017 Jun;27(2):239-246.

Arwert HJ, Keizer S, Kromme CH, Vliet Vlieland TP, Meesters JJ. Validity of the Michigan Hand Outcomes Questionnaire in Patients With Stroke. Arch Phys Med Rehabil. 2016 Feb;97(2):238-44.

Arwert HJ, Groeneveld IF, Vliet Vlieland TPM, Meesters JJL. Health care use and its associated factors 5 – 8 years after stroke. Submitted in J Stroke Cerebrovasc.

Arwert HJ, Borcherts JHR, van Vree FM, Groeneveld IF, Meesters JJL, Vliet Vlieland TPM, Goossens PH. Primary care networks for the management of stroke patients. Submitted in Int J of Integrated Care.

Not Related to the Thesis:

Wentink MM, van Bodegom-Vos L, Brouns B, Arwert HJ, Vlieland TPMV, de Kloet AJ, Meesters JJL. What is Important in E-health Interventions for Stroke Rehabilitation? A Survey Study among Patients, Informal Caregivers and Health Professionals. Int J Telerehabil. 2018 Aug 3;10(1):15-28.

Groeneveld IF, Goossens PH, van Braak I, van der Pas S, Meesters JJL, Rambaran Mishre RD, Arwert HJ, Vliet Vlieland TPM; SCORE-study group. Patients' outcome expectations and their fulfilment in multidisciplinary stroke rehabilitation. Ann Phys Rehabil Med. 2018 Jul 24 (e-pub ahead of print).

Groeneveld IF, Meesters JJ, Arwert HJ, Roux-Otter N, Ribbers GM, van Bennekom CA, Goossens PH, Vliet Vlieland TP. Practice variation in the structure of stroke rehabilitation in four rehabilitation centres in the Netherlands. J Rehabil Med. 2016 Mar;48(3):287-92.

de Boer KS, Arwert HJ, de Groot JH, Meskers CG, Mishre AD, Arendzen JH. Shoulder pain and external rotation in spastic hemiplegia do not improve by injection of botulinum toxin A into the subscapular muscle. J Neurol Neurosurg Psychiatry. 2008 May;79(5):581-3.

Arwert HJ, van Doorn-Loogman MH, Koning J, Terburg M, Rol M, Roebroeck ME. Residual-limb quality and functional mobility 1 year after transtibial amputation caused by vascular insufficiency. J Rehabil Res Dev. 2007;44(5):717-22.

Meskers CG, de Groot JH, Arwert HJ, Rozendaal LA, Rozing PM. Reliability of force direction dependent EMG parameters of shoulder muscles for clinical measurements. Clin Biomech (Bristol, Avon). 2004 Nov;19(9):913-20.

de Groot JH, Rozendaal LA, Meskers CG, Arwert HJ. Isometric shoulder muscle activation patterns for 3-D planar forces: a methodology for musculo-skeletal model validation. Clin Biomech (Bristol, Avon). 2004 Oct;19(8):790-800.

de Groot JH, Valstar ER, Arwert HJ. Velocity effects on the scapulo-humeral rhythm. Clin Biomech (Bristol, Avon). 1998 Dec;13(8):593-602.

Arwert HJ, de Groot J, Van Woensel WW, Rozing PM. Electromyography of shoulder muscles in relation to force direction. J Shoulder Elbow Surg. 1997 Jul-Aug;6(4):360-70.

Lacroix H, Arwert H, Snijders CJ, Fontijne WP. Prevention of fracture at the distal locking site of the gamma nail. A biomechanical study. J Bone Joint Surg Br. 1995 Mar;77(2):274-6.

Woensel W van, Arwert HJ: Effects of external load and abduction angle on EMG level of shoulder muscles during isometric action. Electromyogr Clin Neurophysiol 3, 1993: 185-191.

Curriculum vitae

Hendrik Jaap Arwert (1964) is opgegroeid in Leidschendam en Bleiswijk. Na het behalen van het VWO eindexamen aan het Oranje Nassau College te Zoetermeer in 1982 werd hij ingeloot voor de studie Geneeskunde in Rotterdam. Eind 1989 behaalde hij het artsexamen. Aansluitend ving de dienstplicht aan, eerst met een training in de Van Oudheusden Kazerne in Hollandse Rading; daarna was hij als dienstplichtig officier-arts tot mei 1991 werkzaam in het Militair Revalidatie Centrum te Doorn. Hij deed aansluitend onderzoek naar de functie van schouderspieren in relatie tot stabiliteit van het schouder gewricht bij de afdeling orthopedie van het Academisch Ziekenhuis Leiden. In maart 1993 kon hij starten met de opleiding revalidatiegeneeskunde (circuit Katwijk – Leiden – Den Haag – Delft).

Vanaf maart 1997 is hij werkzaam als revalidatiearts bij Sophia Revalidatie te Den Haag. In eerste instantie werkte hij in het pijn / amputatie team op de hoofdlocatie (Vrederustlaan) en als consulent in het ziekenhuis Bronovo-Nebo. In 2002 kreeg hij de mogelijkheid de afdeling Revalidatiegeneeskunde in het Westeinde Ziekenhuis te Den Haag op te bouwen. Een jaar later startte het poliklinisch behandelteam Sophia Revalidatie locatie Westeinde. Sinds 2005 is het Medisch Centrum Haaglanden erkend als opleidingsinrichting Revalidatiegeneeskunde en is hij opleider. Hij werkt nog steeds in het Haaglanden Medisch Centrum op de locaties Westeinde en Bronovo, gedetacheerd vanuit Sophia Revalidatie.

Vanaf 2012 nam het wetenschappelijk onderzoek naar de lange termijn gevolgen van een beroerte concrete vormen aan, onder begeleiding van Professor Dr Thea Vliet Vlieland en Dr Jorit Meester, primair gefaciliteerd door Sophia Revalidatie en door de Jacobus Stichting.

Naast deze werkzaamheden is hij in verschillende rollen actief geweest; bij Sophia revalidatie onder andere als voorzitter van de medische staf en als medisch manager bij de RVE volwassenen; bij de VRA (Nederlandse Vereniging van Revalidatieartsen) was hij lid van het Concilium en voorzitter van de Scholingscommissie. Momenteel maakt hij als penningmeester deel uit van het dagelijks bestuur van de VRA.

Hij woont samen met Nicole Beckers, samen hebben ze twee dochters, Ilse en Floor.

Dankwoord

Een van de charmes van promoveren is dat je dat niet alleen doet. Velen hebben een bijdrage gehad, kleiner of groter, en verdienen een woord van dank.

Als eersten mogen de promotor en co-promoter genoemd worden. Geachte Professor dr. Vliet Vlieland en dr. Meesters, beste Thea en Jorit, het is een bijzondere vaardigheid om een promovendus op een positieve manier te stimuleren en tegelijk altijd kritisch te blijven op de resultaten. Jullie beiden beheersen deze balanceeract tot in de puntjes. Veel dank voor jullie ondersteuning, humor, opbouwende feedback en geduld. Zonder dergelijke goede begeleiding ben je als promovendus kansloos.

Iris Groeneveld, Saskia Keizer, Marco Schults, Jelis Boiten, Ferdi Balk, Ron Wolterbeek, Selma Schut, Paulien Goossens, Cedric Kromme, Jetty Borcherts en Felicie van Vree: jullie bijdragen aan de verschillende artikelen waren essentieel. Daarnaast is er hulp geweest van Anne Hanscke van het Leindsteiner Instituut en van Ilse en Floor Arwert bij het schrijven en de data verzameling; ook die hulp mag niet onvermeld mag blijven.

Ik heb mij met veel genoegen laten bijstaan door mijn twee paranimfen. Lucas Savalle, al vele jaren de beste loop / fiets / zeil / koffie maat die je je kunt wensen; het is je eindelijk gelukt me te laten trouwen, ook al is het ‘slechts’ een academisch huwelijk. Eelco Sengers, groots in alles, een begenadigd fysiotherapeut en mensenkenner, ik heb in verschillende rollen met je samengewerkt, dat was en is elke keer weer een feestje.

Er zijn weinig promovendi die door vier opeenvolgende raden van bestuur zijn ondersteund in hun noeste wetenschappelijke arbeid. Eric Boldingh, Hans Borgsteede, Marien van der Meer, Wardy Doosje en Willem Wiegersma, dank voor de gelegenheid die jullie mij boden om dit (deels) in Sophia Revalidatie tijd te kunnen doen. Verder heb ik waardevolle ondersteuning gehad van het Haaglanden Medisch Centrum, het Landsteiner Instituut en de Jacobus Stichting.

De deur van Kenniscentrum van Sophia / RRC, het brandpunt van kwaliteit, veiligheid, opleiden, onderzoek en innovatie, stond altijd open. Als ik binnen liep was er altijd een grap en een grol en een goed advies, doorgaans in die volgorde. In het LUMC was Anika Rabelink-Hoogenstraaten mijn steun en toeverlaat bij de bureaucratische jungle die blijkbaar hoort bij promoveren.

Ik werd omringd door geinteresseerde mensen, zoals de teamleden van Sophia Revalidatie locatie Westeinde, de stafleden van Sophia Revalidatie en van het Haaglanden MC. Die op het juiste moment en op de juiste toon durfden te vragen hoe het “eigenlijk gaat met de promotie”. Ik wil met name ook de vakgroepleden bedanken. Esther Los, Rinske Grond en Alina Teplova hebben vaak een stapje harder moeten lopen. En natuurlijk Thessa Veenis, die helaas de promotie niet meer mee mocht maken. Dank voor jullie stimulans, steun en betrokkenheid.

Familie, vrienden, dank dat jullie min of meer geduldig en begrijpend luisterden waarom het toch nog wat langer duurde voor de eindstreep bereikt was. Mijn boodschap dat de weg erheen vaak belangrijker is dan het doel op zich was niet alleen een excuus.

Verder gaat dankbaarheid uit naar mijn ouders, zij hebben het volgen van onderwijs altijd belangrijk gevonden en mij gesteund in mijn keuzes. Ik heb me pas later gerealiseerd dat dat niet voor iedereen zo vanzelfsprekend is, veel dank daarvoor.

Dit promotie traject was voor mij alleen mogelijk dankzij de werkelijke support vanuit mijn eerste milieu, mijn partner Nicole en de kinderen, Ilse en Floor. Niet alleen hebben zij op inhoud ieder een eigen bijdrage geleverd, ook hebben ze mij op gezette tijden vanachter de laptop vandaan gehaald om het echte leven te vieren.