The long term consequences of stroke

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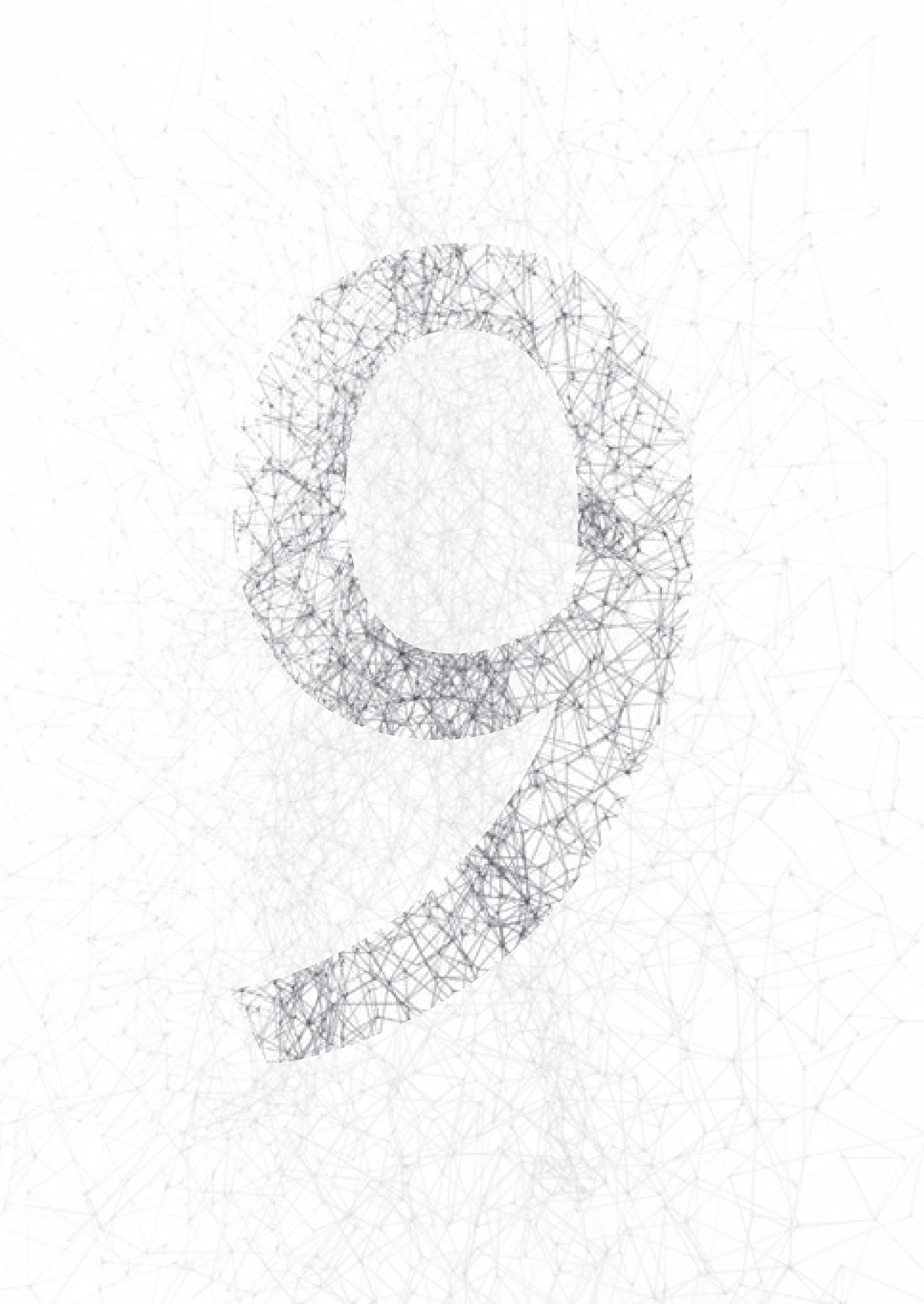
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Chapter 9

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/).

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