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

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## Chapter 8

### Summary and General Discussion

### Summary

Stroke, or cerebrovascular accident is a common condition. Despite the improvement of the acute treatment of in particular ischemic stroke, it has a considerable impact on many patients' lives. Stroke can result in impairments, limitations and/or restrictions in the areas of physical, cognitive, emotional, communicative, social and societal functioning. The consequences of stroke thus not only constitute a burden for individual patients and their caregiver, but for healthcare systems and societies as a whole as well.

In order to describe, monitor and evaluate the complexity of outcomes after stroke, a comprehensive framework for health status is needed, either or not comprising specific outcome measures. The World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) is an example of such a framework<sup>1,2</sup>. Specifically for stroke the ICF Core Sets for stroke were developed, covering the areas of health status most relevant for patients with stroke<sup>2</sup>. The Standard Set for Stroke of the International Consortium of Health Outcome Measurement (ICHOM)<sup>3</sup> and a Minimal Data Set (MDS) Acquired Brain Injury (ABI)<sup>4</sup> are alternatives, both including measurement instruments covering domains overlapping with the ICF Core Sets.

Although in stroke research there is a considerable amount of literature addressing most of the domains of health that are most relevant for patients with stroke, there are still areas where knowledge is relatively scarce. The current thesis addresses six of these knowledge gaps, focusing on the subgroup of stroke patients who receive multidisciplinary rehabilitation. Moreover, this thesis does not only focus on the subacute (rehabilitation) phase, but on the chronic phase until 30 months after stroke as well.

This thesis includes, with the exception of one study (Chapter 3), data from the Stroke Cohort Outcomes of Rehabilitation (SCORE) study, that was designed and initially executed in two rehabilitation centres, Rijnlands Rehabilitation Centre in Leiden and Sophia Rehabilitation in The Hague (currently: Basalt)<sup>5-7</sup>. The SCORE study had a prospective observational design, including consecutive stroke patients admitted for multidisciplinary inpatient or outpatient rehabilitation.

The research aims of the SCORE study were to describe the functions, activities, participation, and quality of life of stroke patients on the short and long-term, and to describe stroke-related costs from the perspectives of rehabilitation, healthcare, and society. This thesis addresses both of the abovementioned overarching research questions, thereby covering all four components of the ICF, i.e. upper extremity pain (Body functions and structures), functional independence and paid employment (Activities and participation), patient activation (Personal Factors), caregiver burden and healthcare usage and costs (Environmental Factors).

**Chapter 1** provides a general introduction to the definition, epidemiology and clinical management of stroke, and various frameworks and sets of outcome measures capturing the complexity of its consequences.

Moreover, this chapter introduces the general aims of this thesis, being:

- to describe the long-term course of pain, participation, patient activation, caregiver burden, healthcare usage and costs and;
- to assess whether the USER or the Barthel Index can be used best to describe functional independence in stroke patients receiving rehabilitation.

Regarding the consequences of stroke on the level of the ICF component Body functions, the study presented in **Chapter 2** aimed to describe the course of the occurrence and severity of upper extremity pain in stroke patients. A total of 678 stroke patients who received multidisciplinary rehabilitation completed a question on the presence of upper extremity pain (yes/no) at three, 18 and 30 months after starting rehabilitation. If present, they rated its intensity with a visual analogue scale, ranging from 0 (i.e. no pain at all) to 10 (i.e. the worst imaginable pain). Generalized estimating equations models and linear mixed models were used to evaluate changes in proportions of patients and severity over time, respectively.

The proportions of patients reporting upper extremity pain were 260/622 (41.8%), 187/519 (36.0%) and 146/446 (32.7%), at three, 18 and 30 months respectively. This decrease in proportions over time reached statistical significance (odds ratio 0.82, 95% confidence interval (CI) 0.74-0.92,  $p < 0.001$ ). In those reporting upper extremity pain, the median intensity was 5.0 (interquartile range (IQR) 3.0) at three and 18 months and 5.0 (IQR 4.0) at 30 months, respectively. In the 73 patients who reported pain at all time points, the median pain intensity scores were in the same range, with no significant changes over time ( $\beta$  -0.22, CI -0.46-0.01,  $p = 0.06$ ). In other words, the proportion of patients reporting upper extremity pain after stroke is considerable, despite a significant decrease from 41.8% to 32.7% over a period of 2.5 years. In those reporting pain, the intensity did not change over time. These results suggest that there is need for improvement of assessment, monitoring and treatment of upper extremity pain in stroke patients.

Within the ICF component Activities and Participation, the ability to perform daily activities is crucial in people's lives. To measure daily activities, a number of outcome measures are available. The Utrecht Scale for Evaluation of Rehabilitation (USER)<sup>8</sup> and the Barthel Index<sup>9</sup> are two examples of frequently used measurement instruments. The USER is included in the basic set of performance indicators that were accepted as measures of effect of inpatient rehabilitation in the Netherlands since 2013<sup>10</sup>. The USER covers, apart from the domain Functional Independence (comprising Mobility and Self-care) also the aspects Cognitive functioning, Pain, Fatigue, and Mood.

As knowledge on the extent to which USER subscales were sensitive to changes over time and how their responsiveness compares to that of the Barthel Index, the aim of the observational

study described in **Chapter 3** was to determine the responsiveness of each subscale of the USER as compared to the Barthel Index in stroke patients who received inpatient multidisciplinary rehabilitation. In this study, the USER and the Barthel Index were administered by a nurse at admission and discharge in consecutive stroke patients admitted for inpatient rehabilitation. The Effect Size and Standardized Response Mean (SRM) were calculated as measures of responsiveness. The study included 198 patients with both admission and discharge data. Their mean age was 61.5 years (standard deviation (SD) 11.8) and 125 (63.1%) were male. At admission and discharge the mean USER subscale Functional independence scores were 43.1 (SD 18.9) and 59.3 (SD 13.8) and the mean Barthel Index scores 13.3 (SD 5.4) and 18.4 (SD 3.3), respectively. The Effect Size of the USER Functional Independence scale was 0.86 and of the Barthel Index 0.94, whereas the Effect Size of the subscales Mobility, Self-care, Cognitive functioning, Pain, Fatigue and Mood were 0.85, 0.77, 0.48, 0.19, 0.40 and 0.28, respectively. The results for the SRM were in the same range. The results of this study suggested that in inpatient rehabilitation after stroke the USER was less responsive than the Barthel Index.

With respect to the impact of stroke on participation of patients with paid employment, the study described in **Chapter 4** aimed to describe the long-term course of participation in stroke patients who were in paid employment before stroke and received multidisciplinary rehabilitation. This study included 170 working patients who were <66 years 30 months after starting rehabilitation and completed the questionnaire on paid employment at 30 months. The main outcomes in this study concerned questions on their employment status (at the start of the rehabilitation and six, 12, 18, 24 and 30 months thereafter) and the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) (Frequency, Restrictions and Satisfaction scales, range 0-100; at six, 12 and 24 months after starting rehabilitation). These USER-P scale scores (with and without items on employment) were compared between those who did and did not report paid employment at the various time points by means of Mann-Whitney U tests. The median age of the patients was 54.2 years (IQR 11.2) and 68 (40.0%) were female. The proportions of patients reporting to be in paid employment were 84.3%, 84.2%, 75.2%, 58.4% and 50.6% at 6, 12, 18, 24 and 30 months after starting rehabilitation, respectively. In those reporting paid employment, the proportions of full sick leave decreased from 61.3% to 8.0% between six and 30 months. At 24 months, all three USER-P scale scores were statistically significantly higher in patients with paid employment than in those without ( $p < 0.001$ ). Similar results were seen without employment items, except for the Frequency scale. The Frequency scale scores without employment items diminished over time in patients with paid employment ( $\beta$  -1.74, CI -2.96 – -0.52,  $p = 0.005$ ). With respect to USER-P scale scores over time with items on employment, there were no statistically significant changes over time. In conclusion, about half of working patients had paid employment at 30 months after starting stroke rehabilitation. At 24 months, patients with paid employment experienced less restrictions and more satisfaction with participation than those without. However, without the item on employment, frequencies of participation did not differ. These results in patients with and without paid employment

might improve by implementing more consistently effective work-directed interventions and interventions for achieving meaningful participation outside of employment.

Given the substantial consequences of stroke in many patients, effective self-management skills are very important. According to the ICF, such skills could be classified under Personal Factors. Patient activation is a concept that is closely related to self-management. Patient activation was found to be related to more favourable outcomes in a number of conditions, however knowledge on patient activation and its course in stroke patients was scarce. Therefore, the study described in **Chapter 5** aimed to examine patient activation at the start of stroke rehabilitation and its course during six months follow-up. This study included 478 stroke patients who received inpatient or outpatient multidisciplinary rehabilitation and were included in the SCORE study. They had a median age of 63.0 years (IQR 56.0-70.0 years) and 308 (64.2%) were male. Patient activation was measured with the Patient Activation Measure (PAM, score 0-100, four levels, higher score and level denotes more patient activation)<sup>11</sup>. The PAM was measured at the start of the rehabilitation, and three and six months thereafter. At the start of the rehabilitation, the mean PAM score was 60.2 (SD 14.3), with the number of patients in PAM levels 1, 2, 3 and 4 being 76 (17.8%), 85 (19.9%), 177 (41.4%) and 90 (21.0%), respectively. Multivariate mixed model analysis demonstrated that the PAM score increased over time (start of the rehabilitation 60.2 (SD 14.3) versus three months 60.7 (SD 14.8) versus six months 61.9 (SD 18.0),  $p = 0.007$ ). Between the start of the rehabilitation and six months, 122 (41.4%) patients remained at the same PAM level, whereas in 105 (35.6%) patients the level increased and in 68 (23.1%) patients the level decreased. At all timepoints >35% of patients had a score matching PAM levels 1 or 2. This study concluded that PAM scores increased slightly over time from the start of the rehabilitation up to six months follow-up. However, more than a third of patients had relatively low levels (i.e. levels 1 and 2) of patient activation, indicating that specific interventions during rehabilitation to increase patient activation might be of value.

Within the ICF, 'support and relationships' are an element of Environmental factors. For stroke patients, support from their immediate family is very important. This support may however also place a burden on caregivers. The study presented in **Chapter 6** aimed to describe the course of burden in individual caregivers in the first year after stroke. For that purpose, caregivers of patients included in the SCORE study were asked to complete the Caregiver Strain Index (13 items with dichotomous outcome categories (yes/no); a score of seven or more indicates a high level of burden)<sup>12</sup> at six and 12 months after starting rehabilitation. A total of 129 caregivers were included, of whom 19 (26.4%) were male, with a median age of 59 (range 27-78) years. Of those caregivers, 72 completed the Caregiver Strain Index twice. A consistently high or low burden was reported by 15 (20.8%) and 49 (68.1%) caregivers, respectively, whereas 8 (11.1%) reported a high burden at either six ( $n = 3$ ) or 12 months ( $n = 5$ ). About a third of the caregivers of stroke patients experiences a high burden, with that burden being persistent in about two-

thirds of this subgroup. As in a minority (11.1%) the caregiver burden changes from six to 12 months, it should be measured repeatedly until 12 months after stroke.

Another category of Environmental Factors are 'services, systems and policies', which includes the use of the healthcare system. However knowledge on healthcare usage in stroke patients, in particular those admitted for multidisciplinary rehabilitation, and on the longer term, is relatively scarce. When healthcare usage is studied, not only its relationship with the patients' health status and overall quality of life are relevant, but the associated costs are of interest as well. From a societal perspective, apart from healthcare costs, the costs incurred due to productivity losses must be taken into account as well. These indirect costs are directly associated with the ICF component Activities and Participation, of which work and employment are important aspects. The extent and course of participation in working stroke patients have already been addressed in **Chapter 4**. The study described in **Chapter 7** focused on both direct and indirect costs of stroke in the total population of stroke patients who received multidisciplinary rehabilitation. It aimed to estimate the societal costs and changes in health-related quality of life in stroke patients, up to one year after the start of multidisciplinary rehabilitation. Consecutive patients included in the SCORE study completed questionnaires on their health-related quality of life (EuroQol-5 Dimensions-3Levels, EQ-5D-3L)<sup>13</sup>, absenteeism, out-of-pocket costs and healthcare use at the start and end of rehabilitation and six and 12 months thereafter. Clinical characteristics and rehabilitation costs were extracted from the medical and financial records, respectively. Data from 313 stroke patients were analysed for this cost analysis study, their mean age was 59 (SD 12) years, 185 (59.1%) were male, and 244 (78.0%) were inpatients. The mean costs for inpatient and outpatient rehabilitation were US\$70,601 and US\$27,473, respectively. For inpatients, health-related quality of life increased significantly between baseline and six months (EQ-5D-3L index 0.66 to 0.73,  $p = 0.01$ ; visual analogue scale 0.77 to 0.82,  $p < 0.001$ ) and between baseline and 12 months (EQ-5D-3L index 0.66 to 0.69, not significant; visual analogue scale 0.77 to 0.81,  $p < 0.001$ ). It was concluded that the societal costs in the year after admission to a rehabilitation centre for stroke are considerable, yet it was also found that health-related quality of life increased significantly over time.

## General Discussion

This thesis aimed to describe the long-term course of pain, participation, patient activation, caregiver burden, healthcare usage and costs in stroke patients who received multidisciplinary rehabilitation. Furthermore, it aimed to assess whether the USER or the Barthel Index can be used best to describe functional independence in stroke patients admitted for rehabilitation. At the time the studies described in this thesis were designed, the ICF<sup>1</sup>, and in particular the ICF Core Set for Stroke<sup>2</sup> was the most commonly used framework capturing the complex outcomes of stroke. According to that framework, this thesis addressed a number of areas that were underrepresented in the literature so far. The knowledge gaps did not so much relate to the topics per se, but rather to a lack of insight into their extent and/or course over time, in the specific population of stroke patients who received multidisciplinary rehabilitation.

Overall it was found that the long-term consequences of stroke are substantial. These consequences do not only affect the individual stroke patient (pain, limitations in daily activities, restrictions in participation, reduced patient activation), but also affect their caregivers (caregiver burden) and healthcare and society as well (healthcare use and direct and indirect societal costs).

## Methodological Considerations

### *Measuring outcomes in stroke care and research*

In the past years, a number of frameworks or sets of instruments to measure outcomes in stroke have been published, apart from the ICF Core Set for Stroke<sup>2</sup>. In particular the International Consortium of Health Outcome Measurement (ICHOM) Standard Set for Stroke<sup>3</sup> and the Minimal Data Set Acquired Brain Injury (MDS-ABI)<sup>4</sup> are noteworthy. These sets recommend specific outcome measures to be used, in contrast to the ICF Core Set for Stroke, that comprises only the aspects of health that are most relevant for stroke patients<sup>2</sup>.

In general, all of the areas addressed in this thesis (upper extremity pain, functional independence, participation in stroke patients with paid employment, patient activation, caregiver burden, and healthcare usage and costs) with the exception of costs, are included in the comprehensive ICF Core Set for Stroke<sup>2</sup>. However, the brief version does not include pain, paid employment or participation, or Personal factors reflecting patient activation.

The ICHOM Standard Set for stroke and the MDS-ABI lack measurements related to patient activation, caregiver burden or healthcare usage and costs, whereas the MDS-ABI does not include measures reflecting pain either<sup>3,4</sup>. The studies presented in this thesis underpin the relevance of all of these aspects, thereby confirming the appropriateness of the selection of most relevant aspects of stroke patients' health in the comprehensive ICF Core Set for Stroke<sup>2</sup>.

Although the ICHOM Standard Set for Stroke and the MDS-ABI do not cover all categories or aspects relevant for stroke, the benefit of these frameworks or sets of instruments is that they recommend specific measurement instruments and thereby a uniform measuring method. Regarding the recommended instruments in the ICHOM Standard Set for stroke and MDS-ABI it must be noted that knowledge on their ability to serve as a means to monitor, evaluate and improve the quality of rehabilitation care for stroke patients is still unknown. An example is the Patient Reported Outcomes Measurement Information System (PROMIS)-10 that is included in the ICHOM Standard Set for Stroke. That instrument has so far been mainly used in hospital-based stroke populations<sup>14</sup>. Despite of the use of uniform outcomes measures, it should be noted that due to differences in study and patient characteristics and reference values, comparisons should be made with caution.

Apart from the optimal composition of the set of outcome measures reflecting the complex outcome of stroke, the timing of the measurements is also important. The studies presented in this thesis make it clear that in the rehabilitation population long-term follow-up is essential, because longstanding consequences of stroke are substantial and change over time for a proportion of patients. Indeed, it appeared from our studies that at 12-30 months after admission, there was a considerable proportion of patients with upper extremity pain and reduced participation and satisfaction with participation, substantial healthcare usage and of caregivers experiencing a high burden. However, in a paper on the ICHOM Standard Set for Stroke a full assessment is only recommended until 90 days after the initial event and survival is recommended to measure yearly<sup>3</sup>. The authors of the MDS-ABI<sup>4</sup> and the ICF Core Set for Stroke<sup>2</sup> give no recommendations on when to measure. In order to better capture the extent of the longstanding consequences of stroke (international) agreement on both the content of a comprehensive set of outcome measures and the recommended frequency of its administration on the longer term is needed.

### Strengths and limitations of the SCORE study

A prospective cohort study including consecutive patients with stroke admitted for rehabilitation is ideal to study the long-term outcomes in this specific patient group. A strength of the SCORE study concerns its sample size, because, as compared to other cohort studies, it comprises a relatively large number of stroke patients (901 by 2021). Moreover, as it only includes patients who receive multidisciplinary inpatient or outpatient rehabilitation, it gives a profound insight into the outcomes and their course in this specific subgroup of stroke patients. The follow-up duration of 30 months after the start of the rehabilitation provides insight into the course of several outcome measures on the long-term. This is important from the clinical point of view, as the duration of routine follow-up is usually limited, so that rehabilitation professionals are generally unaware of the eventual outcomes of their treatment. This includes also the possible occurrence of new problems or aggravating of persisting ones, constituting a possible

renewed indication for consultation of a rehabilitation physician. Another strength concerns the broad range of outcome measures employed, including relatively under-studied areas such as pain, patient activation or costs.

The setup of a large prospective cohort study enables the conduct of embedded studies evaluating the effectiveness of interventions. An example of such studies are those with a pre-test post-test design, where outcomes are compared between patients admitted in a period where an intervention was not used and a period where it was implemented. This methodology was used in the Fit After Stroke (FAST)@Home study, evaluating the effectiveness of an integrated eHealth platform by efficiently making use of data gathered in the context of the ongoing SCORE study<sup>15</sup>.

Although more knowledge about the subgroup of stroke patients who received multidisciplinary rehabilitation is valuable, it can also be seen as a limitation. Extending the cohort study to all patients with stroke could yield valuable insights into differences and similarities of outcomes of patients discharged to their homes or admitted for geriatric rehabilitation. For that purpose, the SCORE+ Study was developed, that included patients from September 2020 to September 2021 in the Haaglanden Medical Centre (led by HJ Arwert, K Jellema, SJ Tamminga and TPM Vliet Vlieland) and included 342 patients.

Another limitation concerning the selection of patients is that patients with severe aphasia and severely affected patients were not able to participate, as they could not complete questionnaires. Moreover, the treating physicians needed to personally invite patients for the study, which led to more administrative tasks for them and therefore some eligible patients might be missed. Another form of selection occurred with the analyses, that were in some of the studies in this thesis performed within a subgroup of patients, namely those who completed the follow-up. It was found in a number of analyses that the patients completing the measurements differed from those who did not with respect to living alone, having a prior myocardial infarction, alcohol consumption, higher level of frailty and education level<sup>7,16</sup>.

Another drawback of the study concerns the intervention. Overall, multidisciplinary inpatient or outpatient rehabilitation is, despite the availability of guidelines<sup>17,18</sup>, overall not very much standardized and in part not sufficiently recorded on the individual patient level. A previous comparison of the structure (four centres)<sup>6</sup> and processes (two centres)<sup>19</sup> of stroke rehabilitation indeed found significant differences. For the structure of rehabilitation these concerned aspects such as admission and discharge criteria, the presence and content of patient subgroups, the presence and duration of care pathways, the timing of team meetings, the timing of clinical assessments, the maximum time from hospital discharge to admission, the content of aftercare and return to work modules, the types of medical and paramedical treatment disciplines, the types of facilities for treatment and diagnosis, and the content

of strategies for caregiver involvement<sup>6</sup>. Regarding the process of care, differences were seen with respect to the number of hours of speech and language therapy, psychology and recreational therapy. However it appeared that overall the outcomes were in general similar<sup>19</sup>.

Finally, the downside of the wealth of data concerns the burden for patients to complete all the questionnaires and questions at multiple time points. This is a considerable drawback, in particular as the data were gathered alongside of clinical care and were not used by clinicians and patients to set and evaluate treatment goals.

### Patient Research Partners

Besides the above mentioned strengths of the SCORE study, there is another one, worth mentioning separately: the involvement of patient research partners. In order to ensure that the design of the SCORE study, including the research questions, were relevant to stroke patients and their caregivers, a panel of patient research partners was set up from the beginning of the study<sup>20</sup>. Patient participation in research is important, because the views of all those with legitimate interests should be included and it increases the social impact of research<sup>21,22</sup>.

The panel of research partners of the SCORE study comprised about eight patients and one caregiver. These patients suffered from stroke or acquired brain injury, received inpatient and/or outpatient rehabilitation at Basalt and were motivated to share their perspective and thereby improving research. In the period 2013 until present the research partners met with the investigators once or twice per year. During the meetings long-term changes and needs after stroke and return to work were mentioned, which resulted in an amendment and article, respectively. The research partners also played a role in preparing the invitation and programme of the SCORE day in 2019 held in Leiden and the Hague. The SCORE day was organised in honour of the fifth anniversary of the SCORE study and at this day all participants of the study were informed about the results of the SCORE study. Ninety patients and their partners attended the SCORE day in Leiden and 123 in the Hague and they appreciated sharing experiences with fellow patients and partners.

Due to the valuable contribution of the research partners to the SCORE study, this concept has been extended within Basalt to other studies and the formation of a new panel: patient innovation partners. The patient innovation partners are giving their input on eHealth innovations and its implementation in rehabilitation care. They are involved in composing plans on eHealth, in helping to develop and test innovations and in giving critical advices. This involvement will ensure more successful implementation of eHealth in rehabilitation care.

## Measurement instruments

To adequately measure the outcome of interest, a measurement instrument should have adequate measurement properties<sup>23</sup>. It must be noted that for a number of instruments that are recommended in the ICHOM Standard Set for Stroke and the MDS-ABI not all measurement properties, interpretability and cut-off values in a stroke rehabilitation population are known. For example, concerning content validity, criterion validity and cross cultural validity/measurement invariance in stroke populations of the PROMIS Global Health no studies were found<sup>24</sup>.

To evaluate treatment, responsiveness, i.e. the ability to capture improvement or deterioration of a patient's health status is an important measurement property<sup>23</sup>. In this thesis, the responsiveness of the USER was evaluated, by computing its effect size (ES) and standardized response mean (SRM) between admission and discharge of stroke patients in rehabilitation and comparing these with those of the Barthel Index. Although with ES and SRM some insight into responsiveness can be obtained, it must be noted that the most adequate methodology to evaluate an instrument's responsiveness should include an assessment of longitudinal validity. In analogy to construct validity, longitudinal validity should be assessed by testing predefined hypotheses, e.g., about expected correlations between changes in measures, or expected differences in changes between "known" groups<sup>23</sup>. A weakness of this methodology concerns the formulation of hypotheses, where the expectations of the strength of the correlations may vary among researchers. Since our study did not use an assessment of longitudinal validity, the conclusions must be interpreted with some caution.

A challenge regarding the optimal composition of the set of outcome measurements, is the potential tension among the major objectives of the measurements: for individual patient care or for quality of care purposes, within or across institutions. For a number of generic instruments, relevant measurement properties in specific patient groups have been insufficiently established, with the uncertain suitability of the PAM in stroke patients admitted for rehabilitation (**Chapter 5**) as an example. In general, for many instruments the cut-off values to distinguish individual patients with different levels of health problems and healthcare needs are absent, so that their usability in individual patient care is limited. A specific drawback of generic measurement instruments is that they might not be applicable in patients with a specific condition such as stroke.

## Implications for research

Overall the SCORE study showed that in stroke patients admitted for inpatient or outpatient rehabilitation long-term assessments consisting of a comprehensive set of outcome measures are feasible and provide valuable insights<sup>7</sup>.

Given the abovementioned strengths and limitations of the SCORE study, a number of recommendations for the continuation of this study can be made, which could also be applicable to other observational cohort studies:

1) The recruitment process can be facilitated by decreasing administrative activities for the treating physicians needed to invite patients for the study; in this way the missing of patients for logistic reasons can be diminished; 2) The set of questionnaires should in general be limited and simplified so that the willingness to participate and compliance will increase; 3) The optimal composition of the set of measurement instruments can be reconsidered, based on the instruments advised in the ICHOM Standard Set for Stroke and/or MDS-ABI. In this respect, currently recommendations on outcome measures in stroke care in the Netherlands are developed as part of the national program *Uitkomstgerichte Zorg*<sup>25</sup> and should be taken into account. Moreover, from an international perspective there are initiatives to monitor the quality of rehabilitative care by assessing the responsiveness of newly developed quality indicators for rehabilitation<sup>26</sup>; 4) The use of CAT versions of questionnaires could be considered, to limit the number of questions to be answered; Such formats are available for a number of PROMIS instruments; 5) As communication problems are common in stroke patients, the inclusion of clinical tests could be considered, but that would require adequate resources for the time and other expenses associated with the execution of such tests. Another option would be the use of questionnaires which can be filled in by all patients despite communication problems. Such using digital technology are currently being developed<sup>27</sup>.

Besides selecting the appropriate measurement instruments other challenges regarding research in a stroke rehabilitation population are present. For rehabilitation in general, the evidence for specific interventions, either or not consisting of single or multiple treatment modalities delivered by one or more professions, is scanty. For example, this thesis found that patient activation was low in stroke patients who received rehabilitation<sup>28</sup>. However, we do not know yet which interventions are successful for this group. In stroke rehabilitation in particular, the presence of practice variation was indeed suggested<sup>6,19</sup>, a finding that may point into the possibility of suboptimal care delivery. More research into the cost-effectiveness of multidisciplinary rehabilitation interventions is needed to unravel the “black box”, e.g. by comparing the outcomes (effectiveness, costs and satisfaction of patients and healthcare providers) of different care pathways for patients with specific patterns of problems and limitations.

The availability of an ongoing cohort study at multiple locations may facilitate the conduct of such research, as this enables the execution of pre-test post-test studies as well as nested randomized controlled trials. However, for the execution of these types of studies it is important that the delivery of the interventions is accurately registered at patient level. This registration needs improvement.

## Implications for clinical practice

### *Assessments during rehabilitation*

The results of studies presented in this thesis suggest that in stroke patients who receive multidisciplinary rehabilitation more attention is needed for diagnosis and treatment of upper extremity pain, other means of meaningful participation in case return to paid employment seems unattainable, and increasing patient activation as a prerequisite for effective self-management<sup>28</sup>. In addition, it was also found that a considerable proportion of caregivers experiences a large burden<sup>29</sup>.

This enhanced attention should not be limited to the recognition of these problems, but to the institution of adequate interventions as well. It is conceivable that the subacute phase is not the optimal timing for some of these interventions. In that case, an appropriate report to healthcare providers in outpatient rehabilitation or primary care is of utmost importance. By incorporating the abovementioned topics in routine work flows, e.g. in designated care pathways, the awareness of the importance of these elements will increase. The addition of patient-reported outcome measures in routine work flows could aid in identifying topics where support is needed.

### *Follow-up after rehabilitation*

With respect to clinical practice, currently, in the Netherlands, follow-up after discharge from multidisciplinary rehabilitation is usually temporarily (until 6-12 months) whereas the results of this thesis suggests that on the long-term new limitations might arise. For example some restrictions in participation may only become clear on the longer term, such as permanent work disability, which is only final after two years of sick leave in many patients. Furthermore, this thesis showed that pain and caregiver burden can arise on the long-term<sup>29</sup>. Improvements could consist of the implementation of a standardized system of surveillance, to identify patients at risk for deterioration. As it appeared that long-term healthcare usage in primary care was substantial, the setup of a surveillance system could well be done in close collaboration with e.g. general practitioners, specialized stroke nurses working in the community and physical therapists<sup>30</sup>. Furthermore, general practitioners and stroke nurses should know to which paramedics and rehabilitation physicians they can refer stroke patients. In the region Zuid-Holland occupational therapists, physical therapists and speech and language therapist in primary care with experience with patients with neurological complaints are gathered in a network (Neuronet) in order to secure and possibly improve care for patients with neurological complaints<sup>31</sup>.

Overall, this thesis filled some knowledge gaps on long-term outcomes after stroke rehabilitation. However, many challenges remain regarding research and clinical practice.

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