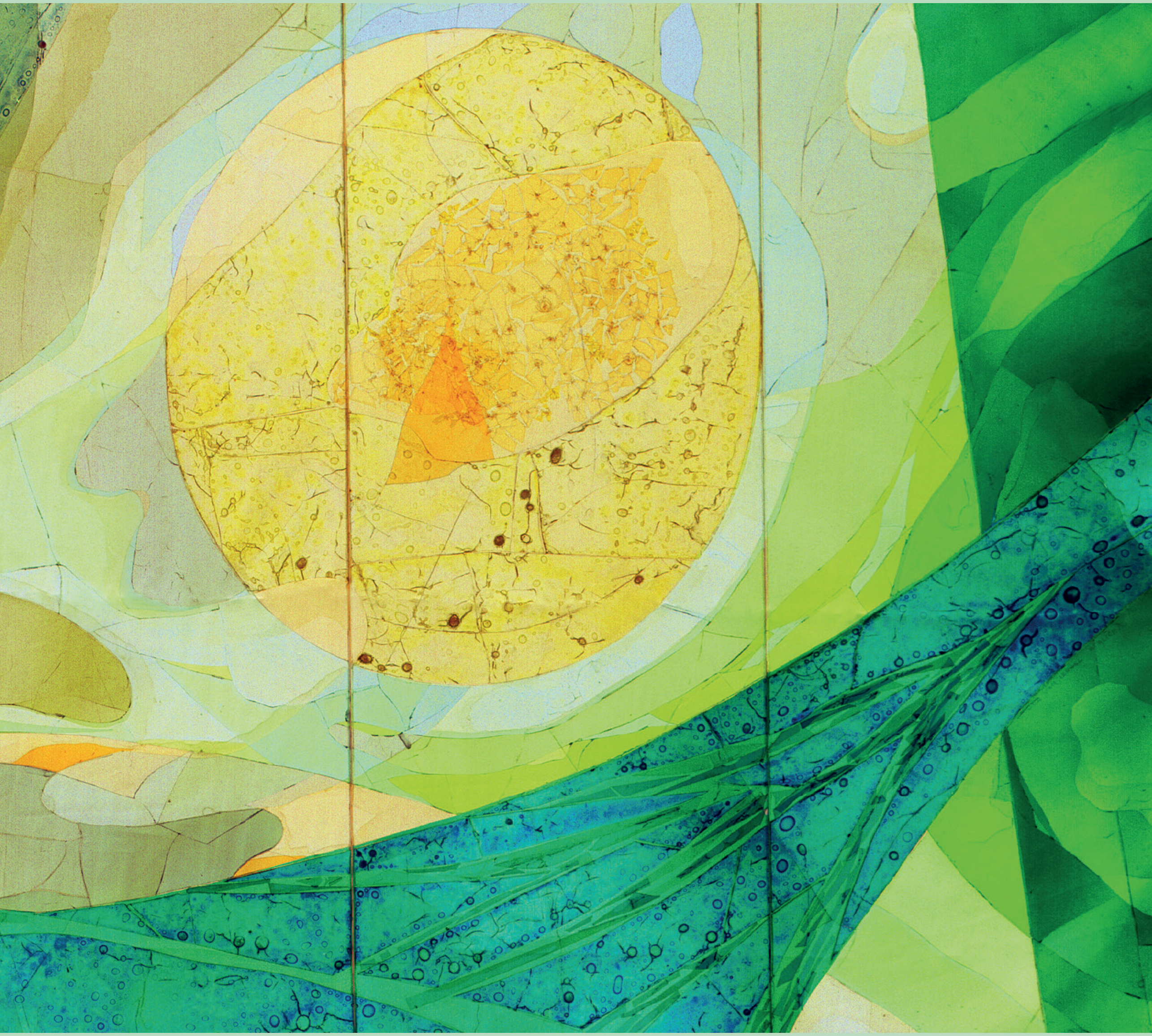
# Post-stroke lives in Dutch nursing homes

## Recognizing interrelated problems and expressed agency towards optimizing supportive care



Suzanne van Almenkerk

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**Suzanne van Almenkerk**

**Colofon**

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# POST-STROKE LIVES IN DUTCH NURSING HOMES

Recognizing interrelated problems and expressed agency
towards optimizing supportive care

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prof.dr. D.J.A. Janssen
dr. M.C. Visser

**Voor mijn moeder**
vol levenslust en -wijsheid

# Contents

# 1

# CHAPTER 1

# General introduction

# General introduction

This thesis is about persons who are living in nursing homes (NHs) because of post-stroke impairments and the search how to optimize care for them. This general introduction will first explain how this group of institutionalized stroke patients is an under researched population, both on the continuum of stroke care and in long-term NH-care. Subsequently, the framework of supportive NH-care to enhance the quality of life of NH-residents is presented, followed by what knowledge is needed to tailor this care to institutionalized stroke patients. Finally, the overarching goal and research questions of this *CAre for STroke In LOng term care facilities in the Netherlands* (CASTILON) study are addressed, together with the outline of this thesis.

## Institutionalized stroke patients: an under researched population

While survival after stroke has improved sharply in the last decades, and stroke incidence declined as well, its global burden remains high. Worldwide the absolute number of people with a hemorrhagic or ischemic stroke increased to more than 80 million stroke survivors between 1990 and 2016, largely due to population growth and ageing (GBD-2016-Stroke-Collaborators, 2019). In the Netherlands every year approximately 40.000 people suffer from stroke, and almost 360.000 people have to live with the consequences of it (Koop *et al.*, 2021).

Stroke survivors often suffer from problems in multiple domains of functioning. In addition to physical impairments, many have to deal with cognitive, psychological and behavioral, communicative and social problems as well (Limburg *et al.*, 2012). These needs require the coordination between a large number of disciplines and organizations that are involved during the acute, the rehabilitation and the chronic phases of stroke care (Minkman *et al.*, 2005). In 1995 and 2006 pan-European consensus meetings were convened to set targets for the development of such integrated stroke care (Kjellstrom *et al.*, 2007), mainly focused on the improvement of prevention, acute care and rehabilitation. It led to the foundation of the Stroke Knowledge Network in the Netherlands in 2006 (Limburg *et al.*, 2010). Nevertheless, a considerable proportion of stroke survivors remain severely dependent after rehabilitation and require long-term NH-care. Population-based studies in high-income countries showed that institutionalization occurs to approximately 11% to 15% of stroke survivors. This proportion seems independent of the duration of the post-stroke period, which differed in studies from 3 months (Glader *et al.*, 2003) to 5 years (Feigin *et al.*, 2010; Liman *et al.*, 2012; Luengo-Fernandez *et al.*, 2013) and 10 years post-stroke (Hardie *et al.*, 2004). Luengo-Fernandez *et al.* (2013) even found a cumulative risk of institutionalization of 19% over a 5-year period.

Already in the nineties, Dutch NHs were involved in the start of the development of integrated stroke care. Stroke units in hospitals worked together with specialized rehabilitation wards within NHs to coordinate care for stroke patients (Vat *et al.*, 2016). This has developed into a geriatric rehabilitation route after hospitalization for frail and multimorbid older people, in addition to medical specialist rehabilitation with higher therapy intensity in rehabilitation centres (Buijck & Bushnik, 2018). The presence of multidisciplinary (or interdisciplinary) teams in Dutch NHs - which include nursing staff, an elderly care physician, a psychologist, a social worker, a recreational therapist, and paramedical disciplines – provides an excellent infrastructure to deliver coherent, multidisciplinary stroke care. Regarding the entire chain of stroke care, however, the important contribution of NHs remains mostly focused on the geriatric rehabilitation route with the intention of discharge to home. No specific attention is paid to improving care for chronic stroke patients who ultimately remain dependent of long-term care in NHs. This is all the more remarkable because, in addition to dementia, stroke is a common main diagnosis for admission to long-term NH-care, although exact data on this are lacking. Moreover, Smalbrugge *et al.* (2008) showed that the majority of chronic stroke patients is residing in somatic wards, in Dutch NHs differentiated from psychogeriatric wards, even when severe cognitive impairment is present. Compared to the huge attention to improving dementia care for people who are residing in psychogeriatric wards, we have to conclude that institutionalized stroke patients are not only an under researched population on the continuum of stroke care, but also in long-term NH-care.

## A supportive care approach to enhance the quality of life of nursing home residents

NHs are not considered anymore as medical institutions for chronically ill, but acknowledged as residences where people live the last stages of their lives. As a result of this shift in the last decades from a traditional, biomedical to a person-centered approach in care philosophy, the main purpose of NH-care today is to make the best possible contribution to a resident's quality of life (Hertogh & Ribbe, 2008; Zorginstituut-Nederland, 2017, updated in 2021). In fact, this is known as the overarching goal of the palliative care approach as defined by the World Health Organization (Sepulveda *et al.*, 2002; World-Health-Organization, 2020). Originating as pain relief for terminal cancer patients, palliative care is now considered as an integral, multidisciplinary approach to improve the quality of life of people with any chronic disease that is ultimately fatal. Moreover, the WHO-definition emphasizes that palliative care-principles should not be limited to the terminal phase, but be integrated as early as possible in a disease trajectory. Already in the nineties, NH-medicine in the Netherlands adopted it as an adequate framework for good care for people with dementia (Hertogh & Ribbe, 2008). Moreover, Hertogh and Ribbe (2008) argued that the palliative care approach is applicable to all NH-residents to enhance the quality of their last years of life.

Although the WHO-definition underlines that palliative care “affirms life”, and “intends neither to hasten or postpone death”, it is in clinical practice still mainly associated with death and dying, limiting it to the very last stages of care. To emphasize the incorporation of a palliative care approach in earlier stages of disease trajectories, the use of the equivalent term “supportive care” is gaining popularity in the literature (Fadul *et al.*, 2009; Hui *et al.*, 2013). With regard to institutionalized stroke patients, this thesis prefers to adopt this term. Not only does it emphasize NHs as places of living instead of places of dying, it also emphasizes NH-care for chronic stroke patients as being a part of the continuum of stroke care.

## Tailoring supportive nursing home care to institutionalized stroke patients

This thesis focuses on tailoring two core components of supportive NH-care to institutionalized stroke patients to enhance their quality of life. Its first, most fundamental component is to provide relief from distressing symptoms (Hertogh & Ribbe, 2008; Sepulveda *et al.*, 2002). While it is clear that the post-stroke impairments that caused NH-dependency are severe across multiple domains of functioning, reliable data are lacking. This thesis aims to fill this gap, in order to identify key problems that need further relief. Hereby, it is very important to include persons with severe cognitive and/or communicative impairments and/or limited physical endurance, as they form a considerable part of this group of NH-residents. The use of observational measurement instruments enables this.

The second and equally important component of supportive NH-care, is to offer residents support to enable them to live as actively as possible (Hertogh & Ribbe, 2008; Sepulveda *et al.*, 2002). Hereby, it is essential that this support is centered around the experienced needs of the residents themselves, who are after all the experts in living their everyday NH-lives. They are the ones who can tell what they find most important in daily life and about the difficulties they encounter, possibly accompanied by concrete wishes about what support could resolve or alleviate these needs. This thesis aims, therefore, to identify the needs of institutionalized stroke patients in everyday life for which they need support, through research of their own perspectives. A qualitative study design enables to explore these needs in a “bottom-up” way, allowing residents to tell in their own words and with own priorities about their experiences in everyday life. Hereby, it is again important to include also persons with (moderate) cognitive and/or communicative impairments.

In addition to the need for identifying key problems and needs of institutionalized stroke patients, the question arises what the optimal starting point for a supportive care approach should be for stroke patients who ultimately become dependent on institutional long-term care. According to the WHO-definition, it should be integrated as early as possible, in conjunction with other therapies that are focused on prolonging of life or recovery. On the continuum of stroke care, this would mean that supportive NH-care could be started during the geriatric rehabilitation phase, in which Dutch NHs already play an active role. A reliable prognostication soon after stroke for institutionalization and/or severe disability would serve such early integration (Moons *et al.*, 2009). It would enable early planning of realistic rehabilitation goals and would prepare stroke patients and their relatives better for limited recovery and the possibility of not being able to return home. Until the start of this CASTILON-study, however, studies of prognostication after an acute stroke have focused mainly on the prediction of a favorable outcome (Sulter *et al.*, 1999; Veerbeek *et al.*, 2011). In contrast, the CASTILON-study investigates what is already known about prognostic factors for a poor stroke outcome.

## Overarching goal, research questions and outline of the thesis

The overarching goal of this thesis is to formulate key elements for optimizing supportive care for persons who live post-stroke lives in NHs. To this end we need a better understanding of the problems and needs of this group of NH-residents, as well as of prognostic factors for a poor stroke outcome. Accordingly, we formulated the following research questions to investigate in the CASTILON-study:

1. *Which factors in the first month post-stroke have a predictive value for institutionalization and/or severe disability?*

In order to answer this research question, **Chapter 2** describes the results of a systematic literature review.

2. *What problems in functioning do institutionalized stroke patients have in the physical, cognitive, emotional, communicative and social domains, and how are these problems interrelated?*

A cross-sectional, observational study was designed to collect quantitative data about the functioning of NH-residents with stroke as main diagnosis for NH-admission. The data were collected through observation lists that were filled out in structured interviews with qualified nurse assistants who knew the residents well. **Chapter 3** presents the results in the physical, cognitive, emotional, communicative and social domains, together with the relation between the status of functioning and the stroke characteristics that caused the NH-dependency.

Based on these results, we selected pain and apathy as the problems to analyze further in depth. **Chapter 4** describes the prevalence and location of substantial pain, and its relation to emotional distress and social engagement. **Chapter 5** focuses on the prevalence of apathy and its clinical correlates. In addition, results are presented on the relation between the amount of stimulating activities in the NH and the severity of apathetic behavior.

3. *What support do institutionalized stroke patients need to live their everyday lives, seen from their own perspective?*

In order to answer this research question, **Chapter 6** describes the results of a qualitative interview study with 13 persons who live in NHs because of post-stroke impairments.

Finally, **Chapter 7**, the general discussion of this thesis, summarizes and reflects on the main findings of the previous chapters, and tries to formulate key elements for optimizing supportive care for persons who live post-stroke lives in Dutch NHs. These key elements can be considered as “building blocks” to be further developed for a future tailor-made methodological care program to optimize the quality of life of this subgroup of NH-residents. Since publications of CASTILON-results date from the years 2012 to 2015, the main findings are extensively reflected on in the context of more recent literature and current clinical practice.

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# CHAPTER 2

# 2

# What predicts a poor outcome in older stroke survivors? A systematic review of the literature

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Suzanne van Almenkerk, Martin Smalbrugge, Marja F.I.A. Depla, Jan A. Eefsting and Cees M.P.M. Hertogh (2013). What predicts a poor outcome in older stroke survivors? A systematic review of the literature. *Disability and Rehabilitation, 35(21),* 1774-1782.

**Purpose:** To identify factors in the early post-stroke period that have a predictive value for a poor outcome, defined as institutionalization or severe disability.

**Methods:** MEDLINE, PSYCINFO, EMBASE and CINAHL were systematically searched for observational cohort studies in which adult and/or elderly stroke patients were assessed ≤1 month post-stroke and poor outcome was determined after a follow-up of ≥3 months.

**Results:** Thirty three articles were selected from 4063 records, describing 27 independent cohort studies. There are rather consistent findings that greater age, a more severe stroke (measured through a clinical evaluation scale), the presence of urinary incontinence (with impaired awareness) and a larger stroke volume (measured through brain imaging techniques) predict poor stroke outcome. In contrast to clinical expectations, the prognostic value of ADL-dependency and impaired cognition remains unclear, and factors in the domains of emotional and communicative functioning rarely feature. Studies using a selected group of stroke patients tended to identify different predictors.

**Conclusions:** The current evidence is insufficient for the development of a clinical prediction tool that is better than physicians' informal predictions. Future research should focus on the selection of optimal screening instruments in multiple domains of functioning, including the timing of assessment. We suggest developing prediction tools stratified by more homogeneous, clinically distinguished stroke subtypes.

***Implications for rehabilitation:***

- A reliable prognosis soon after a stroke is highly relevant to patients who ultimately have a poor outcome, because it enables early planning of care tailored to their needs.

- In view of the development of a clinical prediction tool that is better than physicians' informal predictions, future research should focus on optimal screening instruments in multiple domains of functioning, including emotional and communicative functioning.

- Clinical prediction tools stratified by more homogeneous, clinically distinguished stroke subtypes, could enable more accurate prognosis in individual stroke patients.

# Introduction

Previous studies of prognostication after an acute stroke have focused mainly on the prediction of a favorable outcome. In contrast, the objective of this literature review is to identify factors in acute stroke patients that have a predictive value for a poor outcome.

Poor outcome, defined here as institutionalization or severe disability, occurs frequently. Previous research with large cohorts showed that approximately 15-20% of stroke survivors in developed countries are dependent on institutional long-term care [1-3]. This proportion seems to be rather persistent at different times post-stroke, ranging from “completed rehabilitation” after 37 ± 41 days [3] to 5 years post-stroke [1]. A reliable prognostication soon after the stroke is highly relevant to patients with a poor outcome of this nature, their relatives and their multidisciplinary stroke teams. It enables early planning of care tailored to their needs, while unrealistic expectations may be avoided by focusing consultation on acceptance of the stroke consequences.

There were some reviews several years ago dealing with the prognosis for institutionalization after stroke rehabilitation [4-6], but they all found insufficient evidence for an evidence-based prediction of the future residence of patients with an acute stroke. Previous reviews of prognoses after strokes for the recovery of functioning [4, 7, 8] did not focus on severe disability as an outcome measure. They included many studies that focused on the prediction of a favorable outcome, such as independence in activities of daily living (ADL) versus lack of independence. Prediction models based on this dichotomy do not fit with clinical practice, which has more categories ranging from full recovery of functioning through partial recovery with moderate disability, to severe disability and institutionalization.

In this literature review we intend to identify factors in the early post-stroke period that have a predictive value for a poor outcome, defined as institutionalization or severe disability. A clinical prediction tool that is simple to use and better than physicians’ informal predictions [9] would be very desirable and helpful for the management of individual patients. We, therefore, focus on factors that can easily be determined in clinical practice.

# Methods

## Search strategy

We searched MEDLINE, PSYCINFO, EMBASE and CINAHL for articles published up to March 2011, in English, German, French, Dutch or Spanish. The search was carried out with the help of a medical information specialist, using the following terms (with synonyms and closely related words): “stroke”, and “prognosis” or “prospective studies” or “risk factors”, and “chronic disease” or “recovery of function” or “convalescence” or “rehabilitation” or “treatment outcome” or “disability evaluation”. The full search strategy is available from the authors. We also reviewed the reference lists of the articles we selected.

## Selection criteria

***Study design.*** We searched for observational cohort studies, both prospective and retrospective, and both community-based and hospital-based.

The prognostic factors had to have been assessed within 1 month of stroke onset. We included both stroke patients assessed in the acute phase on stroke units in hospitals and patients discharged to rehabilitation units or other post-stroke discharge destinations.

The follow-up period had to be 3 months at least. In this follow-up period, majority of patients reach their best level in functional recovery, even patients with severe and very severe strokes [10].

***Patient population.*** We searched for studies that included elderly patients, or a mixed population of adult and elderly patients, with an ischemic, hemorrhagic (intracerebral or subarachnoid) or unclassifiable stroke, either for the first time or recurrent. We excluded studies that included patients with a transient ischemic attack (TIA).

***Outcomes.*** We searched for studies that used institutionalization (long-term care setting) or severe disability as an outcome measure. The Barthel Index (BI) [11], the modified Rankin Scale (mRS) [12], the Glasgow Outcome Scale (GOS) [13] and the motor component of the Functional Independence Measure (FIM) [14] are the most commonly used scales to measure disability or dependence in ADL in stroke victims. We defined severe disability according to these scales as BI <60 (using the 100-point scale) or BI <12 (when the 20-point scale is used), mRS >3 [15] or GOS <IV (or GOS >II when the modified version is used that places the scores in reverse order, see http://www.strokecenter.org). All relevant studies that measured post-stroke disability through the FIM used the FIM as a continuous outcome measure (i.e. without a cut-off point to define severe disability).

***Analyses.*** We only included studies with ≥50 patients. Multivariable regression analyses had to have been used to identify independent prognostic factors, with effects given by point estimates and confidence intervals (CI). These analyses are used in studies designed to develop an association or explanatory model (to explore the causality of the association between one central determinant and the outcome variable, corrected for confounding and effect modification), as well as in studies designed to develop a prediction model (to search for a combination of factors that are associated as strongly as possible with the outcome variable, often using stepwise regression analyses) [16].

### Review procedure

All articles were reviewed by two reviewers independently (SA, MS). The first step in the selection was based on the title, the second on the abstract and the third on the full text, according to the selection criteria. Methodological aspects of the selected studies that were not defined in the selection criteria – such as the risk of bias in selection, selective loss-to-follow-up, the presence of important predictors in the study design and the external validity of the study results – were evaluated by two reviewers independently (SA, MS/MD) using the Dutch Cochrane Centre's assessment form for evaluating scientific publications. Disagreements were resolved in a consensus meeting.

The identified prognostic factors in the selected studies were categorized into patient characteristics, stroke characteristics, biological measures and clinical functioning measures. If a study presented a statistical model for a *favorable* outcome, the inverse of the point estimates and 95% CIs were taken to get the values for a *poor* outcome. We were not able to provide pooled estimates because there was much variation in patient populations, the variables assessed and the measurement instruments used. To summarize the findings for each variable, we assessed the number of independent studies that identified it as a prognostic factor (a), in relation to the number of independent studies that investigated the variable but found it *not* to have a predictive value (b). This proportion will be presented as a:b.

## Results

The electronic search strategy resulted in 3971 titles (after removing duplicates) from which we selected 28 studies. A review of the reference lists in these selected articles resulted in 92 titles, from which we selected another five articles. The reasons for exclusion in the selection process of the 4063 records are presented in Figure 1. The final selection of 33 articles described 27 independent cohort studies, of which 15 studies involved ischemic strokes (IS) [17-35], one study hemorrhagic strokes (HS) [36] and 11 studies both IS and HS [2, 37-48]. Articles that derived data of a same cohort were references [24, 34] (TOAST Study), [27, 32] (Northern Manhattan Study), [28, 30, 33] (GAIN International Trial), [39, 48] (Copenhagen Stroke Study), and [40, 41] (studies by Pettersen *et al.*). The number of patients included in the studies ranged from 60 [26] to 19 547 [2], the mean age ranged from 60.3 [23] to 83 [29] years. The participants' age was not reported in a number of studies [17, 22, 24, 34, 36].

The identified prognostic factors in the first month after stroke for a poor outcome are presented in Tables 1-4, together with point estimates and 95% CIs. The studies that investigated the variable but found it *not* to have a predictive value are listed in the following sections.

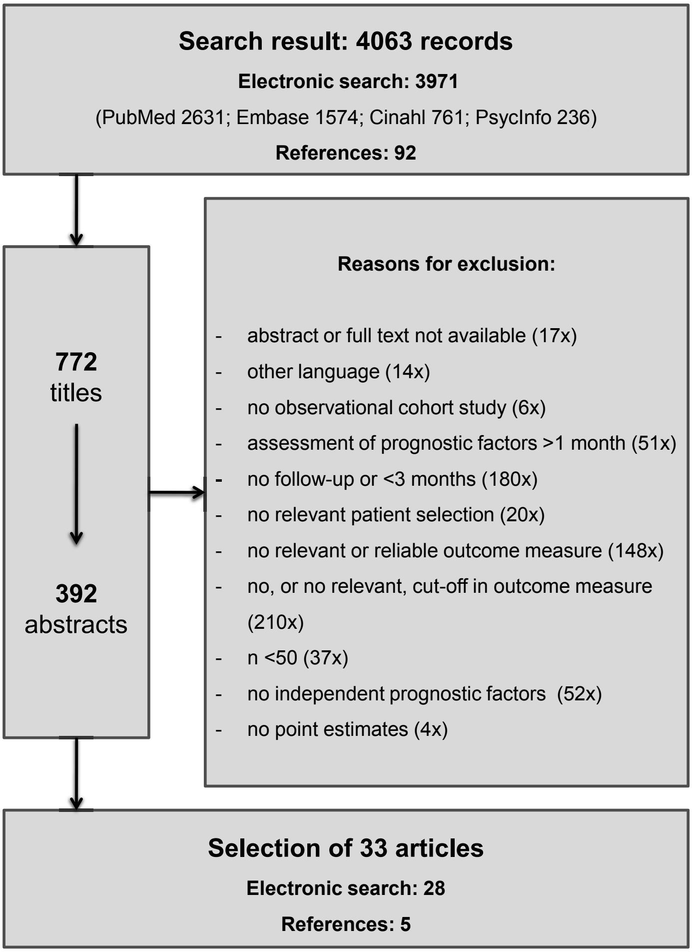

**Figure 1.** Reasons for exclusion in the systematic literature search

## Prognostic factors in patient characteristics predicting a poor outcome

Greater age was identified as a prognostic factor in 12 [2, 23, 25, 32, 34-37, 39/48, 41, 45, 46] :4 [38, 40, 43, 44] studies (i.e. age was identified as a prognostic factor in 12 independent studies and was found not to be a prognostic factor in four independent studies), both for IS and HS and in a wide range of follow-up periods (Table 1). The largest effects were found in the studies by Kammersgaard *et al.* [39], Glader *et al.* [2] and Rost *et al.* [36], which all assessed age as a categorical variable including very great ages (≥80 or ≥85).

Living alone was identified as a prognostic factor in 2 [2, 48]:6 [32, 38, 39, 40/41, 44, 46] studies; a stronger effect was found in a selected cohort of severe stroke patients [48]. Female gender was identified as prognostic factor in 1 [2]:12 [17, 32, 34, 36-38, 39/48, 40/41, 43-46] and non-white race in 1 [34]:1 [32] studies. An interaction effect of insurance status and time of follow-up was found in 1 [32]:0 studies; there was an annual decline in functional status among patients with a low insurance status (i.e. no insurance or basic state insurance) in particular.

Finally, level of education (0:3 [32, 44, 46]) and having an occupation (0:2 [44, 48]) were not identified as predictors of a poor outcome.

## Prognostic factors in stroke characteristics predicting a poor outcome

A total or partial anterior circulation syndrome according to the Oxfordshire Community Stroke Project (OCSP) classification [49] was identified as a prognostic factor in 1 [40]:2 [38, 41] studies (i.e. these syndromes were identified as a prognostic factor in one study but not in two other independent studies) (Table 2). Intracerebral HS, as opposed to IS, was identified as a prognostic factor in 1 [2]:6 [38, 39/48, 40, 44-46] studies. Non-lacunar infarcts according to the Trial of ORG 10172 in Acute Stroke Treatment (TOAST) classification in IS [50] were identified as a prognostic factor in 2 [20, 34]:1 [25] studies and cardioembolic infarcts in 1 [20]:1 [46] studies, all with large effects. Adams *et al.* [34] also found an interaction effect of lacunar infarcts with baseline stroke severity, implying that more severe lacunar infarcts have a worse outcome than other stroke subtypes of the same severity. Intracerebral HS that is lobar in location was identified as a prognostic factor in 1 [36]:0 studies, with a large effect.

An increase in stroke volume was identified as a prognostic factor in 3 [23, 25, 36]:0 studies, both in IS and HS. The largest effect was found in the study by Rost *et al.* [36], which assessed stroke volume in (intracerebral) HS as a categorical variable. With respect to the side of the lesion, left-sided [32] and bilateral strokes [44] were both identified as a prognostic factor in 1:0 studies.

Stroke characteristics that were not identified as prognostic factors were: the presence of asymptomatic hemorrhagic transformation of infarction (0:1 [31]), a visible infarction

**Table 1. Prognostic factors in the first post-stroke month for a poor outcome: patient characteristics**

| | Reference | *N* | Poor outcome | Follow up (m) | Factor category/value | OR | 95% CI |
|---|---|---|---|---|---|---|---|
| **Age** | | | | | | | |
| IS + HS | 39 [a] | 1197 | IN+ | 84 | ≥85 | 3.90 | 2.10-7.30 |
| | 37 | 171 | IN | 12 | <75 (ref) versus 75-79 versus ≥80 [b] | 3.13 | 1.45-6.67 |
| | 41 | 234 | IN+ | 12 | ≥80 | 2.40 | 1.00-5.60 |
| | 45 | 752 | IN | 12 | <65 (ref) versus 65-74 versus 75-84 versus ≥85 [c] | 2.00 | 1.40-2.80 |
| | 48 [a] | 84 | SD | 3 | per 10-year increase [d] | 2.00 | 1.01-4.00 |
| | 46 | 165 | IN | 36 | per 1-year increase | 1.08 | 1.03-1.15 |
| | 2 | 11041 | IN | 3 | • ≥85 | ref | |
| | | | | | • versus 75-84 | 0.62 | 0.53-0.73 |
| | | | | | • versus 65-74 | 0.36 | 0.29-0.44 |
| | | | | | • versus <65 | 0.15 | 0.11-0.21 |
| IS | 25 | 256 | SD+ | 3 | per 1-year increase | 2.28 [e] | 1.22-4.28 |
| | 35 | 404 | IN+ | 6 | per 10-year increase [f] | 1.92 | 1.41-2.56 |
| | 32 | 525 | SD | 60 | per 1-year increase [c] | 1.08 | 1.05-1.11 |
| | 34 | 1268 | SD+ | 3 | per 1-year increase | 1.06 | 1.05-1.09 |
| | 23 | 476 | SD+ | 6 | per 1-year increase [g] | 1.06 | 1.02-1.09 |
| HS | 36 | 418 | SD+ | 3 | ≥80 (ref) versus <70 [h] | 0.12 | 0.05-0.24 |
| **Living status** | | | | | | | |
| IS + HS | 48 | 84 | SD | 3 | living single [d] | 3.10 | 1.10-8.80 |
| | 2 | 11041 | IN | 3 | living alone | 2.28 | 2.28-3.05 |
| **Gender** | | | | | | | |
| IS + HS | 2 | 11041 | IN | 3 | female | 1.18 | 1.01-1.38 |

**Table 1. Continued**

| | Reference | *N* | Poor outcome | Follow up (m) | Factor category/value | OR | 95% CI |
|---|---|---|---|---|---|---|---|
| **Race** | | | | | | | |
| IS | 34 | 1268 | SD+ | 3 | non-white | 1.56 | 1.12-2.13 |
| **Insurance status** | | | | | | | |
| IS | 32 | 525 | SD | 60 | time of follow-up per 1-year increase, for people with no insurance or Medicaid (United States) [c] | 1.19 | 1.06-1.33 |

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[a] References [39,48], Copenhagen Stroke Study.

[b] only patients in rehabilitation departments.

[c] only first stroke.

[d] only patients with Scandinavian Stroke Scale <15.

[e] only results for outcome measured with BI are presented.

[f] only first lacunar stroke.

[g] only men with anterior circulation stroke.

[h] only primary intracerebral hemorrhage.

IN, institutionalization; SD, severe disability; +, including death; IS, ischemic stroke; HS, hemorrhagic stroke; OR, odds ratio; CI, confidence interval.

**Table 2. Prognostic factors in the first post-stroke month for a poor outcome: stroke characteristics**

| | Reference | *N* | Poor outcome | Follow up (m) | Factor category/value | OR | 95% CI |
|---|---|---|---|---|---|---|---|
| **Stroke subtype** | | | | | | | |
| IS + HS | 40 | 222 | IN+ | 3 | partial or total anterior (OCSP) | 3.60 | 1.40-9.00 |
| | 2 | 11041 | IN | 3 | intracerebral hemorrhage | 1.27 | 1.02-1.58 |
| IS | 20 | 159 | SD+ | 6 | cardioembolic infarct (TOAST) | RR 7.10 | 1.00-50.30 |
| | | | | | lacunar infarct (TOAST) | RR 0.07 | 0.01-0.50 |
| | | | | | other determined etiology (TOAST) | RR 0.07 | 0.01-0.50 |
| | 34 | 1268 | SD+ | 3 | lacunar infarct (TOAST) | 0.15 | 0.05-0.44 |
| | | | | | • interaction with baseline NIHSS | 1.16 | 1.03-1.32 |
| HS | 36 | 418 | SD+ | 3 | lobar versus infratentorial [a] | 0.15 | 0.05-0.43 |
| **Lesion volume** | | | | | | | |
| IS | 25 | 256 | SD+ | 3 | change from 0 to 63 $cm^3$ (CT scan) | 2.70 [b] | 1.74-4.19 |
| | 23 | 476 | SD+ | 6 | per 1 ml increase (DWI) [c] | 1.01 | 1.00-1.02 |
| HS | 36 | 418 | SD+ | 3 | • >60 $cm^2$ (CT scan) [a] | ref | |
| | | | | | • 30-60 $cm^2$ | 0.12 | 0.02-0.59 |
| | | | | | • <30 $cm^2$ | 0.02 | 0.00-0.09 |
| **Side of lesion** | | | | | | | |
| IS + HS | 44 | 151 | IN | 6 | bilateral [d] | 4.44 | 1.45-13.6 |
| IS | 32 | 525 | SD | 60 | left-sided [e] | 0.53 | 0.30-0.93 |

[a] only primary intracerebral hemorrhage. [b] only results for outcome measured with BI are presented. [c] only men with anterior circulation stroke.
[d] only patients in rehabilitation departments. [e] only first stroke.

IN, institutionalization; SD, severe disability; +, including death; IS, ischemic stroke; HS, hemorrhagic stroke; OR, odds ratio; CI, confidence interval.; OCSP, Oxfordshire Community Stroke Project classification; TOAST, Trial of ORG 10172 in Acute Stroke Treatment classification; NIHSS, National Institute of Health Stroke Scale; DWI, diffusion-weighted imaging; RR, relative risk.

on CT scans in lacunar stroke patients compared with those in whom no such lesion had been identified (0:1 [35]) and intraventricular hemorrhage in HS (0:1 [36]).

## Prognostic factors in biological measures predicting a poor outcome

Blood pressure (BP) values in IS were identified as a prognostic factor in 4 [19, 22, 24, 28/30]:2 [21, 48] studies (i.e. BP values were identified as a prognostic factor in four independent studies but not in two other independent studies) (Table 3). Many different measurements were studied, all with a follow-up period of 3 months. Taking the first 24 h after the stroke, extremely low or high night-time BP values [19], significant falls in BP [22] , and elevated baseline pulse pressure [30] were all identified as prognostic factors. A higher BP [24, 28/30] or a spontaneous BP decrease [19] in the following week were also identified as prognostic factor.

With respect to comorbidity, chronic kidney disease was identified as a prognostic factor in 1 [42]:0 studies, “other disabling diseases” in 1 [39]:2 [38, 48] studies, and atrial fibrillation in 1 [39]:2 [32, 48] studies. Diabetes mellitus was identified as a prognostic factor in 2 [2, 17]:7 [23, 25, 32, 36, 39/48, 44, 45] studies: one of these two studies was restricted to first lacunar stroke patients [17]. The unexpected factor of “never smoked” (in a selected study population of men with anterior circulation stroke) was identified as a prognostic factor in 1 [23]:2 [32, 39] studies. Other comorbidities that are known to be risk factors for strokes were not identified as prognostic factors for a poor outcome: a history of strokes (0:9 [2, 23, 25, 34, 39/48, 40/41, 43, 44, 46]), a history of hypertension (0:7 [17, 23, 32, 36, 39/48, 44, 45]), although in some studies this variable was combined with hypertension during hospital stay), a history of heart disease (0:6 [17, 32, 36, 39, 44, 45]) and a history of hypercholesterolemia (0:2 [23, 32]).

With respect to other biological measures, infectious complications (pneumonia and urinary tract infection) were identified as a prognostic factor in 1 [33]:1 [43] studies, body temperature in 1 [48]:0 studies (in a selected cohort of severe stroke patients) and leukoaraiosis in 1 [17]:1 [26] studies (in a selected cohort of patients with a first lacunar stroke). Variables that were not identified as prognostic factors were serum insulin-like growth factor (0:1 [29]), and APOE genotype (0:1 [18]).

## Prognostic factors in clinical functioning measures predicting a poor outcome

A more severe stroke at baseline (as an “overall” measure of clinical functioning) was identified as a prognostic factor in 8 [23, 25, 32, 34, 39/48, 43, 46, 47]:0 studies (i.e. this factor was identified in all eight independent studies that assessed stroke severity), both in IS and HS (Table 4). The largest effect was found in the study by Dhamoon *et al.* [32] in which stroke severity was assessed as a categorical variable: a severe stroke

**Table 3. Prognostic factors in the first post-stroke month for a poor outcome: biological measures**

| | Reference | *N* | Poor outcome | Follow up (m) | Factor category/value | OR | 95% CI |
|---|---|---|---|---|---|---|---|
| **Blood pressure (BP)** | | | | | **First 24h:** | | |
| IS | 19 | 403 | SD+ | 3 | low night-time diastolic BP (≤60 mmHg) [a] | 8.13 | 1.13-58.28 |
| | | | | | high night-time systolic BP (≥165 mmHg) [a] | 2.76 | 1.12-6.79 |
| | 30 [b] | 1455 | SD+ | 3 | elevated pulse pressure | 1.06 | 1.00-1.12 |
| | 22 | 551 | SD+ | 3 | substantial decline in overall systolic BP (≥50 mmHg) | >1 | NA |
| | | | | | substantial decline in short-term systolic BP (≥30 mmHg) | >1 | NA |
| | | | | | **Following week:** | | |
| | 19 | 403 | SD+ | 3 | first 5 d: decrease in daytime diastolic BP (≥10 mmHg) [a] | 2.97 | 1.11-7.94 |
| | 28 [b] | 1455 | SD+ | 3 | first 2.5 d: substantial increase from baseline mean arterial BP (30%) | 2.39 | 1.42-4.03 |
| | 24 | 1281 | SD+ | 3 | first 7 d: increase in weighted average mean arterial BP (per 10 mmHg) | 1.19 | 1.02-1.39 |
| | 30 [b] | 1455 | SD+ | 3 | first 2.5 d: elevated weighted average pulse pressure | 1.13 | 1.05-1.22 |
| | 24 | 1281 | SD+ | 3 | first 7 d: increase in weighted average systolic BP (per 10 mmHg) | 1.12 | 1.02-1.23 |
| **Comorbidity** | | | | | | | |
| IS + HS | 42 | 821 | IN+ | 12 | chronic kidney disease (eGFR 15-40) | 4.6 | 1.6-13.2 |
| | 39 | 1197 | IN+ | 84 | disabling diseases other than stroke | 2.8 | 1.8-4.3 |
| | | | | | atrial fibrillation | 2.2 | 1.20-3.80 |
| | 2 | 11041 | IN | 3 | diabetes mellitus | 1.34 | 1.14-1.56 |
| IS | 17 | 333 | SD+ | 24 | diabetes mellitus [c] | 2.33 | 1.21-4.14 |
| | 23 | 476 | SD+ | 6 | current smoker versus never smoked [d] | 0.29 | 0.12-0.67 |

**Table 3. Continued**

| | Reference | *N* | Poor outcome | Follow up (m) | Factor category/value | OR | 95% CI |
|---|---|---|---|---|---|---|---|
| **Complications** | | | | | | | |
| IS | 33 | 1455 | SD | 3 | aspiration pneumonia in first 7 d | 3.8 | 2.20-6.70 |
| | | | | | urinary tract infection in first 7 d | 1.9 | 1.20-2.90 |
| **Other** | | | | | | | |
| IS + HS | 48 | 84 | SD | 3 | body temperature: per 1°C decrease [e)] | 0.56 | 0.32-0.91 |
| IS | 17 | 333 | SD+ | 24 | leukoaraiosis [c)] | 3.02 | 1.95-5.75 |

[a)] only first stroke.

[b)] References [28,30], GAIN International Trial.

[c)] only first lacunar stroke.

[d)] only men with anterior circulation stroke.

[e)] only patients with Scandinavian Stroke Scale <15.

IN, institutionalization; SD, severe disability; +, including death; IS, ischemic stroke; HS, hemorrhagic stroke; OR, odds ratio; CI, confidence interval.; eGFR=estimated Glomerular Filtration Rate (Mayo Clinic).

gave a much greater likelihood of a poor stroke outcome than a moderate stroke. The study by Jorgensen *et al.* [48], which included only patients with a severe stroke on admission, still found a considerable predictive effect for stroke severity measured after one week, reflecting the amount of neurological recovery in the first post-stroke week.

Urinary incontinence (UI) was identified as a prognostic factor in 4 [32, 37, 40/41, 45]:0 studies. The largest effect was found in the studies by Pettersen *et al.* [40/41] who defined this factor as UI with impaired awareness (patients with a reduced ability to be aware of bladder signals before leakage, to notice leakage when it takes place, or both) as opposed to urge UI (patients with frequent micturitions, a strong urge to urinate and subsequent leakage, and who are aware of and embarrassed about their problem).

A low level of consciousness was identified as a prognostic factor in 2 [2, 36]:1 [48] studies, a high degree of dependency in basic ADLs in 4 [38, 40/41, 43, 45]:3 [37, 38, 47] studies, a lower level of pre-stroke physical functioning in 3 [25, 41, 43]:2 [32, 40] studies, impaired cognition in 3 [41, 44, 47]:2 [37, 40] studies, and pre-stroke cognitive impairment in 2 [36, 46]:1 [40/41] studies. The measurement instrument used for these variables varied, with the exception of the measurement of levels of consciousness and pre-stroke cognitive impairment.

With respect to emotional functioning, an effect was found in 1 [27]:1 [47] study: an early depressed mood was identified as a prognostic factor for a poor outcome at 6 months through to 2 years after the stroke. A depressed mood before the stroke was not identified as a prognostic factor (0:1 [32]). Finally, we found no studies that identified prognostic factors in the domain of communicative functioning.

## Discussion

A reliable prognostication soon after the stroke is highly relevant to patients with a poor outcome after a stroke, defined as institutionalization and/or severe disability. It enables early planning of care tailored to their needs, while unrealistic expectations may be avoided by focusing consultation on acceptance of the stroke consequences. We carried out this literature review with the aim of identifying factors in the first month after a stroke that have a predictive value for a poor outcome. The selection criteria led to a result of less than 1% of the almost 4000 titles screened. The major reason for exclusion of studies was the lack of a relevant cut-off point in the outcome measure, which emphasizes the huge gap in research focus on a poor outcome of this nature. The majority of the articles finally selected (18 out of 33) date from 2005 or later, which might indicate that the interest in this topic is hopefully growing.

**Table 4. Prognostic factors in the first post-stroke month for a poor outcome: clinical functioning measures**

| | Reference | *N* | Poor outcome | Follow up (m) | Factor category/value | OR | 95% CI |
|---|---|---|---|---|---|---|---|
| **Baseline stroke severity** | | | | | | | |
| IS + HS | 39 [a)] | 1197 | IN+ | 84 | SSS per 10-pt decrease | 1.90 | 1.70-2.30 |
| | 47 | 141 | SD | 6 | NIHSS [b)] | 1.74 | 1.13-2.63 |
| | 43 | 412 | SD+ | 3 | mNIHSS | 1.16 | 1.07-1.25 |
| | 46 | 165 | IN | 36 | Orgogozo's score per 1-pt increase | 0.97 | 0.96-0.99 |
| | 48 [a)] | 84 | SD | 3 | SSS at week 1 per 10-pt increase [c)] | 0.31 | 0.13-0.91 |
| IS | 32 | 525 | SD | 60 | • NIHSS 0-5 (mild) [d)] | ref | |
| | | | | | • NIHSS ≥14 (severe) | 50 | 20.00-100 |
| | | | | | • NIHSS 6-13 (moderate) | 3.85 | 2.08-7.14 |
| | 25 | 256 | SD+ | 3 | NIHSS per 1-pt increase | 2.31 [e)] | 1.22-4.38 |
| | 23 | 476 | SD+ | 6 | mNIHSS per 1-pt increase [f)] | 1.32 | 1.19-1.46 |
| | 34 | 1268 | SD+ | 3 | NIHSS per 1-pt increase | 1.18 | 1.15-1.22 |
| **Urinary continence** | | | | | | | |
| IS + HS | 40 [a)] | 222 | IN+ | 3 | new impaired awareness UI | 27.5 | 7.00-108.20 |
| | 41 [a)] | 234 | IN+ | 12 | new impaired awareness UI | 13.4 | 3.40-52.40 |
| | 45 | 752 | IN | 12 | UI at day 7 [d)] | 4.4 | 2.10-9.60 |
| | 37 | 171 | IN | 12 | UI on admission [b)] | 3.57 | 1.18-11.11 |
| IS | 32 | 525 | SD | 60 | UI within 7-10 days [d)] | 3.32 | 1.83-6.04 |
| **Level of consciousness** | | | | | | | |
| IS + HS | 2 | 11041 | IN | 3 | fully conscious on admission | 0.32 | 0.27-0.38 |
| HS | 36 | 418 | SD+ | 3 | conscious (GCS ≥9) [g)] | 0.13 | 0.05-0.29 |

**Table 4. Continued**

| | Reference | *N* | Poor outcome | Follow up (m) | Factor category/value | OR | 95% CI |
|---|---|---|---|---|---|---|---|
| **ADL functioning / disability** | | | | | | | |
| IS + HS | 38 | 103 | IN | 36 | BI on admission 0-15 [b] | 11.5 | 2.20-60.30 |
| | 40 [a] | 222 | IN+ | 3 | mobility: walk speed <0.64 m/s | 8.2 | 2.60-26.20 |
| | 41 [a] | 234 | IN+ | 12 | BI (without UI item) on admission <9 | 3.9 | 1.30-11.80 |
| | 45 | 752 | IN | 12 | BI at day 7 <10 [d] | 2.3 | 1.10-4.80 |
| | 43 | 412 | SD+ | 3 | mRS | 1.44 | 1.02-2.05 |
| **Prestroke ADL functioning / disability** | | | | | | | |
| IS + HS | 41 | 234 | IN+ | 12 | poor instrumental ADL (NEADL <52) | 2.6 | 1.00-6.60 |
| | 43 | 412 | SD+ | 3 | mRS | 1.36 | 1.02-1.80 |
| IS | 25 | 256 | SD+ | 3 | presence of any disability (GOS) | 4.40 [e] | 1.34-14.44 |
| **Cognitive functioning** | | | | | | | |
| IS + HS | 41 | 234 | IN+ | 12 | cognitive impairment (SINIS <54) | 3.9 | 1.40-10.70 |
| | 44 | 151 | IN | 6 | impaired orientation (item SSS) [b] | 3.09 | 1.05-9.10 |
| | 47 | 141 | SD | 6 | better cognitive performance (AMT) [b] | 0.68 | 0.48-0.97 |
| **Prestroke cognitive functioning** | | | | | | | |
| IS + HS | 46 | 165 | IN | 36 | worse cognitive performance (IQCODE per 1-pt increase) | 1.03 | 1.00-1.06 |
| HS | 36 | 418 | SD+ | 3 | no previous cognitive impairment [g] | 0.23 | 0.08-0.67 |
| **Emotional functioning** | | | | | | | |
| IS | 27 | 340 | SD | 24 | early depressed mood [d] | 3.72 | 1.29-10.71 |
| | | | | 12 | | 2.91 | 1.07-7.91 |
| | | | | 6 | | 2.81 | 1.13-6.99 |

[a] References [39,48] Copenhagen Stroke Study; Pettersen *et al.* [40,41].

[b] only patients in rehabilitation departments.

[c] only patients with Scandinavian Stroke Scale <15.

[d] only first stroke.

[e] only results for outcome measured with BI are presented.

[f] only men with anterior circulation stroke.

[g] only primary intracerebral hemorrhage.

IN, institutionalization; SD, severe disability; +, including death; IS, ischemic stroke; HS, hemorrhagic stroke; OR, odds ratio; CI, confidence interval; SSS, Scandinavian Stroke Scale; (m)NIHSS, (modified) National Institute of Health Stroke Scale; UI, urinary incontinence; GCS, Glasgow Coma Scale; BI, Barthel Index; mRS, modified Rankin Scale; NEADL, Nottingham Extended ADL scale; GOS, Glasgow Outcome Scale; SINIS, Screening Instrument for Neurocognitive Impairments in Stroke; AMT, Abbreviated Mental Test; IQCODE, Informant Questionnaire for Cognitive Decline in the Elderly.

This review does have some limitations. First, publications may have been missed despite a thorough research with the help of a medical information specialist. Second, this review does not define "levels of evidence" for the identified prognostic factors based on the risks of bias in the selected studies. Recently, Veerbeek *et al.* [8] concluded that most prognostic studies in the early post-stroke phase are still of insufficient methodological quality. Rather than simply confirming this conclusion, we wanted to explore the full range of possible prognostic factors for a poor outcome after a stroke. We believe that this exploratory study is valid as crucial aspects of methodological quality were taken into consideration in our selection criteria (such as a follow-up period of sufficient length, reliable and valid outcome measures and the use of multivariable regression analyses), and other potential sources of bias are evaluated in this discussion. Strength of this review is that we also systematically assessed the number of studies that did *not* find a statistically significant effect for a possible prognostic factor. Previous reviews based their evidence on the number and quality of "positive" studies, regardless of the number and quality of "negative" studies. However, the contributions of positive and negative studies are equally important in assessing the overall evidence.

Based on the ratio of the number of studies that identified a variable as a prognostic factor to those that did not, there are rather consistent findings that greater age (12:4), a more severe stroke (8:0), the presence of UI (4:0) and a larger stroke volume (3:0) are predictors for a poor stroke outcome. In contrast to our clinical expectations, however, there are inconsistent findings regarding the prognostic value of a high degree of dependency in basic ADLs (4:3) and impaired cognition (3:2). Furthermore, prognostic factors in the domains of emotional and communicative functioning rarely feature in studies on predictors of a poor stroke outcome. The major conclusion of this literature review has to be therefore, that the current evidence for prognostic factors for poor outcome is insufficient for the development of a clinical prediction tool that is better than physicians' informal predictions. However, the studies provide much information to guide future research.

Greater age and a more severe stroke are well-known predictors for stroke outcomes (see for example Veerbeek *et al.* [8]). The results of this review suggest that the effect of these two variables on poor stroke outcome is not linear: studies that included "very great age" or "severe stroke" as a separate category (as opposed to older patients or a more severe stroke in general) found larger effects. With respect to very great age, this hypothesis is supported by the International Stroke Trial data, which shows a much higher frequency of poor outcomes in people aged over 80 [51].

The presence of UI was identified previously as a predictor for ADL after a stroke in the review by Meijer *et al.* [5], but not in the review by Veerbeek *et al.* [8]. When predicting a poor stroke outcome as we defined it, UI seems to play an important role as a marker of considerable brain damage. It seems obvious that it is important to distinguish newly diagnosed UI from premorbid UI, but this is not done consistently in the studies selected [32, 37]. A very interesting finding is that of Pettersen *et al.* [40, 41] that only patients with a reduced awareness of bladder needs were at higher risk of a poor outcome, not patients who were aware of and embarrassed about their problem. They found very large effects for this clinical subtype of UI, both at 3 months and at 1 year after a stroke, and even when measures of attention were added in a second statistical model. However, their cohort only contained a small number of patients with a poor outcome, so a larger sample would be necessary to confirm these results.

Stroke volume directly reflects the amount of brain damage, and its predictive value therefore seems obvious. Rather large effects were found in a selected population of IS patients [25] and of (intracerebral) HS patients [36], independent of stroke subtype (lacunar or not in IS [25] and lobar, deep or infratentorial in HS [36]). However, both studies analyzed data retrospectively.

When viewing the inconsistent findings with regard to impaired cognition (3:2), there appears to be a clear distinction in the measurement instruments used. All studies that identified impaired cognition as a prognostic factor for a poor outcome used a measurement instrument other than the widely used Mini-Mental State Examination (MMSE) [52]. In contrast, impaired cognition was not identified as a prognostic factor when the MMSE was used. Although the MMSE is one of the most commonly used brief mental tests, its disadvantage is that it compresses many cognitive functions together. Meanwhile it does not account for specific cognitive disabilities such as neglect and problems in executive functioning [53]. It seems essential to use a screening instrument that deliver insight in profiles of cognitive functioning, such as The Screening Instrument for Neuropsychological Impairments in Stroke (SINIS) [54] that was used in the study of Pettersen *et al.* [41].

With regard to the findings regarding ADL functioning/disability, we did not find such a clear distinction in measurement instruments used, although there is growing consensus that the BI is the optimal tool [55]. However, the inconsistent findings could also be explained by differences in timing of assessment. A recent study explored that the most optimal timing for assessment of the BI to predict outcome of ADL at 6 months seems to be at day 5 post-stroke [55].

Prognostic factors in the domain of emotional functioning rarely feature in studies on predictors of a poor stroke outcome. This is remarkable because it has been generally recognized that post-stroke depression predicts poorer physical functioning [56]. In our review only Willey *et al.* [27] found an effect of early depressed mood in IS on a poor outcome; this effect increased from 6 months up to 2 years after the stroke. In contrast, Saxena *et al.* [47] observed that depressive symptoms were only associated with the *rate* of functional recovery. They therefore concluded that depressive symptoms may slow down physical functional recovery but may not influence the level of dependence finally achieved. However, the follow-up period in this study was 6 months, so that an effect of depressive symptoms on stroke outcome in the long term could have been missed.

Furthermore, it is striking that we did not find any study that evaluates prognostic factors in the domain of communicative functioning. Although screening of stroke-related communication disorders is part of the procedure for stroke severity scales, this provides no accurate information on the prognostic value of aphasia and/or dysarthria for poor stroke outcome. It seems that prognostic studies in this field mainly focus on specific outcome measures in the communication domain [57, 58]. We suggest that future research should also focus on the predictive value of communication parameters for poor stroke outcome as we defined it. It is our clinical experience that a substantial proportion of stroke patients who are institutionalized and/or severely disabled have aphasia and/or dysarthria. In addition, there are studies beyond our selection criteria that support our notion. For example, a study among rehabilitating stroke patients (with a median onset-admission interval of >1 month) showed that the presence of global aphasia increases the risk of no improvement in ADL nearly five times [59].

Finally, we would like to focus on prognostic factors that have been studied many times. First, there are rather consistent findings that female gender (1:12) and a history of strokes, heart disease, and hypertension (0:6 to 0:9) do not predict a poor outcome (see also, Veerbeek *et al.* [8]). The non-effect of the latter three classical stroke risk factors emphasizes the fact that the factors known to influence stroke *incidence* do not necessarily have to be the same as the factors influencing stroke *outcome*.

Second, there still appears to be uncertainty about which BP component (4:2) gives the best information for prognosis. In general, BP is known to rise within the first 24 h and then gradually fall over the following week [60], but its influence in IS is complicated. Elevated BP may be of benefit in terms of increasing blood flow in the ischemic areas of the brain, but conversely it can also increase the risk of cerebral edema and hemorrhagic transformation of the infarct. It should be noted that all the studies involving BP in our review analyzed data from randomized controlled trial cohorts (except Boreas *et al.*

[19]), which limits the generalization of the results. Given the fluctuations in BP after a stroke, it seems that future research on the prognostic value of BP should focus on repeated measurements to describe the BP trajectory in the first post-stroke week.

A clinical prediction tool should give the best possible prediction of a poor stroke outcome with as few variables as possible, using variables that can easily be determined in clinical practice. The results of this review showed that age (including very great age), stroke severity, and the presence of UI (with impaired awareness) are important candidate variables. Furthermore, the combination with brain imaging information (stroke volume) seems to be very valuable [25], at least in developed countries. However, the prognostic performance of merely these variables in the first month after stroke will not be better than a physician's informal prediction for an individual stroke patient. The results of this review reveal the need for research on optimal screening instruments in multiple domains of functioning. The timing of assessment is hereby a crucial aspect, because clinical functioning in the early post-stroke period is time-dependent and also influenced by medical interventions in the acute stroke care, such as thrombolysis or decompressive hemiocraniectomy.

Although, it is the ultimate goal to develop a clinical prediction tool that could be used for all stroke patients, it is a fact that the stroke population is very heterogeneous. It seems it will be necessary to develop clinical prediction tools for more homogeneous subgroups to enable more accurate prediction for individual patients. One possibility is to stratify the stroke population by stroke subtype. In our review for example, Rost *et al.* [36] developed a prediction tool for patients with an intracerebral HS, the most devastating and least treatable form of stroke in general. For the group of IS it should also be considered to develop clinical prediction tools for clinically distinguished subtypes. The studies in our review that used a selected group of IS patients tended to identify different prognostic factors for a poor stroke outcome. In a cohort of patients with a first lacunar infarct, De Jong *et al.* [17] found diabetes mellitus and leukoaraiosis as independent prognostic factors. The remarkable finding of Bang *et al.* [23] is that, current smoking has a positive effect on stroke outcome applied to atherosclerotic stroke patients. Although, we did not find convincing evidence for a main effect of stroke subtypes according to the OCPS [49] or the TOAST classification [50] on poor stroke outcome, we suggest that future research focuses on the interaction of stroke subtypes with other predictors. If stratified by stroke subtype, clinical prediction tools could enable prognostication for individual stroke patients that is more accurate than physicians' informal predictions.

## Conclusion

There are rather consistent findings that greater age (including very great age), a more severe stroke (measured through a clinical evaluation scale), the presence of UI (with impaired awareness), and a larger stroke volume (measured through brain imaging techniques) are predictors in the first month post-stroke for a poor stroke outcome. In contrast to our clinical expectations, the prognostic value of a high degree of dependency in basic ADLs and impaired cognition remains unclear. Furthermore, there are very few studies in the domains of emotional and communicative functioning. This current evidence is insufficient for the development of a clinical prediction tool that is better than physicians' informal predictions. Future research should focus on the selection of optimal screening instruments in multiple domains of functioning, including the timing of assessment. We suggest developing clinical prediction tools stratified by more homogeneous, clinically distinguished stroke subtypes to enable more accurate prognostication in individual stroke patients.

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## CHAPTER 3

# 3

# Institutionalized stroke patients: status of functioning of an under researched population

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# Abstract

**Objectives:** In view of the development of an integrated care and treatment program for institutionalized stroke patients tailored to their needs, we aimed to explore their status of functioning in the physical, cognitive, emotional, communicative and social domains. In addition, we explored the relation between status of functioning and stroke characteristics.

**Design:** A cross-sectional, observational study.

**Setting:** Dutch nursing homes (NHs).

**Participants:** Residents with stroke as main diagnosis for NH-admission, who experienced a stroke >3 months ago and stayed ≥1 month on a long-term care ward.

**Measurements:** Attending physicians provided information about stroke subtype, stroke location and time post-stroke. Status of functioning was measured through an observation list comprising the Barthel Index, the Neuropsychiatric Inventory Questionnaire, and sections of the Resident Assessment Instrument for Long Term Care Facilities. The list was filled out in a structured interview with a qualified nurse assistant who knew the resident well.

**Results:** We included 274 residents (mean age 76.6, 58.4% female). The stroke that caused NH-dependency was in 81.3% ischemic, and in 49.8% right-sided. Median time post-stroke was 47 months; 90.9% of the residents were severely dependent in basic activities of daily living and 58% were in pain. Nearly half of the residents showed moderate (24.4%) or severe (23%) cognitive impairment. Irritability (52.9%), depressive symptoms (52.6%) and apathy (34.3%) occurred as the most frequent neuropsychiatric symptoms; 27.7% had a poor ability to express themselves and 30.3% had a low social engagement. We found more severe cognitive impairment, agitation/aggression and poor expression in left-sided strokes, more nighttime behavioral disturbances and delusions in right-sided strokes, and lower social engagement in residents with the largest time-interval post-stroke.

**Conclusion:** This study among institutionalized stroke patients in Dutch NHs revealed very high prevalence of impairments on all domains of functioning, above the well-known severe disabilities in basic activities of daily living. The monitoring and management of both pain and neuropsychiatric symptoms should be key elements in an integrated care and treatment program.

# Introduction

There is much attention for improving integrated care for stroke patients, for example shown by the Helsingborg Declaration 2006 on Stroke Strategies (Kjellstrom *et al.*, 2007). However, service development and research are mainly focused on prevention, acute care and rehabilitation after stroke, whereas relatively little attention is paid to the improvement of care for chronic stroke patients (Rodgers & Thomson, 2008). Although the continuity of services for chronic stroke patients discharged to the community has gained interest (Bhogal *et al.*, 2003), there has not been an equivalent research focus on the needs of chronic stroke patients who are dependent of institutional long term care. We agree with Cowman *et al.* (2010) that there needs to be an increased societal awareness that institutionalized stroke patients are community residents whose home address happens to be a nursing home (NH). On the continuum of care for stroke patients, they are until now an under researched population.

Institutionalization after stroke occurs frequently. Previous research with large cohorts showed that approximately 15% to 20% of stroke survivors in developed countries are dependent on institutional long term care (Feigin *et al.*, 2010; Glader *et al.*, 2003; Jørgensen *et al.*, 1995). This proportion seems to be rather persistent at different times post-stroke, ranging from "completed rehabilitation" after 37 ± 41 days (Jørgensen *et al.*, 1995) to 5 years post-stroke (Feigin *et al.*, 2010). Similarly, Dutch research revealed that 21% of stroke survivors at 6 months lived in a NH (Huijsman *et al.*, 2001).

In the *CAre for STroke In LOng term care facilities in the Netherlands* (CASTILON) study, we aim to develop guidelines for an integrated care and treatment program for this under researched group of institutionalized stroke patients, tailored to their needs. This program needs to be based on reliable data about the functioning of the residents in multiple domains, the current care they receive and their needs of care, which are all investigated in the project. The objective of the study described in this article is to explore the status of functioning of institutionalized stroke patients in the physical, cognitive, emotional, communicative and social domains. In addition, we explored the relation between the status of functioning and the characteristics of the stroke that caused NH-dependency.

# Methods

## Study design

From May 2008 to July 2009 a cross-sectional, observational study design was used to collect data about functioning of stroke patients who received long term care in

Dutch NHs. We approached 22 NHs in the Northern, Middle and Western parts of The Netherlands of which 17 agreed to participate. The study protocol was approved by the medical ethics committee of the VU University Medical Center.

## Patient selection

Institutional long-term care in The Netherlands is differentiated into somatic and psychogeriatric care, mainly based on the presence or absence of dementia (as main diagnosis for NH-admission). Because the majority of stroke patients are residing on somatic wards, even when severe cognitive impairment is present (Smalbrugge *et al.*, 2008), we only included residents on somatic wards.

Medical care in Dutch NHs is delivered by specifically trained physicians, who are referred to as elderly care physicians (ECPs). ECPs were asked to select their patients according to the following inclusion criteria: 1) stroke was the main diagnosis for NH-admission, 2) the last stroke occurred ≥3 months ago, 3) the need for long term care was indicated by the multidisciplinary stroke team and discussed with the stroke patient and his or her relatives, and 4) the resident stayed ≥1 month on a somatic long term care ward.

## Data collection

Information about stroke characteristics was provided by a resident's ECP through a digital questionnaire. Data of functioning were collected through an observation list that was filled out in a structured interview with a qualified nurse assistant who knew the resident well. All nurse assistants were interviewed by the same trained research assistant.

## Measurements

***Stroke characteristics.*** CPs provided information about stroke subtype (hemorrhagic stroke [HS] or ischemic stroke [IS]), stroke location (left-sided [L], right-sided [R] or other location) and time post-stroke.

***Physical functioning.*** Performance in basic activities of daily living (ADL) was measured by the 20-point Barthel Index (BI; Mahoney & Barthel, 1965). We defined a BI score <12 for the resident to be severely dependent (Sulter *et al.*, 1999). Pain was measured using the items "pain frequency" and "pain intensity" of the Resident Assessment Instrument for Long Term Care Facilities (RAI-LTCF; Fries *et al.*, 2001; Morris *et al.*, 1995). Pain frequency is coded as "no pain", "less than daily pain", and "daily pain" in the last 7 days. Pain intensity is categorized as "no pain", "mild pain", "moderate pain", and "severe pain" (times when pain is horrible or excruciating) in the last 7 days. We defined residents with daily or less than daily pain as having "any pain". Residents with daily pain that was moderate or greater were defined as having "substantial daily pain" (Sawyer *et* *al.*, 2007). To the best of our knowledge there is no valid observation instrument to measure fatigue (Lerdal *et al.*, 2009). To get an indication of the amount of fatigue, we asked the nurse assistant how many hours in a 24-hour day the resident stayed in bed.

***Cognitive functioning.*** Cognitive functioning was measured by the RAI-LTCF Cognitive Performance Scale (CPS; Morris *et al.*, 2006; Morris *et al.*, 1994), which has good agreement with the Mini Mental State Examination (MMSE; Folstein *et al.*, 1975) in the detection of cognitive impairment in NH residents (Hartmaier *et al.*, 1995; Paquay *et al.*, 2007). The CPS is a 7-category index, ranging from cognitively intact (0) to very severely impaired (6). We categorized the CPS by combining the 3 severe categories as "severe" (CPS 4-6), the middle 2 categories as "moderate" (CPS 2-3), and the remaining 2 categories as "no or mild" cognitive impairment (CPS 0-1).

***Emotional functioning.*** We assessed behavioral and psychological symptoms using the Neuropsychiatric Inventory Questionnaire (NPI-Q; de Jonghe *et al.*, 2003; Kaufer *et al.*, 2000), which covers a broad range of behavioral and psychological symptoms in 12 domains. Each domain is assessed by a screening question that covers core symptom manifestations. When these symptoms are present in the last month, symptom severity is evaluated on a 3-point scale (1-mild, 2-moderate, 3-severe). The total NPI-Q score represents the sum of individual symptom scores and ranges from 0 to 36.

***Communicative functioning.*** Cognitive functioning was measured using the RAI-LTCF items "ability to make him/herself clear" (expression) and "ability to understand others" (comprehension; Morris *et al.*, 2006). Both items are evaluated on a 5-point frequency scale (always, usually, often, sometimes, and rarely or never). We dichotomized the scores by combining the first 3 categories in "good or moderate" and the last 2 categories in "poor".

***Social functioning.*** Social functioning was measured by the RAI-LTCF Revised Index for Social Engagement (RISE; Gerritsen *et al.*, 2008; Morris *et al.*, 2006), which is constructed from the following 6 items: (a) at ease interacting with others, (b) at ease doing planned or structured activities, (c) accepts invitations into most group activities, (d) pursues involvement in life of facility, (e) initiates interaction(s) with others, and (f) reacts positively to interactions initiated by others. The RISE ranges from 0 (lowest level of social engagement [SE]) to 6 (highest level of SE). We categorized the RISE in "low" (RISE 0-2), "moderate" (RISE 3-4) and "high" SE (RISE 5-6; Achterberg *et al.*, 2003; Schroll *et al.*, 1997).

## Statistical analyses

Descriptive statistics were generated for both the total sample and for subgroups according to the assessed stroke characteristics. To test differences of mean scores between subgroups, an independent t-test (2 groups) or an ANOVA test (3 groups) was used when the data were normally distributed; otherwise a nonparametric Mann-Whitney U test (2 groups) or Kruskal Wallis test (3 groups) was used. We used $\chi^2$ statistics to compare dichotomous variables (Fisher's exact test 2-sided for 2 groups and Pearson $\chi^2$ 2-sided for 3 groups) and categorical variables (Pearson $\chi^2$ 2-sided). When the Fisher's exact test was used, we calculated the odds ratio (OR) and 95% confidence interval (CI). Statistical analyses were performed using PASW Statistics 18 (SPSS Inc., Chicago, IL, USA).

# Results

We collected data of 284 residents, of which 10 cases were excluded because of incomplete questionnaires. The number of residents per NH ranged from 3 to 31. Table 1 shows the resident and stroke characteristics of the total sample. Age was rather normally distributed (mean 76.6 ± 10.6, median 78 years). In 7.5% of the residents the stroke was not specifically located in the left or right hemisphere, due to for example bilateral or multi-infarcts. The distribution of time post-stroke was skewed to the right (mean 62.3 months ± 57.63, range 3-400 months) and therefore the median of 47 months is presented. Table 2 shows the functioning measures, both for the total sample and for the subgroups according to stroke subtype (HS vs IS), stroke location (L vs R) and time post-stroke. With regard to the time post-stroke we split the sample in three equal proportions, which resulted in the categories ≤2.5 years, 2.5-5.5 years and ≥5.5 years. We found no differences between the subgroups on age and sex.

## Physical functioning

A total of 90.9% of the residents were severely dependent in basic ADL. The prevalence of any type of pain was 58%, and of substantial daily pain 26.6%. More than half of the residents stayed more than 12 hours a day in bed. Comparison of the subgroups showed no differences in these physical functioning measures.

## Cognitive functioning

A total of 47.4% of the residents showed moderate or severe cognitive impairment. We found a significant difference between left- and right-sided strokes (Pearson $\chi^2$ [2, n = 245] = 16.17, p = 0.000), showing more residents with severe cognitive impairment in the subgroup of left-sided strokes.

## Emotional functioning

The most common neuropsychiatric symptoms were irritability and depressive symptoms (in more than 50% of the residents), followed by apathy (34.3%), agitation/aggression (29.6%) and disinhibition (28.5%). We found a lower prevalence of agitation/

**Table 1. Resident and Stroke Characteristics**

| N=274 | | n (%) |
|---|---|---|
| Age (mean ± SD [range]) | 76.6 ± 10.6 [41-97] | |
| <65 | | 39 (14.2) |
| 65-74 | | 54 (19.7) |
| 75-84 | | 108 (39.4) |
| ≥85 | | 73 (26.6) |
| Female sex | | 160 (58.4) |
| Marital status | | |
| Single or widowed | | 169 (61.7) |
| Education (*n missing=102)* | | |
| only primary education | | 65 (37.8) |
| secondary education | | 80 (46.5) |
| higher education | | 27 (15.7) |
| Stroke type * *(n missing=12)* | | |
| hemorrhagic | | 49 (18.7) |
| ischemic | | 213 (81.3) |
| Stroke location * *(n missing=9)* | | |
| left-sided | | 113 (42.6) |
| right-sided | | 132 (49.8) |
| other | | 20 (7.5) |
| Time post-stroke (median [25-75%], months) * | 47 [22-81] | |

* the stroke that caused nursing home dependency

aggression (OR 0.46 [0.27-0.80], p = 0.008), and a higher prevalence of nighttime behavioral disturbances (OR 2.19 [1.14-4.21], p = 0.019) and delusions (OR 2.97 [1.14-7.72], p = 0.021) in right-sided strokes.

## Communicative functioning

A total of 11.7% of the residents had a poor ability to understand others, and 27.7% had a poor ability to make him/herself clear. We found a much higher prevalence of poor expression in left-sided strokes (OR 8.00 [4.12-15.63], p = 0.000).

## Social functioning

A percentage (30.3% and 36.1%) of the residents showed low, respectively high SE. We found a significant difference between the time post-stroke subgroups (Pearson $\chi^2$ [4, n = 274] = 15.45, p = 0.004), showing more residents with low SE and less residents with high SE in the group of ≥5.5 years post-stroke.

### Table 2. Status of Functioning in Relation to Stroke Characteristics

| | Total sample | Stroke type * | | Stroke location** | | Time interval post-stroke | | |
|---|---|---|---|---|---|---|---|---|
| | | HS | IS | L | R | ≤2.5 y | 2.5-5.5 y | >5.5 y |
| | N=274 | n=49 | n=213 | n=113 | n=132 | n=90 | n=93 | n=91 |
| | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) |
| Age (mean ± SD) | 76.6 ± 10.6 | 74.2 ± 11.3 | 76.9 ± 10.4 | 76.7 ± 9.6 | 76.9 ± 10.9 | 77.3 ± 9.8 | 76.5 ± 11.3 | 76.1 ± 10.8 |
| Female gender | 160 (58.4) | 27 (55.1) | 124 (58.2) | 64 (56.6) | 78 (59.1) | 57 (63.3) | 57 (61.3) | 46 (50.5) |
| **Physical functioning** | | | | | | | | |
| Barthel Index (mean ± SD) | 5.28 ± 3.95 | 5.69 ± 4.52 | 5.16 ± 3.86 | 5.39 ± 4.17 | 5.21 ± 3.64 | 5.46 ± 4.18 | 5.24 ± 4.04 | 5.15 ± 3.67 |
| severely dependent (BI<12) | 249 (90.9) | 42 (85.7) | 196 (92.0) | 99 (87.6) | 124 (93.9) | 82 (91.1) | 84 (90.3) | 83 (91.2) |
| Pain | | | | | | | | |
| any type of pain | 159 (58.0) | 29 (59.2) | 125 (58.7) | 64 (56.6) | 81 (61.4) | 53 (58.9) | 55 (59.1) | 51 (56.0) |
| substantial daily pain | 73 (26.6) | 12 (24.5) | 57 (26.8) | 23 (20.4) | 41 (31.1) | 30 (33.3) | 23 (24.7) | 20 (22.0) |
| Bed rest | | | | | | | | |
| < 12 h | 135 (49.3) | 30 (61.2) | 100 (46.9) | 61 (54.0) | 61 (46.2) | 47 (52.2) | 48 (51.6) | 40 (44.0) |
| 12-16 h | 103 (37.6) | 13 (26.5) | 84 (39.4) | 38 (33.6) | 55 (41.7) | 35 (38.9) | 29 (31.2) | 39 (42.9) |
| >16 h | 36 (13.1) | 6 (12.2) | 29 (13.6) | 14 (12.4) | 16 (12.1) | 8 (8.9) | 16 (17.2) | 12 (13.2) |
| **Cognitive functioning** | | | | | | | | |
| Cognitive impairment | | | | | | | | |
| no or mild (CPS 0-1) | 144 (52.6) | 25 (51.0) | 112 (52.6) | **49 (43.4)** | **77 (58.3)** | 50 (55.6) | 49 (52.7) | 45 (49.5) |
| moderate (CPS 2-3) | 67 (24.4) | 13 (26.5) | 53 (24.9) | **25 (22.1)** | **38 (28.8)** | 24 (26.7) | 20 (21.5) | 23 (25.3) |
| severe (CPS 4-6) | 63 (23.0) | 11 (22.4) | 48 (22.5) | **39 (34.5)** | **17 (12.9)** | 16 (17.8) | 24 (25.8) | 23 (25.3) |
| **Emotional functioning** | | | | | | | | |
| NPIQ score (mean ± SD) | 6.27 ± 5.21 | 6.10 ± 5.76 | 6.40 ± 5.13 | 6.17 ± 5.13 | 6.62 ± 5.44 | 5.83 ± 4.83 | 6.70 ± 5.76 | 6.27 ± 5.00 |
| Irritability/Lability | 145 (52.9) | 23 (46.9) | 115 (54.0) | 58 (51.3) | 72 (54.5) | 40 (44.4) | 50 (53.8) | 55 (60.4) |
| Dysphoria/Depression | 144 (52.6) | 23 (46.9) | 117 (54.9) | 58 (51.3) | 71 (53.8) | 49 (54.4) | 45 (48.4) | 50 (54.9) |

**Table 2. Continued**

| | Total sample | Stroke type * | | Stroke location** | | Time interval post-stroke | | |
|---|---|---|---|---|---|---|---|---|
| | | **HS** | **IS** | **L** | **R** | **≤2.5 y** | **2.5-5.5 y** | **>5.5 y** |
| | N=274 | n=49 | n=213 | n=113 | n=132 | n=90 | n=93 | n=91 |
| | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) | n (%) |
| Apathy/Indifference | 94 (34.3) | 12 (24.5) | 80 (37.6) | 40 (35.4) | 45 (34.1) | 24 (26.7) | 36 (38.7) | 34 (37.4) |
| Agitation/ Aggression | 81 (29.6) | 13 (26.5) | 66 (31.0) | **44 (38.9)** | **30 (22.7)** | 18 (20.0) | 31 (33.3) | 32 (35.2) |
| Disinhibition | 78 (28.5) | 16 (32.7) | 60 (28.2) | 31 (27.4) | 43 (32.6) | 18 (20.0) | 32 (34.4) | 28 (30.8) |
| Anxiety | 65 (23.7) | 13 (26.5) | 50 (23.5) | 26 (23.0) | 35 (26.5) | 24 (26.7) | 21 (22.6) | 20 (22.0) |
| Nighttime behavioral disturbances | 57 (20.8) | 11 (22.4) | 44 (20.7) | **16 (14.2)** | **35 (26.5)** | 21 (23.3) | 17 (18.3) | 19 (20.9) |
| Appetite/eating disturbances | 38 (13.9) | 3 (6.1) | 34 (16.0) | 16 (14.2) | 21 (15.9) | 18 (20.0) | 10 (10.8) | 10 (11.0) |
| Elation/Euphoria | 38 (13.9) | 9 (18.4) | 27 (12.7) | 15 (13.4) | 19 (14.4) | 13 (14.4) | 17 (18.5) | 8 (8.8) |
| Delusions | 27 (9.9) | 7 (14.6) | 18 (8.5) | **6 (5.4)** | **19 (14.4)** | 9 (10.1) | 12 (12.9) | 6 (6.6) |
| Aberrant motor behaviors | 25 (9.1) | 6 (12.2) | 19 (8.9) | 11 (9.7) | 13 (9.8) | 9 (10.0) | 7 (7.5) | 9 (9.9) |
| Hallucinations | 10 (3.6) | 2 (4.1) | 8 (3.8) | 4 (3.5) | 6 (4.5) | 3 (3.3) | 5 (5.4) | 2 (2.2) |
| **Communicative functioning** | | | | | | | | |
| Poor comprehension | 32 (11.7) | 6 (12.2) | 25 (11.7) | 18 (15.9) | 13 (9.8) | 6 (6.7) | 16 (17.2) | 10 (11.0) |
| Poor expression | 76 (27.7) | 10 (20.4) | 63 (29.6) | **55 (48.7)** | **14 (10.6)** | 17 (18.9) | 31 (33.3) | 28(30.8) |
| **Social functioning** | | | | | | | | |
| Social engagement | | | | | | | | |
| low (RISE 0-2) | 83 (30.3) | 9 (18.4) | 69 (32.4) | 40 (35.4) | 34 (25.8) | **25 (27.8)** | **23 (24.7)** | **35 (38.5)** |
| moderate (RISE 3-4) | 92 (33.6) | 18 (36.7) | 71 (33.3) | 37 (32.7) | 46 (34.8) | **23 (25.6)** | **32 (34.4)** | **37 (40.7)** |
| high (RISE 5-6) | 99(36.1) | 22 (44.9) | 73 (34.3) | 36 (31.9) | 52 (39.4) | **42 (46.7)** | **38 (40.9)** | **19 (20.9)** |

**Bold = p<0.05**, HS, hemorrhagic stroke; IS, ischemic stroke; L, left-sided; R, right-sided; CPS, Cognitive Performance Scale; NPIQ, Neuropsychiatric Inventory Questionnaire; RISE, Revised Index for Social Engagement.

*n missing=12, **n missing=29.

## Discussion

As part of our aim to develop an integrated care and treatment program for institutionalized stroke patients tailored to their needs, we explored the functioning of this population in multiple domains. The main findings are that (1) almost 60% of the residents are in pain, (2) nearly half of the residents have moderate or severe cognitive impairment, (3) irritability, depressive symptoms and apathy occur as the most frequent neuropsychiatric symptoms, (4) more than a quarter of the residents have poor expressive abilities, and (5) almost a third of the residents have a low social engagement (SE). The relation between status of functioning and the characteristics of the stroke that caused NH-dependency, revealed some differences with regard to stroke location (more severe cognitive impairment, agitation/aggression and poor expression in left-sided strokes; more nighttime behavioral disturbances and delusions in right-sided strokes), and with regard to time post-stroke (lower SE in residents with the largest time-interval post-stroke).

A major strength of this study is the uniqueness of the study population, representing an under researched population on the continuum of stroke care. In addition, through the use of observation instruments we were able to include stroke patients with severe cognitive and/or communicative impairments. A second strength is the broad, multifocal approach we used in exploring the status of functioning. A limitation of the study is its cross-sectional design that does not allow us to gain insight in the evolution of symptoms. The fact that the residents in this study lived on average almost 4 years in the NH, indicates that longitudinal research would be very desirable in the future. A second limitation is the lack of depth in some measurement instruments, such as the CPS and the NPI-Q. However, the used measurement instruments provide good insight in the manifestation of disturbances in everyday clinical practice.

Comparison of our findings to what is known from previous stroke studies is mainly limited by our unique study population. Cowman *et al.* (2010) studied a similar population in the Republic of Ireland (n=570), but did not use specific measurement instruments to identify functional and cognitive problems (with exception of the Barthel Index). As a consequence, we compare our findings to what is known from studies in the general stroke population, in which prevalence of impairments can be expected to be lower. Nevertheless, the prevalence of impairments found in our study population appears to be astonishingly high on all domains.

Previous research showed that post-stroke pain is prevalent in 11% to 44.6% of patients at 6 months to 2 years post-stroke, measured through self-report (Appelros, 2006; Jonsson *et al.*, 2006; Klit *et al.*, 2011; Lundstrom *et al.*, 2009; Naess *et al.*, 2010). The prevalence of 58% in our study is even more alarming when we realize that observation of pain by professionals often lead to underestimation (Sawyer *et al.*, 2007).

Previous studies found prevalence of cognitive impairment in 11.8% to 38% of patients at 1 to 3 years post-stroke (Appelros, 2005; Liman *et al.*, 2011; Patel *et al.*, 2003; Patel *et al.*, 2002), compared to 47.4% in our study population. All these studies used the Mini-Mental State Examination (Folstein *et al.*, 1975) that has good agreement with the CPS we used.

A systematic review on post-stroke depression found a pooled estimate of 33% at any time during following up (Hackett *et al.*, 2005; compared to 52.6% in our study population), and apathy following stroke has been consistently estimated between 20% to 25% of patients (Jorge *et al.*, 2010; compared to 34.3%), although it is hazardous to compare prevalence of formal neuropsychiatric diagnoses to our results of the NPI-Q. Two other studies that also used (other versions of) the NPI in a stroke population up to 1 year post-stroke (Angelelli *et al.*, 2004; Buijck *et al.*, 2012), reported remarkably lower frequencies of irritability (12%-33%) and apathy (9%-26.6%) than our study.

The higher frequency of poor expression in left-sided strokes in our study population suggests that aphasia is the most important underlying impairment (rather than dysarthria and/or cognitive deficits; Morris *et al.*, 2006), because of the well-known lateralization of language in the left hemisphere. Previous research showed that aphasia is present in about one-third of stroke patients in the acute phase (Engelter *et al.*, 2006), in 20%-25% at 3 months (Pedersen *et al.*, 1995), and in approximately 15% at 18 months (Laska *et al.*, 2001). A part of these patients will have a severe aphasia and neither be able to use other strategies (non-verbal or through the use of communication devices) to make themselves clear in everyday life. From this perspective it seems alarming that 27.7% of the residents in our study population can express themselves poorly.

The higher frequency of agitation we found in left-sided strokes, could be related to the higher prevalence of poor expression: Angelelli *et al.* (2004) found that patients with aphasia had a three times greater risk of becoming agitated. Our finding that severe cognitive impairment is more frequent in left-sided strokes, is supported by a study of Patel *et al.* (2002), while other studies found no relation to stroke lateralization (Appelros, 2005; Barker-Collo *et al.*, 2012). Our result could, however, also be caused by a bias in the measurement instrument (CPS) that contains an item of expression. It has been shown that such a bias toward deficits associated with left-sided lesions is also present in standard clinical scales to measure stroke severity (Fink *et al.*, 2008). Finally, the higher frequency of residents with low SE in the group with the largest time-interval post-stroke, might suggest a decline of SE over time. As mentioned before, however, longitudinally research would be necessary to evaluate this evolution. As the RISE has been developed as an indicator of social well-being – itself a relevant component of quality of life (QoL; Gerritsen *et al.*, 2008; Gerritsen *et al.*, 2004) – this hypothesized decline is supported by the results of a recent longitudinally, population-based research showing an annually decline of QoL, up to 5 years post-stroke and independent of other risk factors (Dhamoon *et al.*, 2010).

The primary goal of an integrated care- and treatment program for institutionalized stroke patients is to enhance their quality of life. The data of this cross-sectional, observational study revealed clearly that the monitoring and management of both pain and neuropsychiatric symptoms should be key elements in the program. The characteristics of pain and its relation with neuropsychiatric symptoms should, therefore, be the subject of further research. With regard to cognitive functioning, the question arises whether it should be better monitored. Given the fact that we only included residents living in somatic wards as opposed to dementia special care units, the proportion of residents with severe cognitive impairment (23%) seems very high. It should be questioned whether these residents could be diagnosed as having vascular dementia. Our clinical experience is that formal assessments on the diagnosis of dementia are mostly initiated when cognitive deficits are accompanied by "challenging" behavior, often an important reason for admission to a dementia special care unit. We hypothesize that the severe cognitive deficits in our study population are related to more "silent" neuropsychiatric symptoms, such as the frequently occurring symptom of apathy. There is a great risk of ignoring such "silent" behavior without exploring the possibilities of treatment. The phenomenon of apathy and its clinical correlates should, therefore, be another subject of further research. Finally, with regard to communicative functioning the question is whether there are – at present – realistic options to improve the management of poor expressive abilities.

## Conclusion

This study among institutionalized stroke patients in Dutch NHs revealed very high prevalence of impairments on all domains of functioning. Above the well-known severe disabilities in basic ADL, many residents suffered from pain and many had neuropsychiatric problems. A substantial proportion had poor expressive abilities, and there were many residents with severe cognitive impairment in the context of the somatic wards where they resided. The monitoring and management of both pain and neuropsychiatric symptoms should be key elements in an integrated care and treatment program.

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# CHAPTER 4

4

# Pain among institutionalized stroke patients and its relation to emotional distress and social engagement

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# Abstract

**Objectives:** Pain is a frequent long-term consequence of stroke, but its relation to emotional and social well-being is poorly studied in stroke populations. We aimed to identify the prevalence of substantial pain among institutionalized stroke patients and to explore its relation to emotional distress (ED) and low social engagement (SE).

**Methods:** In a cross-sectional design, we collected data of 274 chronic stroke patients in Dutch nursing homes. Observation lists were filled out in structured interviews with qualified nurse assistants who knew the residents well. Pain and SE were measured with the Resident Assessment Instrument for Long-Term Care Facilities, and ED was measured with the Neuropsychiatric Inventory Questionnaire (NPIQ).

**Results:** Substantial pain was present in 28% of the residents, mostly located in the affected body side (68%). Multilevel regression analyses revealed that this pain was independently related to a 60% increase in NPIQ-score ($\beta$ 3.18 [1.84-4.53]) and to clinically relevant symptoms of delusions (odds ratio [OR] 8.45 [1.82-39.05]), agitation/aggression (OR 3.82 [1.76-8.29]), depression (OR 3.49 [1.75-6.98]), and anxiety (OR 2.32 [1.08-4.97]). Substantial pain was associated with low SE when adjusted for clinical covariates (OR 4.25 [1.72-10.53]), but only in residents with no/mild or severe cognitive impairment. This relation disappeared when additionally corrected for NPIQ-score (OR 1.95 [0.71-5.39]).

**Conclusions:** Pain is a serious and multidimensional problem among institutionalized stroke patients. It is related to increased ED, which in turn can be a pathway to low SE as an indicator of social vulnerability. Future research should reveal how pain management in nursing homes can be tailored to the needs of this patient group.

# Introduction

Pain is a frequent long-term consequence of stroke, encompassing hemiplegic shoulder pain, pain due to muscle stiffness or spasm, headache, and central post-stroke pain as the most common pain types (Klit *et al.*, 2011). Previous research showed that chronic pain following stroke is prevalent in 11-55% of patients at 6 months to 2 years post-stroke (Appelros, 2006; Jonsson *et al.*, 2006; Sackley *et al.*, 2008; Lundstrom *et al.*, 2009; Naess *et al.*, 2010; Klit *et al.*, 2011; Hansen *et al.*, 2012). In a study population of institutionalized stroke patients, we even found a total of 58% suffering from some type of pain (van Almenkerk *et al.*, 2012).

Suffering from pain is not only restricted to physical discomfort but also affects emotional and social well-being. With respect to emotional distress (ED), the association between pain and depression is well-known, and has also been demonstrated in stroke populations (Appelros, 2006; Jonsson *et al.*, 2006; Lundstrom *et al.*, 2009; Klit *et al.*, 2011). Research in various study populations also showed a relationship with anger (in chronic pain patients; Gatchel *et al.,* 2007), agitation and aggression (in nursing home [NH] residents with dementia; Husebo *et al.,* 2011), and anxiety (in patients with fibromyalgia; Gatchel *et al.,* 2007; or osteoarthritis; Smith and Zautra, 2008; and in NH-residents; Smalbrugge *et al.* 2007; Lapane *et al.* 2012). With regard to social well-being, pain is shown to be adversely related to participation in social activities (e.g., in osteoarthritis patients; Machado *et al.,* 2008; and in NH residents; Lapane *et al.,* 2012). Shega *et al.* (2012) demonstrated that pain in community-dwelling older adults is associated with an index of "social vulnerability", that they operationalized as a compilation of variables characterizing a person's social circumstance, including social engagement (SE).

Although the amount of pain studies in stroke populations increased in recent years, the relation of pain to emotional and social well-being in stroke patients is still poorly studied. In this study, we focus on chronic stroke patients who are dependent on institutional long-term care, as part of our aim to develop an integrated care and treatment program for this population. We aim to answer the following research questions:

1) What is the prevalence of substantial pain among institutionalized stroke patients, and where is this pain located?
2) Is this substantial pain independently associated with increased ED? And if so, how is this increased ED characterized?
3) Is this substantial pain independently associated with low SE, as an indicator of social vulnerability?

# Methods

This study is part of the *CAre for STroke In LOng term care facilities in the Netherlands* (CASTILON) study. From May 2008 to July 2009, a cross-sectional, observational study design was used to collect data of chronic stroke patients who received long term care in 17 Dutch NHs (van Almenkerk *et al.*, 2012). Attending physicians (in Dutch NHs delivered by specifically trained physicians, referred to as elderly care physicians [ECPs]) were asked to select their patients according to the following inclusion criteria: (1) stroke was the main diagnosis for NH-admission; (2) the last stroke occurred ≥3 months ago; (3) the need for long-term care was indicated by the multidisciplinary stroke team and discussed with the stroke patient and his or her relatives; and (4) the resident stayed ≥1 month on a long-term care ward. We collected data of each resident through an observation list that was filled out in a structured interview with a qualified nurse assistant who knew the resident well. The use of observation instruments enabled us to include also residents with severe cognitive and/or communicative impairments. All nurse assistants were interviewed by the same trained research assistant. As we will describe in the following measurements section, additional information was provided by the attending ECP. A total of 284 residents were included (ranging from 3 to 31 residents per NH), of which 10 cases were excluded because of incomplete questionnaires. The study protocol was approved by the medical ethics committee of the VU University Medical Center.

## Measurements

***Pain.*** Pain was measured with the pain scale of the Dutch version of the Minimum Data Set of the Resident Assessment Instrument for Long Term Care Facilities (RAI-LTCF), which is easy to administer and commonly used in NH studies (e.g., Achterberg *et al.*, 2010). It defines pain as "any type of physical pain or discomfort of the body. Pain may be localized to one area, or be more generalized. It may be acute or chronic, continuous or intermittent (comes and goes), occur at rest or with movement." The validity and precision of pain measurement with the RAI-LTCF items have been established against the Visual Analogue Scale in a study involving 95 US NH-residents (Fries *et al.*, 2001).

The RAI-LTCF pain scale addresses the following pain characteristics: *pain frequency,* coded as no pain (0), less than daily pain (1), and daily pain (2) in the last 7 days; *pain intensity,* categorized as no pain, mild pain (0), moderate pain (1), and severe pain (2, defined as "times when pain is horrible or excruciating") in the last 7 days; and *pain location,* with the following categories: (i) back pain; (ii) bone pain; (iii) chest pain while doing usual activities; (iv) headache; (v) hip pain; (vi) incisional pain; (vii) joint pain, other than hip; (viii) soft tissue pain (e.g., lesion and muscle); (ix) stomach pain; and (x) other pain. For the purpose of this study we added the category "pain in the affected body side." For additional information, researchers MS, JE, and CH reviewed medication lists to identify the prescription of analgesics and psychotropics, coded as yes/no.

We defined pain as substantial when the product of pain frequency and pain intensity was ≥2, referring to severe or daily moderate pain (Pieper *et al.*, 2011).

***Emotional distress.*** The amount of ED was assessed using the NPIQ (de Jonghe *et al.*, 2003), which covers a broad range of neuropsychiatric (NP) symptoms in 12 domains. Each domain is assessed by a screening question that covers core symptom manifestations. When these symptoms are present in the last month, symptom severity is evaluated on a 3-point scale (1-mild, 2-moderate, 3-severe).

The total NPIQ-score is the sum of individual symptom scores and represents the amount of ED, ranging from 0 (no NP symptoms present) to 36 (all NP symptoms present with maximum severity).

We defined an individual NP symptom to be clinically relevant when its severity was ≥2 (moderate or severe; Kaufer *et al.*, 2000).

***Social engagement.*** SE was measured by the RAI-LTCF Revised Index for Social Engagement (RISE; Gerritsen *et al.*, 2008), which is constructed from the following six items: (i) at ease interacting with others; (ii) at ease doing planned or structured activities; (iii) accepts invitations into most group activities; (iv) pursues involvement in life of facility; (v) initiates interaction(s) with others; and (vi) reacts positively to interactions initiated by others. The RISE ranges from 0 (lowest level) to 6 (highest level of SE).

We considered a RISE-score of 0-2 to be indicative of low SE (Achterberg *et al.*, 2003).

***Clinical covariates.***

*Demographics.* A resident's age, gender and marital status were administered.

*Stroke characteristics.* ECPs provided information about stroke subtype (hemorrhagic or ischemic), stroke location (left-sided or right-sided; the category "other location" is not included in the analyses), and time post-stroke.

*Comorbidity.* ECPs provided information about the presence of diagnoses other than stroke that influenced a resident's current status of functioning. We counted the total number of different diagnoses according to the *International Statistical Classification of*

*Diseases and Related Health Problems,* 10th revision coding system (Quail *et al.*, 2011), and dichotomized it on the median.

*Physical functioning.* Performance in basic activities of daily living (ADL) was measured by the 20-point Barthel Index (BI). We categorized ADL-dependency as “very severe” (BI 0-4; de Haan *et al.*, 1993), “severe” (BI 5-11), and “moderate/mild” (BI ≥12; Sulter *et al.*, 1999). To the best of our knowledge, there is no valid observation instrument to measure fatigue (Lerdal *et al.*, 2009). To have an indication of the amount of fatigue, we asked the nurse assistant how many hours in a 24-hour day the resident stayed in bed.

*Cognitive functioning.* Cognitive functioning was measured by the RAI-LTCF Cognitive Performance Scale (CPS), which has good agreement with the Mini Mental State Examination in the detection of cognitive impairment in NH-residents (Paquay *et al.*, 2007). The CPS is a seven-category index, ranging from cognitively intact (0) to very severely impaired (6). We categorized the CPS by combining the three severe categories as “severe” (CPS 4-6), the middle two categories as “moderate” (CPS 2-3), and the remaining two categories as “no/mild” cognitive impairment (CPS 0-1).

*Communicative functioning.* Communicative functioning was measured using the RAI-LTCF items “ability to make him/herself clear” (expression) and “ability to understand others” (comprehension; Morris *et al.*, 2006). Both items are evaluated on a 5-point frequency scale (always, usually, often, sometimes, and rarely or never). We dichotomized the scores by combining the first three categories in “good or moderate” and the last two categories in “poor”.

## Statistical analyses

Descriptive statistics were firstly generated for the assessed pain characteristics and medication categories and secondly for the other variables stratified to the presence or absence of substantial pain. To explore differences in the clinical covariates between the subgroups, we performed univariable analyses using IBM SPSS Statistics version 20 (Armonk, NY, USA): an independent t-test for age (normally distributed), a nonparametric Mann-Whitney U test for time post-stroke (not normally distributed), and $\chi^2$-statistics for dichotomous variables (Fisher’s exact test 2-sided) and categorical variables (Pearson $\chi^2$ 2-sided).

To investigate the association between substantial pain (independent variable) and ED and low SE (outcome measures), we used multilevel analyses to adjust for possible dependence of observations, due to the clustering of residents within ECPs (second level) and NHs (third level; Twisk, 2006). The relations were analyzed with linear multilevel regression techniques (pain and NPIQ-score; assumptions of linearity and normality were checked with an analysis of residuals) and logistic multilevel regression techniques (pain and clinically relevant NP-symptoms; pain and low SE). Possible confounders were entered into the models in two consecutive steps: (1) all clinical covariates and (2) the other outcome measure (NPIQ-score or low SE). Furthermore, we investigated whether age, gender, stroke location, cognitive impairment, and poor expression modified the relations (only with respect to the outcome measures NPIQ-score and low SE), by adding each interaction term separately to the crude models (significance level $P < 0.10$). All multilevel analyses were performed with second-order penalized quasi-likelihood estimation procedures, using MLwiN 2.24 (Centre for Multilevel Modeling, University of Bristol, UK).

## Results

Table 1 shows the prevalence of the assessed pain characteristics and the prescription of medication. In the total study population ($n = 274$), 58% experienced some type of pain (i.e., daily or less than daily pain). In two-thirds of these residents, pain intensity was evaluated as moderate or severe (47.2% and 18.9%). A total of 27.7% suffered from substantial pain. This was mostly located in the stroke-affected body side (68.4%), followed by soft tissue pain (23.7%) and back pain (21.1%).

Table 2 demonstrates the characteristics of the study population, stratified by the presence or absence of substantial pain. Univariable analyses only showed that residents in pain had more bed rest, relative to residents not in pain (Pearson $\chi^2$ [2, n = 274] = 15.39, p = 0.000).

Mean NPIQ-score was 8.68 (± 6.12) and 5.35 (± 4.50), respectively, for residents with and without substantial pain (Table 2). In the crude multilevel analysis (Table 3), substantial pain contributed 3.08 [1.81-4.34] points to the NPIQ-score, without any identified effect modification. This association sustained when the model was corrected for clinical covariates (model 1, $\beta$ 3.56 [2.18-4.93]) and when additionally corrected for low SE (model 2, $\beta$ 3.18 [1.84-4.53]). Relative to residents not in pain (mean NPIQ-score 5.35), this indicates an increase of almost 60%.

The most occurring clinically relevant NP symptom was irritability/lability (in 52.6% and 39.4% of residents with and without substantial pain, respectively), followed by dysphoria/depression (51.3% and 34.3%), and apathy/indifference (38.2% and 23.2%; Figure 1). In the multilevel analyses (Table 3), substantial pain appeared to be independently related to the symptoms of delusions (model 2, OR 8.45 [1.82-39.05]),

**Table 1. Pain Characteristics of Institutionalized Stroke Patients and Prescription of Analgesics and Psychotropics**

| | n (%) |
|---|---|
| Pain frequency (*n* = 274) | |
| no pain | 115 (42.0) |
| less than daily | 65 (23.7) |
| daily | 94 (34.3) |
| Pain intensity (*n* = 159)[a] | |
| mild | 54 (34.0) |
| moderate | 75 (47.2) |
| severe | 30 (18.9) |
| Substantial pain (n = 274)[b] | 76 (27.7) |
| Pain location (*n* = 76)[c] | |
| in the affected body side | 52 (68.4) |
| soft tissue pain | 18 (23.7) |
| back pain | 16 (21.1) |
| joint pain, other than hip | 13 (17.1) |
| other pain | 9 (11.8) |
| hip pain | 9 (11.8) |
| headache | 6 (7.9) |
| stomach pain | 2 (2.6) |
| chest pain | 2 (2.6) |
| incisional pain | 1 (1.3) |
| bone pain | 0 (0.0) |
| Analgesics (*n* = 274) | |
| acetaminophen | 111 (40.5) |
| nonsteroidal anti-inflammatory drugs | 22 (8.0) |
| weaker opioids | 16 (5.8) |
| stronger opioids | 14 (5.1) |
| Psychotropics (*n* = 274) | |
| antidepressants | 101 (36.9) |
| anxiolytics/hypnotics | 86 (31.4) |
| antiepileptics | 58 (21.2) |
| antipsychotics | 22 (8.0) |

[a] in residents with (less than) daily pain.

[b] defined as severe or daily moderate pain.

[c] in residents with substantial pain.

agitation/aggression (OR 3.82 [1.76-8.29]), dysphoria/depression (OR 3.49 [1.75-6.98]), and anxiety (OR 2.32 [1.08-4.97]).

A low SE was present in 40.8% and 26.3% of residents with and without substantial pain, respectively (Table 2). In the crude multilevel analyses, the association between substantial pain and low SE appeared to be modified by the level of cognitive impairment ("moderate" versus "no/mild", Wald $\chi^2$ 4.61, df=1, p <0.05; "moderate" versus "severe", Wald $\chi^2$ 3.67, df=1, p <0.10; but no modification by "no/mild" versus "severe", Wald $\chi^2$ 0.01, df=1, p >0.10). Therefore, we present stratified results (Table 3). Only residents with no/mild or severe cognitive impairment were more likely to have low SE when they were in pain, both in the crude model (OR 2.72 [1.44-5.15]) and when adjusted for clinical covariates (model 1, OR 4.25 [1.72-10.53]). However, when the model was additionally corrected for NPIQ-score, the relationship disappeared (model 2, OR 1.95 [0.71-5.39]). Furthermore, the model showed an independent association between the NPIQ-score and low SE (OR 1.19 [1.08–1.31] per 1-point increase of the NPIQ-score).

## Discussion

This explorative, cross-sectional study among institutionalized stroke patients shows that a total of 28% experience substantial pain (severe or daily moderate), which is mostly located in the side of the body that is affected by the stroke. Residents with (substantial) pain have more ED as opposed to residents without pain, expressed by a 60% increase of NP symptoms. They are especially more likely to exhibit clinically relevant symptoms of delusions, agitation/aggression, depression, and anxiety. Furthermore, substantial pain is associated with social vulnerability, expressed by a four times higher prevalence of low SE. However, the results suggest that this relationship is only present in residents with no/mild or severe cognitive impairment and disappears when the amount of ED is taken into account.

Pain prevalence among institutionalized stroke patients (58% have some type of pain in our study) can be expected to be higher than in the general stroke population (11%-45%). We are aware of one study with a similar study population to ours: Sackley *et al.* (2008) investigated complications in patients with severe strokes (BI score ≤10) and found during the first year shoulder- and other types of pain in 52-55% of patients, comparable with our findings. However, they did not investigate pain frequency and intensity, so we are not able to compare our finding that 28% suffer from substantial pain.

**Table 2. Characteristics of Institutionalized Stroke Patients With and Without Substantial Pain (Pain+ and Pain–, respectively)**

| | Pain+ (n=76) | Pain– (n=198) | *p*-value |
|---|---|---|---|
| | n (%) | n (%) | |
| Age (mean ± SD, years) | 75.7 ± 10.9 | 77.0 ± 10.5 | 0.393 |
| Female | 45 (59.2) | 115 (58.1) | 0.892 |
| Single/widowed | 44 (57.9) | 125 (63.1) | 0.488 |
| Ischemic stroke | 58 (80.6) | 155 (81.6) | 0.860 |
| Right-sided stroke *(n missing=29)* | 42 (63.6) | 90 (50.3) | 0.083 |
| Time post-stroke (median [IQR], months) | 41 [16.50-72] | 49 [26.75-87.75] | 0.108 |
| ≥2 comorbid diagnoses | 45 (59.2) | 102 (51.5) | 0.280 |
| Dependency in basic ADL | | | |
| very severe | 45 (59.2) | 87 (43.9) | |
| severe | 27 (35.5) | 90 (45.5) | 0.059 |
| moderate/mild | 4 (5.3) | 21 (10.6) | |
| Bed rest | | | |
| <12h | 27 (35.5) | 108 (54.5) | |
| 12-16h | 30 (39.5) | 73 (36.9) | 0.000 |
| >16h | 19 (25.0) | 17 (8.6) | |
| Cognitive impairment | | | |
| no/mild | 44 (57.9) | 100 (50.5) | |
| moderate | 17 (22.4) | 50 (25.3) | 0.537 |
| severe | 15 (19.7) | 48 (24.2) | |
| Poor comprehension | 9 (11.8) | 23 (11.6) | 1.000 |
| Poor expression | 17 (22.4) | 59 (29.8) | 0.231 |
| NPIQ-score (mean ± SD) | 8.68 ± 6.12 | 5.35 ± 4.50 | NT |
| Low social engagement | 31 (40.8) | 52 (26.3) | NT |

Values are *n* (%) unless otherwise indicated.

NT, not tested because these characteristics are outcome measures in multilevel analyses; IQR, interquartile range; ADL, activities of daily living; NPIQ, Neuropsychiatric Inventory Questionnaire.

**Table 3. Multilevel Analyses of the Association Between Substantial Pain, and Emotional Distress and Low Social Engagement**

| Outcome measure | Crude model | Model 1 | Model 2 |
|---|---|---|---|
| | ***β*** | ***β*** | ***β*** |
| NPIQ-score | 3.08 [1.81-4.34]* | 3.56 [2.18-4.93]* | 3.18 [1.84-4.53]* |
| Clinically relevant NP-symptoms: | **OR** | **OR** | **OR** |
| Delusions | 5.71 [3.16-18.20]* | 7.79 [1.86-32.71]* | 8.45 [1.82-39.05]* |
| Hallucinations | 2.67 [0.53-13.52] | 3.68 [0.45-29.97] | 3.32 [0.38-28.89] |
| Agitation/Aggression | 3.27 [1.78-6.00]* | 4.13 [1.93-8.86]* | 3.82 [1.76-8.29]* |
| Dysphoria/Depression | 2.02 [1.18-3.45]* | 3.78 [1.91-7.49]* | 3.49 [1.75-6.98]* |
| Anxiety | 2.00 [1.05-3.80]* | 2.30 [1.08-4.91]* | 2.32 [1.08-4.97]* |
| Elation/Euphoria | 1.90 [0.78-4.65] | 2.66 [0.79-8.96] | 3.01 [0.88-10.31] |
| Apathy/Indifference | 1.70 [0.89-3.25] | 1.95 [0.81-4.69] | 1.48 [0.53-4.18] |
| Disinhibition | 1.53 [0.51-4.61] | 1.63 [0.34-7.79] | 1.62 [0.39-6.70] |
| Irritability/Lability | 1.71 [1.00-2.91]* | 1.42 [0.75-2.69] | 1.25 [0.65-2.40] |
| Aberrant motor behaviors | 2.85 [1.14-7.14]* | 2.83 [0.95-8.40] | 2.71 [0.89-8.25] |
| Nighttime behavioral disturbances | 2.03 [1.01-4.09]* | 2.09 [0.90-4.82] | 2.03 [0.87-4.72] |
| Appetite/eating disturbances | 1.18 [0.49-2.83] | 1.67 [0.59-4.75] | 1.67 [0.59-4.74] |
| Low social engagement (SE) | | | |
| • moderate cognitive impairment | 0.60 [0.17-2.12] | 0.16 [0.01-1.82] | 0.15 [0.01–1.77] |
| • no/mild or severe cognitive impairment | 2.72 [1.44-5.15]* | 4.25 [1.72-10.53]* | 1.95 [0.71-5.39] |

*β* and OR presented with 95% confidence interval. Model 1, adjusted for clinical covariates; Model 2, additionally adjusted for low SE, or NPIQ-score (with regard to low SE as outcome measure). NPIQ, Neuropsychiatric Inventory Questionnaire; NP, neuropsychiatric; SE, social engagement.

**p* <0.05.

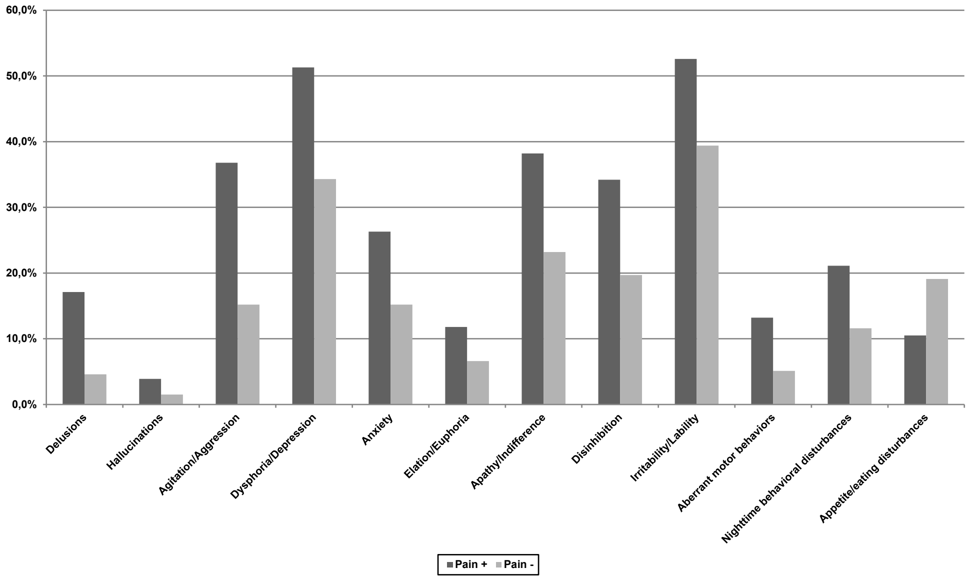

**Figure 1.** Prevalence of clinically relevant neuropsychiatric symptoms among institutionalized stroke patients with and without substantial pain (pain+ and pain–, respectively).

Our finding that the most common pain location is the affected body side suggests that in many residents the pain is stroke-related. This argues for further research on stroke-specific pain types in institutionalized stroke patients. For example, a recent NH-study found (possible) central post-stroke pain in 10% of residents, highlighting the need for validated tools to screen and diagnose specific pain types (van Kollenburg *et al.*, 2012).

The increased ED we demonstrated in residents with substantial pain is in line with studies in various patient populations as outlined in the introduction. Because of the cross-sectional design of our study, we are not able to draw conclusions about the direction of the causal pathway. However, from a biopsychosocial perspective (Gatchel *et al.*, 2007), it can be expected that the relationship between pain and ED is bidirectional. In this view, biological (sensory) and emotional processes are tightly integrated in the pain experience in the brain, especially with regard to chronic pain. As a result, ED not only occurs in response to pain but also triggers, maintains, or exacerbates pain. Longitudinal research on this subject would be very desirable.

The use of the NPIQ allowed us to explore the relation of pain with a broad range of NP symptoms. For the most part though, the increased ED is characterized by symptoms known from previous research as outlined in the introduction (agitation/aggression, depression, and anxiety). With regard to depression, our result is rather in line with the mentioned stroke studies, showing ORs ranging from 2.1 to 4.1. In addition, our results demonstrated that residents in pain are much more likely to show delusions. Although this association was also revealed in a study among NH-residents with cognitive impairment (Tosato *et al.*, 2012), we are not able to explain it. Further research is needed to confirm or reject this result.

With respect to the relation between substantial pain and low SE, we firstly want to consider the finding that the demonstrated association in model 1 (in residents with no/mild or severe cognitive impairment) disappeared when additionally corrected for the amount of ED. This result suggests that ED acts as a pathway in the relation between pain and low SE, meaning that pain is associated with increased ED (relation A1), which in turn is related to low SE (relation A2). Our results show that the conditions for such a mediated model (Baron & Kenny, 1986) are satisfied: relations A1 and A2 are significant, and the direct relation between pain and low SE is no longer significant when it is controlled for relations A1 and A2. This suggests that substantial pain is not directly related to low SE as an indicator of social vulnerability, but only through ED. This finding is in line with a longitudinal study among patients with osteoarthritis, in which psychological (depressive) symptoms also were shown to be a pathway between physical symptoms (including pain) and subsequent participation restrictions 18 months later (Machado *et al.*, 2008).

Assuming an association between pain and low SE that is mediated by ED, we want to evaluate our finding that this relation seems to be modified by cognitive functioning. Of course, we have to interpret this result very cautiously, owing to the small size of subgroups in the analyses. But in relation to what is known from literature, this finding might be clinically relevant. Although the relation between pain and the *amount* of increased ED appeared to be similar across levels of cognitive impairment, it is still possible that the *character* of this increased ED is modified. It is known from research in NH-residents that the prevalence of individual NP symptoms is related to the severity of cognitive impairment (Zuidema *et al.*, 2009) and changes over time (Wetzels *et al.*, 2010). For example, symptoms of depression and anxiety tend to decrease as dementia progresses. Therefore, we hypothesize that the increased ED associated with pain among institutionalized stroke patients is characterized by other (combinations of) NP symptoms across levels of cognitive impairment. In turn, the relation with low SE (relation A2) could differ across these (combinations of) individual NP symptoms.

This study has some limitations. We already mentioned the cross-sectional design that does not allow us to gain insight in the evolution of symptoms and the direction of causal pathways. Secondly, in the context of the explorative character of the study, we tested many relations and interactions, possibly affecting the robustness of the results. A third limitation is the lack of detailed information about pain management strategies, such as adequacy of drug dosing or identification of co-analgesics and non-pharmacological interventions. Although it was not the purpose of this paper to evaluate pain management, differences in treatment could bias the relation between pain and NP symptoms. We partly compensated this by performing multilevel analyses that adjust for possible differences between ECPs and NHs. A major strength of this study is the uniqueness of the study population, representing an under researched population on the continuum of stroke care. The use of observation instruments enabled us to include all residents, even those with severe cognitive and/or communicative impairments.

Pain management is a key element to improving quality of care (Morley, 2012), and our findings underline that there still is much to improve. A critical step will be the successful implementation in NHs of existing clinical practice guidelines regarding assessment and treatment of pain (e.g., Achterberg *et al.,* 2012), in which organizational and educational aspects play important roles (Swafford *et al.*, 2009; Barry *et al.*, 2012). In addition, future research should reveal how pain management can be tailored to the needs of institutionalized stroke patients. Firstly, accurate pain assessment needs to be optimized for those residents who are limited in self-report because of cognitive and/or communicative impairments, just as has been acknowledged for dementia patients (Achterberg *et al.*, 2013). Secondly, it is of major importance that this group of chronic stroke patients will be included in research on stroke-specific pain types. Finally, gaining further insight into the interaction between pain and emotional and social well-being could open new areas of intervention. More adequate pain interventions could hopefully reduce related ED, as shown in dementia patients (e.g., Husebo *et al.,* 2014). In complement, interventions targeting ED may also reduce the experience of pain, especially with regard to chronic pain. As far as we know, this has not been evaluated in stroke patients to date.

## Conclusion

This explorative study is the first to show that pain is a serious and multidimensional problem among institutionalized stroke patients. It is related to increased ED, which in turn can be a pathway to low SE as an indicator of social vulnerability. Future research should reveal how pain management in NHs can be tailored to the needs of this patient group.

## Key points

- Substantial pain is prevalent in 28% of institutionalized stroke patients, mostly located in the stroke-affected body side.
- This pain is independently associated with increased emotional distress, characterized by clinically relevant symptoms of delusions, agitation/aggression, depression, and anxiety.
- This pain is independently associated with low social engagement, possibly mediated by the emotional distress.
- Future research should reveal how pain management in nursing homes can be tailored to the needs of these chronic stroke patients.

## Ethics Statement

This study was approved by the medical ethics committee of the VU University Medical Center, Amsterdam, the Netherlands.

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# CHAPTER 5

# 5

# Apathy among institutionalized stroke patients: prevalence and clinical correlates

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# Abstract

**Objectives:** Apathy is a frequent neuropsychiatric consequence of stroke. In the under researched population of institutionalized stroke patients, we aimed to explore the prevalence of apathy, its clinical correlates, and the relation to the amount of stimulating activities in the nursing home (NH).

**Design:** A cross-sectional, observational study.

**Setting:** Dutch NHs.

**Participants:** 274 chronic stroke patients.

**Measurements:** Data were collected through observation lists that were filled out in structured interviews with qualified nurse assistants who knew the residents well. The lists comprised the NH-version of the Apathy Evaluation Scale (AES10), the Barthel Index, the Neuropsychiatric Inventory Questionnaire, and sections of the Resident Assessment Instrument for Long-Term Care Facilities. Attending physicians and therapists provided additional information.

**Results:** Apathy (AES10-score ≥30) was present in 28% of residents. Multilevel regression analyses revealed that this apathy was independently related to (moderate, severe) cognitive impairment (odds ratio [OR] 11.30 [95% confidence interval (CI): 4.96-25.74], OR 5.54 [95% CI: 2.48-12.40]), very severe ADL-dependency (OR 12.10 [95% CI: 1.35-108.66]), and being >12 hours per day in bed (OR 2.10 [95% CI: 1.07-4.13]). It was not related to depressive mood symptoms (OR 1.75 [95% CI: 0.91-3.37]). Only in residents aged less than 80 years were a higher amount of activities independently related to a lower AES10-score (-0.70 [95% CI: -1.18 to -0.20] points per four extra activities in a 4-week period).

**Conclusions:** Apathy is prevalent in largely one-quarter of institutionalized stroke patients, and that is most strongly related to cognitive impairment in this explorative study. We discuss the need for research on the relation with distinct dimensions of depression and fatigue as partly overlapping constructs, and on (individualized) stimulating activities as a possible intervention method.

# Introduction

The interest in the wide variety of neuropsychiatric consequences of stroke is growing worldwide (Robinson, 2013). This neuropsychiatric spectrum includes the syndrome of apathy, defined as a persisting disorder of motivation that can be manifested in reduced goal-directed behavior, reduced goal-directed cognition, and reduced emotions (Starkstein & Leentjens, 2008; Robert *et al.*, 2009). Two recent meta-analyses found a pooled rate of post-stroke apathy of 35%-36% (Caeiro *et al.*, 2013; van Dalen *et al.*, 2013). It seems to be rather stable over time, as shown by longitudinal studies with a follow-up of 6-15 months post-stroke (Mayo *et al.*, 2009; Castellanos-Pinedo *et al.*, 2011; Withall *et al.*, 2011).

In this study we focus on the under researched population of chronic stroke patients who are dependent on institutional long-term care. From several perspectives we may expect this group of stroke survivors to be highly prone to apathy. Firstly, apathy can arise as a direct consequence of brain damage, which is most severe in this population. Neuroimaging and pharmacological studies on apathy in various patient populations indicate the involvement of frontal lobes and connected subcortical structures (van Reekum *et al.*, 2005; Ishii *et al.*, 2009). Secondly, post-stroke apathy is shown to be consistently associated with depression, higher rates of cognitive impairment, and increased disability (Caeiro *et al.*, 2013; van Dalen *et al.*, 2013). These impairments are all highly prevalent in our study population (van Almenkerk *et al.*, 2012). Finally, apathy may occur as a normal human response to the environment of the nursing home (NH) in which the usual resources of stimulation are removed. Some evidence exists that an increase of stimulation, such as cognitive stimulation activities (Niu *et al.*, 2010), individual activity therapy (Politis *et al.*, 2004), and multi-sensory stimulation (Verkaik *et al.*, 2005), might reduce apathy in NH-residents with dementia.

Results of longitudinal studies on post-stroke apathy indicate negative effects on physical and cognitive recovery (Santa *et al.*, 2008; Mikami *et al.*, 2013), social participation, and health perception (Mayo *et al.*, 2009). In a large cohort of NH-residents with and without dementia, apathy appeared as the most significant risk factor for weight loss (Volicer *et al.*, 2013). These adverse outcomes highlight the need for a better recognition and understanding of post-stroke apathy in the NH, and for exploring possible intervention strategies that might enhance quality of life. As part of our aim to develop an integrated care and treatment program for institutionalized stroke patients, we aim to explore the following research questions:

1) What is the prevalence of apathy among institutionalized stroke patients?
2) What are the clinical correlates of this apathy?
3) Is the amount of stimulating activities in the NH in which a resident participates, related to the severity of apathetic behavior?

# Methods

This study is part of the *CAre for STroke In LOng term care facilities in the Netherlands* (CASTILON) study. From May 2008 to July 2009 a cross-sectional, observational study design was used to collect data of chronic stroke patients who received long-term care in 17 Dutch NHs (van Almenkerk *et al.*, 2012). Attending physicians (in Dutch NHs delivered by specifically trained physicians, referred to as elderly care physicians [ECPs]) were asked to select their patients according to the following inclusion criteria: 1) stroke was the main diagnosis for NH-admission, 2) the last stroke occurred 3 months or more ago, 3) the need for long-term care was indicated by the multidisciplinary stroke team and discussed with the stroke patient and their relatives, and 4) the resident stayed 1 month or more on a somatic long-term care ward. We collected data on each resident through an observation list that was filled out in a structured interview with a qualified nurse assistant who knew the resident well. All nurse assistants were interviewed by the same trained research assistant. As we will describe subsequently, additional information was provided by the attending ECP and therapists. A total of 284 residents were included (ranging from 3-31 residents per NH), of which 10 cases were excluded because of incomplete questionnaires. The study protocol was approved by the medical ethics committee of the VU University Medical Center.

## Measurements

***Apathy.*** Apathetic behavior was measured with a NH-version of the Apathy Evaluation Scale (AES10; Lueken *et al.*, 2007). This AES10 strongly correlates to the original 18-item AES that is one of the most psychometrically robust measures for assessing apathy (Clarke *et al.*, 2011). It consists of ten items, each giving an example of apathetic behavior. Each item is evaluated on a four-point scale, ranging from 1 (not at all characteristic) to 4 (very characteristic), based on observations of the resident's behavior in the last month.

*Severity of apathetic behavior.* The AES10-score (sum of all item scores) represents the severity of apathetic behavior, ranging from 10 (no apathetic behavior) to 40 (maximum apathetic behavior).

*Apathy.* We considered an AES10-score of 30 or higher as indicative for apathy. In a first and preliminary validation study against the first and only formal diagnostic criteria for apathy to date (Robert *et al.*, 2009), this cut-off score had the highest sum of sensitivity (0.71) and specificity (0.70) in a heterogeneous NH-population (Leontjevas *et al.*, 2012).

***Clinical covariates.***

*Demographics*. We administered age, sex, marital status, and educational level.

*Stroke characteristics*. ECPs provided information about stroke subtype (hemorrhagic or ischemic), stroke location (left-sided or right-sided, the category "other location" not included in the analyses), and time post-stroke.

*Comorbidity*. ECPs provided information about the presence of diagnoses other than stroke that influenced a resident's current status of functioning or for which active treatment was given. We counted the total number of different diagnoses according to the *International Statistical Classification of Diseases and Related Health Problems,* 10th revision coding system, and dichotomized it on the median.

*Dependency in basic activities of daily living (ADL)*. ADL-dependency was measured by the 20-point Barthel Index (BI), categorized as "very severe" (BI 0-4; de Haan *et al.*, 1993), "severe" (BI 5-11), and "moderate/mild" (BI ≥12; Sulter *et al.*, 1999).

*Pain:* We assessed pain frequency and intensity through the corresponding items of the Dutch version of the Minimum Data Set of the Resident Assessment Instrument for Long-Term Care Facilities (RAI-LTCF; Fries *et al.*, 2001). Pain frequency is coded as no pain (0), less than daily pain (1), and daily pain (2) in the last 7 days; pain intensity is coded as no pain, mild pain (0), moderate pain (1), and severe pain (2, defined as "times when pain is horrible or excruciating") in the last 7 days. We defined pain as substantial when the product of pain frequency and pain intensity was greater than or equal to 2 (Pieper *et al.*, 2011), referring to severe or daily moderate pain.

*Fatigue or bedrest.* To the best of our knowledge there is no valid observation instrument to measure fatigue. Based on a "case definition" of post-stroke fatigue ("the patient experiences a persistent lack of energy, or an increased need to rest every day or nearly every day, leading to difficulty taking part in everyday activities"; Lynch *et al.*, 2007), we asked the nurse assistant how many hours in a 24-hour day the resident stayed in bed, and dichotomized this on the median.

*Cognitive functioning.* We assessed cognitive functioning through the RAI-LTCF Cognitive Performance Scale (CPS), which has good agreement with the Mini Mental State Examination in the detection of cognitive impairment in NH-residents (Paquay *et al.*, 2007). The CPS is a seven-category index, ranging from cognitively intact (0) to very severely impaired (6). We categorized the CPS by combining the three severe categories as "severe" (CPS 4-6), the middle two categories as "moderate" (CPS 2-3), and the remaining two categories as "no/mild" cognitive impairment (CPS 0-1).

*Emotional functioning.* We assessed a broad range of neuropsychiatric (NP) symptoms using the Neuropsychiatric Inventory Questionnaire (NPIQ; de Jonghe *et al.*, 2003). Each domain is assessed by a screening question that covers core symptom manifestations. When these symptoms are present in the last month, symptom severity is evaluated on a three-point scale (1-mild, 2-moderate, 3-severe).

- *(i) Clinically relevant depressive symptoms:* We analyzed the NPIQ-item dysphoria/depression as an individual NP-symptom, and defined it to be clinically relevant when its severity was moderate or severe (i.e., score ≥2).
- *(ii) Modified NPIQ-score:* The sum of all item scores, except the items apathy/indifference (already assessed through the AES10) and dysphoria/depression (analyzed as an individual NP-symptom). The modified score represents the amount of emotional distress in the domains of delusions, hallucinations, agitation/aggression, anxiety, elation/euphoria, disinhibition, irritability/lability, aberrant motor behaviors, nighttime behavioral disturbances, and appetite/eating disturbances, and ranges from 0 (no NP-symptoms present) to 30 (all remaining NP-symptoms present with maximum severity).

*Communicative functioning.* We assessed expression through the RAI-LTCF item "ability to make him/herself clear" (Morris *et al.*, 2006), which is evaluated on a five-point frequency scale (always, usually, often, sometimes, and rarely or never). We dichotomized the score by combining the first three categories in "good/moderate" and the last two categories in "poor".

*Psychotropic drugs.* The researchers MS, JE, and CH reviewed medication lists to identify the use of psychotropics in the following categories: antipsychotics (AP), antidepressants (AD), anxiolytics/hypnotics (Anx/Hyp), antiepileptics (AE), and other psychotropics (OP). Additionally, we counted for each resident the total number of categories.

***Stimulating activities.*** We defined a stimulating activity as any therapeutical or social activity that was offered by a NH-professional outside routine daily care, and in which the resident participated. All attending paramedical therapists (physical therapist, occupational therapist, speech/language therapist, dietician), psychosocial therapists (psychologist, social worker, spiritual carer), and activity therapists provided information about the amount of individual and group activities in which the resident participated. We counted the total amount of activities in the last 4 weeks that lasted more than 15 minutes.

### Statistical analyses

We generated descriptive statistics for all assessed variables using IBM SPSS Statistics version 20.

To investigate the clinical correlates of apathy, we performed multilevel logistic regression techniques with AES10-score 30 and higher as the outcome measure. Firstly, we conducted bivariate regression analyses, resulting in crude odds ratios (ORs) and 95% confidence intervals (CIs). Assumptions of linearity were checked for all continuous measures, but were not confirmed for age and time post-stroke. As a consequence, we transformed these variables into categories. Subsequently, we selected the variables that were associated with apathy at the $p < 0.20$ level, entered these into the multivariate model, and checked for collinearity. We used a backward selection procedure based on the Wald-statistic, until all clinical covariates were associated with apathy at the $p < 0.10$ level. The level of significance was set at $p < 0.05$.

To investigate the relation between the amount of stimulating activities and the severity of apathetic behavior, we performed multilevel linear regression techniques with the AES10-score as outcome measure. We investigated whether age and sex modified the relation, by adding each interaction term separately to the bivariate model (significance level $p < 0.10$). Then all assessed clinical covariates were entered into the model as possible confounders. Assumptions of linearity and normality of the final model were checked with an analysis of residuals.

We used multilevel analyses to adjust for possible dependency of observations, due to the clustering of individual residents (first level) within ECPs (second level) and NHs (third level; Twisk, 2006). These analyses were performed with second-order penalized quasi-likelihood estimation procedures, using MLwiN 2.24 (Centre for Multilevel Modeling, University of Bristol, UK).

## Results

### Prevalence of apathy

In the total study sample of 274 residents (mean age 76.6 years, 58.4% women, median time post-stroke 47 months), the mean AES10-score was 23.73 (± 9.10, range 10-40). Apathy (defined as AES10-score ≥30) was prevalent in 28.1% of the residents (n = 77). Across the NHs, the mean AES10-score ranged from 19.67 ± 4.93 to 31.32 ± 7.91, and the apathy rate from 0% (n = 0 out of 3) to 59.1% (n = 13 out of 22).

## Clinical correlates of apathy

Table 1 describes the characteristics of the residents with and without apathy, together with the results of the multilevel bivariate regression analyses on apathy (crude ORs). In these analyses apathy appeared to be associated with more dependency in basic ADL, being more than 12 hours per day in bed, more cognitive impairment, and poor expression, all at the $p < 0.01$ level. All clinical covariates associated with apathy at the $p < 0.20$ level were selected for the multilevel multivariate regression analysis. Table 2 shows the final result after the backward selection procedure. Based on evaluation of the Wald-values, apathy showed the strongest association with cognitive impairment (OR 11.30 [95% CI: 4.96-25.74] for severe, and OR 5.54 [95% CI: 2.48-12.40] for moderate cognitive impairment). Very severe ADL-dependency (OR 12.10 [95% CI: 1.35-108.66], referenced to the category moderate/mild), and being more than 12 hours per day in bed (OR 2.10 [95% CI: 1.07-4.13]) appeared as the other clinical correlates of apathy. The presence of clinically relevant depressive symptoms was not significantly associated with apathy (OR 1.75 [95% CI: 0.91-3.37], $p = 0.096$)

## Relation between apathetic behavior and amount of stimulating activities

In the total study sample, residents participated in a median amount of 10 (interquartile range [IQR]: 5-17, range: 0-72] activities in a 4-week period. The association between the amount of activities and the AES10-score appeared to be modified by age (Wald $\chi^2 = 6.95$, df = 1, $p < 0.01$). Because of this interaction effect, we present the results for both age groups separately.

Residents aged less than 80 years and 80 years and older participated in a median amount of 11 [IQR: 5-18, range: 0-72] respectively 8 [IQR: 4-15, range: 0-46] activities (Mann-Whitney U-test, $z = -2.48$, $p = 0.01$). The relation between the amount of activities and the AES-score for both age groups is illustrated in Figure 1. Table 3 shows the stratified results of the multilevel regression analyses. Only in the younger residents did the association appear to be significant: four extra activities in a 4-week period were associated with a lower AES10-score of -0.94 (95% CI: -1.38 to -0.50) points in the crude model. This association sustained when the model was corrected for all assessed clinical covariates (-0.70 [95% CI: -1.18 to -0.20] points).

**Table 1. Characteristics of Institutionalized Stroke Patients With and Without Apathy and Multilevel Bivariate Regression Analyses with Apathy as Outcome Measure**

| | Apathy (n=77) | No Apathy (n=197) | crude OR | 95% CI | |
|---|---|---|---|---|---|
| | n (%) | n (%) | | lower | upper |
| Age ≥ 80 years | 38 (49.4) | 82 (41.6) | 1.51 | 0.87 | 2.62 *** |
| Female sex | 44 (57.1) | 116 (58.9) | 0.98 | 0.57 | 1.69 |
| Single/widowed | 49 (63.6) | 120 (60.9) | 1.20 | 0.69 | 2.09 |
| Education *(n missing=102)* | | | | | |
| only primary | 17 (34.7) | 48 (39.0) | 1.05 | 0.37 | 2.96 |
| secondary | 25 (51.0) | 55 (44.7) | 1.35 | 0.50 | 3.69 |
| high | 7 (14.3) | 20 (16.3) | reference | | |
| Ischemic stroke *(n missing=12)* | 63 (85.1) | 150 (79.8) | 1.60 | 0.75 | 3.41 |
| Right-sided stroke *(n missing=29)* | 34 (48.6) | 98 (56.0) | 0.76 | 0.43 | 1.34 |
| Time post-stroke (years) | | | | | |
| ≤2 | 18 (23.4) | 54 (27.4) | reference | | |
| 2≤4 | 20 (26.0) | 48 (24.4) | 1.27 | 0.59 | 2.74 |
| 4≤7 | 25 (32.5) | 43 (21.8) | 1.80 | 0.85 | 3.80 *** |
| >7 | 14 (18.2) | 52 (26.4) | 0.74 | 0.33 | 1.68 |
| ≥2 comorbid diagnoses | 42 (54.5) | 105 (53.3) | 1.06 | 0.62 | 1.81 |
| Dependency in basic ADL | | | | | |
| moderate/mild (BI ≥12) | 1 (1.3) | 24 (12.2) | reference | | |
| severe (BI 5-11) | 20 (26.0) | 97 (49.2) | 4.78 | 0.58 | 39.60 *** |
| very severe (BI 0-4) | 56 (72.7) | 76 (38.6) | 18.32 | 2.27 | 147.73 * |
| Substantial pain | 24 (31.2) | 52 (26.4) | 1.16 | 0.64 | 2.10 |
| Bedrest > 12 hr per day | 51 (66.2) | 88 (44.7) | 2.50 | 1.41 | 4.40 * |

**Table 1. Continued**

| | Apathy (n=77) | No Apathy (n=197) | crude OR | 95% CI | |
|---|---|---|---|---|---|
| | n (%) | n (%) | | lower | upper |
| Cognitive impairment | | | | | |
| no/mild (CPS 0-1) | 15 (19.5) | 129 (65.5) | reference | | |
| moderate (CPS 2-3) | 24 (31.2) | 43 (21.8) | 5.34 | 2.48 | 11.52 * |
| severe (CPS 4-6) | 38 (49.4) | 25 (12.7) | 15.67 | 7.28 | 33.73 * |
| Clinically relevant depressive symptoms | 37 (48.1) | 70 (35.5) | 1.68 | 0.96 | 2.85 ** |
| Modified NPIQ-score (mean±SD[range]) | 5.00±4.25[0-20] | 4.28±4.17[0-19] | 1.03 | 0.97 | 1.10 |
| Poor expression | 38 (49.4) | 38 (19.3) | 4.31 | 2.40 | 7.74 * |
| Psychotropics | | | | | |
| Antipsychotics | 9 (11.7) | 13 (6.6) | 1.66 | 0.67 | 4.14 |
| Antidepressants | 32 (41.6) | 69 (35.0) | 1.26 | 0.73 | 2.19 |
| Anxiolytics/Hypnotics | 22 (28.6) | 64 (32.5) | 0.80 | 0.44 | 1.45 |
| Antiepileptics | 14 (18.2) | 44 (22.3) | 0.71 | 0.36 | 1.41 |
| Other | 1 (1.3) | 3 (1.5) | 0.88 | 0.09 | 8.85 |
| No. of categories (mean±SD[range]) | 1.01±0.94[0-3] | 0.98±0.87[0-3] | 0.98 | 0.72 | 1.34 |

ADL, activities of daily living; BI, Barthel Index; CPS, Cognitive Performance Scale; modified NPIQ-score, Neuropsychiatric Inventory Questionnaire score except the items dysphoria/depression and apathy/indifference; SD, standard deviation; OR, odds ratio; CI, confidence interval.

*p*-values are based on a Wald $\chi^2$ test with df = 1. * $p < 0.01$, ** $p < 0.10$, *** $p < 0.20$.

**Table 2. Clinical Correlates of Apathy Among Institutionalized Stroke Patients: Multilevel Multivariate Regression Analysis**

| | | 95% CI | | |
|---|---|---|---|---|
| | **adj OR** | lower | upper | **Wald $\chi^2$** |
| Dependency in basic ADL | | | | |
| moderate/mild (BI ≥12) | reference | | | |
| severe (BI 5-11) | 5.50 | 0.60 | 50.69 | 2.27 |
| very severe (BI 0-4) | 12.10 | 1.35 | 108.66 | 4.96 ** |
| Bedrest > 12 hr per day | 2.10 | 1.07 | 4.13 | 4.67 ** |
| Cognitive impairment | | | | |
| no/mild (CPS 0-1) | reference | | | |
| moderate (CPS 2-3) | 5.54 | 2.48 | 12.40 | 17.35 * |
| severe (CPS 4-6) | 11.30 | 4.96 | 25.74 | 33.34 * |
| Clinically relevant depressive symptoms | 1.75 | 0.91 | 3.37 | 2.77 |

ADL, activities of daily living; BI, Barthel Index; CPS, Cognitive Performance Scale; SD, standard deviation; adj OR, adjusted odds ratio; CI, confidence interval. This table shows the final result of the multilevel multivariate regression analysis of preselected variables (*p* <0.20 level in the multilevel bivariate regression analyses, see Table 1) after backward selection. *p*-values are based on a Wald $\chi^2$ test with df = 1.

* *p* <0.01, ** *p* <0.05.

**Table 3. Multilevel Linear Regression Analyses of the Association Between the Amount of Stimulating Activities and Severity of Apathetic Behavior (AES10-score)**

| | | 95% CI | | | | 95% CI | | |
|---|---|---|---|---|---|---|---|---|
| **Per increase of 4 activities in 4 weeks** | **crude $\beta$** | lower | upper | | **adj $\beta$** | lower | upper | |
| Age <80 | −0.94 | −1.38 | −0.50 | * | −0.70 | −1.18 | −0.20 | * |
| Age ≥80 | 0.13 | −0.54 | 0.81 | | 0.22 | −0.47 | 0.91 | |

$\beta$ indicates the difference in AES10-score; adj, adjusted for all assessed clinical covariates.

*p*-values are based on a Wald $\chi^2$ test with df = 1. * *p* <0.05.

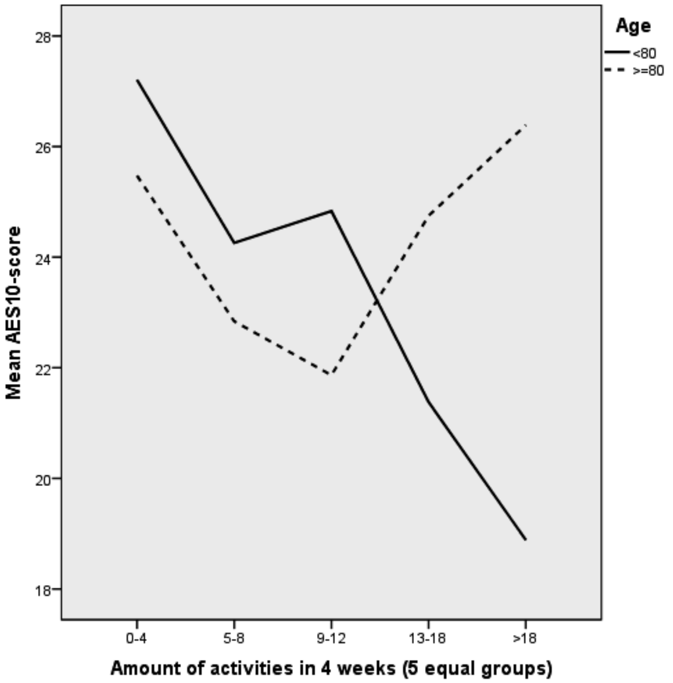

**Figure 1.** Relation between the amount of stimulating activities in a 4-week period (in five equal groups) and the severity of apathetic behavior (measured through the Apathy Evaluation Scale - nursing home version) for residents aged less than 80 years and 80 years and older.

## Discussion

This explorative, cross-sectional study among institutionalized stroke patients indicates that apathy is prevalent in 28% of residents. This apathy is most strongly associated with cognitive impairment, but not related to clinically relevant depressive symptoms. Other clinical correlates are very severe ADL-dependency, and being in bed more than 12 hours per day. Finally, the results suggest that the greater number of activities in which a resident participates is related to less severe apathetic behavior. This association is of small size, however, and appears only in residents less than 80 years.

A major strength of this study is the uniqueness of the study sample, representing an under researched population on the continuum of stroke care. The use of observation instruments enabled us to include all residents, even those with severe cognitive and/or communicative impairments. A second strength is that we classified apathy through an assessment instrument that is not only psychometrically robust, but also for the first time (preliminary) validated against the first and only diagnostic criteria for apathy to date, in contrast to most previous studies on apathy (van Reekum *et al.*, 2005). However, the observed sensitivity and specificity of the optimal cutoff score (AES10 ≥30) still represent a certain misclassification of the presence or absence of apathy. Much more validation research has to be done in the NH- and stroke population, both on the diagnostic criteria as gold standard and on assessment instruments. Our study is mainly limited by its cross-sectional design, which does not allow us to gain insight in the evolution of symptoms and the direction of causal pathways. Nevertheless, the results provide good insight in the manifestation of apathy in everyday clinical practice, in relation to what is already known from the literature. This should encourage NH-professionals to further examine the presence of post-stroke apathy and to explore interventions that may enhance quality of life.

We found a lower prevalence of post-stroke apathy than the pooled rate of 35%-36% in the recent meta-analyses (Caeiro *et al.*, 2013; van Dalen *et al.*, 2013). Van Dalen *et al.* (2013) additionally performed a sensitivity analysis of studies using the recommended AES and/or the apathy subscale of the NPI (Clarke *et al.*, 2011), which resulted in an estimated apathy prevalence of 26.3% (20.5% -33.1%), similar to our result of 28%. The meta-analysis, though, also showed a substantial and persistent heterogeneity, making a comparison of results difficult. Given the long time post-stroke in our study population (median: 47 months), longitudinal research on apathy using validated apathy measures is very desirable. As mentioned in the introduction, existing longitudinal studies seem to indicate that apathy is rather stable over time (Mayo *et al.*, 2009; Castellanos-Pinedo *et al.*, 2011; Withall *et al.*, 2011). Recently, however, Mikami *et al.* (2013) showed that apathy in the first year post-stroke lasted on average almost 6 months. Their study population, however, was small and very selective (56 patients who received placebo as part of a larger treatment trial).

In accordance with the literature, cognitive impairment appeared as a strong clinical correlate of apathy. Firstly, it is likely that loss of cognitive capacities limits a person's ability to organize goal-directed behavior (Marin, 1990). In this view, apathy appears as an intrinsic symptom (or marker) of cognitive deterioration rather than a distinct neuropsychiatric syndrome. This might be true for a subgroup of apathetic residents in our study. Secondly, both apathy and cognitive impairment might be caused by the same underlying brain damage. The frontal lobes and connected subcortical structures that are thought to be involved in apathy are also related to various cognitive functions (van Dalen *et al.*, 2013). It seems relevant to investigate in future research the relation between apathy and distinct cognitive functions. For example, a study among ischemic stroke patients showed that apathy was associated with reduced attention and speed of information processing (Brodaty *et al.*, 2005).

In contrast to what we expected from the recent reviews, we were not able to demonstrate an independent relationship between apathy and (moderate or severe) depressive symptoms. As Hama *et al.* (2011) argued, the current concept of post-stroke depression incorporates both an affective (depressed mood) and an apathetic (loss of interest) dimension. As shown by previous stroke studies, apathy can then be expected to be associated as partly overlapping construct. In contrast, the NPIQ-item dysphoria/ depression only addresses a depressed mood that appeared not to be related to apathy in our study. The importance of the distinction between isolated post-stroke apathy and apathy in the context of post-stroke depression is consistently underlined in the literature, mainly because both conditions lead to different treatment options (Ishii *et al.*, 2009; Robert *et al.*, 2009; van Dalen *et al.*, 2013). When apathy is misdiagnosed as depression and treated by selective serotonine reuptake inhibitors, this may even induce apathy (Barnhart *et al.*, 2004). To increase our understanding of the relation between both constructs, our result supports the notion that future research should focus on the distinct dimensions of depression, rather than on the formal, multidimensional diagnosis. A careful selection of rating scales could make this possible (Ishii *et al.*, 2009). Also research on the relation with stroke location would be very valuable. Recent brain imaging findings suggest that affective and apathetic symptoms after stroke are associated with different neuroanatomic pathways (Murakami *et al.*, 2013).

The demonstrated relation between apathy and dependency in basic ADL is in line with previous findings (van Dalen *et al.*, 2013). Severe dependency may cause apathetic behavior, either as an emotional response (Hama *et al.*, 2011) or because the dependency limits a person’s ability to respond to the environment (Marin, 1990). Reversely, some evidence exists that apathy can lead to less recovery in ADLs (Santa *et al.*, 2008; Mikami *et al.*, 2013). Finally, we would like to focus on a possible underlying factor causing both apathy and ADL-dependency. In the context of the third clinical correlate we found (being in bed >12 hours per day), we hypothesize that fatigue might be this underlying factor. With respect to ADL-dependency, fatigue was identified as an independent predictor in a large cohort-study (Glader *et al.*, 2002). We will now further discuss the relation between fatigue and apathy.

Although we have to be very cautious to interpret the amount of bedrest as an indicator for fatigue, we may at least assume that fatigue is a considerable problem in our study population of survivors of the most severe strokes. From the literature we know that post-stroke fatigue is prevalent in 35%-92% of patients in the first 6 months post-stroke, likely to persist in the long term for patients who develop it (Duncan *et al.*, 2012), and is an independent predictor for institutionalization after stroke (Glader *et al.*, 2002). Moreover, evidence exists that apathetic behavior can be an expression of experienced fatigue. In the development of a self-report instrument, Smets *et al.* (1995)

identified reduced motivation and reduced activity as relevant dimensions of fatigue (besides general, physical, and mental fatigue). To the best of our knowledge, the relation between apathy and fatigue has not been studied in stroke patients to date. Again, to improve our understanding of the relation between both constructs, our results suggest that future research should focus on the distinct dimensions of fatigue, rather than on a general definition of fatigue.

With respect to our last research question, we found that a higher amount of stimulating activities was independently related to less apathetic behavior in residents less than 80 years, suggesting that an increase of stimulation might reduce apathetic behavior. Of course, our cross-sectional design cannot reveal such a causal relationship, and only future experimental research could verify this hypothesis and evaluate its clinical relevancy. Then, it will be important to use a broader definition of stimulating activities, including activities that are offered by informal caregivers and/or relatives. Although we were not able to demonstrate an independent relationship in the high-aged group, the results showed that these residents participated in significantly fewer activities than the younger residents. Therefore, the absence of the association could be explained by loss of statistical power, implicating that high-aged residents should not be excluded beforehand from future research. It might even be – as Figure 1 suggests – that there is an optimum number of stimulating activities to reduce apathetic behavior in residents aged 80 years and older, beyond which an adverse effect arises. It is imaginable that too many stimulating activities could lead to an increase of apathetic behavior (e.g., due to mental fatigue or resistance), and that this point is reached sooner in the high-aged. Finally, the most interesting question to answer with respect to this topic is which elements of stimulating activities are crucial for (possibly) reducing apathy. Are these general aspects as time and attention (in some small intervention trials among dementia patients used as control elements; Politis *et al.*, 2004; Niu *et al.*, 2010), and/or the specific nature of an activity? For example, previous research showed that introducing a nursing guideline that focused on increasing individualized pleasant activities reduced depression in NH-residents with dementia (Verkaik *et al.*, 2011), and possibly in institutionalized stroke patients (Verkaik *et al.*, 2013). We would recommend that future research investigates the efficacy of such intervention methods on both depression and apathy. This might be combined with pharmacological interventions, that showed promising results (Spiegel *et al.*, 2009).

In conclusion, this explorative study shows that apathy is prevalent in largely one-quarter of institutionalized stroke patients. It is most strongly related to cognitive impairment, but not to depressive mood symptoms. Further research on apathy in relation with distinct dimensions of depression and fatigue would improve our understanding of the possible overlap with these multidimensional constructs. The demonstrated relation between a greater number of stimulating activities and less severe apathetic behavior encourages future experimental research on this possible intervention method.

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# CHAPTER 6

6

# How do institutionalized stroke patients express agency in everyday life? Insights into needs for support from a qualitative interview study

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# Abstract

This qualitative interview-study deepens our understanding how institutionalized stroke patients express agency in everyday life, by identifying domains of spending daytime and the formal care-relationship. Preferences in spending daytime are related to either a private-based, social-based, or outdoor-based sense of home. We discussed this as residents' ongoing striving to gain a sense of home within the nursing home, revealing the important role of physical space to support these home-making efforts. Efforts in the formal care-relationship (asking for help, holding on to a familiar and friendly interaction, or holding on to rules and routines) are discussed as residents' ongoing striving to find their own place in an extraordinary relationship, requiring feeling secure and equal as basic needs. It reveals the important role of formal caregivers to understand and support this process in daily interactions. Insight into residents who lack a striving to individualize themselves in the nursing home needs further exploration.

# Introduction

Qualitative research has an important role in healthcare research and development to explore the perspectives and lived experiences of patients and their relatives (Lou *et al.*, 2017). It is increasingly recognized that listening to patients (and relatives) as experts in their everyday lives, is the only way to get more insight into the professional care they may need to support them. Also in stroke research, the dominant focus on quantitative outcome measures is complemented by a growing number of qualitative studies investigating stroke survivors' experiences with life after stroke (McKevitt *et al.*, 2004; Salter *et al.*, 2008; Satink *et al.*, 2013; Hole *et al.*, 2014; Sarre *et al.*, 2014; Woodman *et al.*, 2014). Lou *et al.* (2017) summarize in an overview that stroke is experienced as a profound disruption of life as known, and that during rehabilitation at home stroke survivors are in a difficult and non-linear process of adapting and rebuilding a post-stroke life. Research on the longer-term experience of stroke survivors, varying from 1-13 years post-stroke, even demonstrates that this is an ongoing and continually shifting process (Pallesen, 2014; Arntzen *et al.*, 2015; Hawkins *et al.*, 2017).

The focus in these qualitative studies has been on stroke survivors who are living at home, but there is little knowledge about stroke patients' experiences with living in a nursing home (NH). A considerable proportion of 11%-15% of stroke survivors is dependent on institutional long-term care (Feigin *et al.*, 2010; Liman *et al.*, 2012; Luengo-Fernandez *et al.*, 2013). In their post-stroke lives they have to deal with severe impairments on multiple domains of functioning (van Almenkerk *et al.*, 2012), but also with a living environment that is very different from their pre-stroke home. In this qualitative study, we explore the experiences of these institutionalized stroke patients under these extraordinary circumstances. Central to this phenomenological approach is the recognition that they – like every other human-being - possess agency, i.e. the possibility of acting based on intention (Rose, 2005). As agents, institutionalized stroke patients are still free to undertake actions of their own choice or preference, albeit in circumstances that are not of their own choosing. Only by deepening our understanding how they live their everyday lives as agents within the NH-environment, we will gain insight into what support they may or may not need.

# Methods

## Study design

We performed a qualitative interview study as part of the *Care for STroke In LOng term care facilities in the Netherlands* (CASTILON) project.

## Participants

Participants eligible for this study were NH-residents with stroke as main diagnosis for NH-admission, who experienced a stroke >3 months ago and stayed ≥1 month on a long-term care ward. We approached 14 NHs in the Northern, Middle, and Western part of the Netherlands that had also participated in a quantitative study of the CASTILON-project (van Almenkerk *et al.*, 2012). In consultation with elderly care physicians (ECPs) in these NHs, participants were purposefully selected by socio-demographic characteristics (age, gender, marital status, cultural background, and education level), stroke characteristics (location [left-sided or right-sided] and time post-stroke), and clinical characteristics (cognitive abilities and the ability to make him/herself clear [good, or mildly or moderately impaired]). NH-residents with severe communication deficits, residents for whom participating would cause too much physical and/or emotional burden, and residents who were not able to give informed consent were excluded. The consultations identified 15 potential participants who all suffered an ischemic stroke and were severely dependent in basic activities of daily living (ADL, Barthel-Index <12). They were approached by their attending ECP and received written information about the study. After a two-week-period for reflection and the possibility to consult the ECP or researcher SvA, 14 residents agreed to participate. Prior to the interview, information about the study was verbally repeated by the researcher after which all 14 participants provided written informed consent.

## Data collection

The participants' stories about their everyday post-stroke NH-lives were collected through narrative face-to-face interviews, combined with semi-structured methods (Anderson & Kirkpatrick, 2016). All participants were interviewed in the NH where they resided. In one case, the partner was present at the resident's request. All interviews were conducted by researcher SvA, who had extensive experience in working with NH-residents as speech and language therapist.

The interviews started with questions about personal background, such as place of birth and family situation, to encourage residents to talk freely and in their own words about their life. Then, openly formulated questions followed as:

> *Can you describe how your life in the NH looks like / can you describe a typical day?*
> *What is important to you / what do you miss in daily life? What does this mean to you?*
> *Is there something you would like to change?*

The interviewer emphasized the importance of the residents' experiences, used both verbal and non-verbal encouragement, and asked clarifying questions to obtain the best possible understanding of the stories. When residents continued to find it challenging to tell their story, the interviewer encouraged them by introducing everyday life topics such as meals, personal care, activities or social relations.

The interviews lasted approximately 45 minutes (range 28-60 minutes) and were digitally recorded. Due to technical problems in recording, one interview could not be included in the analysis. The overall outcome and course of each of the remaining 13 interviews was evaluated within the research team. The material of these interviews was considered to contain enough variety and common features to enrich the purpose of the study.

## Analyses

To provide a rich thematic description of the entire data set, all interview recordings were transcribed verbatim and subjected to thematic analysis as described by Braun and Clarke (2006). Familiarization with the data (phase 1) occurred through reading and rereading, writing descriptive summaries of the interviews, and discussing potential patterns in the data (MD, SvA). From an inductive, data-driven approach, the detailed analysis started with generating initial codes from the transcripts (phase 2). In repeated discussions between the researchers (MD, SvA), these codes were collated into potential themes and sub-themes at an explicit, descriptive level (phase 3). In discussion with the other members of the research team (CH, MS, MdB), the (sub)themes were reviewed, further refined and interpreted (phase 4 and 5). It resulted in a final thematic map in which the "keyness" of each theme in relation to the research question was identified and defined. Producing the report (phase 6) involved a progression from descriptive analytic narratives to an overall interpretation of the analysis in relation to existing literature. Due to the cyclic character of thematic analysis, the writing was constantly discussed in the entire research team.

## Ethics

The study protocol was approved by the Medical Ethics Review committee of Amsterdam UMC, location VU University Medical Center (number NL21477.029.08). Participation was voluntary and all participants signed an informed consent form after receiving information about the study, both verbally and in writing. The use of high-frequent words and short sentences maximized the comprehensibility, and the information was repeated prior to the interview. All interview data has been pseudonymized.

# Results

The participant characteristics are displayed in Table 1. Within the participants' stories about their everyday post-stroke lives in the NH, we identified two overarching themes: 1) agency in spending daytime; and 2) agency in the formal care-relationship. The final thematic map with themes and subthemes is displayed in Figure 1.

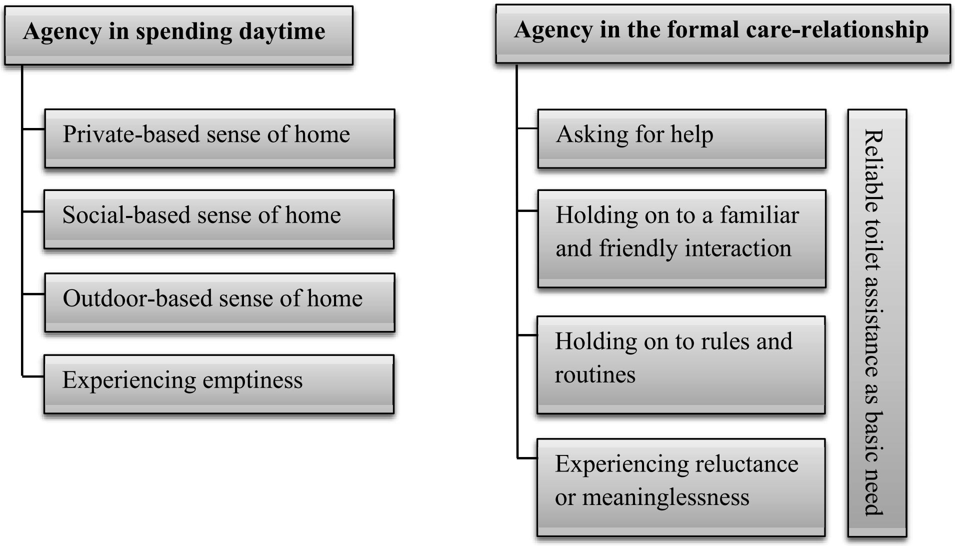

**Figure 1.** How do institutionalized stroke patients live their everyday lives as agents? Thematic map.

## Agency in spending daytime

Many residents tell about everyday activities they prefer to spend the day with. Their stories reveal places and situations where they feel most comfortable, whether this is inside or outside the NH-environment. Our analysis resulted in the identification of differences in a fundamental sense of home to which a resident's preferred activities are related: 1) a private-based sense of home, when someone feels most comfortable on one's own, or 2) a social-based sense of home, when someone feels most comfortable with closest others, or 3) an outdoor-based sense of home, when someone feels most comfortable in outdoor places. However, some residents do not express agency in spending their daytime, experiencing emptiness in which they do not know what to do.

***Private-based sense of home.*** Mrs. 2, Mrs. 5, and Mr. 7 tell about a life in the NH in which they feel most comfortable being "on their own", therefore spending much time

**Table 1. Participant characteristics**

| Pseudonym | Age | Gender | Marital status | Cultural background | Education level | Stroke location* | Time post-stroke* (months) | Cognitive abilities | Ability to make him/ herself clear |
|---|---|---|---|---|---|---|---|---|---|
| **Mr. 1** | 66 | male | single | Dutch | unknown | right-sided | 20 | mildly impaired | good |
| **Mrs. 2** | 85 | female | widowed | Dutch | secondary | right-sided | 22 | good | good |
| **Mrs. 3** | 87 | female | married | Dutch | only primary | left-sided | 61 | moderately impaired | good |
| **Mrs. 4** | 84 | female | widowed | Dutch | only primary | unknown | 90 | moderately impaired | moderately impaired |
| **Mrs. 5** | 88 | female | widowed | Dutch | only primary | left-sided | 81 | good | good |
| **Mr. 6** | 74 | male | married | Dutch | secondary | left-sided | 11 | good | good |
| **Mr. 7** | 81 | male | widowed | Indonesian | higher | left-sided | 145 | good | moderately impaired |
| **Mr. 8** | 78 | male | married | Dutch | higher | right-sided | 47 | good | good |
| **Mrs. 9** | 72 | female | married | Dutch | secondary | right-sided | 50 | mildly impaired | good |
| **Mrs. 10** | 86 | female | widowed | Dutch | secondary | right-sided | 9 | good | good |
| **Mr. 11** | 62 | male | married | Surinamese | secondary | right-sided | 63 | mildly impaired | mildly impaired |
| **Mrs. 12** | 79 | female | widowed | Dutch | secondary | right-sided | 165 | good | good |
| **Mr. 13** | 68 | male | married | Dutch | unknown | right-sided | 5 | moderately impaired | good |

* the stroke that caused nursing home dependency. All participants suffered an ischemic stroke and have a Barthel-Index score <12.

in their single-person rooms. Moreover, Mrs. 2 emphasizes how this room really feels like home to her.

> **Mrs. 5:** *What does it mean to you [to have your own room]?* Well, that you, well, that you are on your own. Whereas before, you would always be in a group. *Yes.* No, I love it.

> **Mrs. 2:** Then they come and get me to go for a walk; and when I am home, I like [that] again. *You like...* Home, that's here. *Okay, yes, exactly, home is here.* Yes. *Yes.* That really is my house.

They prefer activities as reading, listening to music, drawing (Mr. 7), or 'going for a walk' on their own in their (electric) wheelchair when they "feel like it" ("I drove around the building last week. It just depends on how much I feel like it.", Mrs. 5). Moreover, they tell how they are occupied with memories and reflections.

> **Mrs. 2:** Naturally, your life is completely different. *Yes.* So you have to flip quite a few switches. (...) I used to do a lot of sports and if there was some sport to do, I would often go and join and everything, I did. *Yes.* I was very erm... *You were very active.* Yes. I was always extremely active. *Yes, yes.* For instance, playing outside as a child and always: 'Oh, Top Dog is it again'. *Ha ha ha, were you really called 'Top Dog'?* Yes, that is true. My mother always called me 'Top Dog'.

> **Mr. 7:** If I think of the piano... *If you think of the piano...* I think of the old days. *You think of the old days, yes. And does that make you feel good?* No. (…) *No?* Then I focus on myself more.

They limit their social contacts to closest relatives or friends, and are barely socially engaged within the NH-community. While Mr. 7 completely rejects any kind of contact with other NH-residents ("I don't want."), Mrs. 2 and Mrs. 5 prefer superficial contact with their neighbors. Mrs. 2 emphasizes that keeping this distance means freedom to her.

> **Mrs. 2:** No, talking and such, about one thing and another, but really associate, that is not what I want. *No.* And then I don't want to go on with it myself, that people think: 'Well, that is a really nice friendship', that you get together... *No.* ...and such. *You already said, you don't like that too much.* I like my freedom.

***Social-based sense of home.*** Other residents tell about a life within the NH in which they feel most comfortable when they spend time with their closest relatives. The stories of Mrs. 3, Mrs. 10 and Mrs. 12 show a strong relationship with one daughter ("Karin takes wonderful care of me.", Mrs. 3), respectively a bigger circle of (grand) children ("Child, I am immensely rich, honestly, with such children.", Mrs. 12), where they very much like to tell about throughout the interview. The stories of Mr. 6 and Mr. 11 show a persistent longing for being together with their wives who are still living at their former home. By using the present tense, for example, Mr. 6 subtly makes clear that this pre-stroke joint household remains his real living space.

> **Mr. 6:** *Do you ever go out on your own?* No. Yes, or I visit my wife at home. For I actually live close by across the road. (...) Once a week. *Okay.* (...) *What does your wife do for you?* Well, she erm... makes sure that the entire... the entire household keeps running. *Hmm.* And she is a good cook. At least, if I, at least, I erm... visited her erm... Sunday, then I said: 'Well, you go and get some steaks...' *Yes.* '...because I don't get them in here.'

Around this core network of closest relatives, these residents are also socially engaged within the NH-community. They like to have daily conversations with other NH-residents (or especially with formal caregivers as Mrs. 10 emphasizes), they join organized activities, or participate in the Client Counsel like Mrs. 12. However, the stories show that these contacts are regarded as functional rather than as personal relations.

> **Mrs. 3:** *And how many people are in your cooking group?* Well, this afternoon there were eleven of us. *And do you all know each other?* Well, by face maybe, but not on a very erm erm... personal level.

> **Mr. 6:** Quite repetitive actually, it's the same every day. [...] Usually it's with the... same couple at the table... so erm... you know each other.

Moreover, despite her many social contacts in the NH-community, Mrs. 12 experiences her NH-life as "a life sentence", mainly due to her small, shared room in which she cannot spend time with her closest relatives.

> **Mrs. 12:** I have a nice room, there are two of us, but, oh well. I'm by the window. I have a small cubby-hole. I always say: 'I am doing... I am doing... I am doing life in here.' It doesn't sound nice, but it is true. (...) My children have seen it, they sometimes say: 'You can come and live with me or with someone else', I don't want that. They all have their own families, as I had. (...) There is no other way.

Only Mrs. 10 tells to feel "quite at home" for which her single-person room plays a central role. The room not only enables her to receive her "boys" and other visitors, but also to distance herself from other NH-residents.

> **Mrs. 10:** That communal eating, I got sick of it, I couldn't stand it. I mean, those people can't help it, right, but then they're being fed and then the food spills all over them, and that's while you are eating too. And then I said: 'Can't I eat in my room?'

***Outdoor-based sense of home.*** Mr. 1 and Mr. 8 tell about a life within the NH in which they continue to long for being in outdoor places where they felt most comfortable in pre-stroke life. Both men use the words "home" or "dwelling" when they tell about their vegetable garden ("I have a vegetable garden at home. I grow flower gardens, they are very close by.", Mr. 8) or former houseboat (Mr. 1). Frustrated they cannot find their fundamental sense of home within the NH, they tell how they keep their dream alive.

> **Mr. 1:** *Can you describe for me what your life is like here?* Yes, very complicated, right. *Can you explain?* Yes, I can't do any of the things that I used to do any more. *No.* Because I wanted to live on a boat. Well, that's got to... go through the system as to whether that is possible. *That was always your big wish?* Still is. *It still is, yes?* Yes, and I had already placed an order in France. Luckily I could cancel, put the contract on hold. *And what did you like so much about a houseboat?* Well, you can move around, can't you, you don't just stay in one spot. [...] *So your plans have actually been thwarted?* More or less, yes. *And how do you look at that now?* Well, with pity. But I'm not giving up. *(...) You still have the idea...* Yes, sure. *…that you would like that?* (...) If I can ever move decently again... *Yes.* ...then it's going to happen, trust me.

In line with their dream, they aim at least to expand their outdoor activities in the neighborhood of the NH for which they need an electric wheelchair or scooter. When this is discouraged by the professionals, they keep on fighting for this bottom-line.

> **Mr. 8:** *So you would be able to go out a little further with a battery chair?* Yes, yes. Yes. *Yes. And... you say: they are working on it?* Am working on it, but failed. *Oh, you failed?* Failed. *Okay. And why is that? Do you know?* My eyesight is slightly less on the left. *Yes?* And then I have Annely behind me. 'Right, be careful! Left, be careful! Right!', she kept on saying. It drove me bonkers. *Yes.* 'Be careful, left! Be careful, right!' You know? *Yes. You didn't quite see it, where you... you had to pay attention to everything?* Yes. *Yes, yes. And how do you feel about that now? That you*

> *failed?* I have regret. *Yes. Yes. And do you understand it?* I do. *Yes?* Still, I want to try it one more time. *Okay.* Can you write that down?

In the meantime these residents do participate in many recreational activities and trips that are organized by the NH. They really appreciate these initiatives ("Well, I think they do a lot for the residents here.", Mr. 1), but obviously regard these as 'second best'. If only to bridge the time their dream has not come true yet ("All a waste of time, right.", Mr. 1).

***Experiencing emptiness.*** Mrs. 4, Mrs. 9 and Mr. 13 tell about a life in the NH in which they merely experience emptiness. Despite activities as reading and watching the television, or social activities with a closest relative or other NH-residents, they emphasize they just don't know what to do.

> **Mrs. 4:** *And then, what do you do after breakfast?* Not much. *No.* Yes, you're annoyed, you can't do anything anymore.

> **Mr. 13:** *I'll start right off with what you're saying, Mr 13. You say: 'It sucks here!'* Yes. *Why do you think so?* Well erm... In the morning, you get washed and you erm... and then you go eat and then... forget it. Until erm... until there is coffee and then, once more, we have to... Then it is finished. *Okay. So, when you have eaten, when you have been washed and have eaten...* Not their problem! *...Not their problem! Well, what do you do then?* Nothing. No, what should I do?

Mr. 13 tells about "home", greatly frustrated that he cannot return to it. The stories of Mrs. 4 and Mrs. 9 show how they feel defeated in this post-stroke NH-life. While Mrs. 9 tells explicitly about her wish "to disappear from the earth", Mrs. 4 more cautiously makes clear she does not need to live longer.

> **Mrs. 4:** The coming years, I will... I will... I will see. But I don't need them. […] *Do you mean like: 'Well, if the coming years are not to come, that is fine by me?'* Yes, fine by me too.

## Agency in the formal care-relationship

The stories show that being dependent on formal caregivers, especially with respect to personal care and mobility, is another essential part of post-stroke life in the NH to deal with. First of all, the stories call attention to the great importance of reliable toilet assistance. On top of this basic need, many residents tell about their efforts to find their way in interacting with formal caregivers. Our analysis resulted in the identification of a resident's main effort in the relationship: 1) asking for help, or 2) holding on to a familiar and friendly interaction, or 3) holding on to rules and routines. However, some residents experience reluctance or meaninglessness to find their way in the relationship with formal caregivers.

***Reliable toilet assistance as basic need.*** The residents' stories emphasize that they feel most dependent when they have to be helped with going to the toilet. Frustration about offered toilet assistance is expressed at clear terms early in the interview, such as by Mr. 6 and Mr. 8. But also when adequate care is met, the dependency remains bothersome as Mrs. 5 shows.

> **Mr. 6:** You are fully dependent on other people, right. *Yes, yes. In what, for instance? In what...* Well, erm... if I have to go to the bathroom, I need help. *Yes.* And sometimes it might take a long time, and then I have an accident. Those are the sort of things yes erm... that you know (xxx) 'Why, why, why?'
>
> **Mr. 8:** Not getting to the bathroom [on time], no, that's murder.
>
> **Mrs. 5:** Once every so often you feel… or I'm in the patient lift… I sometimes think… that then I feel unhappy. *Then you feel unhappy?* When they lift me in the patient lift, for the toilet and such. *Yes.* Then I think: 'What a wretched bugger you are'.

Moreover, Mrs. 5 emphasizes how uncomfortable she feels when she needs to be helped outside the NH. This influences her choices in activities to spend the day with.

> **Mrs. 5:** *Do you ever go on outings?* They offer it sometimes, I don't feel like it any more. Don't like it. *And what don't you like about it?* I don't like it! [...] *Not that you necessarily have to criticise, but just... what do you like?* Do... do they also say if they... whether I join, half a day. *Half a day.* Otherwise, I won't make it to the toilet. […] *Yes, yes. So the toilet is actually the main reason for you to think, like: 'I just want to do that at home'.* It does leak sometimes. And I cannot be helped everywhere. *No, no.* That cannot be done anywhere else but here. An afternoon is just about what I can manage.

***Asking for help.*** Mr. 1, Mrs. 2, Mrs. 5 and Mr. 11 show how they are focused on asking formal caregivers for help when they find it necessary. Mrs. 2 concisely makes clear how this is based on her sense of being equal to her caregivers: "If the nurse asked for something and I would be able to, I would do it too." While Mrs. 5 and Mr. 1 give examples of relationships in which they feel comfortable by taking these initiatives, Mr. 11 tells about his distress when his questions are not being answered by the caregivers as he expects.

> **Mrs. 5:** I go down to the physio, to the room. And then I ask René, who is in charge of it, do you have another chair for me then and then, because I am slipping. *Okay.* Well, and then I get a chair, put it down here. No, that is... *That's well taken care of.* Yes, sure.
>
> **Mr. 1:** But now I've made a deal with Michael.. I say: 'Isn't it about time for us to talk about a mobility scooter?' I say: 'Who pays for these things?' *Hmm.* 'Funded under the Exceptional Medical Expenses Act', he says. 'Well then', says I, 'apply for one for me'. *Hmm.* It's possible, right? But he is inclined to do so, so...
>
> **Mr. 11:** *What do you think is the worst?* That you are treated very badly here. *That is what you think is the worst. Yes. And can you say a little bit more about that? What happens then, for example?* For example, I want... call a nurse (xxx) to straighten out my left foot (xxx). *Yes.* No. *No.* And I feel that in here. *You feel that in your heart, yes.* And I already have a sick heart. *Yes, yes. How would you like to see things, Mr. 7? What is important to you? How would you like to be treated?* If I ask for something, I would like it to be done.

***Holding on to a familiar and friendly interaction.*** Mr. 6, Mrs. 10 and Mrs. 12 show how they are focused on having a familiar and friendly relationship with the formal caregivers. Most basically, they tell how a friendly approach from the caregivers supports them to feel "equal" and "not pathetic". On top of that, they tell how they feel most comfortable when they can interact with the caregivers in a "familiar" way, as they are used to in their informal social network.

> **Mr. 6:** *Do you find it difficult to talk about this?* Yes. I don't want to be pitied. (...) No, but here... it is great here. All these girls are enormously sweet to you. *Yes?* At least... yes, most of them. *Yes.* So, erm... I have no complaints. *No, no. Okay. For that is important to you...* Yes. *...that people who help you... What, what, what then is important to you, if erm...* Well, that, that they are kind to you, that they treat you as an equal. *Yes, yes.* And they do, fortunately. *Yes.* So I have no complaints whatsoever in that respect. *No, no. And how does that show? When do you believe they treat you as an equal?* Well, they address me with [the informal versions of] 'you' and 'your'. We're on familiar terms, say.
>
> **Mrs. 10:** That is what I say, I believe it so important that I can get along well with all the staff. *That is, in fact, the thread in your story, isn't it.* Yes, it... you really have to have a bond of trust with them, and be able to tell them things and such. I mean, my grandson...

> **Mrs. 12:** *When is a doctor a good doctor?* That he deals with you as you are, not like a pathetic old woman. (...) It is a young doctor, yes. The nurses too, all girls, they could be my daughters. That's how you often deal with them. *What do you mean by that? Do you like that?* Yes, Mariska had become pregnant recently, I knew. Then, whenever she had to help me, I said: 'Go and fetch someone to help you, you should not do that by yourself.' *Yes, yes. So you watch over them a bit too?* Yes. If they are pregnant, they shouldn't lift. Then they say: 'How did you manage with all those children when you had your seventh?' I know that, I'm not stupid! *Ha ha ha, yes, yes. You believe that to be important?* I am on good terms with them.

***Holding on to rules and routines.*** Mrs. 3, Mr. 8 and Mr. 13 show how they are focused on the formal caregivers' rules and routines to hold on to. They especially emphasize their feelings of uncertainty when they do not know what care they can count on. Just as Mr. 8 experienced to be "completely at the mercy" of unfamiliar caregivers on a holiday trip, Mr. 13 retains the same feeling within the NH ("You are in a nursing home and that is it, that is all I know."). Searching for 'solid ground' in the experienced uncertainty, they are focused on receiving stable care they can hold on to. As Mr. 13 firmly expresses: "[A good nurse] she sticks to the rules, as they have been written. She doesn't make a mess of things." Mrs. 3 emphasizes her desire that the routines of the caregiver with whom she feels most secure, would be rules for all caregivers.

> **Mrs. 3:** I say: it's fine, but it differs in who is helping you. A great many just muck about. I mean, I have a nurse who... Maria, that one is very meticulous but, then, later, I think: what is a must, what is everything.. Isn't that necessary, or is she doing that on her own accord? But I dare not raise it, for then erm... I would challenge that nurse, of course. *Yes. I don't quite understand you yet. You say she is very meticulous and she does everything.* Yes, but during washing, I mean, right. *Yes, yes. And what then would you like to change?* Well, that others do that too.

***Experiencing reluctance or meaninglessness.*** Other residents experience reluctance (Mr. 7) or meaninglessness (Mrs. 4 and Mrs. 9) to find their way in the relationship with formal caregivers. Mr. 7 tells how he prefers to be helped by his daughter, who helps him taking a bath every day. Mrs. 4 and Mrs. 9, however, show how they feel defeated by their dependency.

> **Mrs. 4:** That I cannot walk anymore… *Yes.* ...that is lunacy. *Hmm, yes, yes. And do you ever tell the sisters... that you feel so bad about that?* Yes. *And what do they say?* Yes, what can they say? They cannot say anything. *Or can they help you with it?* Well, yes... *Hmm.* They don't help. *No.* There is no point. *There is no point.* No. *No. Do they say so, or is that what you believe?* I believe so.

> **Mrs. 9:** *And if you eat in the living room, is that well taken care of too?* That's really well taken care of, but yes... what I'm trying to say, well, you have... you always need, you need someone to go with you to the bathroom. And so on and so on. *Yes. You always need someone...* Yes. *How do you feel about that?* Well, I feel bad about it. For I used to do everything by myself before.

## Discussion

This qualitative study explored the everyday life experiences of stroke patients who depend on institutional long-term care. Our findings provide a thorough insight in how severely impaired stroke survivors express their agency – i.e. how they actually act based on intention - in a NH- environment, not only through their preference in activities to spend the day with, but also through their efforts in the relationship with formal caregivers. The first main finding is that institutionalized stroke patients prefer daily activities that are related to their fundamental sense of home, that can be: 1) private-based (feeling most comfortable on one's own), or 2) social-based (feeling most comfortable with closest others), or 3) outdoor-based (feeling most comfortable in outdoor places). The second main finding is that, on top of the need for reliable toilet assistance as basic need, institutionalized stroke patients express agency in the formal care-relationship through: 1) asking for help, or 2) holding on to a familiar and friendly interaction, or 3) holding on to rules and routines. Finally, not all residents express agency in either or both identified domains in their post-stroke NH-lives. They are left with feelings of emptiness, reluctance or meaninglessness. We will discuss how our findings give insight into what support institutionalized stroke patients need to live their everyday lives.

### Home-making efforts in spending daytime

Our first main finding that expressing agency in spending daytime is related to a resident's fundamental sense of home is in line with the common view in phenomenological philosophy that "being at home" and "dwelling" are fundamental aspects of human existence (Dekkers, 2011). Or in other words: being human *is* about seeking or establishing one's own place in the world, that can be understood in both a literal and metaphorical way. Also in sociology a sense of home is recognized as an important and intense emotion, motivating people to undertake action to maintain or regain it (Duyvendak, 2009). Although our results show that it is possible to experience a complete sense of home within the NH-environment, they also reveal that undertaking daily activities from a fundamental sense of home is often accompanied by struggle. This gives rise to the view that residents are in an ongoing process of home-making within the NH. Such a process-oriented view corresponds with study results among community-dwelling stroke survivors as mentioned in the introduction, showing a continually shifting process to rebuild a post-stroke life at home (Pallesen, 2014; Arntzen *et al.*, 2015; Hawkins *et al.*, 2017). Moreover, this view fits into the ethical framework for long-term care as introduced by Agich (1993, 2003). In his phenomenological approach, human-beings are viewed as agents who are never fully formed, but who are throughout life "individualizing themselves in particular circumstances through effortful striving" (Agich, 1993, p. 89). This process of identification with changing circumstances in everyday life, is what Agich views as the core feature of what he calls "actual autonomy". Especially in the out-of-the-ordinary circumstances of a NH-environment this will be an effortful process. Based on this study, we could paraphrase that institutionalized stroke patients - as autonomous agents - are in an effortful process of home-making within the NH.

The differences we found in a fundamental sense of home (private-, social-, or outdoor-based) deepen our understanding of the important role of physical space in supporting a resident's home-making efforts. This is in line with a review of Rijnaard *et al.* (2016) that identified the built environment as an important theme in trying to improve the sense of home of NH-residents. Firstly, the home-making of private-based residents appears to be mainly supported by the physical "own" single-person room, as this is the best place within the NH-environment to undertake activities on their own. Hereby, our study underlines these residents' need of being able to undertake not directly visible activities like recollecting memories or reflecting on their lives. The importance of such an active "being-in-place" as a mechanism through which people can create meaningful lives of their choosing, is also identified by Doroud *et al.* (2018) who explored the role of place in mental health recovery. Secondly, one's own physical space also appears to be crucial in supporting the home-making process of social-based residents, despite the many social activities NHs offer to spend the day with. They primarily need space that enables them to spend time with close relatives in private, but also to withdraw from social activities and contacts with co-residents that they do not prefer. Thirdly, within the physical boundaries of the NH the home-making efforts of outdoor-based residents appear to be least supported. It underlines their great need to have independent access to outdoor spaces as gardens and neighborhoods as an integrated part of their NH-lives, as Rijnaard *et al.* (2016) also emphasize. This asks not only for wheelchair accessibility of the outdoor environment, but also for a further development of innovative mobility devices that support them to freely undertake outdoor activities. Given the development of self-driving cars, self-driving wheelchairs should not be a utopia.

## Basic needs to feel secure and equal in the formal care-relationship

Our second main finding about the ways residents express agency in the relationship with formal caregivers, underlines how important this particular social interaction is to them within the forced circumstances of being physically severely dependent. This social context of agency is reflected as another important pillar of the ethical framework for long-term care as we discussed above. Agich (1993, 2003) emphasizes the interconnected or "shared social world" in which human agents strive to individualize themselves, as opposed to the unrealistic view of persons as independent centers of action and decision-making. A resident's acting in the formal care-relationship then also appears as an effortful process of identification. In the context of spending daytime we paraphrased this as a process of home-making within the extraordinary circumstances of the NH. In a similar way, we could circumscribe it in the context of the formal care-relationship as a process of seeking or establishing one's own place in a relationship that is quite out-of-the-ordinary as opposed to informal, self-chosen interactions in the social network of residents. Our results show that it is possible to be satisfied with the formal care-relationship, which we can interpret as having found one's "own place" or position in the relation. But again, we also found that expressed agency in the relationship is often accompanied by struggle. It reveals the important role of formal caregivers to understand and support the effortful identification process of residents in their mutual interaction.

Looking closer to the different main efforts of residents in the formal care-relationship, we further our understanding of underlying needs. We found how asking for help is based on a sense of being equal to the caregiver, while holding on to a familiar and friendly interaction is associated with a need to feel equal. Finally, we found how holding on to caregivers' rules and routines is associated with feelings of uncertainty. These underlying experiences give rise to the view that feeling secure and equal are preconditions for residents to be able to individualize themselves in the care-relationship. This is in line with Hertogh (2005), who points to the central elements of *safety* and *self-esteem* in an "ethic of psychogeriatric care". Hertogh outlines the need of NH-residents with dementia for formal caregivers who are attentive to their feelings of anxiety and undermined self-esteem in a world they understand less and less. Although our study reveals these emotional challenges in a less explicit way among institutionalized stroke patients – that might be explained by the rather stabilized stroke sequelae as opposed to the progressive nature of dementia – it indicates a similar basic need for formal caregivers providing them safety and security and promoting their self-esteem.

In this context, our result of the explicit need for reliable toilet assistance also appears to be a fundamental element in feeling secure. Although this basic need is well-known, our study sheds a light on the important role of basic functional caring in the whole identification process of residents in the care-relationship. It reveals how basic care moments on a day to day basis offer opportunities to support residents to feel secure and equal, giving them room to find their "own place" in the care-relationship.

### Feelings of emptiness, reluctance or meaninglessness: indications for underlying needs

Looking closer to the residents who are left with feelings of emptiness, reluctance or meaninglessness, different indications for underlying needs emerge. It is alarming when residents express their agency neither in spending daytime nor in the formal care-relationship and feel defeated. As opposed to residents who do express agency, albeit often accompanied by struggle, we could say that these residents do not strive (anymore) to individualize themselves in the forced circumstances of the NH. It might point to a post-stroke trajectory of "ongoing disruption" as identified by Hawkins *et al.* (2017), in which stroke survivors keep focused on returning to their pre-stroke body and life. However, it might also be that these residents already had difficulties in pre-stroke life to gain a sense of home or to find their place in relationships. It reveals the need for specialized caregivers who invest in the further understanding of these residents' lack of striving to individualize themselves in the NH-environment.

Other residents do not express agency in only one domain of their post-stroke NH-lives. With regard to spending daytime, this was shown by a resident with an explicit wish to return to his former home. Although the need for long-term care was already indicated, he suffered his stroke rather recently, pointing to a sense of disruption that most stroke survivors experience in initial post-stroke stages (Hawkins *et al.*, 2017). However, he simultaneously showed his focus on rules and routines in the formal care-relationship, underlining his fundamental need to feel secure in this new, not self-chosen relationship. It raises the question whether agency support in initial post-stroke stages should focus on the formal care-relationship, but also whether the "start-up" of a resident's home-making could be better supported. Longitudinal research should deepen our insight how residents' expressions of agency develop along the whole trajectory of their post-stroke NH-lives.

Finally, explicit reluctance to find one's place in the formal care-relationship is in this study associated with a resident's preference for receiving assistance in personal care from a close relative. In fact, in this case agency *is* expressed by choosing an alternative care-relationship that is available. Although our data do not provide insight in the background of this choice – the resident may have previously felt unsafe or unequal in the formal care-relationship, or conversely felt free to set demands that could not be met – the reluctance suggests a need for formal caregivers who create constructive partnerships with informal caregivers. All the more, because the involvement of families has been acknowledged as one of the best guarantees of a resident's well-being (Haesler *et al.*, 2010).

### Strengths and limitations

A major strength of this study is the in-depth data collection due to the communication skills of the interviewer together with the analysis of not only the responses of the residents but also the context of the interview as a whole. This combination resulted in very "rich data", providing a unique insight into the experiences of institutionalized stroke patients, which was to date not available. This also pleas for an interview/conversation setting in clinical practice to gain insight into a resident's agency as a basis for providing support, rather than a checklist on needs and wishes. Hereby, future research should also focus on adapted communication methods to include residents with severe communication deficits.

A second strength is the uniqueness of the study population, representing an under researched population on the continuum of stroke care and also including participants with cognitive impairment and communicative problems. Generalization of our findings to the whole population of institutionalized stroke patients might be hampered by the fact that residents with severe cognitive impairment or severe communication deficits were excluded, and all participants were over 60 years old. Nonetheless, with reference to the universal character of the identified themes we expect our findings to be applicable to all severely disabled stroke survivors in the NH. Moreover, our study might even provide guidance for the care of non-stroke NH-residents who are severely impaired in basic activities of daily living, as most of the results found do not seem to be stroke-specific.

## Conclusion

A single-person room supports the home-making efforts of "private-based" residents the best, while "social-based" and "outdoor-based" residents need better support through space that enables them to be with closest others in private, respectively to undertake outdoor-activities independently. Formal caregivers have an important role in supporting residents to feel secure and equal in their daily interactions, hereby enabling them to find their own place in this extraordinary relationship. Further understanding is needed of residents who lack a striving to individualize themselves in the NH-environment and of the evolution of residents' agency along the whole trajectory of their post-stroke NH-lives.

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# CHAPTER 7

# 7

# General discussion

# General discussion

The overarching goal of this thesis was to formulate key elements for optimizing supportive care for persons who live post-stroke lives in nursing homes (NHs), also referred to as institutionalized stroke patients, based on the results of the *CAre for STroke In LOng term care facilities in the Netherlands* (CASTILON) study. Although much time has passed since the start of this project, the overarching goal is still highly relevant. To start with, the Action Plan for Stroke in Europe 2018-2030 (Norrving *et al.*, 2018) identified "life after stroke" as an additional domain in the development of the entire chain of stroke care, acknowledging the importance of providing longer term support after stroke. However, especially the continuity of services for chronic strokes patients discharged to the community has gained interest, for example shown by the *Managing Aftercare for Stroke* study in Germany (Hotter *et al.*, 2018) and the Dutch development of a geriatric rehabilitation program for stroke patients that integrates tailor-made aftercare in the home situation (Vluggen *et al.*, 2021). There is still not an equivalent research focus on the needs of chronic stroke patients who require institutional long-term care, underlined by Burton and Walker (2021). Meanwhile, Bouwstra *et al.* (2017) showed that the proportion of Dutch geriatric stroke rehabilitants who are discharged to long-term NH-care hardly changed between 2007 and 2015 (19% respectively 17%). Furthermore, the overarching goal of this thesis is exactly in line with the main purpose of NH-care as formulated in the Dutch NH Care Quality Framework (Zorginstituut-Nederland, 2017, updated in 2021), i.e. "making the best possible contribution to the quality of life of residents". Improving NH-care is a core focus of the Dutch Ministry of Health, Welfare and Sport, although a recent evaluation showed that residents perceived their quality of life still as unchanged over the period 2015 to 2019 (Verbeek-Oudijk & Koper, 2021).

The CASTILON-study aimed to reach a better understanding of the key problems and needs of institutionalized stroke patients, in order to tailor two core components of the supportive care approach in NHs to them: 1) providing relief from distressing symptoms, and 2) offering support to enable residents to live their everyday lives as actively as possible. In addition, the CASTILON-study aimed to investigate what is already known about prognostic factors for a poor stroke outcome, in order to shed a light on the optimal starting point of supportive NH-care on the continuum of stroke care. In this discussion chapter, a summary of the main research findings of the preceding chapters 2-6 is presented, followed by a reflection on the main findings in order to meet the overarching goal of this thesis. Subsequently methodological considerations are discussed, followed by recommendations for clinical practice and future research.

## Summary of main findings

We summarize the main findings of the CASTILON-study according to the formulated research questions of this thesis:

1. *Which factors in the first month post-stroke have a predictive value for institutionalization and/or severe disability?*

We systematically reviewed the literature on prognostic factors for poor outcome in the early post-stroke period (**Chapter 2**). This literature review revealed rather consistent findings that greater age (including very great age), a more severe stroke (measured through a clinical evaluation scale), the presence of urinary incontinence (with impaired awareness) and a larger stroke volume (measured through brain imaging techniques) are predictors in the first month post-stroke for a poor stroke outcome. In contrast to our clinical expectations, the prognostic value of a high degree of dependency in basic activities of daily living (ADL) and impaired cognition remained unclear. Furthermore, factors in the domains of emotional and communicative functioning rarely featured. We concluded that this evidence is insufficient for the development of a clinical prediction tool that is better than informal clinical outcome predictions by physicians.

2. *What problems in functioning do institutionalized stroke patients have in the physical, cognitive, emotional, communicative and social domains, and how are these problems interrelated?*

In order to answer this research question, we performed a cross-sectional, observational study among 274 residents (mean age 77 years, 58% female) in 17 Dutch NHs. The stroke that caused NH-dependency was in 81% ischemic, and in 50% right-sided. The median time post-stroke was almost 4 years (47 months). Data about functioning were collected through observation lists that were filled out in structured interviews with qualified nurse assistants who knew the residents well. The lists comprised the Barthel-Index (BI), sections of the Resident Assessment Instrument for Long-Term Care facilities (RAI-LTCF), the Neuropsychiatric Inventory Questionnaire (NPIQ), and the nursing home-version of the Apathy Evaluation Scale (AES-10).

***High prevalence of impairments on all domains of functioning.*** In comparison to what is known from stroke studies in the general stroke population, our study revealed very high prevalence of impairments on all domains of functioning (**Chapter 3**). Above the well-known severe disabilities in basic ADL (91% of the residents had a BI<12), many residents suffered from some type of pain (58%). Nearly half of the residents showed moderate (24%) or severe (23%) cognitive impairment, which is a high proportion in the context of the somatic wards where they resided. With regard to emotional functioning, irritability (53%), depressive symptoms (53%) and apathy (34%) occurred as the most frequent neuropsychiatric symptoms. In the communicative and social domains of functioning, more than a quarter of the residents (28%) had poor expressive abilities, and almost a third (30%) had a low social engagement. The relation between the problems in functioning and the characteristics of the stroke that caused NH-dependency (hemorrhagic or ischemic, left-sided or right-sided, and time post-stroke) revealed only some differences.

On the basis of these results, we first selected pain as key problem to analyze further in depth, in relation to problems in the emotional and social domains. Secondly, we aimed to reach a better understanding of apathy and its clinical correlates. In clinical practice, there is a great risk of ignoring this "silent" problem without exploring the possibilities to relieve it.

***Substantial pain is related to emotional distress***. Pain appeared as a serious and multidimensional problem among institutionalized stroke patients (**Chapter 4**). A total of 28% of the residents experienced severe or daily moderate pain, that we defined as substantial pain. It was mostly located in the affected body side, suggesting that in many residents the pain was stroke-related. Substantial pain was independently associated with increased emotional distress, expressed by a 60% increase of neuropsychiatric symptoms. Residents with substantial pain were especially more likely to exhibit clinically relevant symptoms of delusions, agitation/aggression, depression and anxiety. Furthermore, it appeared that substantial pain was independently associated with low social engagement, as an indicator of social vulnerability. However, the results suggested that the increased emotional distress acted as a pathway in this relation.

***Apathy is related to cognitive and physical problems, but not to depressive symptoms.*** Apathy appeared to be prevalent in 28% of institutionalized stroke patients, when classified through the AES-10 (**Chapter 5**)**.** It was most strongly related to cognitive impairment, but not to clinically relevant depressive symptoms. Accordingly, we discussed the relation between apathy and the distinct dimensions of post-stroke depression (affective and apathetic). Other clinical correlates were in the physical domain of functioning: very severe ADL-dependency (BI 0-4), and being in bed more than 12 hours per day as an indicator for fatigue. As possible explanation, we discussed how fatigue might be an underlying factor causing both apathy and ADL-dependency. Additionally, the results suggested that a greater amount of activities in which a resident participates is related to less severe apathetic behavior. However, this association was of small size and appeared only in residents under 80 years. We discussed the need for research on (individualized) stimulating activities as possible intervention method.

3. *What support do institutionalized stroke patients need to live their everyday lives, seen from their own perspective?*

The qualitative interview-study showed that the residents talked most vividly about their own activities and efforts in daily life, rather than expressing directly needs for which they need support. It emphasized residents' own active role to give shape to their NH-lives, leading to the identification of "agency" - i.e. the possibility of acting based on intention - as central theme in the interviews. The thematic analysis further identified not only spending daytime, but also the formal care-relationship as domains in which residents express agency in everyday life (**Chapter 6**). We discussed how these findings gave insight into what support institutionalized stroke patients need to live their everyday lives.

***Agency in spending daytime to support.*** The first main finding was that institutionalized stroke patients prefer daily activities that are related to their fundamental sense of home, that can be: 1) private-based (feeling most comfortable on one's own), or 2) social-based (feeling most comfortable with closest others), or 3) outdoor-based (feeling most comfortable in outdoor places). We discussed this as residents' ongoing striving to gain a sense of home within the nursing home environment, revealing the important role of physical space to support these home-making efforts. A single-person room supports the home-making efforts of "private-based" residents the best, while "social-based" and "outdoor-based" residents need better support through space that enables them to be with closest others in private, respectively to undertake outdoor-activities independently.

***Agency in the formal care-relationship to support.*** The second main finding was that, on top of the need for reliable toilet assistance as basic need, institutionalized stroke patients express agency in the formal care-relationship through: 1) asking for help, or 2) holding on to a familiar and friendly interaction, or 3) holding on to rules and routines. We discussed this as residents' ongoing striving to find their own place in an extraordinary relationship, requiring feeling secure and equal as basic needs. It reveals the important role of formal caregivers to understand and support this process in daily interactions.

***Further understanding is needed when agency is not expressed.*** Finally, not all residents express agency in either or both identified domains in their post-stroke NH-lives. They are left with feelings of emptiness, reluctance or meaninglessness. It reveals the need for specialized caregivers who invest in the further understanding of these residents' lack of striving to individualize themselves in the NH-environment.

## Reflections on main findings

### Both a problem-oriented and an agency-oriented view is needed

As a foundation for tailoring supportive care to institutionalized stroke patients, the main purpose of the CASTILON-study was to identify both their problems and their experienced needs for support in everyday life. The findings of the quantitative part of CASTILON substructure the clinical knowledge that there are serious impairments across all domains of functioning, that all raise the question of whether and how these can be further relieved. Within this range of problems, CASTILON identified both pain and apathy as serious and multidimensional problems in relation to other domains of functioning.

In the qualitative part of CASTILON, the finding of the central theme of "agency" urges a rethink of the direct focus on "needs for support" when we aim to understand the perspectives of institutionalized stroke patients on their everyday lives. The interviews clearly showed how they focus on their own active role in daily life, instead of the active roles that caregivers should play in supporting them. Moreover, the found patterns in their expressions of agency – i.e. the actions and efforts they undertake both in spending daytime and in the formal care-relationship – deepened our understanding of their fundamental human strivings. It highlighted them as autonomous agents that give shape to their lives in extraordinary circumstances, albeit often accompanied by struggle, as opposed to the traditional view on them as passive care-recipients. Ultimately, these findings did further our insight into how these strivings could be better supported. In other words, identifying how institutionalized stroke patients express agency in daily life – in fact the most direct way "to be in their shoes" - has proven to be a good foundation to gain insight in what support they may (or may not) need.

In conclusion, the CASTILON-study shows how supportive care for institutionalized stroke patients should be centered around their problems that need relief, as well as around their expressed agency in everyday life that needs support. In other words: we need both a problem-oriented and an agency-oriented view to understand how supportive NH-care can make the best possible contribution to their quality of life. In the following paragraphs, the results on pain and apathy as serious key problems, and on expressed agency will be further reflected upon in the context of the current scientific literature. In addition, we will reflect on our findings with regard to prognostic factors for a poor stroke outcome.

## Pain as a multidimensional problem that needs further relief

Our results on pain are in line with the current overall knowledge that it is a common complication after stroke (Harrison & Field, 2015; Delpont *et al.*, 2018), highly prevalent in older adults in general, and best viewed as a complex biopsychosocial problem (Williams & Craig, 2016; Schwan *et al.*, 2019).

***High pain prevalence.*** The demonstrated pain prevalence of 58% (some type of pain) and 28% (substantial pain) are still difficult to compare with the great variety in reported estimates in the stroke literature. With regard to the chronic post-stroke phase, recent studies show pain prevalence of 22% at 3 months post-onset (Bovim *et al.*, 2018), 32% at a mean duration of 6 months (Paolucci *et al.*, 2016), and 40% at 5 years post-onset (Westerlind *et al.*, 2020). With regard to the measurement of pain, our study can best be compared with that of Westerlind *et al.* (2020) which also did not distinguish between stroke-related pain and pain unrelated to stroke, which partly explains higher pain prevalence. However, their findings of 40% (some type of pain) and 15% (frequent pain) are still substantially lower than our results. This can be explained by the fact that their study population was younger, included more men, and suffered milder strokes. Female gender and older age are known as risk factors for the development of post-stroke pain (Harrison & Field, 2015; Delpont *et al.*, 2018), while increased stroke severity even appeared as the most robust risk factor for chronic pain in a large, international study (N=15.754) with a mean follow-up of two-and-a-half years (O'Donnell *et al.*, 2013). These risk factors underline our finding that institutionalized stroke patients are highly prone to pain.

***Stroke-related pain syndromes.*** Our finding that the pain is mostly located on the affected body-side indicates the presence of stroke-related pain syndromes which can develop through both neuropathic and nociceptive mechanisms. Recent systematic reviews focus on central post-stroke pain (Liampas *et al.*, 2020) and the complex regional pain syndrome (Su *et al.*, 2021), revealing overall estimates of 11% respectively 33%. A prospective, population-based study showed that hemiplegic shoulder pain is prevalent in approximately 30% of stroke survivors (Adey-Wakeling *et al.*, 2015). With regard to the time course following stroke, these pain syndromes can develop after the rehabilitation phase. Adey-Wakeling *et al.* (2015) showed a clear pattern of increasing frequency of hemiplegic shoulder pain over the first year, with a peak incidence at 4 months. Liampas *et al.* (2020) revealed that approximately 40% of patients that will suffer from central post-stroke pain, will do so between the first month and first year, and 5% even after that. Furthermore, Paolucci *et al.* (2016) showed that the prevalence of spasticity-related pain peaked in the chronic post-stroke stage. Also headache (occurring in 14% of stroke patients in the acute phase) can persist for months or years (Harriott *et al.*, 2020). With regard to characteristics of our study population, however, older age and increased stroke severity do not appear as general risk factors across the different pain types in the mentioned studies. Identified risk factors are more specified, such as strokes affecting the somatosensory tract for central post-stroke pain, an absence of upper limb motor function for hemiplegic shoulder pain, or spasticity for the complex regional pain syndrome. Especially the increased knowledge about the evolution of stroke-specific pain types over time, supports our suggestion that institutionalized stroke patients should be included in further research on specific, targeted (pharmacological) interventions.

***Relation with emotional distress.*** The increased emotional distress we demonstrated in residents with substantial pain – which in turn could be a pathway to low social engagement – is in line with a biopsychosocial perspective on pain, as we already introduced in Chapter 4. In general, recent research has further confirmed the understanding of pain as a biopsychosocial phenomenon (Williams & Craig, 2016). Moreover, large-scale population-based studies with follow-up periods of 3 years (Gutierrez *et al.*, 2022) or even 10 years (Bondesson *et al.*, 2018) provided robust evidence that pain and depression/anxiety among (older) adults have a bidirectional influence on one another, like the Dutch longitudinal study of Geerlings *et al.* (2002) already suggested. It underlines that pain management should include diagnosis and treatment of comorbid emotional stress.

In the stroke literature, our findings are supported by the integrative review of Payton and Soundy (2020) that identified depression and anxiety as (two out of three) primary factors influencing the experience of post-stroke pain. Next to quantitative evidence, the review also identified qualitative evidence that pain is associated with "high energy" unpleasant moods such as anger, supporting the relation we found between pain and symptoms of agitation/aggression.

Next to Tosato *et al.* (2012) referenced in Chapter 4, the demonstrated relation between pain and symptoms of delusions has been further confirmed by Habiger *et al*. (2019; 2021). In a broad NH-population both with and without dementia this association persisted over time. Although psychotic symptoms are often the result of dementia or delirium, they can also be triggered by medications. As Habiger *et al.* (2021) discussed, it could be that long-term use of (opioid) analgesics or psychotropics causes more harm through unwanted side effects than benefit, especially in older people with multimorbidity and polypharmacy (Achterberg, 2016; Schwan *et al.*, 2019). The high odds ratio (OR) of 8.45 that we found (i.e. residents in pain are more than 8 times more likely to show delusions relative to residents not in pain) suggests this might be a serious problem among chronic stroke patients in NHs. It underlines the need for regular evaluation of these residents' medication use, but also the need to include them in further pharmacological research (e.g. on dose-effect relations, drug-drug and drug-disease interactions (Achterberg, 2019). Furthermore, it raises the question how non-pharmacological interventions – carrying little risk for harmful side-effects – could play a greater role in pain relief.

***Relation with fatigue.*** In addition, we want to reflect on the third primary factor that Payton and Soundy (2020) identified to affect post-stroke pain, and that is fatigue. Our study did not aim to investigate this specific relation, because of the lack of a valid observation instrument to measure fatigue. Instead, we measured how many hours in a 24-hour day a resident stayed in bed to get an indication, and the univariable analysis did show that residents in pain had more bed rest relative to residents not in pain, in line with the conclusion of Payton and Soundy (2020). It underlines that further research on post-stroke pain among NH-residents should also take into account the relation with fatigue. Currently, there is a trend of research on post-stroke fatigue to more fully understand the complex relations with many factors, such as neurological/physical deficits, comorbidities and medication, but also pain and depression/anxiety (Hinkle *et al.*, 2017; Aali *et al.*, 2020). Fatigue might even have a modifying role in the relation between pain and emotional distress that we demonstrated. For example, Naess *et al.* (2012) found pain and depression only to be associated in fatigued stroke patients, who were relatively young and suffered from mild strokes.

***Optimizing pain relief.*** In conclusion, the current scientific literature supports our finding that pain is a serious and complex, biopsychosocial problem among institutionalized stroke patients that needs further relief. To start with, the Dutch multidisciplinary guideline *"Recognizing and treatment of chronic pain in vulnerable elderly"* (Verenso, 2011, updated in 2016; Achterberg *et al.*, 2012) tries to optimize pain relief in the entire population of vulnerable older people, including NH-residents. Although its implementation into clinical NH-practice appears to be difficult and time-consuming (Akker *et al.*, 2021), its basic elements are beyond question: a) a methodological approach that follows the well-known cyclical process of detection, diagnostics (assessment and analysis), treatment and evaluation; b) a multidisciplinary approach that includes both pharmacological and non-pharmacological interventions, as this is the most likely to be effective to break a multidimensional, biopsychosocial "cycle of pain" (Schwan *et al.*, 2019); and c) a specific approach for residents with (severe) cognitive or communicative impairments who are limited in self-report, for whom additional observational instruments to detect, analyze and evaluate pain behavior are recommended. However, since these tools have been developed for persons with dementia (the Pain Assessment IN Advanced Dementia [PAINAD] or the Dutch version of the Pain Assessment Checklist for Seniors with Limited Ability to Communicate [PACSLAC-D]; Zwakhalen *et al.,* 2006, 2007), we recommended in Chapter 4 further research towards adequate pain assessment in persons with stroke-related cognitive and/or communicative problems. This is confirmed by a systematic review of de Vries *et al.* (2017), which concluded that a feasible, reliable and valid instrument to assess pain in persons with aphasia is not available yet. Among the currently available self-report scales, the review recommended the use of the vertical Visual Analogue Scale (VAS) and the Faces Pain Scale (FPS). A recent study of de Vries *et al.* (2023) showed that the observational PACSLAC-D might be a useful alternative to capture pain in persons with aphasia (during ADL and physiotherapy, but not in rest), but again concluded that more research on validity and reliability of various observation instruments is needed.

Towards further tailoring of pain management to the needs of NH-residents living with stroke impairments, our discussed findings point to the following directions:

Firstly, further research is needed on adequate management of stroke-specific pain syndromes, extending to the chronic post-stroke stages. With regard to pain assessment tools specifically developed for use in people living with stroke, a recent systematic review only found a focus on shoulder pain but not on neuropathic pain or headache (Edwards *et al.*, 2020). Moreover, no assessment tool could be recommended based on published psychometric properties. As we discussed in Chapter 4, it is of major importance that the group of institutionalized stroke patients will be included in further research on this (including those who are limited in self-report). This is confirmed by Achterberg (2019), who still identified the relative lack of pain studies in older, vulnerable individuals as one of the key barriers to better pain management. Also with regard to pharmacological treatment of stroke-specific pain syndromes, a recent systematic review illustrates this barrier: Bo *et al.* (2022) identified effective and promising pharmacotherapies for central post-stroke pain, but did not include patient characteristics such as age and lacked the long-term effect and safety with regard to side effects.

Secondly, further research is needed on how treatment of comorbid emotional distress – such as symptoms of depression, anxiety or agitation/aggression – can contribute to pain relief, in light of the growing evidence for the bidirectional influence on one another. In general, the potential of psychological interventions to break a biopsychosocial "cycle of pain" in (vulnerable) older adults is acknowledged, all the more because they carry little risk for side effects unlike pharmacological interventions. Unfortunately, evidence for effective interventions still remains scarce. A recent systematic review on psychological interventions on chronic post-stroke pain even found only three case-studies (Kneebone *et al.*, 2022), investigating mindfulness meditation, eye movement desensitization and reprogramming, and a multimodal intervention including biofeedback with progressive muscle relaxation and cognitive behavioral therapy. However, the overall poor quality and high risk of bias made it impossible to recommend which intervention should be investigated further. Moreover, with regard to clinical NH-practice the question also arises whether less intensive, activity-based interventions on symptoms of comorbid emotional distress could be of value for pain relief. This would be in line with the stepped-care approach as adopted by the Dutch multidisciplinary care program *"Act in case of Depression"* (Gerritsen *et al.*, 2019). This care program recommends to start with basic interventions consisting of a personalized day program and a pleasant activities plan (with special attention for physical activities), as soon as a NH-resident (whether in pain or not) exhibits depressive symptoms. Only when symptoms are more severe or the effect of these basic interventions is insufficient, more intensive therapeutic interventions can be added.

Finally, we recommend not to lose sight of an agency-oriented view on how the quality of a resident's life could be improved, even when he/she is in need of pain relief. Although substantial pain could limit or even prevent a resident's active role, it should also be considered that his/her intended (or motivated) actions and efforts in everyday life could form an important counterpart to the experienced pain. Recognizing and supporting this expressed agency – i.e. recognizing and supporting a resident's efforts to promote his/her own well-being, as we will reflect on in more detail further on – could then even be a protective factor for developing comorbid emotional distress. It would be very valuable to further investigate this potential of agency support among residents in pain. In comparison to the basic activity-based interventions as discussed above, it involves a proactive approach in which the initiatives of the resident are the starting point, rather than a reactive approach when signals of comorbid emotional distress are detected.

## Apathy as a multidimensional problem that needs further relief

Our results on apathy are largely in line with the state-of-the-art knowledge that apathy occurs in every third patient after stroke, as a distinct construct from depression, that is consistently associated with reduced cognitive function and increased disability (van Dalen *et al.*, 2013; Tay *et al.*, 2021). In contrast to other stroke studies, we found apathy not to be related to depressive symptoms, but possibly to fatigue.

***Apathy prevalence.*** Our prevalence rate of 28% among NH-patients who are in the chronic stroke phase with a median post-stroke time of almost 4 years, seems to support the notion that post-stroke apathy is rather stable over time (van Dalen *et al.*, 2013). In Chapter 5, we referred to longitudinal studies with a follow-up of 6-15 months post-stroke that indicated this (Mayo *et al.*, 2009; Castellanos-Pinedo *et al.*, 2011; Withall *et al.*, 2011). However, the longitudinal study of Brodaty *et al.* (2013) found that rates of apathy in stroke patients steadily rose from 27% at index assessment (3-6 months post-stroke) to even 39% at 5 years post-onset. This is remarkably high compared to the prevalence rate of 28% in our study population. All the more, because Brodaty *et al.* (2013) used an informant-rated version of the Apathy Evaluation Scale (AES) that estimates relatively low apathy rates compared to clinician-rated assessments, according to a sub-analysis in the meta-analysis of van Dalen *et al.* (2013). It places additional emphasis on the need for longitudinal research on post-stroke apathy using the most recommended apathy measures.

***Most strongly related to cognitive impairment.*** The demonstrated relation between apathy and cognitive impairment is further confirmed in a recent longitudinal study among stroke patients from the post-acute through the chronic stroke phase (the *Cognition and Affect after Stroke: a Prospective Evaluation of Risks* [CASPER] study; Douven *et al.,* 2018), although patients with worse global cognitive functioning (MMSE <15) were not included. It appeared that levels of apathy increased in patients with impairments in at least one cognitive domain that was measured at baseline (verbal memory, information processing speed, or executive function), and even more when multiple cognitive domains were affected. Moreover, the apathetic symptoms appeared to develop at a later stage (9-15 months post-stroke). As Tay *et al.* (2021) outlined in their narrative review, the recent network-approach explains this by assuming that not only lesion-related brain damage, but also more generalized brain damage can lead to apathy, for which is growing evidence. Also the CASPER-study showed that especially imaging markers of generalized brain pathology (degenerative and vascular) appeared to be important predictors for the development of apathy (Douven *et al.*, 2020). Altogether, these results emphasize that especially in patients with cognitive impairment apathy may evolve over time, even when it might be absent early after stroke.

***Not related to depressive mood symptoms.*** In contrast to the systematic reviews as referenced in Chapter 5 (Caeiro *et al.*, 2013; van Dalen *et al.*, 2013), we found apathy not related to depressive symptoms. We explained this by the fact that we only assessed an affective (depressed mood) dimension through the NPIQ-item dysphoria/depression, while a formal diagnosis of post-stroke depression also incorporates an apathetic (loss of interest) dimension (Hama *et al.*, 2011), resulting in overlapping symptoms with apathy. This explanation is confirmed by Tay *et al.* (2021) who review that "negative emotionality" is a key characteristic of depression after stroke that distinguishes it from apathy, despite shared symptoms. Also among NH-residents with dementia, Leontjevas *et al.* (2009) found that apathy was strongly correlated with so-called depressive "motivational" but not with depressive mood symptoms. A recent meta-analysis, however, once again underlined the association between apathy and depression in patients with stroke or traumatic brain injury (Green *et al.*, 2022) without distinguishing the two different dimensions of depression. Among the 13 studies included, only our study addressed depressive mood symptoms separately, resulting in the lowest correlation of included studies (Pearson r of 0.19). It shows that it is not widely accepted yet that focusing on the different dimensions of post-stroke depression would enhance our understanding of its relation with post-stroke apathy.

***Possible relation with fatigue.*** The possible relation between apathy and fatigue that we found, has been scarcely studied yet in stroke patients. The most recent systematic review of research on post-stroke fatigue (Aali *et al.*, 2020) identified only the CASPER-study on this topic, showing contradictory results (Douven *et al.*, 2017). No association between fatigue and the baseline level or course of apathy symptoms was found, nor in the reverse direction, as no association between post-stroke apathy and the baseline level or course of fatigue symptoms was found. Furthermore, a significant difference in apathy scores between the fatigue and no-fatigue group at 15 months post-stroke disappeared by adding the personality trait neuroticism and history of depression to the model. Our study did not include these covariates. However, our study population of severely disabled stroke patients was not included in the CASPER-study population, in which ADL-dependency was mild or even absent (mean BI 19.44). The relation between fatigue and apathy in the context of severe ADL-dependency remains to be explored further.

***Optimizing reduction of apathetic behavior.*** In conclusion, the current scientific literature supports our conclusion that apathy is a serious problem among institutionalized stroke patients that needs relief, especially in those with cognitive impairment and very severe ADL-dependency. To start with, the revised multidisciplinary care program *"Act in case of depression"* (Gerritsen *et al.*, 2019) has added a structural detection and assessment of apathetic symptoms for the whole NH-population. The recommended AES-10 as observational screening instrument (like in our research), and the proposed diagnostic criteria for apathy of Robert *et al.* (2009; like we referred to in Chapter 5) also enables the inclusion of residents with (severe) cognitive or communicative impairments. With regard to multidisciplinary treatment, however, there is a great lack of high-quality evidence (Manera *et al.*, 2020; Tay *et al.*, 2021). Non-pharmacological interventions are currently employed as frontline treatment in people with various brain disorders, and the overview of Manera *et al.* (2020) shows a wide range of methods, such as group therapies, therapeutic dialogues, meditation, and sensory, physical or brain stimulation. The care program of Gerritsen *et al.* (2019) limits its recommendation for treatment of apathetic symptoms to the basic, activity-based interventions (i.e., a personalized day program and a pleasant activities plan), based on the finding of Leontjevas *et al.* (2013) that especially this part of the (depression) care program also contributed to the reduction of apathy in dementia NH-units. In line with this activation-approach, we hypothesized in Chapter 5 that therapeutic and social NH-activities (outside routine daily care) have a stimulating character that might reduce apathetic behavior. The demonstrated relation between the greater number of NH-activities in which a resident participates and less apathetic behavior, might point to such a causal relationship as we discussed. However, the association was of small size and only present in residents less than 80 years. Moreover, the study of Leontjevas *et al.* (2013) also showed that in somatic NH-units the activation strategies had no effect on apathy. Instead, psychotherapy (as another module of the care program) was associated with a decrease of depressive motivational symptoms and possibly of apathy. It underlines the call for more research on the effectiveness of various non-pharmacological interventions on both apathetic and depressive (mood and motivational) symptoms.

Again, the question arises whether an agency-oriented view on apathetic behavior could be of additional value. Not at first glance. Defined as a persisting disorder of motivation, the syndrome of apathy actually reflects the inability of a resident to undertake intended (or motivated) actions and efforts in everyday life towards his/her own well-being. Because of this inability, the *Samen in Actie bij Apathie* (SABA) study investigates how specifically developed tools can support (in)formal caregivers to “break” apathetic behavior in NH-residents with dementia (Nijsten *et al.*, 2023). In case of less severe apathetic behavior, however, we hypothesize that an agency-oriented view might have the potential to reinforce a resident’s initiatives again. As we will reflect on in the coming paragraph, the different ways in which residents express agency in everyday life provide a deeper insight in their individualized motivations. This would enable more tailored support to enhance this motivation, in contrast to the generic recommendation in the care program that especially social activities should be stimulated in residents with apathetic behavior. It would be very valuable to further investigate this potential of agency support for reducing apathetic behavior.

## Expressed agency in everyday life as basis for providing support

Our results of the qualitative interview study emphasize the importance of identifying residents’ expressed agency in everyday life - i.e. the actions and efforts they undertake both in spending daytime and in the formal care-relationship - when we aim to capture their own perspectives on what support they need. It reflects the need for a fundamental recognition of them as active agents who - like every other human-being - give shape to their everyday lives, even though they find themselves in the difficult circumstances of living severely disabled in a NH-environment. As discussed in Chapter 6, this general view of the human-being - also in the context of dependency - underlies the ethical framework for long-term care as introduced by Agich (1993, 2003). In his concept of “actual autonomy”, human-beings are viewed as autonomous agents who are never fully formed, but who are throughout life “individualizing themselves in particular circumstances through effortful striving in the shared social world” (Agich, 1993, p. 89). Then, our empirical results on residents’ expressed agency in everyday life appear as diverse operationalizations of individuals’ ongoing processes of identification, that we paraphrased as 1) an effortful process of home-making within the NH, and 2) a process of seeking or establishing one’s own place in the formal care-relationship. This context of fundamental human strivings in extraordinary circumstances, highlights the hard work residents perform every day. It reveals the importance to recognize and acknowledge this hard work, if we strive to understand residents’ perspectives on their everyday NH-lives.

Our central agency theme fits very well into Agich’s ethical framework, because his phenomenological approach invites us “to step into the shoes” of residents, to empathize with their intended (or motivated) actions and efforts, and thus to come closest to their perspective on how the quality of their lives could be improved. In contrast, much recent research on the quality of life or well-being of NH-residents has a theory-driven approach (Gerritsen, 2017; Kloos *et al.*, 2019), for example based on the premises of the Social Production Function-theory (SPF; Ormel *et al.,* 1997) or the Self Determination Theory (SDT; Ryan and Deci, 2000). To start with, these prominent theories support our findings in a fundamental way: both SPF and SDT also postulate that people are active producers of their own well-being, thereby assuming universal, innate needs that people try to satisfy through their actions. It parallels our arguing that residents express agency in daily life that is motivated by general human strivings. The further focus of the theories, however, is on differentiating universal basic needs: while SPF holds that people try to fulfill both physical needs (comfort and stimulation) and social needs (affection, behavioral confirmation and status), SDT focuses on psychological needs that people aim to satisfy in interaction with their social environment (relatedness, autonomy, and competence). On the other hand, our findings point to the concrete ways in which institutionalized stroke patients try to actively promote their overall wellbeing in daily life.

With regard to the ways in which residents try to gain a sense of home (their “home-making efforts” in spending daytime) we can recognize a joint production of physical and social well-being like SPF proposes. Next to a variety of social activities that residents undertake related to social needs, our findings also reflect residents’ efforts to satisfy their physical needs for comfort (in terms of being in a pleasant environment) and stimulation (in terms of activities that produce the optimal level of arousal). It supports the important role of appropriate physical space to enable preferred activities as we discussed in Chapter 6. In addition, however, the differences we found in residents' fundamental sense of home (private-, social-, or outdoor-based) point to different balances between these needs: while "social-based" residents try most to satisfy their social need for affection (in line with Steverink and Lindenberg, 2006), we might say that "private-based" and "outdoor-based" residents try most to achieve comfort and sufficient stimulation in their own single-person room respectively in the outdoor environment. This is in line with Nieboer and Cramm (2018) who showed that diverse older populations (general, frail, and Turkish community-dwelling) differ in their realizations of physical and social SPF-goals. It prompted them to recommend "appropriate weighting" of the different SPF-components. In the same way, our subthemes with regard to home-making efforts - referring to recognizable "portraits" of residents - shed a light on how individuals *within* the population of institutionalized stroke patients differ in their realizations of well-being.

The different ways in which residents try to find their own place in the formal care-relationship (asking for help, holding on to a familiar and friendly interaction, or holding on to rules and routines) deepened our understanding of how feeling secure and equal are of special importance for residents in this particular social interaction, in line with Hertogh (2005). These specific needs were not taken into account in SDT-based research on the total quality of interactions between Dutch somatic NH-residents (including chronic stroke patients) and their professional caregivers (Custers *et al.*, 2010; Custers *et al.*, 2011). The used measurement scales with regard to the SDT-need for relatedness reflect globally the amount of warm interest and emotional support that is perceived or provided. Meanwhile, the measurements with regard to the SDT-needs for autonomy and competence appear to be narrowed to choices concerning, for example, the clothes residents want to wear respectively to carrying out self-care tasks as independently as possible. In contrast, Agich's ethical perspective emphasizes a more fundamental concept of *actual* autonomy, in which residents' concrete efforts to find their own place in the care-relationship are in themselves expressions of autonomy. Then, specific support to feel safe and equal as our findings indicate, could make residents more competent in this fundamental, autonomous striving. We might say that our findings point to a more comprehensive view on SDT-needs in the formal care-relationship, capturing the resident's perspective in a better way.

In sum, our findings on expressed agency in everyday life do reflect basic physical, social and psychological needs as postulated by the SPF and SDT, supporting our conclusion that our subthemes provide a promising framework to recognize and acknowledge individualized realizations of well-being in clinical practice.

Finally, our finding that not all residents express agency in everyday life is also supported by SDT through the "self-determination continuum". In contrast to intrinsic or extrinsic motivated behavior, it defines amotivation as a state in which people either do not act at all or act without intent. It parallels our arguing that these residents do not strive (anymore) to gain a sense of home or to find their own way in the formal care-relationship, limiting our insights how they can be supported to live their everyday lives. It reveals the need for specialized caregivers who invest in the further understanding of these residents' amotivation. There may be too severe or too many problems that undermine the active role of a resident towards his/her own well-being.

## Prognostic factors for a poor stroke outcome

We carried out a systematic review of the literature with the aim of exploring factors in the first month after a stroke that could have a predictive value for a poor outcome. To enable the detection of a wide range of possible prognostic factors, we used a broad definition of "poor outcome" that covered not only institutionalization due to stroke, but also severe disability (in line with Sulter *et al.,* 1999). We also included observational cohort studies that combined these outcome measures with death, mainly because this is often done through the commonly used modified Rankin Scale (mRS) to measure disability (van Swieten *et al.*, 1988). Despite this broad literature search, however, the found predictors remained limited to greater age, a more severe stroke (measured through a clinical evaluation scale), the presence of urinary incontinence, and a larger stroke volume (measured through brain imaging techniques). In view of a possible development of a clinical prediction tool, we concluded that the prognostic performance of merely these variables would not be better than a physician's informal outcome prediction for an individual stroke patient. To enable more accurate prognosis, we recommended more research on the selection of optimal screening instruments in multiple domains of functioning, including emotional and communicative functioning. We will discuss these findings and conclusions in the context of more recent stroke research that focused on a single rather than on a composite measure of poor outcome.

With respect to (very) severe disability as single poor outcome measure, a recent review of prognostic stroke scales revealed 4 instruments that are designed to predict a longer-term mRS-score of 5-6 (i.e. very severe disability or death) from baseline clinical data in the acute phase, with reasonable and promising prognostic performances (Drozdowska *et al.*, 2019). Moreover, there is growing evidence that these tools can predict patient outcomes more accurately than physicians (Ntaios *et al.*, 2016; Reid *et al.*, 2017). The FSV (Five Simple Variables-"devastating") and PLAN (Preadmission comorbidities, Level of consciousness, Age, and Neurological Deficit) scores are simple prediction scales without the use of brain imaging findings, for both ischemic and hemorrhagic stroke patients. In line with our findings, both tools include age and simple clinical baseline variables that indicate stroke severity (e.g., "not able to lift both arms" [FSV] or "either/both neglect or aphasia" [PLAN], but not the presence of urinary incontinence which we identified as candidate predictor variable). In addition, however, both scales also include pre-stroke functional status/disability as important predictor variable. The other 2 scales in the review (DRAGON and STI-P) are developed for thrombolysis-treated ischemic stroke patients. Next to age and stroke severity (measured through the National Institutes of Health Stroke Scale [NIHSS]; Brott *et al.,* 1989), both tools incorporate brain imaging findings (CT or MRI) and a biological measure (acute glucose) as important predictors for this group of stroke patients. Overall, the promising prognostic performances of these prognostic tools, contradict our conclusion in Chapter 2 that we need more knowledge on predictor variables in other domains of functioning to enable more accurate prognosis, at least as far as a (very) poor functional prognosis in the acute stroke phase is concerned. It reveals the potential of these tools to support the triage-process in the Netherlands to decide on the most appropriate place of stroke rehabilitation after hospitalization (van Weperen *et al.*, 2021).

With regard to institutionalization (long-term NH-care) as single poor outcome measure, the systematic review of Burton *et al.* (2018) also confirmed the prognostic value of age and stroke severity (measured through the NIHSS), but could not reveal other consistent predictors. In addition to the functional prognosis in the acute stroke phase, however, this prognostication remains highly relevant to stroke patients who are after hospitalization admitted to an inpatient (geriatric) rehabilitation setting, but ultimately are unable to return home. For this purpose, we still subscribe our conclusion that it is important to gain more insight in other possible prognostic factors, but then in the early post-stroke (geriatric) rehabilitation period *after* hospitalization. It is in line with Vluggen *et al.* (2020) who concluded the same with regard to the opposite outcome after geriatric rehabilitation, namely successful home discharge. Further research into predictors for both future living situations would not only enable a more reliable prognostication for individual stroke patients, but could also guide the setting of goals and exploration of therapy options during rehabilitation to increase the likelihood of returning home.

For the optimal choice of measurement instruments in multiple domains of functioning in future prognostic research, it seems valuable to connect to those recommended for the Dutch acute care setting to support stroke rehabilitation triage (Schiemanck *et al.*, 2021; van Weperen *et al.*, 2021), such as the Geriatric Depression Scale for stroke patients older than 70 years (Yesavage *et al.*, 1982; Jongenelis *et al.*, 2007). Furthermore, it seems relevant to incorporate pre-stroke functioning and other possibly missed factors, such as the level of frailty, the availability of informal caregivers or financial means (Vluggen *et al.*, 2020; de Groot *et al.*, 2022). Finally, with regard to stroke severity as established predictor for discharge to long-term NH-care, recent research of

Tarvonen-Schröder *et al.* (2023) pleas for reassessing NIHSS in the rehabilitation phase. Among stroke rehabilitants with initially severe strokes (NIHSS>15), they showed this second NIHSS-score (on average 1 to 2 months post-stroke) to be the most powerful predictor of discharge destination (home versus institution), superior to the predictive value of the acute (24h) NIHSS.

As we introduced in Chapter 1, a more accurate prognosis of a poor stroke outcome would serve an early integration of supportive NH-care in the chain of stroke care, in conjunction with geriatric rehabilitation care that is focused on recovery. This would be in accordance with the WHO-definition of palliative care (Sepulveda *et al.*, 2002), which we have referred to as supportive care in this thesis. A European consensus review on the development of palliative care for patients with chronic and progressive neurological diseases, including stroke, again confirmed the relevance of early integration during a disease trajectory (Oliver *et al.*, 2016). Moreover, a longitudinal study of Kendall *et al.* (2018) showed that survivors of severe (total anterior circulation) strokes and their relatives felt the need for more preparation for, and discussion of, the possibility of (death and) living with severe disability, while professionals mainly focused on active physical rehabilitation, recovery, motivation and hope during the acute and rehabilitation phases. This further supports our hypothesis that an optimal starting point of a supportive care approach for stroke patients likely to require long-term NH-care, would be during the geriatric rehabilitation period. However, further research is needed to gain insight how such early integration can occur without impeding an individual's options for optimal recovery. From a problem-oriented view, we might say that geriatric rehabilitation already includes several aspects of the supportive care approach, such as addressing a wide range of problems with the involvement of a multidisciplinary team, and incorporating compensation and adaptation techniques to live as well as possible with remaining disabilities (Grund *et al.*, 2020). It would also very valuable to investigate further whether an agency-oriented view in the rehabilitation phase could be of additional value.

Finally, we would like to draw attention to stroke patients who may not be admitted to a geriatric rehabilitation setting due to a poor (functional) prognosis in the acute phase. Both Bouwstra *et al.* (2017) and Holstege *et al.* (2017) have pointed to the suspected development of a stricter selection of patients who can sustain the increased treatment intensities and have a high probability of returning home. It would mean that the accessibility of geriatric rehabilitation is hampered for very frail patients, including stroke patients with a poor prognosis, although there may still be options for them to regain certain functional abilities. This may lead to a gap in care for stroke survivors who remain dependent of long-term NH-care compared to those who are able to return to their own home, like a prospective cohort study over a 20-year period in the United

Kingdom suggested (Clery *et al.*, 2021). Therefore, there is need for a clear overview of current care trajectories for (medically stable) stroke survivors with a poor prognosis in the acute phase, and we urge Dutch policy-makers, hospitals and NHs to maintain geriatric rehabilitation options for them. Regardless of what the future living situation will be, an optimal recovery of functions will contribute to the quality of every post-stroke life.

## Methodological considerations

The basic strength of the CASTILON-project is the uniqueness of the study population, that still represents an under researched population on the continuum of stroke care. It is the very reason why the study was designed. It might be considered a limitation that the study only included post-stroke NH-residents living in somatic wards, excluding those living in psychogeriatric wards (dementia care units). As introduced in Chapter 1, this choice was based on the knowledge that the majority of Dutch institutionalized stroke patients are residing in somatic NH-wards, even when severe cognitive impairment is present (Smalbrugge *et al.*, 2008) and on the clinical experience that the gap in tailored care for stroke patients is especially present in somatic wards. Nevertheless, it is a limitation that the study results cannot be generalized to the whole population of institutionalized stroke patients. At the same time, the results of especially the qualitative interview part of the study might also be of significance for other subgroups of the NH-population residing on somatic wards, as these results do not seem to be stroke-specific.

A strength of the quantitative part of the study is the broad, multifocal approach we used in exploring the problems in functioning. Furthermore, through the use of solely observation instruments we were able to include residents with severe cognitive and/or communicative impairments and residents with limited physical endurance. A limitation is the cross-sectional design that did not allow us to gain insight in the direction of causal pathways and the evolution of symptoms. Neither were pre-stroke variables taken into account in the analyses, such as pre-stroke functioning, history of depression or personality traits. Another limitation is the lack of depth in some measurement instruments, such as the Cognitive Performance Scale, the Neuropsychiatric Inventory Questionnaire or the RAI-LTCF items to measure communicative functioning. In accordance with the explorative character of the study, however, the used measurements instruments provided a good overview of manifestations of disturbances in everyday clinical practice and enabled the exploration of multidimensional problems. In addition, we classified apathy through the psychometrically robust and validated AES-10, that is currently recommended for clinical NH-practice.

A strength of the qualitative interview study is the in-depth data-collection through the use of narrative interview techniques that allowed residents to tell in their own words and with their own priorities about their everyday lives. Together with the communication skills of the interviewer as experienced speech and language therapist in the NH-setting, which also enabled the inclusion of residents with moderate communicative and/or cognitive problems, this resulted in very "rich stories". Given the value of fully open-structured narrative methods that is currently advocated for use in NHs towards quality improvement (Sion *et al.*, 2024), it might be considered a limitation that we combined a narrative approach with semi-structured interview techniques. However, the interviewer's introduction of topics proved valuable if residents continued to find it challenging to tell their story. Furthermore, it is a limitation that the interview design prohibited the inclusion of residents with severe cognitive and/or communicative deficits.

Although qualitative research is generally characterized by an open and inductive approach, there are differences in the extent to which theory is used to guide and structure a study (Plochg & van Zwieten, 2007). The minimal theoretical influence at the start of the thematic analysis has proven to be a strength, because the first phase of familiarization with the data and reflecting on the individual stories as a whole, led to the identification of an unexpected central theme (i.e. agency). Of course, literature was used to reflect on the thematic description of the participants' stories, but in a way "to illuminate the meaning" of the empirical data, to "make explicit the existing meaning and not about imposing certain meanings or concepts on the data" (van der Meide, 2018). It reveals the phenomenological character of our study towards a growing understanding of what it means to live a post-stroke life in a NH. The different professional backgrounds of the research teams members enriched the discussion on this. Together with the richly described, recognizable "portraits" and efforts of residents in our study, the results are highly relevant for clinical practice.

It is a limitation that we did not explore the perspectives of relatives and professional caregivers on the support residents need in everyday live, although the original study design did include this. It would have revealed similarities and differences in experiences. However, the finding of the central theme of agency instead of a direct focus on "needs for support" in the residents' interviews, led to our choice to focus on their perspective and analyze this further in depth. The fundamental insights this has yielded, provide a fruitful starting point for future qualitative research on agency that should take into account the different perspectives in the "care-triangle" (the triad combination of resident-relative-professional caregivers). It can reveal similarities and differences in perceptions how agency is expressed and could be supported, thereby contributing to integrated and workable recommendations for clinical practice (Kendall *et al.*, 2009).

## Recommendations for clinical practice: key elements for optimizing supportive care

From our reflections on the main findings in the preceding sections of this chapter, we can distill key elements for optimizing supportive care for institutionalized stroke patients, for which we focused on two core components: 1) providing relief from distressing symptoms, and 2) offering support to enable residents to live their everyday lives as actively as possible. These key elements can be considered as "building blocks" to be further developed for a future tailor-made methodological care program to optimize the quality of life of this subgroup of NH-residents.

With regard to the first core component, this thesis stresses the importance of further optimizing the relief of pain and the reduction of apathetic behavior, in concordance with the multidisciplinary NH-guideline "*Recognizing and treatment of chronic pain in vulnerable elderly"* (Verenso, 2011, updated in 2016) respectively the multidisciplinary care program "*Act in case of depression, with attention to apathy"* (Gerritsen *et al.*, 2019). With regard to pain management, a tailor-made care program should stress a structural detection, assessment and evaluation of stroke-specific pain syndromes that can evolve over time, and of comorbid emotional distress (especially symptoms of depression, anxiety, and agitation/aggression). The detection of symptoms of delusions should lead to an advanced evaluation of residents' pain medication use to detect unwanted side effects. The repertoire of non-pharmacological interventions on pain should be expanded to include the treatment of comorbid emotional distress, preferably in concordance with existing guidelines or care programs like *"Act in case of depression"* (Gerritsen *et al.*, 2019). With regard to apathy management, a tailor-made care program should stress a continued structural recognition of apathetic symptoms in especially stroke residents with (moderate or severe) cognitive impairment and very severe ADL-dependency, which also can evolve over time. It could be considered to analyze the problem in conjunction with the separate "mood" and "motivational" dimensions of depression. The repertoire of non-pharmacological interventions as frontline treatment for apathy is still in its infancy and will hopefully grow. Finally, a structural detection and assessment of fatigue can be expected to become part of the care program, with the potential to improve the analysis of both pain and apathy as multidimensional problems as well.

With regard to the second, equally important core component of supportive NH-care, this thesis stresses the importance of identifying residents' expressed agency in everyday live that is motivated by fundamental human strivings. This will come closest to residents' own perspectives on what support they need. A future care program should promote a basic approach of recognizing and acknowledging individualized ways in which residents actively try to gain a sense of home in spending daytime, and to feel secure and equal in the formal care-relationship. The identified differences in a fundamental sense of home (private-based, social-based or outdoor-based) and in main efforts in interactions with formal caregivers (asking for help, holding on to a familiar and friendly interaction, or holding on to rules and routines) provide a promising framework to guide this recognition. It could support multidisciplinary discussions on this, based on how the team has come to know residents so far. It would stimulate conversations with residents (and their relatives) about their active role to give shape to their NH-lives, hereby confirming their competence as active autonomous agents. On top of that, it would enable a shared exploration with residents on what support would be fruitful and possible (or not). In other words, it means that professional caregivers should give priority to recognizing and empathizing with residents' own efforts towards their well-being, as basis for discussing (missing) support options. For example, to be alert when residents use words like "home" and "dwelling" in daily conversations; to give priority to talk with a resident about his/her motivation to gain an outdoor-based sense of home, rather than to re-explaining why the use of an electric wheelchair is problematic; to engage in conversations about feelings of uncertainty when a resident complains about a lack of rules and routines. Without claiming that these examples do not occur in current clinical practice, we use them to underline our recommendation that an agency-oriented view should be consolidated within a basic multidisciplinary team approach. At the same time, a future care program should also guide the recognition of residents who do not strive (anymore) to gain a sense of home or to find their own way in the formal care-relationship. It reveals the need for specialized caregivers, for example a psychologist or a spiritual caregiver, who invest in the further understanding of these residents' amotivation.

For residents with (severe) cognitive and/or communicative deficits, a future tailor-made care program should offer a specific approach. With regard to the relief of pain and the reduction of apathetic behavior, this approach is integrated in the fore-mentioned current guideline respectively care program. With regard to recognizing expressed agency when verbal communication is difficult or impossible, it will be a precondition to enhance everyday "functional" communication through adapted methods.

## Recommendations for future research

To provide more robust evidence for the "building blocks" for a tailor-made care program for persons who live post-stroke lives in the NH, as discussed above, the following directions for future research emerged from our reflections:

With regard to optimizing pain relief and the reduction of apathetic behavior, it is of great importance that institutionalized stroke patients - also those with severe cognitive and/or communicative impairments - will be included in further research on adequate management, extending to the chronic post-stroke stages. This recommendation relates to research on assessment tools as well as on pharmacological and non-pharmacological interventions:

a) there should be a focus on the development of feasible, reliable and valid (self-report and observational) instruments to assess stroke-specific pain types and to assess pain in persons with aphasia;
b) research on pharmacological treatment of (general and stroke-specific) pain should include the long-term effect and safety as outcome measures, whereby symptoms of delusions should be taken into account as unwanted side-effect;
c) research on non-pharmacological interventions should be intensified for both pain and apathy management. This thesis specifically stresses to investigate how treatment of comorbid emotional distress – especially symptoms of depression, anxiety, and agitation/aggression - can contribute to pain relief.

In addition, our reflections point to the need for further longitudinal research on the relation between post-stroke pain (including comorbid emotional distress) and fatigue, between post-stroke apathy and fatigue, and between post-stroke apathy and the separate "mood" and "motivational" dimensions of depression. It will enhance our understanding how several multidimensional problems interconnect.

With regard to recognizing residents' expressed agency in everyday live and optimizing support for this, the first steps in further research will be: 1) to evaluate the preliminary framework presented in this thesis, and 2) to gain more insight into the facilitators and barriers to this expressed agency, capturing the roles of both (in)formal caregivers and physical space. It would be very valuable to conduct ethnographic research on this, that combines participant observation in the natural NH-environment with in-depth interviews with both residents, relatives and formal caregivers (multiperspective). To include residents with severe communicative and/or cognitive impairments, there should be a special focus on how to recognize non-verbal expressions of agency, especially in the formal care-relationship. Trained researchers could observe resident-nurse interactions during morning care, for example, followed by an interview with adapted communication methods to check for interpretations. We recommend to follow individual residents and their relatives over a longer time-period, to discover possible evolutions in the expressions of agency. Hereby, it would be very valuable to include the preceding geriatric rehabilitation period to shed more light on the optimal starting point for agency support. We hypothesize that especially an early start of support to feel secure and equal in the formal care-relationship would be of additional value. Furthermore, it seems valuable to combine longitudinal qualitative research on agency with quantitative measurements on subjective well-being - for example, "life satisfaction" like both stroke studies (van Mierlo *et al.*, 2016) and NH-studies (Kloos *et al.*, 2019) have used - and potential key problems such as pain, depression or apathy. It would be a first exploration whether agency support actually promotes the quality of life of residents and relatives, and/or adds relief to problems. Finally, it might be considered to include other subgroups of the NH-population who are residing in somatic wards in future research on agency.

Towards an optimal start of supportive NH-care, future research should enable a reliable prognostication of institutionalization in the early post-stroke (geriatric) rehabilitation period *after* hospitalization. At the same time, such research could reveal intervention options to increase the likelihood of returning home. In addition, we should further our understanding how an early start of a supportive NH-care approach can best be integrated into geriatric rehabilitation. We urge Dutch policy-makers, hospitals and NHs to maintain geriatric rehabilitation options for survivors of severe strokes who are unlikely to be able to return home.

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# Appendix

# List of participating Dutch nursing homes

**Argos Zorggroep**, locaties DrieMaasStede (Schiedam) en DrieMaasHave (Maassluis)

**Cordaan**, locaties Slotervaart (tegenwoordig Hof van Sloten, Amsterdam)
en Berkenstede (Diemen)

**Evean**, locatie Oostergouw (Zaandam)

**Omring**, verpleeghuis Lindendael (Hoorn)

**Quarijn**, locatie het Zonnehuis Doorn (Doorn)

**Verpleeg- en zorgcentrum Lindestede** (Wolvega; tegenwoordig onderdeel van **Alliade**)

**Vivium Zorggroep**, locatie Naarderheem (Naarden)

**Warande**, locatie Bovenwegen (Zeist)

**Woonzorgcentra Westerkwartier** (tegenwoordig **Zonnehuisgroep Noord**),
locatie het Zonnehuis Zuidhorn (Zuidhorn)

**Zonnehuisgroep Amstelland**, locatie het Zonnehuis (Amstelveen)

**Zonnehuisgroep Vlaardingen**, locatie het Zonnehuis (Vlaardingen)

**Zorgbalans**, verpleeghuis Velserduin locatie Driehuis (Driehuis)

**Zorgcombinatie Zwolle** (tegenwoordig **Vereen**), locatie het Zonnehuis (Zwolle)

**Zorggroep Apeldoorn e.o**, locatie Randerode (Apeldoorn)

**Zorggroep Solis**, locatie PW Janssen (Deventer)

# Summary

# Post-stroke lives in Dutch nursing homes

Recognizing interrelated problems and expressed agency towards optimizing supportive care

**This thesis is about persons who are living in nursing homes (NHs) because of post-stroke impairments, and the search how to optimize care for them.** Although integrated stroke care has improved in the last two decades, especially with regard to prevention, acute care and rehabilitation, a considerable proportion of 11% to 15% of stroke survivors remain severely dependent and require long-term NH-care. In this thesis they are also referred to as “institutionalized stroke patients”, but the description “persons who live post-stroke lives in NHs” remains preferred.

In the Netherlands, NHs make an important contribution to integrated stroke care. They provide a geriatric rehabilitation route after hospitalization for frail and multimorbid older people, in addition to rehabilitation centres that provide a medical specialist rehabilitation route with higher therapy intensity. Regarding the entire chain of stroke care, however, NHs do not pay specific attention to improving care for chronic stroke patients who remain dependent on long-term NH-care. They are mostly residing on somatic wards, even when severe cognitive impairment is present. Compared to the huge attention to improving dementia care for people who are residing on psychogeriatric wards, we have to conclude that people who live post-stroke lives in NHs are not only an under researched population on the continuum of stroke care, but also in long-term NH-care.

The main purpose of long-term NH-care is to make the best possible contribution to the quality of life of NH-residents. This is also known as the overarching goal of the palliative care approach as defined by the World Health Organization, for which “supportive care” is an equivalent term. It provides an adequate framework for good care for all NH-residents. Towards tailoring NH-care to persons who live post-stroke lives, this thesis focuses on two core components of the supportive care approach: 1) providing relief from distressing symptoms, and 2) offering support to enable residents to live their everyday lives as actively as possible. To this end the *CAre for STroke In LOng term care facilities in the Netherlands* (CASTILON) study aimed to reach a better understanding of 1) their problems across multiple domains of functioning that need relief and 2) their experienced needs for support in everyday life. Hereby, the starting point was to include also persons with severe cognitive and/or communicative impairments and/or limited physical endurance, as they form a considerable part of this group of NH-residents.

In addition, this thesis tries to shed a light on the optimal starting point of supportive NH-care on the continuum of stroke care. According to the WHO-definition, it should be integrated as soon as possible, possibly in conjunction with geriatric rehabilitation care that is focused on recovery. A reliable prognostication soon after stroke for institutionalization and/or severe disability would serve such early integration. To this end the CASTILON-study investigated what is already known about prognostic factors for such a poor stroke outcome.

In sum, the overarching goal of this thesis is to formulate key elements for optimizing supportive care for persons who live post-stroke lives in NHs. Although much time has passed since the start of the CASTILON-study, this goal is still highly relevant and in line with the Action Plan for Stroke in Europe 2018-2030 as well as with the Dutch NH care Quality Framework.

**In order to identify factors in the first month post-stroke that have a predictive value for institutionalization and/or severe disability (research question 1), Chapter 2** describes the results of a systematic literature review. There were rather consistent findings that greater age (including very great age), a more severe stroke (measured through a clinical evaluation scale), the presence of urinary incontinence (with impaired awareness) and a larger stroke volume (measured through brain imaging techniques) are predictors in the first month post-stroke for a poor stroke outcome. In contrast to our clinical expectations, the prognostic value of a high degree of dependency in basic activities of daily living (ADL) and impaired cognition remained unclear. Furthermore, factors in the domains of emotional and communicative functioning rarely featured. We concluded that this evidence is insufficient for the development of a clinical prediction tool that is better than clinical outcome predictions by physicians. To enable more accurate prognosis, we recommended more research on the selection of optimal screening instruments in multiple domains of functioning, including emotional and communicative functioning.

**In order to identify the problems that institutionalized stroke patients have in the physical, cognitive, emotional, communicative and social domains of functioning**, **and how these problems are interrelated (research question 2)**, we performed a cross-sectional, observational study in 17 Dutch NHs. Attending elderly care physicians were asked to select the residents with stroke as main diagnosis for NH-admission, who experienced a stroke 3 months or more ago, and stayed 1 month or more on a (somatic) long-term care ward. A total of 274 residents were included (58% female) with a mean age of 77 years (range 41-97 years). The stroke that caused NH-dependency was in 81% ischemic, and in 50% right-sided. The median time post-stroke was almost 4 years.

Quantitative data about functioning were collected through observation lists that were filled out in structured interviews with qualified nurse assistants who knew the residents well. The use of observational measurement instruments enabled us to include persons with severe cognitive and/or communicative impairments and/or limited physical endurance as well. The lists comprised the Barthel-Index (BI), sections of the Resident Assessment Instrument for Long-Term Care facilities (RAI-LTCF), the Neuropsychiatric Inventory Questionnaire (NPIQ), and the NH-version of the Apathy Evaluation Scale (AES-10). The results are presented in the Chapters 3, 4 and 5.

In **Chapter 3** is described that our study revealed very high prevalence of problems on all domains of functioning. Above the well-known severe disabilities in basic ADL, almost 60% of the residents suffered from pain. Nearly half of the residents showed moderate (24%) or severe (23%) cognitive impairment, which is a high proportion in the context of the somatic wards where they resided. With regard to emotional functioning, irritability (53%), depressive symptoms (53%) and apathy (34%) occurred as the most frequent neuropsychiatric symptoms (measured through the NPIQ). In the communicative and social domains of functioning, more than a quarter of the residents (28%) had poor expressive abilities, and almost a third (30%) had a low social engagement. The relation between the problems in functioning and the characteristics of the stroke that caused NH-dependency (hemorrhagic or ischemic, left-sided or right-sided, and time post-stroke) revealed only some differences.

On the basis of these results, we first selected **pain as key problem** to analyze further in depth **in relation to problems in the emotional and social domains**. In **Chapter 4** is described that substantial pain (i.e., severe or daily moderate pain) was prevalent in 28% of the residents, mostly located in the stroke-affected body side. This substantial pain was independently associated with increased emotional distress, expressed by a 60% increase of neuropsychiatric symptoms. Residents with substantial pain were especially more likely to exhibit clinically relevant symptoms of delusions, agitation/aggression, depression and anxiety. Furthermore, substantial pain was associated with low social engagement when adjusted for clinical covariates, but only in residents with no/mild or severe cognitive impairment. This relation disappeared when the amount of emotional distress was taken into account. It suggests that the increased emotional distress acts as a pathway in the relation between pain and low social engagement.

On the basis of the results presented in Chapter 3, we also aimed to reach a better understanding of **apathy as key problem and its clinical correlates**. In clinical practice, there is a great risk of ignoring this “silent” problem without exploring the possibilities to relieve it. **Chapter 5** describes that apathy was present in 28% of institutionalized stroke patients, when classified through the AES-10 (score 30 or higher). It was most strongly related to cognitive impairment, but not to clinically relevant depressive (mood) symptoms. Accordingly, we discussed the relation between apathy and the distinct dimensions of post-stroke depression (affective and apathetic). Other clinical correlates were in the physical domain of functioning: very severe ADL-dependency (BI 0-4) and being in bed more than 12 hours per day as an indicator for fatigue. As possible explanation, we discussed how fatigue might be an underlying factor causing both apathy and ADL-dependency. Additionally, the results suggested that a greater number of activities in which a resident participates is related to less severe apathetic behavior. This association was of small size, however, and appeared only in residents aged less than 80 years. We discussed the need for research on (individualized) stimulating activities as possible intervention method.

**In order to identify what support institutionalized stroke patients need to live their everyday lives, seen from their own perspectives (research question 3)**, we performed a qualitative interview study among a purposive selection of 13 residents from the quantitative study population. They were aged from 62 to 88 years and suffered the stroke that caused NH-dependency from less than 1 year to almost 14 years ago. A total of 7 residents had impaired cognitive and/or communicative abilities. A narrative approach was used to allow residents to tell in their own words and with their own priorities about their everyday lives, combined with semi-structured interview techniques. All interview recordings were transcribed verbatim and subjected to thematic analysis.

**We identified "agency" – i.e. the possibility of acting based on intention – as central theme in the interviews**. It reflects residents' focus on their own active role to give shape to their NH-lives, rather than a direct focus on what support they need. It led to the insight that only by deepening our understanding how residents live their everyday lives as active agents within the NH-environment, we would come closest to their own perspectives on what support they may or may not need.

**Chapter 6** describes how residents express agency in the domains of spending daytime and the formal care-relationship. The first main finding was that they prefer daily activities that are related to their fundamental sense of home, that can be (1) private-based (feeling most comfortable on one's own), or (2) social-based (feeling most comfortable with closest others), or (3) outdoor-based (feeling most comfortable in outdoor places). We discussed this as residents' ongoing striving to gain a sense of home within the NH, revealing the important role of physical space to support these home-making efforts. A single-person room supports the home-making efforts of "private-based" residents the best, while "social-based" and "outdoor-based" residents need better support through space that enables them to be with closest others in private respectively to undertake outdoor-activities independently.

The second main finding was that, on top of the need for reliable toilet assistance as basic need, institutionalized stroke patients express agency in the formal care-relationship through: (1) asking for help, or (2) holding on to a familiar and friendly interaction, or (3) holding on to rules and routines. We discussed this as residents' ongoing striving to find their own place in an extraordinary relationship, requiring feeling secure and equal as basic needs. It reveals the important role of formal caregivers to understand and support this process in daily interactions. Finally, we found that not all residents express agency in either or both identified domains in their post-stroke NH-lives. They are left with feelings of emptiness, reluctance or meaninglessness. It reveals the need for specialized caregivers who invest in the further understanding of these residents' lack of striving to individualize themselves in the NH-environment.

**The General Discussion (Chapter 7)** summarizes and reflects on the main research findings, discusses methodological considerations, and tries to formulate key elements for optimizing supportive care for persons who live post-stroke lives in Dutch NHs, the overarching goal of this thesis.

Since publications of CASTILON-results date from the years 2012 to 2015, the main findings are extensively reflected on in the context of more recent literature and current clinical practice.

With regard to pain, we can still conclude that this is a serious and multidimensional (biopsychosocial) problem that needs further relief. The multidisciplinary guideline *"Recognizing and treatment of chronic pain in vulnerable elderly"* provides a solid basis for this. Towards further optimizing pain relief in post-stroke NH-lives, we concluded that more research is needed on: (1) adequate management of stroke-specific pain syndromes that can evolve over time, extending to the chronic post-stroke stages; and (2) how treatment of comorbid emotional distress – especially symptoms of depression, anxiety or agitation/aggression – can contribute to pain relief, in light of the growing evidence for the bidirectional influence on one another. The relation between pain and symptoms of delusions has also been further confirmed in the literature and is probably caused by the long-term use of pain medication. Finally, we discussed that further research on post-stroke pain among NH-residents should also take into account the relation with fatigue.

With regard to apathy, we can conclude as well that this is still a serious problem, especially in post-stroke NH-residents with cognitive impairment and very severe ADL-dependency. We discussed emerging evidence that post-stroke apathy may evolve over time, even when it might be absent early after stroke, possibly caused by generalized next to lesion-related brain damage. Furthermore, we concluded there is still need for research on the relation with distinct dimensions of depression and fatigue as partly overlapping constructs. Towards optimizing the reduction of apathetic behavior, the revised multidisciplinary care program *"Act in case of depression"* has added a structural detection and assessment of apathetic symptoms for the whole NH-population. But much more research is needed on the effectiveness of various non-pharmacological interventions that is currently employed as frontline treatment in people with various brain disorders.

With regard to our results on residents' expressed agency in everyday life, we further reflected upon the context of fundamental human strivings. The central agency theme fits very well into the ethical framework of Agich which we discussed in Chapter 6, because his concept of "actual autonomy" invites us "to step into the shoes" of residents and to empathize with their ongoing actions and efforts that are intended to individualize themselves (to find their "own place") in extraordinary circumstances. But also the Social Production Function-theory and the Self Determination Theory assume that people are active producers of their own well-being. We discussed how our empirical findings on agency do reflect basic physical, social and psychological needs as postulated by these prominent theories of well-being. It supports our conclusion that our demonstrated subthemes (the different ways in which residents try to gain a sense of home and to find their own place in the formal care-relationship) provide a promising framework to recognize and acknowledge individualized realizations of well-being in clinical practice. We recommend future longitudinal, ethnographic research to evaluate this framework and to gain more insight into the facilitators and barriers to residents' expressed agency, capturing the roles of both (in)formal caregivers and physical space. We hypothesize that especially an early start of support to feel secure and equal in the formal care-relationship would be of additional value (possibly already in the geriatric rehabilitation phase), and that agency support might have the potential to add relief from problems (such as pain, depression or apathetic behavior).

Also the results on prognostic factors were further reflected upon in the context of more recent literature that focused on a single rather than on a composite measure of a poor stroke outcome. With respect to prognostication of (very) severe disability, several prognostic scales for use in the acute stroke phase show promising performances. Next to age and stroke severity variables, these scales include pre-stroke functional status, brain imaging findings or biological measures. This contradicts our conclusion in Chapter 2 that we need more knowledge on prognostic factors in other domains of functioning (including emotional and communicative functioning) to enable more accurate prognosis. However, we still subscribe this conclusion with respect to prognostication of long-term NH-care (institutionalization) in the early post-stroke (geriatric) rehabilitation period *after* hospitalization, in line with prognostic research on successful home discharge after rehabilitation. It seems valuable to connect to those measurement instruments that are currently recommended in the Netherlands to support the stroke rehabilitation triage process in the acute care setting.

**Finally, the General Discussion summarizes the key elements** that emerged from the reflections for optimizing supportive care for post-stroke lives in Dutch NHs. These key elements can be considered as "building blocks" to be further developed for a future tailor-made methodological care program. Future research as summarized in the reflections above, should provide more robust evidence for these "building blocks".

***With regard to providing relief from problems***, this thesis stresses the importance of further optimizing the relief of pain and the reduction of apathetic behavior. The multidisciplinary guideline *"Recognizing and treatment of chronic pain in vulnerable elderly"* respectively the multidisciplinary care program *"Act in case of depression, with attention to apathy"* provide a solid basis for this. A tailor-made care program should pay special attention to:

(1) the structural recognition and management of stroke-specific pain syndromes that can evolve over time, and of comorbid emotional distress (especially symptoms of depression, anxiety, and agitation/aggression). The detection of symptoms of delusions should lead to an advanced evaluation of residents' pain medication use to detect unwanted side effects. The repertoire of non-pharmacological interventions on pain should be expanded to include the treatment of comorbid emotional distress.

(2) the structural recognition and management of apathetic symptoms in especially stroke residents with (moderate or severe) cognitive impairment and very severe ADL-dependency, which also can evolve over time. It could be considered to analyze the problem in conjunction with the separate "mood" and "motivational" dimensions of depression. The repertoire of non-pharmacological interventions as frontline treatment for apathy is still in its infancy and will hopefully grow.

(3) the structural recognition and management of fatigue, with the potential to improve the analysis of both pain and apathy as multidimensional problems as well.

***With regard to offering support to enable residents to live their everyday lives as actively as possible***, this thesis stresses the importance of an agency-oriented view. A future care program should promote a basic approach of recognizing and acknowledging individualized ways in which residents actively try to gain a sense of home in spending daytime, and to feel secure and equal in the formal care-relationship. It would confirm residents' competence as active autonomous agents and would enable a shared exploration with residents and relatives on what support would be fruitful and possible (or not). A care program should also guide the recognition of residents who do not express agency in everyday life. Specialized caregivers, for example a psychologist or a spiritual caregiver, should invest in the further understanding of these residents' amotivation.

***For residents with (severe) cognitive and/or communicative deficits***, a future tailor-made care program should offer a specific approach. With regard to the relief of pain and the reduction of apathetic behavior, this approach is integrated in the fore-mentioned current guideline respectively care program, although more research is needed on adequate pain assessment in persons with aphasia. With regard to recognizing expressed agency when verbal communication is difficult or impossible, it will be a precondition to enhance everyday "functional" communication through adapted methods.

***Towards an optimal start of supportive NH-care***, future research should enable a reliable prognostication of institutionalization in the early post-stroke (geriatric) rehabilitation period *after* hospitalization. At the same time, such research could reveal intervention options to increase the likelihood of returning home. In addition, we should further our understanding how an early start of a supportive NH-care approach can best be integrated into geriatric rehabilitation. We urge Dutch policy-makers, hospitals and NHs to maintain geriatric rehabilitation options for survivors of severe strokes who are unlikely to be able to return home.

**In conclusion**, this thesis shows how recognizing residents' interrelated problems together with recognizing their expressed agency in everyday life form a solid basis to understand how supportive care can make the best possible contribution to the quality of their post-stroke lives in Dutch NHs. Especially future longitudinal research on agency will be important to incorporate the perspectives of NH-residents and their relatives the best.

# Samenvatting

# Leven na een beroerte in Nederlandse verpleeghuizen

Het herkennen van samenhangende problemen en *agency* om ondersteunende zorg te verbeteren

**Dit proefschrift gaat over mensen die in een verpleeghuis wonen na een beroerte, en de zoektocht naar optimalisering van de aan hen verleende zorg.** Hoewel de integrale zorg en behandeling na een beroerte (ook wel stroke of CVA [cerebrovasculair accident] genoemd) in de laatste twee decennia flink verbeterd is – met name wat betreft preventie, acute zorg en revalidatie - blijft 11% tot 15% van de mensen die een beroerte overleven afhankelijk van langdurige verpleeghuiszorg.

In Nederland leveren verpleeghuizen een belangrijke bijdrage aan de geïntegreerde zorg na een beroerte. Zij verzorgen een geriatrisch revalidatietraject na ziekenhuisopname voor veelal kwetsbare ouderen met multimorbiditeit, naast revalidatiecentra die een medisch specialistisch revalidatietraject aanbieden met een hogere therapie-intensiteit. Echter, binnen het geheel van de ketenzorg na een beroerte besteden verpleeghuizen geen specifieke aandacht aan het verbeteren van de zorg voor mensen die in de chronische fase afhankelijk blijven van langdurige verpleeghuiszorg. Meestal verblijven zij op somatische afdelingen, zelfs als zij ernstige cognitieve problemen hebben. Vergeleken met de enorme aandacht voor het verbeteren van de dementiezorg voor mensen die op psychogeriatrische afdelingen wonen, moeten we concluderen dat mensen die na een beroerte in een verpleeghuis wonen niet alleen een vergeten groep zijn in de ketenzorg na een beroerte, maar ook in de langdurige verpleeghuiszorg.

Het hoofddoel van langdurige verpleeghuiszorg is het leveren van een zo goed mogelijke bijdrage aan de kwaliteit van leven van verpleeghuisbewoners. Dit is ook het overkoepelende doel van een palliatieve zorgbenadering zoals de Wereldgezondheidsorganisatie (WHO) die heeft gedefinieerd, ook wel “ondersteunende zorg” genoemd. Deze benadering biedt een adequaat kader voor goede verpleeghuiszorg voor alle verpleeghuisbewoners. In de zoektocht naar hoe verpleeghuiszorg het beste afgestemd kan worden op mensen na een beroerte, richt dit proefschrift zich op twee kerncomponenten van de ondersteunende zorgbenadering: 1) het bieden van verlichting van belastende symptomen en 2) het bieden van ondersteuning om bewoners in staat te stellen hun dagelijks leven zo actief mogelijk te leiden. Het *CAre for STroke In LOng term care facilities in the Netherlands* (CASTILON) onderzoek had daarom tot doel meer inzicht te krijgen in 1) de problemen in meerdere domeinen van functioneren die verlichting behoeven en 2) de ervaren behoeften aan ondersteuning in het dagelijks leven. Hierbij was het uitgangspunt om ook mensen met ernstige cognitieve en/of communicatieve beperkingen en/of een beperkt fysiek uithoudingsvermogen te includeren, omdat zij een aanzienlijk deel van deze groep verpleeghuisbewoners vormen.

Daarnaast probeert dit proefschrift een licht te werpen op het optimale startpunt van ondersteunende verpleeghuiszorg in de ketenzorg voor mensen na een beroerte. Volgens de WHO-definitie zou deze zorg zo snel mogelijk aangeboden moeten worden, zo mogelijk in combinatie met de geriatrische revalidatiezorg die gericht is op herstel. Een betrouwbare prognose kort na de beroerte voor verpleeghuisopname (institutionalisatie) en/of ernstige invaliditeit, zou zo'n vroege integratie ten goede komen. Daarom heeft de CASTILON-studie onderzocht welke prognostische factoren al bekend zijn voor een dergelijke slechte uitkomst.

Samenvattend is het overkoepelende doel van dit proefschrift om speerpunten te formuleren voor het optimaliseren van ondersteunende zorg voor mensen die na een beroerte in een verpleeghuis wonen. Hoewel er veel tijd is verstreken sinds de start van de CASTILON-studie, is dit doel nog steeds zeer relevant en in overeenstemming met het Actieplan voor Beroerte in Europa 2018-2030 en met het Nederlandse Kwaliteitskader voor verpleeghuiszorg.

**Om vast te stellen welke factoren in de eerste maand na een beroerte een voorspellende waarde hebben voor verpleeghuisopname en/of ernstige invaliditeit (onderzoeksvraag 1)**, beschrijft **Hoofdstuk 2** de resultaten van een systematische literatuurstudie. Er waren tamelijk consistente bevindingen dat een hogere leeftijd (inclusief een zeer hoge leeftijd), een ernstigere beroerte (gemeten via een klinische evaluatieschaal), de aanwezigheid van urine-incontinentie (met verminderd bewustzijn) en een groter beroertevolume (gemeten via beeldvormende technieken van de hersenen) voorspellers zijn voor een dergelijke slechte uitkomst. In tegenstelling tot onze klinische verwachtingen bleef de prognostische waarde van ernstige afhankelijkheid in basale activiteiten van het dagelijks leven (ADL) en van verminderde cognitie onduidelijk. Bovendien kwamen factoren op het gebied van emotioneel en communicatief functioneren in de literatuur zelden aan bod.

Onze conclusie was dat dit onvoldoende bewijs is voor de ontwikkeling van een klinisch voorspellingsinstrument dat beter is dan de klinische uitkomstvoorspellingen door artsen. Om een nauwkeurigere prognose mogelijk te maken, hebben we onderzoek aanbevolen naar de selectie van optimale screeningsinstrumenten in meerdere domeinen van functioneren, waaronder ook emotioneel en communicatief functioneren.

**Om vast te stellen welke problemen chronische CVA-patiënten in het verpleeghuis hebben in zowel het fysieke, cognitieve, emotionele, communicatieve als sociale**

**domein van functioneren, en hoe deze problemen met elkaar samenhangen (onderzoeksvraag 2),** hebben we een observationeel dwarsdoorsnede-onderzoek uitgevoerd in 17 Nederlandse verpleeghuizen. De betrokken specialisten ouderengeneeskunde hebben de bewoners geselecteerd bij wie een beroerte de hoofddiagnose voor verpleeghuisopname was, die minstens 3 maanden geleden de beroerte hadden doorgemaakt en die minstens 1 maand op een somatische afdeling voor langdurig verblijf woonden. Er werden 274 bewoners geïncludeerd (58% vrouwen) met een gemiddelde leeftijd van 77 jaar (variërend van 41 tot 97 jaar). De beroerte die bepalend was voor langdurige verpleeghuiszorg was bij 81% van de bewoners een herseninfarct en bij 50% rechtszijdig. De mediane tijd na de beroerte was bijna 4 jaar.

Kwantitatieve gegevens over het functioneren zijn verzameld met observatielijsten die in een gestructureerd interview met de eerst verantwoordelijk verzorgende (EVV-er) van een bewoner zijn ingevuld. Door het gebruik van observatie-instrumenten konden ook bewoners met ernstige cognitieve en/of communicatieve problemen of een beperkt lichamelijk uithoudingsvermogen geïncludeerd worden. De lijsten bestonden uit de Barthel-Index (BI), onderdelen van het *Resident Assessment Instrument for Long-Term Care Facilities* (RAI-LTCF), de *Neuropsychiatric Inventory-Questionnaire* (NPIQ) en de *Apathy Evaluation Scale Nursing Home Version* (AES-10). De resultaten zijn beschreven in Hoofdstuk 3, 4 en 5.

**Hoofdstuk 3** beschrijft dat onze studie een zeer hoge prevalentie van beperkingen laat zien in alle domeinen van functioneren. Naast de bekende ernstige afhankelijkheid in ADL, had bijna 60% van de bewoners pijn. Bijna de helft van de bewoners had matige (24%) of ernstige (23%) cognitieve beperkingen. Op een somatische afdeling is dit een erg hoge proportie. Wat betreft emotioneel functioneren, waren prikkelbaarheid (53%), depressieve symptomen (53%) en apathie (34%) de meest voorkomende neuropsychiatrische symptomen (gemeten met de NPIQ). Wat betreft communicatief en sociaal functioneren, kon ruim een kwart van de bewoners (28%) zich slecht uiten en was bijna een derde (30%) weinig sociaal betrokken. De problemen in het functioneren waren slechts beperkt gerelateerd aan de kenmerken van het CVA (bloeding of infarct, links- of rechtszijdig, en de tijd na het CVA).

Op basis van deze resultaten hebben we eerst **pijn als kernprobleem** geselecteerd om verder te analyseren **in relatie tot problemen in emotioneel en sociaal functioneren**. In **Hoofdstuk 4** wordt beschreven dat 28% van de bewoners ernstige of dagelijks matige pijn had, meestal gelokaliseerd in de lichaamszijde die is aangedaan door de beroerte. Deze pijn was onafhankelijk geassocieerd met meer emotionele problemen, blijkend uit een toename van 60% van neuropsychiatrische symptomen. Deze bewoners vertoonden vooral vaker klinisch relevante symptomen van wanen, agitatie/agressie, depressie en angst. Verder was pijn bij hen geassocieerd met een lage sociale betrokkenheid wanneer gecorrigeerd werd voor de andere klinische variabelen, maar alleen bij bewoners met weinig of juist ernstige cognitieve beperkingen. Deze relatie verdween wanneer er rekening werd gehouden met de ernst van de emotionele problemen. Dit suggereert dat de toegenomen emotionele problemen een mediërende rol spelen in de relatie tussen pijn en een lage sociale betrokkenheid.

Op basis van de resultaten gepresenteerd in Hoofdstuk 3 wilden we ook meer inzicht krijgen in **apathie als kernprobleem en de klinische correlaten ervan**. In de klinische praktijk bestaat een groot risico dat dit "stille" probleem genegeerd wordt en dat niet gezocht wordt naar mogelijkheden om het te verlichten. **Hoofdstuk 5** beschrijft dat apathie, gemeten met de AES-10 (score 30 of hoger), aanwezig was bij 28% van de bewoners. Apathie was het sterkst gerelateerd aan cognitieve stoornissen, maar bleek in tegenstelling tot de literatuur niet gerelateerd aan klinisch relevante depressieve symptomen. Daarom zijn we dieper ingegaan op de relatie tussen apathie en de verschillende dimensies van depressie na een beroerte (affectief en apathisch). Andere klinische correlaten lagen op het fysieke domein van functioneren: zeer ernstige ADL-afhankelijkheid (BI 0-4) en meer dan 12 uur per dag in bed als indicator voor vermoeidheid. Als mogelijke verklaring hebben we besproken hoe vermoeidheid een onderliggende factor zou kunnen zijn die zowel apathie als ADL-afhankelijkheid veroorzaakt. Verder suggereerden de resultaten een verband tussen het aantal activiteiten waaraan een bewoner deelneemt en de ernst van het apathisch gedrag, met een afname van apathie bij een toenemend aantal activiteiten. Deze afname was echter klein en kwam alleen voor bij bewoners jonger dan 80 jaar. Als mogelijke interventiemethode attendeerden we op (geïndividualiseerde) stimulerende activiteiten en het belang van verder onderzoek hiernaar.

**Om vast te stellen welke ondersteuning mensen na een beroerte nodig hebben om hun dagelijks leven in een verpleeghuis te leiden, gezien vanuit hun eigen perspectief (onderzoeksvraag 3)**, hebben we een kwalitatief interviewonderzoek uitgevoerd onder 13 bewoners. Dit was een doelgerichte steekproef uit de kwantitatieve onderzoekspopulatie. De deelnemers waren tussen de 62 en 88 jaar oud en hadden minder dan 1 jaar tot bijna 14 jaar geleden de beroerte doorgemaakt. Zeven bewoners hadden cognitieve en/of communicatieve problemen. Door een narratieve aanpak, gecombineerd met het stellen van semi-gestructureerde vragen, konden de bewoners in hun eigen woorden en met eigen prioriteiten vertellen over hun dagelijks leven. Alle interviewopnames zijn woordelijk uitgeschreven en thematisch geanalyseerd.

**We vonden dat "*agency*", het vermogen van de mens om doelgericht en intentioneel te handelen, een centraal thema was in de interviews.** Het weerspiegelt de focus van de bewoners op hun eigen actieve rol om hun verpleeghuisleven vorm te geven, in plaats van een directe focus op welke ondersteuning zij nodig hebben. Het leidde tot het inzicht dat we het dichtst in de buurt zouden komen van hun eigen visie op welke ondersteuning zij wel of niet nodig hebben, als we ons eerst verdiepen in hoe zij als *agents* hun dagelijks leven leiden.

**Hoofdstuk 6** beschrijft hoe bewoners *agency* uitoefenen op het gebied van dagbesteding en de formele zorgrelatie. De eerste belangrijke bevinding was dat zij de voorkeur geven aan dagelijkse activiteiten die verband houden met hun fundamentele thuisgevoel. Dit kan (1) privé-georiënteerd zijn (je het meest op je gemak voelen in je eentje), (2) sociaal-georiënteerd (je het meest op je gemak voelen met je naasten), of (3) buiten-georiënteerd (je het meest op je gemak voelen in de buitenlucht). We hebben dit geduid als verschillende uitingen van het voortdurende streven van bewoners om hun thuisgevoel in het verpleeghuis te vergroten, waarbij de beschikbare fysieke ruimte een belangrijke ondersteunende rol speelt. Een éénpersoonskamer ondersteunt de *home-making* van privé-georiënteerde mensen het best, terwijl sociaal- en buiten-georiënteerde mensen meer behoefte hebben aan ondersteuning om privé met hun naasten te kunnen zijn of zelfstandig activiteiten in de buitenlucht te kunnen uitvoeren.

De tweede belangrijke bevinding was dat bewoners – bovenop de basisbehoefte aan betrouwbare hulp bij toiletgang – op de volgende manieren *agency* uitoefenen in de formele zorgrelatie: (1) om hulp vragen, (2) hechten aan een vertrouwde en vriendelijke interactie, of (3) vasthouden aan regels en routines. We hebben dit geduid als verschillende uitingen van het voortdurende streven van bewoners om hun eigen plek te vinden in een buitengewone relatie, waarbij het je veilig en gelijkwaardig voelen als basisbehoeften naar voren komen. Deze bevindingen laten zien welke belangrijke rol formele zorgverleners hebben om dit proces in dagelijkse interacties te begrijpen en te ondersteunen.

Tot slot is ook gebleken dat niet alle bewoners gemotiveerd handelen op het gebied van dagbesteding en/of de formele zorgrelatie, maar gevoelens van leegte, weerstand of zinloosheid ervaren. Het vóórkomen van zulke gevoelens en ervaringen roept de vraag op waarom een bewoner er niet meer naar streeft een eigen plek te vinden (zich te "individualiseren") in de verpleeghuisomgeving. Om die vraag te beantwoorden lijken gespecialiseerde hulpverleners aangewezen.

**De Algemene Discussie (hoofdstuk 7)** geeft een samenvatting van de belangrijkste onderzoeksbevindingen en reflecteert hierop, bespreekt methodologische overwegingen en probeert speerpunten te formuleren voor het optimaliseren van ondersteunende zorg voor mensen die na een beroerte in Nederlandse verpleeghuizen wonen, het overkoepelende doel van dit proefschrift.

Omdat publicaties van de CASTILON-resultaten uit de jaren 2012-2015 dateren, is er uitgebreid gereflecteerd op de belangrijkste bevindingen in de context van recentere literatuur en de huidige klinische praktijk.

Wat betreft pijn kunnen we nog steeds concluderen dat dit een ernstig en multidimensionaal (biopsychosociaal) probleem is dat verdere verlichting behoeft. De multidisciplinaire richtlijn "*Herkenning en behandeling van pijn bij kwetsbare ouderen*" biedt hiervoor een solide basis. Om de behandeling van pijn bij verpleeghuisbewoners na een beroerte verder te verbeteren, is er meer onderzoek nodig naar: (1) behandeling van beroerte-specifieke pijnsyndromen die zich tot in de chronische fase na een beroerte kunnen ontwikkelen; en (2) hoe de behandeling van bijkomende emotionele problemen – vooral symptomen van depressie, angst of agitatie/agressie – kan bijdragen aan het verlichten van pijn, gezien het groeiende bewijs voor de wederkerige beïnvloeding van pijn en emotionele problemen. De relatie tussen pijn en symptomen van wanen is ook in de literatuur verder bevestigd en wordt waarschijnlijk veroorzaakt door langdurig gebruik van pijnmedicatie. Ten slotte hebben we besproken dat verder onderzoek naar pijn na een beroerte onder verpleeghuisbewoners ook rekening zou moeten houden met de relatie met vermoeidheid.

Met betrekking tot apathie kunnen we ook concluderen dat dit nog steeds een ernstig probleem is, vooral bij verpleeghuisbewoners met cognitieve stoornissen en zeer ernstige ADL-afhankelijkheid na een beroerte. We hebben het groeiende bewijs besproken dat apathie zich in de loop van de tijd kan ontwikkelen, zelfs als dit probleem in de eerste fase na een beroerte niet aanwezig is. Dit wordt mogelijk veroorzaakt door gegeneraliseerde hersenschade naast beroerte-specifieke schade. Verder hebben we geconcludeerd dat er nog steeds onderzoek nodig is naar de relatie tussen apathie en de verschillende dimensies van depressie en vermoeidheid als deels overlappende constructen. Op weg naar een betere behandeling van apathisch gedrag, heeft het herziene multidisciplinaire zorgprogramma *"Doen bij Depressie"* een structurele opsporing van apathische symptomen toegevoegd voor de gehele verpleeghuispopulatie. Maar er is nog veel meer onderzoek nodig naar de effectiviteit van verschillende niet-medicamenteuze interventies. Momenteel hebben die bij mensen met verschillende hersenaandoeningen de voorkeur boven medicamenteuze behandeling van apathie.

Wat betreft onze resultaten over hoe bewoners *agency* uitoefenen in het dagelijks leven, hebben we verder gereflecteerd op de context van fundamentele menselijke strevingen. In hoofdstuk 6 hebben we het centrale *agency*-thema besproken binnen het ethische kader van Agich. Dit past heel goed omdat zijn concept van “actuele autonomie” ons uitnodigt om “in de schoenen te stappen” van de bewoners en ons in te leven in hun voortdurende inspanningen om zichzelf te individualiseren (hun “eigen plek” te vinden) in buitengewone omstandigheden. Maar ook belangrijke welzijnstheorieën zoals de Sociale Productie Functie-theorie en de *Self Determination Theory* gaan ervan uit dat mensen actief aan hun eigen welzijn werken, waarbij verschillende universele behoeften onderscheiden worden (fysiek, sociaal en psychologisch). We hebben besproken hoe deze universele behoeften ook herkend kunnen worden in onze empirische bevindingen over het gemotiveerd handelen van bewoners in het dagelijks leven. Het onderstreept dat de gevonden subthema’s (de verschillende manieren waarop bewoners hun thuisgevoel proberen te vergroten en hun eigen plek proberen te vinden in de formele zorgrelatie) een veelbelovend raamwerk bieden om de persoonlijke manier waarop een bewoner aan zijn/haar eigen welzijn werkt te herkennen en te érkennen. We bevelen longitudinaal, etnografisch onderzoek aan om dit raamwerk te evalueren en verder inzicht te krijgen in wat een bewoner helpt of juist belemmert om *agency* uit te oefenen. Hierbij moet in kaart worden gebracht welke rol (in)formele zorgverleners, alsook de fysieke ruimte hierin spelen. We veronderstellen dat vooral een vroege start om iemand te ondersteunen zich veilig en gelijkwaardig te voelen in de formele zorgrelatie van toegevoegde waarde is (mogelijk al in de geriatrische revalidatiefase), en ook dat ondersteuning van *agency* de potentie heeft om de problemen van iemand (zoals pijn, depressie of apathisch gedrag) verder te verlichten.

Ook hebben we gereflecteerd op onze bevindingen welke voorspellende factoren er zijn voor een slechte uitkomst na een beroerte, waarbij recentere literatuur zich heeft gericht op een enkele i.p.v. een samengestelde uitkomstmaat zoals wij hebben gedaan. Wat betreft de prognose van (zeer) ernstige invaliditeit laten verschillende prognostische instrumenten die in de acute fase worden gebruikt veelbelovende prestaties zien. Naast leeftijd en variabelen die de ernst van een beroerte aangeven, gebruiken deze instrumenten de functionele status van iemand vóór de beroerte, resultaten van hersenscans of biologische factoren. Dit is in tegenspraak met onze conclusie in Hoofdstuk 2 dat we meer kennis nodig hebben van prognostische factoren in andere domeinen van functioneren (waaronder emotioneel en communicatief functioneren) om een nauwkeuriger prognose mogelijk te maken. We onderschrijven deze conclusie echter nog steeds wat betreft de prognose van verpleeghuisopname na een beroerte, maar dan in de vroege (geriatrische) revalidatieperiode ná ziekenhuisopname. Dit is in lijn met prognostisch onderzoek naar succesvol ontslag naar huis na revalidatie. Het lijkt hierbij waardevol om aan te sluiten bij de meetinstrumenten die momenteel in

Nederland worden aanbevolen om het triageproces voor revalidatie na een beroerte te ondersteunen.

**Tot slot geeft de Algemene Discussie een samenvatting van de speerpunten** die naar voren zijn gekomen uit de reflecties om de ondersteunende zorg voor mensen die na een beroerte in een verpleeghuis wonen te optimaliseren. Deze speerpunten kunnen worden beschouwd als "bouwstenen" die verder ontwikkeld moeten worden voor een toekomstig methodologisch zorgprogramma op maat. Toekomstig onderzoek, zoals samengevat in de bovenstaande reflecties, zou robuuster bewijs voor deze "bouwstenen" moeten opleveren.

***Wat betreft het bieden van verlichting van problemen***, benadrukt dit proefschrift dat het verlichten van pijn en het verminderen van apathisch gedrag verder verbeterd zullen moeten worden. De multidisciplinaire richtlijn "*Herkenning en behandeling van pijn bij kwetsbare ouderen*" respectievelijk het multidisciplinaire zorgprogramma "*Doen bij depressie, met aandacht voor apathie*" bieden hiervoor een solide basis. In een zorgprogramma op maat moet bijzondere aandacht worden besteed aan:

(1) de structurele herkenning en behandeling van beroerte-specifieke pijnsyndromen die zich in de loop van de tijd kunnen ontwikkelen, en van bijkomende emotionele problemen (vooral symptomen van depressie, angst en agitatie/agressie). Herkenning van symptomen van wanen moet leiden tot een vervroegde evaluatie van de pijnmedicatie die een bewoner gebruikt om ongewenste bijwerkingen op te sporen. Het repertoire van niet-medicamenteuze behandelingen van pijn moet worden uitgebreid met de behandeling van bijkomende emotionele problemen.

(2) de structurele herkenning en behandeling van apathische symptomen die zich in de loop van de tijd kunnen ontwikkelen, vooral bij bewoners na een beroerte met (matige of ernstige) cognitieve stoornissen en zeer ernstige ADL-afhankelijkheid. Er kan worden overwogen om het probleem te analyseren in samenhang met de afzonderlijke "stemmings-" en "motivationele" dimensies van depressie. Het repertoire van niet-medicamenteuze interventies als voorkeursbehandeling van apathie staat nog in de kinderschoenen en zal hopelijk groeien.

(3) de structurele herkenning en behandeling van vermoeidheid, met de potentie om de analyse van zowel pijn als apathie als multidimensionale problemen te verbeteren.

***Wat betreft het bieden van ondersteuning om bewoners in staat te stellen hun dagelijks leven zo actief mogelijk te leiden***, benadrukt dit proefschrift het belang van een *agency*-perspectief. Een toekomstig zorgprogramma moet zorgverleners stimuleren de persoonlijke manieren te (h)erkennen waarop bewoners proberen hun thuisgevoel te vergroten in het dagelijks leven en zich veilig en gelijkwaardig te voelen in de formele zorgrelatie. Het zou bewoners bevestigen in hun actieve, autonome rol en een gezamenlijke verkenning met bewoners en hun naasten mogelijk maken over welke ondersteuning vruchtbaar en mogelijk zou zijn (of niet). Een zorgprogramma moet ook richting geven aan de herkenning van bewoners die in het dagelijks leven geen *agency* uitoefenen. Gespecialiseerde zorgverleners, bijvoorbeeld een psycholoog of een geestelijk verzorger, moeten dan verder onderzoeken waarom deze bewoners niet meer gemotiveerd zijn hun eigen plek te vinden in de verpleeghuisomgeving.

***Voor bewoners met (ernstige) cognitieve en/of communicatieve beperkingen*** moet een toekomstig zorgprogramma op maat een specifieke aanpak bieden. Met betrekking tot de herkenning en behandeling van pijn en apathisch gedrag is deze aanpak geïntegreerd in de eerdergenoemde huidige richtlijn, respectievelijk zorgprogramma, hoewel er meer onderzoek nodig is naar adequaat pijnonderzoek bij mensen met afasie. Met betrekking tot het herkennen van gemotiveerd handelen wanneer verbale communicatie moeilijk of onmogelijk is, zal het een voorwaarde zijn om de dagelijkse "functionele" communicatie te verbeteren door het inzetten van ondersteunende communicatievormen, -hulpmiddelen en strategieën.

***Op weg naar een optimale start van ondersteunende verpleeghuiszorg*** zou toekomstig onderzoek een betrouwbare prognose van verpleeghuisopname na een beroerte mogelijk moeten maken in de vroege (geriatrische) revalidatieperiode na ziekenhuisopname. Tegelijkertijd zou dergelijk onderzoek interventies aan het licht kunnen brengen die de kans op terugkeer naar huis vergroten. Daarnaast moeten we meer inzicht krijgen in hoe een vroege start van ondersteunende verpleeghuiszorg het beste kan worden geïntegreerd in de geriatrische revalidatie. Wij dringen er bij Nederlandse beleidsmakers, ziekenhuizen en verpleeghuizen op aan om geriatrische revalidatiemogelijkheden te behouden voor mensen die na een ernstige beroerte waarschijnlijk niet naar huis kunnen terugkeren.

**Concluderend** laat dit proefschrift zien dat het herkennen van samenhangende problemen bij mensen die na een beroerte in het verpleeghuis wonen en het herkennen hoe zij gemotiveerd handelen in het dagelijkse leven, samen een solide basis vormen om te begrijpen hoe ondersteunende zorg de best mogelijke bijdrage kan leveren aan hun kwaliteit van leven. Vooral toekomstig longitudinaal onderzoek naar *agency* zal belangrijk zijn om de perspectieven van de bewoners en hun naasten het beste te kunnen integreren.

# Dankwoord

# Dankwoord

Mijn eerste internationale wetenschappelijke congres was in Santiago de Compostela in 2010. Samen met Wim die mee was als mijn *personal assistant* (zijn eigen woorden ;) heb ik daar prachtige herinneringen aan: mijn presentatie op de oude universiteit aldaar, de gezelligheid met een grote groep van de afdeling ouderengeneeskunde, en natuurlijk ook de bijzondere sfeer van de stad met de drukte van alle pelgrims. Ik kon toen nog niet bevroeden dat mijn *camino* naar dit proefschrift zo uitzonderlijk zou verlopen. Waar het in 2014 en 2016 erop leek dat ik de tocht definitief zou moeten staken door mijn haperende gezondheid, schrijf ik 8 jaar later toch dit dankwoord. Natuurlijk zijn er ontelbare momenten geweest waarop ik mij heb afgevraagd of het nog verstandig en zinvol was om door te gaan, zelfs in dit laatste jaar. Maar dankzij vele mensen voelde ik iedere keer weer de wil om de volgende etappe af te leggen, hoe klein die ook was en hoe langzaam het ook ging.

Allereerst gaat mijn dank uit naar de mensen in de verpleeghuizen die belangeloos hebben meegewerkt aan dit onderzoek. Veel dank aan de bewoners van wie ik gegevens mocht verzamelen en die mij hebben willen vertellen over hun leven na een beroerte. Ik heb veel geleerd van hen, net als van alle bewoners en revalidanten met wie ik als logopedist heb samengewerkt. Na al die jaren leven hun verhalen nog steeds en dit is een belangrijke drijfveer geweest om dit proefschrift af te ronden. Ook veel dank aan de partners, kinderen of andere mantelzorgers die ik heb gesproken: hoewel deze interviews niet in dit proefschrift zijn verschenen, hoop ik van harte dat dit onderzoek bijdraagt om de zorg verder te verbeteren in samenwerking met mantelzorgers. Natuurlijk ook veel dank aan de medewerkers van de verpleeghuizen, met name specialisten ouderengeneeskunde en verzorgenden, die veel tijd hebben gestoken in het aanleveren van gegevens over de bewoners: zonder jullie bijdrage was dit onderzoek niet van de grond gekomen. Hierbij wil ik ook graag Anneke van Paridon bedanken die van onmisbare waarde was als onderzoeksassistent. Naast de hulp met logistieke zaken, heeft zij er alles aan gedaan om samen met de verzorgenden de observatielijsten volledig in te vullen. Dankjewel Anneke! Dankzij jouw hulp werd de drukke periode van gegevensverzameling niet alleen behapbaar, maar ook heel gezellig!

En dan de projectgroep. Ik kan mijn promotoren Cees Hertogh en Martin Smalbrugge en mijn copromotor Marja Depla niet genoeg bedanken voor alle begeleiding en persoonlijke steun die zij zijn blijven geven op dit lange traject. Cees, bij onze eerste ontmoeting raakte ik onder de indruk van jouw diepgang en welbespraaktheid, en dat is zo gebleven. Ik heb ontzettend veel geleerd van jouw input, ook al dreigde ik soms kopje onder te raken als je me een geheel boek of weer een andere theorie aanraadde! Maar juist het ontdekken van nieuwe kennis en inzichten heeft me veel plezier gegeven en gaande gehouden, heel veel dank daarvoor. Martin, hoe zou een projectgroep-overleg zonder jou moeten verlopen? Jouw combinatie van rustige aandacht, doel- en praktijkgerichte vragen, bondige samenvattingen en altijd vriendelijke aanmoediging vind ik uniek. Heel veel dank voor alle positieve energie die je me daarmee voortdurend hebt gegeven. Marja, als jij niet in de interviews was gedoken en niet naar Vlaardingen was afgereisd om deze met mij te analyseren, was het traject allang afgebroken geweest. Ik heb me gelaafd aan onze gesprekken en discussies die zowel vakinhoudelijk als privé waren. Heel bijzonder hoe volledig vrij ik me hierin voelde. Soms zelfs tot wanhoop van jou, als ik weer eens erg vasthoudend en eigenwijs was! Maar dat maakte me ook tot een goede onderzoeker hield je me altijd voor. Ik had me geen betere copromotor kunnen wensen. Tenslotte wil ik jullie alle drie heel erg bedanken voor jullie persoonlijke betrokkenheid (zelfs vanuit Nieuw Zeeland!) toen ik dit jaar moest revalideren en de geplande promotie in maart niet kon doorgaan. Achteraf kan ik zeggen dat dit cruciaal is geweest om de handdoek niet alsnog in de ring te gooien.

De leden van de promotiecommissie, prof.dr. A.L. (Anneke) Francke, prof.dr. T.H. (Majon) Muller, prof.dr. D.L. (Debby) Gerritsen, prof.dr. K.G. (Katrien) Luijkx, prof. dr. D.J.A. (Daisy) Janssen en dr. M.C. (Marieke) Visser, dank ik voor de tijd en energie die zij gestoken hebben in het beoordelen van mijn proefschrift. Heel veel dank ook voor jullie bereidheid om na het uitstel van de promotiedatum voor een tweede maal aandacht eraan te schenken. Ook wil ik dr. E.M. (Eefje) Sizoo hartelijk bedanken voor haar bereidheid deel te nemen aan de oppositie.

Mijn dank gaat ook uit naar de mensen die in een eerder stadium bij het onderzoek betrokken waren vanuit de afdeling ouderengeneeskunde en het Universitair Netwerk Ouderenzorg (UNO) Amsterdam. Mijn voormalige promotor Jan Eefsting wil ik hartelijk danken voor zijn waardevolle bijdrage aan de gepubliceerde artikelen. Helaas bereikte ons het bericht dat hij zeer recent is overleden. Mijn voormalige copromotor Miranda Dik, dank voor je deskundige en prettige begeleiding in de jaren waarin ik de gegevens verzameld heb. Je hebt mede aan de basis gestaan van dit onderzoek, maar besloot tot een verrassende carrièreswitch. Ik ben ervan overtuigd dat je een hele goede ergotherapeut bent geworden! En dank aan Wilco Achterberg (voormalig hoofd UNO Amsterdam) en Lizette Wattel voor het waardevolle eerste verkenningsgesprek. Het heeft mij toen over de streep getrokken om dit project aan te gaan.

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Dan mijn paranimfen Marike en Marieke. Marike, vanaf het begin klikte het tussen ons en het was geweldig om jouw paranimf te zijn in 2011. Door de jaren heen ben jij een vertrouwd anker gebleven voor mij op de afdeling, hartelijk, gezellig en altijd tot hulp en een luisterend oor bereid. Heel veel dank dat je enkele jaren geleden ook bent ingesprongen om mij te begeleiden bij het schrijven van het kwalitatieve artikel, jouw expertise. Bovenal blijven mij de bijzondere gesprekken bij die we dit jaar in het revalidatiecentrum hebben gevoerd en die me heel erg hebben geholpen om helder te krijgen wat ik toen moest doen en laten. Ik ben ontzettend blij dat jij als collega-vriendin straks naast mij staat bij de verdediging! Marieke, onze vriendschap is ontstaan omdat we allebei van zingen houden. Wat voelt het vertrouwd en veilig dat jij mijn andere paranimf bent! Net alsof ik weer een duet met jou zing (zoveel fijner dan solo zingen). Dank voor je fijne vriendschap en je geduldige support als ik weer eens in de stress zat over "Amsterdam". Wat er ook gebeurt, laten we blijven genieten van en filosoferen over een "weergaloos" leven!

Tevens wil ik mijn oude kamergenoten en collega's van de afdeling ouderengeneeskunde bedanken. Het beslaat een te lange periode om alle namen hier te noemen, maar weet dat ik zeer goede herinneringen bewaar aan alle gesprekken, adviezen en gezelligheid op de "promovenduskamer" en ook spontaan op de gang. In het bijzonder wil ik graag Salomé, Bernadette en Esther bedanken voor alle onmisbare praktische hulp die zij geboden hebben.

En dan wil ik natuurlijk mijn lieve familie en vrienden bedanken voor hun geduld de afgelopen jaren. Ik was niet altijd even open hoe ver het nu stond met "Amsterdam", vooral omdat ik dat zelf ook niet goed wist. Het was fijn als jullie er af en toe toch naar bleven vragen, maar ik ben vooral heel erg blij met jullie liefde, steun en gezelligheid! Van appjes en kaartjes tot etentjes en af en toe een heerlijk feestje: het maakt het leven zo kleurrijk! Ook dank aan mijn maatjes met wie ik samen kan zingen of roeien, echt heerlijk om te doen. Ook wil ik hier graag Vanessa noemen, praktijkondersteuner ggz van Huisartsenpraktijk De Hogen Hoed in Vlaardingen: heel veel dank voor je prettige begeleidingsgesprekken in de laatste paar jaren. Het heeft me in balans gehouden.

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En dan mijn lieve Wim. Je zei tegen mij dat je niet in het dankwoord genoemd hoefde te worden, omdat je het vanzelfsprekend vindt dat je er voor me bent. Ik ben met je eens dat het eigenlijk niet in woorden te vatten is hoe belangrijk jouw support is geweest tijdens deze *camino* waarvan je elke etappe en elke onderbreking hebt meegemaakt. Hoe je voor ontspanning zorgde, hoe je als een rots in de branding bleef als alles stil lag, hoe je praktisch zorgde dat ik mijn werk kon doen: van meegaan naar Santiago en Praag tot de talloze kopjes thee die je me op de studeerkamer bracht… Ik weet niet of dat allemaal vanzelfsprekend is, maar ik weet wel dat ik ongelooflijk blij ben dat ik samen met jou het leven vorm kan geven. Wie weet verdagen we weer eens in Santiago via een rolstoelvriendelijk wandelpad, maar ons "projectje" langs de Rotte is minstens zo fijn.

november 2024

# Curriculum vitae

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Suzanne van Almenkerk is geboren op 20 augustus 1973 in Vlaardingen. Van 1985 tot 1991 doorliep zij het VWO aan Scholengemeenschap Westland-Zuid in Vlaardingen (later opgegaan in Lentiz onderwijsgroep), waarna zij in 1995 haar diploma Logopedie haalde aan de Hogeschool Rotterdam & Omstreken. Hierna volgde zij de studie Spraak- en Taalpathologie aan de Katholieke Universiteit Nijmegen (tegenwoordig Radboud Universiteit) die zij in 2001 met lof afrondde.

Parallel aan haar studie in Nijmegen deed Suzanne werkervaring op als logopedist in een vrijgevestigde logopediepraktijk en in Geriatrisch Centrum Breede Vliet in Hoogvliet. Ook gaf zij gastlessen Logopedie aan het ROC Zadkine in Rotterdam. Van 1998 tot 2000 was zij als docent verbonden aan de opleiding Logopedie binnen de Fontys Paramedische Hogeschool in Eindhoven. In 1999 verhuisde zij vanuit Nijmegen terug naar Vlaardingen om daar als logopedist te gaan werken in het Zonnehuis (tegenwoordig Zonnehuisgroep Vlaardingen). Hier bekwaamde zij zich verder in de behandeling en begeleiding van mensen met neurologische spraak-, taal- en slikproblemen, zowel in de geriatrische revalidatie na een beroerte als in de somatische en psychogeriatrische langdurige verpleeghuiszorg en dagbehandeling. Vanaf december 2007 heeft zij dit werk gecombineerd met promotieonderzoek binnen het Universitair Netwerk Ouderenzorg van de afdeling Verpleeghuisgeneeskunde van het VU medisch centrum (tegenwoordig afdeling Ouderengeneeskunde van Amsterdam UMC), waar het Zonnehuis Vlaardingen destijds bij aangesloten was. In 2016 is Suzanne om gezondheidsredenen gestopt met haar betaalde werk. In de jaren erna heeft zij in eigen tempo dit proefschrift afgerond.

Suzanne is in 2003 getrouwd met Wim. Zij houdt van zingen, roeien en lezen en ontdekt samen met Wim graag rolstoelvriendelijke wandelpaden.