

Multi-dimensional challenges in geriatric rehabilitation; the GRAMPS-study

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‘Als autonoom handelend persoon ben ik,
en ik alleen,
degene die,
samen met het moleculaire genie van mijn DNA
en de omgevingsfactoren waaraan ik ben blootgesteld,
de ruimte binnen mijn schedeldak moet inrichten’

(J. Bolte Taylor)



Multi-dimensional challenges in geriatric rehabilitation; the GRAMPS-study

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My grandmother

In 2011 my grandmother suffered a severe stroke at the age of 88 years. She had hemianopsia, aphasia and left side hemiplegia with unilateral neglect. The physiatrist (rehabilitation specialist) in the hospital told us that she was going to be referred to a specialized rehabilitation unit in a nursing home. But he expected that she would not be able to go back home and probably would be referred permanently to a unit for long-term care in a nursing home. And I said “well, we shall see....!”

She was very motivated to comply with her low intensity rehabilitation program. What she wanted the most was to go back home. Fortunately, after four months rehabilitation in the skilled nursing facility, my grandmother was discharged home. She is not able to walk anymore, but is using her wheelchair quite easily. Her hand- and arm function restored not completely, but she manages herself in daily life through compensation strategies. In her wheelchair she is able to do her shopping in the grocery store in the building she is living in.

Communicating with her is like playing a word game that results in guessing and sometimes laughing until we find the right word. My grandmother receives professional care from nurses who stimulate and help her in ADL activities and exercises. She receives therapy sessions from a physiotherapist twice a week.

Being family, we support her in some activities such as making telephone calls, doing the administration and laundry and we motivate her to do exercises. It makes us happy that she can maintain a relatively good quality of life.



Chapter 1

General introduction



Geriatric Rehabilitation

Rehabilitation is an important area in both medicine and nursing. It is a multidisciplinary process, which needs to comprise comprehensive assessment, treatment, support and advice and is given by a multidisciplinary team of competent health care professionals.¹ Traditionally, rehabilitation is predominantly aimed at restoring functional status. However, in the past decades there has been a growing interest in treating patients from a holistic perspective. Increasingly, patients are considered individuals with expectations and motivation on their rehabilitation and with a psychosocial context that influences the goals and perceptions of their rehabilitation process.^{1,2} For instance, research has shown that the presence of and relationships with the partner and children, who may become informal caregivers, are important influencing factors.³ This implies that rehabilitation should become more patient centred, meaning that the aims for recovery of certain abilities are different for every patient and that activities are tailored to their individual needs.

As their age is increasing, older persons face many physical, social and psychological changes that can affect the level of functioning and well-being.⁴ Therefore, a holistic approach is especially important in geriatric rehabilitation. Geriatric rehabilitation is rehabilitation for elderly patients who have lower endurance⁵ and includes integrated multidisciplinary care that is aimed at recovery and participation in daily life for elderly people who have functional decline after an acute disease. The intent is to recover to the level of activities and participation as before (if possible), so that patients can return to their own living situation.⁶ Care may also include supporting patients and their relatives to cope with the consequences of the remaining impairments and decreased ability to participate in daily life. Moreover, the treatment of comorbidities such as diabetes mellitus, heart failure, arthrosis, lung- and kidney disease, cognitive and mood disorders has an important place in geriatric rehabilitation.⁷

Rehabilitation can be divided into three different phases: acute care, rehabilitation and long term care.⁸ Dependent on functional status and age, rehabilitation of patients in the Netherlands takes place in hospitals, rehabilitation centers, nursing homes or in the community. Geriatric rehabilitation in the Netherlands takes place in Skilled Nursing Facilities (SNFs).⁹ SNFs are part of a nursing home and have the staff and resources to provide skilled nursing care and/or skilled rehabilitation services. Geriatric rehabilitation in SNFs is aimed at discharging patients back to the community, and is coordinated based on organized programs and protocols. Each patient in the SNF is provided with a rehabilitation program offered by a multidisciplinary team

consisting of an elderly care physician,¹⁰ a physiotherapist, an occupational therapist, a speech-language therapist, a psychologist, a dietician, and nursing staff. SNFs in the Netherlands provide rehabilitation for more than 27.000 patients a year with a budget of an estimated € 316 million per year.¹ Until 2012, SNFs receive reimbursement through the Dutch Resource Utilization Groups (ZZP) which are divided into 10 ZZP budgets, all paid from the exceptional medical expenses act (AWBZ) until 2012.

The overall amount of time that (financially) can be spend on treatment and therapy by the multidisciplinary teams (excluding nursing care) is restricted to and based on the maximum and official treatment time in The Dutch Resource Utilization Group ZZP9.¹¹ The treatment time comprises 4 hours per week, which are to be distributed over 5 working days.

The largest patient groups that are in need of geriatric rehabilitation are patients who have gone through trauma, elective surgery (such as hip or knee replacement) or stroke, and a relatively small group of patients have had a limb amputation. This thesis will focus on the latter two groups of patients, because both conditions are in most cases the consequence of vascular disease. In 2007 about 6500 patients with stroke and 400 patients with amputation were admitted for rehabilitation in nursing homes.¹

Optimizing rehabilitation

Patients with stroke or amputation are characterized by comorbidity and the multidimensional consequences of these conditions. To address their needs, a multidisciplinary approach is essential. Therapists and clinicians attempt to tailor therapy to patients' personal needs and may use a combination of individual and group therapies. Mostly, therapists tailor their treatment to the needs of the patient based on their clinical judgment of the condition at admission. However, not only the degree of physical impairment at admission, but several therapy characteristics and psychosocial factors such as mood,¹² motivation of the patient,¹³ support of relatives,^{14, 15} as well as environment,^{16, 17} early start of therapy^{16, 18} and therapy intensity,¹⁶ are highly significant for discharge destination. It is yet unclear whether specific groups of patients might benefit differently from structured multidisciplinary rehabilitation programs. Therefore, it may be relevant to investigate whether subgroups can be identified on admission in order to design specific rehabilitation programs.

With regard to the above mentioned therapy characteristics, prior research shows that the mean amount of time invested in therapy (physical therapy, speech therapy, occupational therapy, psychologist and medical care) is based on the official treatment time (ZZP9), but differs between types of conditions (stroke and amputa-

tion/elective surgery/trauma) and between SNFs. Relatively more time is spent on therapy for patients with stroke (266 minutes per week) compared to other types of patients (155–165 minutes per week).¹ Yet, rehabilitation not only takes place in the therapy room, but also on the ward, where nurses exercise with patients during activities of daily living. Many simple task-oriented interventions, tailored to patient needs, are known to be effective in improving patient outcomes and are highly relevant for nurses to use in the daily care of patients.¹⁹ These exercises contribute to creating a continued rehabilitation climate that stimulates functional recovery and decrease psychological and social consequences since these multidimensional factors hinder successful discharge.

These psychosocial consequences, possibly revealing themselves as neuro-psychiatric symptoms (NPS), are highly relevant in an optimal rehabilitation climate. Studies show that, although the onset and course is unclear, NPS such as psychosis, depression, apathy, anxiety and agitation play an important role.^{12, 14, 15} NPS are burdensome for patients and may have a negative impact on their quality of life (QoL). Furthermore, NPS and depression may cause readmission to the hospital.²⁰ Therefore, knowledge about the prevalence and course of NPS in individual patients is important for the planning of professional rehabilitation services but also for informal care.

Predominantly, therapists are seen as the professionals in rehabilitation and nursing is viewed as separate from rehabilitation. However, rehabilitation should be multidisciplinary, and far-reaching collaboration improves patient outcomes. Nonetheless, it is unclear to which extent nurses in SNFs contribute to a rehabilitation climate.

After discharge

Generally, geriatric rehabilitation patients and their relatives are faced with remaining impairments and the multidimensional consequences thereof, such as physical disabilities,^{14, 15, 21–24} dependency on care, and NPS.^{14, 25–28} These consequences may negatively affect the patient's QoL. After successful rehabilitation patients are discharged to an independent or assisted living situation, but even geriatric patients who live at home are often dependent on care and social support by professional or informal caregivers. Additionally, there is a lack of knowledge about QoL and the factors that influence QoL after stroke and amputation after discharge. Knowledge about these factors may help to optimize geriatric rehabilitation.

Geriatric rehabilitation in Skilled Nursing Facilities: the GRAMPS study

The issues described above were reasons to study geriatric rehabilitation in SNFs. The Geriatric Rehabilitation in AMPutation and Stroke study (GRAMPS) was conducted to provide more insight into the characteristics of geriatric patients and the course of their rehabilitation process. The GRAMPS study is a longitudinal, multicenter, observational study of geriatric patients admitted to SNFs for rehabilitation. Data were collected from January 2008 until January 2009 in 15 Dutch SNFs, all being part of the Nijmegen University Nursing Home Network (UKON, www.ukonnetwerk.nl) of the Radboud University Nijmegen, Medical Centre, and situated in the Southern parts of the Netherlands. All participating SNFs were selected based on the existence of a specialized rehabilitation unit and the provision of dedicated multidisciplinary care.

Research questions and general outline

The main focus of this thesis is on description of the characteristics and course of patients who are admitted to geriatric rehabilitation, with specific attention to the (course of) neuropsychiatric symptoms, their effect on quality of life and the role of nurses and informal carers during the rehabilitation process in skilled nursing facilities, and after discharge.

Chapter 2 and 3 describe the designs of the GRAMPS study: The study protocols of geriatric rehabilitation in stroke and amputation. These chapters also refer to the predictors of outcomes such as functional status and balance of geriatric patients who underwent rehabilitation in SNFs. These physical aspects of rehabilitation are extensively addressed in a companion thesis by Monica Spruit-van Eijk.²⁹

In this thesis the following research questions are addressed:

1. *What are relevant patient characteristics to distinguish groups of patients based on their admission scores in skilled nursing facilities and what is the course of these particular patient-groups in relation to their discharge destination?*

Chapter 4 describes a study aimed at identifying groups of geriatric patients with stroke, based on individual patient characteristics through cluster analysis. We studied how subgroups improved after admission in characteristics relevant for rehabilitation such as functional status, balance, and neuropsychiatric symptoms.

2. *What is the amount of time that stroke patients spend on therapeutic activities, non-therapeutic activities, social interaction with others, and what is the location where the activities take place?*

Chapter 5 describes the time that is spent on therapeutic activities, non-therapeutic activities, and interaction with others, of patients who were admitted for rehabilitation after stroke. Data were collected using the behavioral mapping method in a separate sample of patients of five SNFs participating in the GRAMPS-study.

3. *What are the prevalence and course of neuropsychiatric symptoms in geriatric patients admitted to skilled nursing facilities for rehabilitation after stroke?*

Chapter 6 gives a description of the actual prevalence and the course of neuropsychiatric symptoms in patients with stroke during rehabilitation in skilled nursing facilities. It was hypothesized that neuropsychiatric symptoms are particularly prevalent in patients who show poor functional recovery and, consequently, could not be discharged to an independent living situation within one year after stroke.

4. *What is the quality of life of patients with stroke or amputation after discharge and what are the factors that influence quality of life?*

Chapter 7 describes the determinants of patients' quality of life and informal caregiver burden in home dwelling geriatric patients with stroke after rehabilitation. We focused particularly on the interrelationship of patients' quality of life, patient characteristics and informal caregiver burden, which may be specifically prominent in geriatric patients. The study aimed to identify:

- 1) determinants of quality of life in home dwelling geriatric patients with stroke three months after rehabilitation, and
- 2) patient related determinants of the burden of their informal caregivers.

Chapter 8 describes the determinants of quality of life in home dwelling geriatric patients after lower limb amputation and rehabilitation in skilled nursing facilities. This study was aimed at investigating quality of life and identifying determinants of quality of life in home dwelling geriatric patients with a history of peripheral arterial disease, on average within a half-year after lower limb amputation and three months after rehabilitation.

Finally, in chapter 9 the main findings of this thesis are summarized by addressing the research questions. The methodological issues of the studies are discussed, fol-

lowed by implications for nurses, physicians, psychologists, therapists, medical directors, (nurse) policy makers and (nurse) researchers. Finally, recommendations for future research are given and the thesis ends with a general conclusion.

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Chapter 2

Geriatric rehabilitation of stroke patients in nursing homes: a study protocol

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BMC Geriatrics - 10 (15)2010

Abstract

Background

Geriatric patients are typically underrepresented in studies on the functional outcome of rehabilitation after stroke. Moreover, most geriatric stroke patients do probably not participate in intensive rehabilitation programs as offered by rehabilitation centers. As a result, very few studies have described the successfulness of geriatric stroke rehabilitation in nursing home patients, although it appears that the majority of these patients are being discharged back to the community, rather than being transferred to residential care. Nevertheless, factors associated with the successfulness of stroke rehabilitation in nursing homes or skilled nursing facilities are largely unknown. The primary goal of this study is, therefore, to assess the factors that uniquely contribute to the successfulness of rehabilitation in geriatric stroke patients that undergo rehabilitation in nursing homes. A secondary goal is to investigate whether these factors are similar to those associated with the outcome of stroke rehabilitation in the literature.

Methods

This study is part of the Geriatric Rehabilitation in AMPutation and Stroke (GRAMPS) study in the Netherlands. It is a longitudinal, observational, multicenter study in 15 nursing homes in the Southern part of the Netherlands that aims to include at least 200 patients. All participating nursing homes are selected based on the existence of a specialized rehabilitation unit and the provision of dedicated multidisciplinary care. Patient characteristics, disease characteristics, functional status, cognition, behavior, and caregiver information, are collected within two weeks after admission to the nursing home. The first follow-up is at discharge from the nursing home or one year after inclusion, and focuses on functional status and behavior. Successful rehabilitation is defined as discharge from the nursing home to an independent living situation within one year after admission. The second follow-up is three months after discharge in patients who rehabilitated successfully, and assesses functional status, behavior, and quality of life. All instruments used in this study have shown to be valid and reliable in rehabilitation research or are recommended by the Netherlands Heart Foundation guidelines for stroke rehabilitation.

Data will be analyzed using SPSS 16.0. Besides descriptive analyses, both univariate and multivariate analyses will be performed with the purpose of identifying associated factors as well as their unique contribution to determining successful rehabilitation.

Discussion

This study will provide more information about geriatric stroke rehabilitation in Dutch nursing homes. To our knowledge, this is the first large study that focuses on the determinants of success of geriatric stroke rehabilitation in nursing home patients.

Background

According to the World Health Organization, 15 million people worldwide suffered a stroke in 2004.¹ It has been reported that the mean stroke incidence rate in Western countries is 94 per 100,000 person years.² Although men are more often affected than women due to a younger age of onset, this gender difference becomes smaller with increasing age.³ Stroke incidence typically increases with age and, due to the ageing of the population, stroke incidence rates are expected to rise. High age and low level of physical endurance, due to significant comorbidity, are characteristic of the geriatric stroke population. Although rehabilitation after stroke is an important activity in many rehabilitation centers worldwide, most geriatric stroke patients are probably not admitted to these centers and, thus, do not participate in intensive rehabilitation programs.⁴ These patients may be referred to nursing homes or skilled nursing facilities (SNF) that provide adapted rehabilitation programs combined with residential care, whereas others may not receive any formal type of multidisciplinary rehabilitation at all. As a result, geriatric stroke patients are greatly underrepresented in outcome studies and factors associated with the successfulness of their rehabilitation are largely unknown.

Few studies have dealt with the influence of comorbidity and age on the outcome of stroke rehabilitation. Atalay and Turhan⁵ found that elderly stroke patients (older than 65 years of age) were less likely to be successfully rehabilitated despite similar Functional Independence Measure (FIM) scores on admission, compared to patients younger than 65 years. Yet, comorbidity and age were not associated with prolonged length of stay in the rehabilitation center. In the same vein, Fischer et al.⁶ found that comorbidity and age did not uniquely contribute to predicting length of hospital stay. On the other hand, there is evidence that comorbidity and age are important factors in determining functional outcome after stroke.⁷ Several additional studies have emphasized the importance of age for functional outcome after stroke, but estimates of the true impact of age seem to vary greatly. Whereas some studies reported a relatively small influence of age,^{8,9} other studies found that very old age, defined as 85 years and older, was a consistently strong predictor of poor outcome.¹⁰

Interestingly, Teasell et al.⁴ have reported that rehabilitation in 'lower band' patients recovering from severe stroke, who were considered inappropriate for conventional inpatient rehabilitation programs, may still be quite successful in terms of gain in independency of self-care and ambulation. However, although the patients were on average 72 years of age, this study did not specifically focus on geriatric rehabilitation and did not examine the influence of comorbidity or age on rehabilitation outcome. Several other studies have shown that a substantial number of stroke

TABLE 1: Factors associated with stroke outcome disability and discharge destination in the literature

Outcome	Factors associated with outcome
ADL scores FIM BI	<ul style="list-style-type: none"> - Initial FIM, age^{8, 9} - Initial BI¹⁴ - Initial NIHSS, age, premorbid disability, DM, infarct volume¹⁵ - Trunk Impairment Scale, static sitting balance¹⁶
Discharge destination	<ul style="list-style-type: none"> - Age, incontinence¹⁸ - initial FIM, age¹⁷ - premorbid social support, FIM bowel, age, CMSA leg, type of premorbid accommodation¹⁹ - initial MMSE, premorbid living with relatives⁸ - discharge BI, LOS, age²⁰ - Initial FIM, age, male gender⁴ - swallowing disorder²¹

FIM functional independence measure, BI barthel index, NIHSS national institute of health stroke scale, DM diabetes mellitus, CMSA Chedoke-McMaster stroke assessment, LOS length of stay

patients that receive rehabilitation in SNFs or nursing homes can be successfully discharged to the community.¹¹⁻¹³ The probability of discharge greatly depends on individual rehabilitation potential, which is related to stroke severity and physical capacities. Besides, it appears that admission to SNFs increases the likelihood of successful rehabilitation in terms of discharge to the community.^{11, 12}

In general, many studies have investigated the clinical, biological and demographic factors associated with the outcome after stroke.^{4-10, 14-25} A large number of such factors has been associated with the outcome after stroke rehabilitation (table 1), but probably many of these factors are interrelated. This implicates that the unique contribution of these factors to stroke outcome, corrected for association with other factors, still has to be determined in order to be of value for clinical prediction in daily practice. In short, initial disability and age seem to be the most promising predictors of long-term activities of daily living (ADL) and discharge destination after rehabilitation.

Against this background, the primary goal of this study is to assess the factors that uniquely contribute to the successfulness of rehabilitation in geriatric stroke patients that undergo rehabilitation in nursing homes. Functional outcome is primarily assessed by discharge to an independent living situation and, secondarily, by various functional scales. A secondary goal is to investigate whether the factors that are uniquely associated with successfulness of rehabilitation in this geriatric population are similar to those associated with the outcome of stroke rehabilitation in the literature. To this end, we have set up a multicenter study in 15 nursing homes in the Southern part of the Netherlands. All participating nursing homes are selected based on the existence of a specialized stroke rehabilitation unit and the provision of dedicated multidisciplinary care. To our knowledge, this is the first study that focuses on the determinants of success of geriatric rehabilitation in nursing home patients.

Methods

Study design

This prospective study is part of the Nijmegen Geriatric Rehabilitation in AMPutation and Stroke (GRAMPS) study and comprises three measurements. Baseline data (T0) are collected within two weeks after admission to the nursing home. Patients and disease characteristics, functional status, cognition, behavior and caregiver information are registered (table 2). The first follow-up (T1) is at discharge from the nursing home, and focuses on functional status and behavior. Successful rehabilitation is defined as discharge from the nursing home to an independent living situation within one year after admission. The second follow-up (T2) is at three months after discharge in patients who rehabilitated successfully and focuses on functional status, behavior and quality of life.

Data collection has started in January 2008, and will end in July 2010.

Patients

All patients who are consecutively admitted to one of the specialized rehabilitation wards of the 15 participating nursing homes are eligible to participate in this study. No other inclusion criteria were applied. Inability to give informed consent is an exclusion criterion. All participating nursing homes collaborate in the Nijmegen University Nursing Home Network of the Radboud University Nijmegen Medical Center. After admission patients are provided with oral information from the treating physician or nurse. In addition, all patients and their caregivers receive written information about the study. The patients indicate themselves whether they are interested to participate. The attending physician judges the legal capacity of his/her patients.

TABLE 2: Research instruments

	Instrument	T0	T1	T2
Patient	Patient characteristics Co-morbidity: Charlson Index Medication list,	X X X	X	
Functional status	Motricity index Arm and Leg* Trunk control test* Trunk impairment scale Barthel index* Social activity: Frenchay activities index* One leg standing balance Frenchay arm test* Berg Balance scale* Functional Ambulation Categories* 10m walking speed* Water swallowing test*	X X X X X X X X X X X	X X X X X X X X X	X X X X X X X X X
Cognition	Mini Mental State Examination Star cancellation test Hetero anamnestic cognition test Apraxia test Communication: SAN score*	X X X X X		
Behavior	Neuropsychiatric inventory questionnaire Neuropsychiatric inventory Nursing Home Global depression scale 8	X X X	X X X	X X X
	RAND 36 version 2			X
Quality of life	Social situation COOP WONCA	X X	X	X X
Caregivers	Caregiver strain index*			X

*: test recommended by the Netherlands Heart Foundation SAN stichting afasie Nederland (Dutch Aphasia Foundation), COOP WONCA The Dartmouth COOP Functional Health Assessment Charts/WONCA

In the case of doubts he/she consults the caregivers. In addition, the GRAMPS website (www.gramps.nl) provides extra information for interested patients and their caregivers.

Ethical approval

This research protocol was presented to the medical ethics committee of the district Nijmegen– Arnhem, the Netherlands. Ethics approval was not deemed necessary, because the design is observational and because legally incapable patients are excluded.

Assessment instruments

Data are collected by the multidisciplinary teams working in the participating nursing homes. Each discipline has the obligation to perform specific assessments. The selected outcome measures have been selected based on previously established reliability and validity or based on recommendations by the Netherlands Heart Foundation guidelines for stroke rehabilitation (table 2).²⁶

- ***Patient characteristics***

General patient characteristics as well as disease characteristics, medication lists, and information about comorbidity, using the Charlson Index (CI), are registered. The CI comprises 19 categories of diagnoses from the International Classification of Diseases, (9th revision Clinical Modification ICD-9CM) and is based on a set of risk factors for one-year mortality risk.²⁷ The CI contains a weighted index for each disease at which the score is a significant predictor of one-year survival. One-year mortality rate for the different scores are: “0” 12%, “1-2” 26%, “3-4” 52% and “>5” 85%.

- ***Functional status***

The Barthel Index (BI), modified by Collin et al. in 1988,²⁸ measures dependency in activities of daily living (ADL). The BI is a valid and reliable instrument in stroke research.²⁸⁻³¹ The total score ranges from 0-20, with 20 representing complete functional independence.

The Frenchay activities index (FAI) is used for assessment of extended ADL. The FAI³² scores the actual activities undertaken by patients and can be divided in three domains: domestic housework, indoor activities and outdoor activities. The 15-item questionnaire is a reliable and valid instrument for measuring functional outcome in stroke patients.^{33, 34} Even proxies give reliable information about FAI items.^{35, 36}

The Frenchay Arm Test (FAT) is used to evaluate arm function after stroke. The patient is asked to perform five activities with his affected arm, for which he receives one point if successfully complete. The FAT is a valid and reliable instrument for use

in stroke research.³⁷

The Motricity Index³⁸ is used to evaluate motor impairment of the limbs. Six movements, divided in arm and leg movements, are observed. Three scores can be measured: arm score, leg score and side score. Both arm and leg scores have good criterion validity and are reliable if used by different observers.^{39–41}

Item three of the Trunk Control Test (TCT) is used to assess static sitting balance: sitting in a balanced position on the edge of the bed for at least 30 seconds, with the feet above the ground.

The Trunk Impairment Scale (TIS), developed by Verheyden and colleagues,⁴² evaluates motor impairment of the trunk after stroke. TIS takes movement and coordination as well as static sitting balance into account. The TCT and TIS both show good validity and reliability.^{40, 42}

The Berg Balance Scale (BBS) is an ordinal 14 item scale (0–56 points) developed by Berg et al.⁴³ to measure balance in stroke patients. Validity and reliability of the BBS is good,^{44–47} however the scale is not suitable for patients with very severe impairments, who cannot maintain a balanced sitting position.⁴⁴ Ceiling effects have also been described by Mao⁴⁴ at 90–180 days post stroke.

The one- leg- standing balance test, first used by Schoppen et al.,⁴⁸ is used to assess standing balance on the unaffected leg.

The Functional Ambulation Categories (FAC)⁴⁹ is a measure of the (in)dependency of gait. The FAC is an ordinal six-point scale with 0 indicating total dependency for walking and 5 indicating independent walking. The use of a walking device is allowed. Berg et al.⁴³ found high correlations between the BBS and FAC scores.

The Ten-Meter-Walking-Speed test (TMWS-test) times the walking speed along a distance of ten meters and can be performed at a comfortable or maximum walking speed.⁵⁰ Because the comfortable walking speed seems to be more responsive to functional recovery after stroke⁵¹ and because the maximum walking speed can be estimated by multiplying comfortable walking speed by 1.32,⁵² the TMWS- test is performed at comfortable walking speed, only by patients with a FAC score of 3 or higher.

The water swallowing test²⁶ is a simple bed-side test and resembles the water swallowing test proposed by Smithard and coworkers.²¹ After drinking three spoons of water safely, half a glass of water is given to the patient. The patient fails in case of signs of choking. The speech therapist assesses food consistency after the patient safely drinks the water.

- **Cognition**

The Mini-Mental-State-Examination (MMSE), developed by Folstein and McHugh,⁵³ is a screening instrument for cognitive impairment, and has a fair reliability and construct validity, with a high sensitivity for moderately-severe cognitive impair-

ment and a lower sensitivity for mild cognitive impairment.⁵⁴ It comprises items testing orientation, attention, memory, language and constructive abilities. Bottom and ceiling effects have been described.⁵⁵ An important bias in using the MMSE in stroke research is the extensive use of language, which leads to unreliable results in aphasic patients. For this reason, we will not use the MMSE in patients with severe aphasia. The Hetero-Anamnestic- Cognition list (HAC list), derived from the MMSE by Meijer in his AMDAS study,⁵⁶ is used to explore the presence of premorbid cognitive disabilities. The proxy, preferably a partner if present, is asked a few simple 'yes' or 'no' questions concerning orientation, attention and calculation, language, memory, and executive skills. Severity is judged on the basis of need of assistance or professional therapy required.

The Star Cancellation Test (SCT), an item of the Behavioral Inattention Test (BIT),⁵⁷ is a screening instrument for detecting unilateral visuospatial neglect. The SCT consists of 52 large stars, 13 characters, 10 words, and 56 small stars. All small stars are to be eliminated. The researcher gives a demonstration by crossing out the two small stars in the middle. The cut-off point is 52.⁵⁷ Rough scores can be used to interpret the outcome of the SCT, rather than the visual lateralization scores.⁵⁸ There is sufficient evidence for good validity of the SCT.⁵⁹⁻⁶¹

Van Heugten et al. developed a diagnostic tool for apraxia in stroke, based on an existing instrument.⁶² This Apraxia test, differentiating between apraxia and non-apraxia, involves demonstration of object use and imitations of gestures. It has good validity and reliability.^{62, 63}

The SAN (Stichting Afasie Nederland = Dutch Aphasia Foundation) score is used to quantify communicative impairment in stroke patients and is part of the Aachen Aphasia Test (AAT).⁶⁴ The SAN score is an ordinal 7-point scale with '1' indicating no communication possible and '7' indicating normal language skills.⁶⁵

• **Behavior**

The NeuroPsychiatric Inventory (NPI), originally developed for dementia patients,⁶⁶ gives a global impression of behavioral problems and is applicable in other patient groups as well. The NPI comprises 12 categories of problem behaviors: delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity, sleeping disorder and eating disorder. If the interviewed person, either a nurse in the NPI-Nursing Home (NPI-NH) version or a partner or close relative in the questionnaire version (NPI-q), positively answers the screening question, both frequency and severity (only in the NPI-NH version) are determined. The NPI closes each category with enquiring about emotional burden. The NPI is a valid and reliable instrument,⁶⁶ has been translated into Dutch, and has previously been used in stroke research.^{67, 68}

The eight item version of the Geriatric Depression Scale (GDS-8) is a shortened

patient-friendly test derived from the GDS-15 version, and has been developed specifically for the nursing home population.⁶⁹ It indicates the presence of depression at a cut-off of 3 out of 8.

- **Quality of life**

The RAND- 36, developed to measure health related quality of life in chronically ill patients, comprises eight dimensions: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and general mental health. It also contains an additional item about perceived health change.⁷⁰ The item scores of all dimensions need to be recoded according to the RAND health sciences program standards.⁷¹ The RAND-36 has been translated into Dutch by van der Zee et al., and was found to be a valid, reliable, and sensitive measurement of general health.⁷²

- **Caregivers**

The Dartmouth COOP Functional Health Assessment Charts/WONCA (COOP/WONCA) subscales⁷³⁻⁷⁵ physical fitness, daily activities, feelings and overall health are used to measure proxy's functional status. Each subscale consists of a short title and an illustrated five-point response scale: scores 16 and up are indicative of high strain.⁵⁶ The Caregiver Strain Index (CSI) is only used after discharge from the nursing home, when participation level of the patient plays a key role.⁷⁶ Optimal reintegration reduces the experienced strain of the caregivers. The CSI consists of 13 'yes' and 'no' questions, is an easy used instrument to identify strain, and shows validity.⁷⁷ A score of 7 or more positive responses indicates a high level of strain⁷⁸. The CSI has been used in research on various diseases.⁷⁹⁻⁸¹

Data analysis

All data is processed using the Statistical Package for Social Science 16.0 (SPSS 16.0). Different techniques will be used to analyze the data, depending on the research question.

- Descriptive analysis will be used for general patient characteristics, disease characteristics, treatment, successfulness of rehabilitation, and functional outcomes.
- Univariate analyses, parametric as well as non-parametric, will be performed for identifying the demographic and clinical factors that are associated with successful rehabilitation ($p < 0.1$).
- Associated factors will then be tested in a multivariate logistic regression analysis to determine their unique contribution and overall explained variance of successfulness of rehabilitation.

Power

The required sample size was estimated using the rule of thumb according to Peduzzi et al.:⁸² At least 10 patients per factor in the smallest group, in the case of a dichotomous outcome. Based on our experience, approximately 35% of the stroke patients, admitted to nursing homes for rehabilitation, cannot be discharged to an independent living situation.

When testing a maximum of seven factors in the multivariate model, 70 patients need to be included in the smallest group (35%). Consequently, a total of 200 stroke patients will be included.

Discussion

To our knowledge, this is the first large study that focuses on the determinants of success of geriatric stroke patients admitted to nursing homes. It will provide more detailed information about the factors that are uniquely associated to the successfulness of geriatric stroke rehabilitation and that can, thus, be used in building a clinical prediction model of discharge destination from nursing homes.

All selected outcome measures have proven to be reliable and valid, or are recommended by the Netherlands Heart Foundation.

Because legally incapable patients are excluded from this study, its external validity may be slightly affected. Therefore, general patient characteristics of the excluded patients are registered and compared to those of the included patients. Besides age, length of stay in the nursing home, and discharge destination are recorded to compare both groups. This multicenter research uses multidisciplinary teams to collect the data over a period of two-and-a-half years and, thus, may suffer from some measurement inaccuracies. To minimize such inaccuracies, over 90 people working in 15 Dutch nursing homes received the same instructions about performing the outcome measures during collective meetings before the start of the study. To ensure the quality of data collection during the study, each nursing home has 2 to 3 specially assigned professionals who maintain contact with the main researchers. In addition, a newsletter is provided every 6-8 weeks to keep everybody involved, informed, and motivated with regard to the progress of the study.

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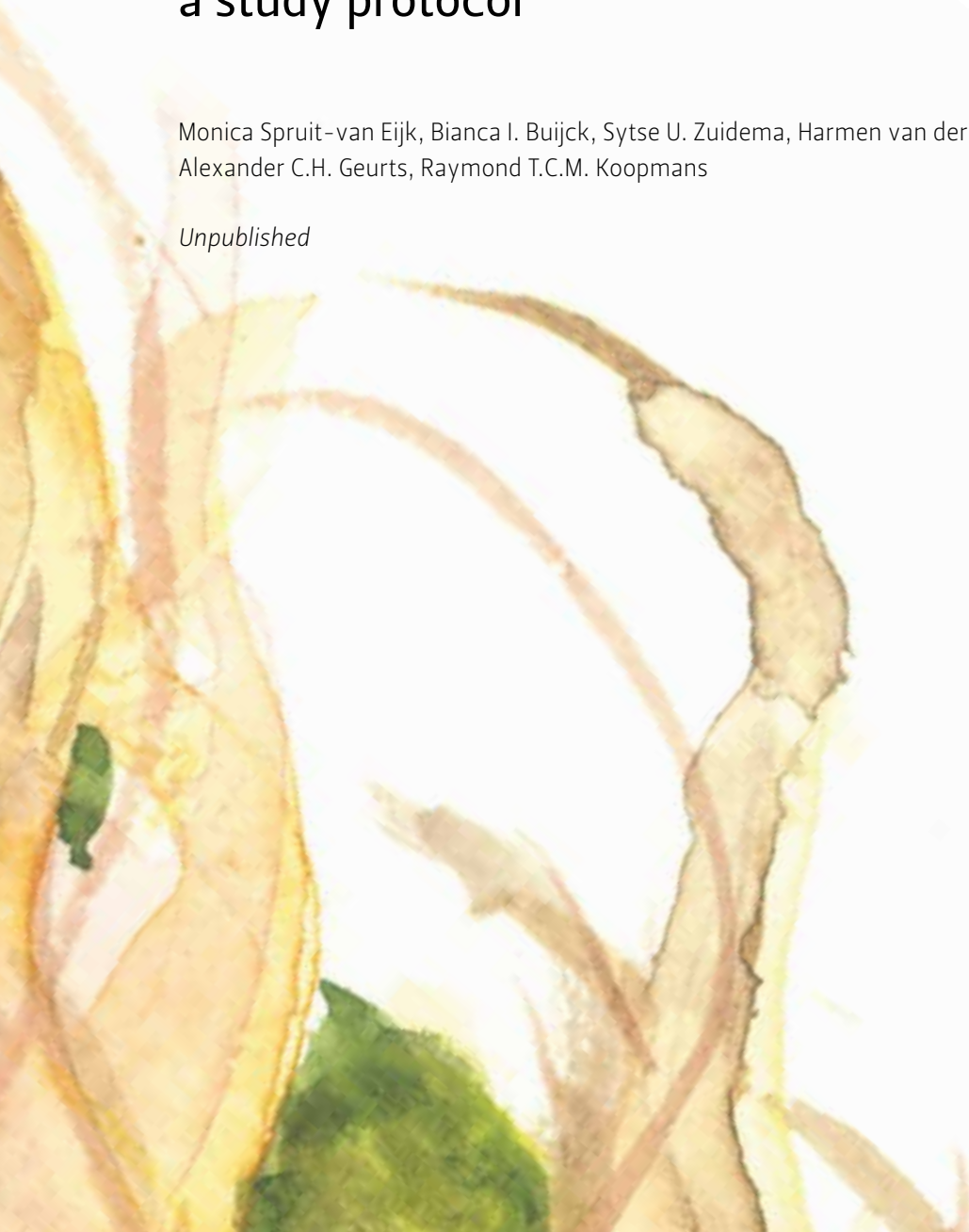


Chapter 3

Geriatric rehabilitation of lower limb amputees in nursing homes; a study protocol

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Unpublished



Abstract

Background

After the acute care in hospital, lower limb amputees are often referred for rehabilitation to a rehabilitation center or a skilled nursing facility (SNF). From the literature it is known that factors determining discharge destination are amputation level, gender, age, and number of comorbidities. However, the existing literature is mainly retrospective and focuses on patients in rehabilitation centers. As a consequence, the results may have been confounded by selection bias. To our knowledge no studies have been published on the factors associated with successful outcome of rehabilitation of patients with lower limb amputation in SNFs.

Methods

This study is part of the Geriatric Rehabilitation in AMPutation and Stroke (GRAMPS) study in the Netherlands. It is a longitudinal, observational, multicenter study in 9 SNFs in the Southern part of the Netherlands that aims to include at least 50 patients rehabilitating after major limb amputation. Only SNFs with a specialized rehabilitation ward and the provision of multidisciplinary care are selected. Patient characteristics, disease characteristics, functional status, cognition, behavior, and caregiver information are collected within two weeks after admission to the SNF. The first follow-up is at discharge from the SNF or one year after inclusion, and focuses on functional status and behavior. Successful rehabilitation is defined as discharge to an independent living situation within one year after admission. The second follow-up is three months after discharge in patients who have been rehabilitated successfully, and assesses functional status, behavior, and quality of life.

Discussion

This is the first study that will provide more information about geriatric rehabilitation after major lower limb amputation in SNF patients. The patients admitted to SNFs differ from patients admitted to rehabilitation centers with respect to age, number of comorbidities, and amputation level. Therefore, factors associated with successful outcome will probably differ as well. By making use of multivariate logistic regression models the independency of associated factors will be established.

Background

Worldwide incidence and prevalence rates of peripheral arterial disease (PAD) are not known, partly because the diagnosis is often unrecognized in primary care settings.¹ A substantial number of PAD patients undergo major lower limb amputation. In 2005, approximately 600.000 people in the United States with a comorbid diagnosis of diabetes mellitus underwent an amputation secondary to vascular disease.² The number of major lower limb amputations in the Netherlands shows a declining trend. In 2004, 1747 elderly, aged 65 years and older, underwent transfemoral amputation (TFA), transtibial amputation (TTA), or a disarticulation of the knee or ankle, whereas in 2007, this number had decreased to 1247.³ Lower limb amputation was more often carried out in men, and in older age groups. Elderly lower limb amputees have reduced survival rates. Dillingham et al.⁴ found that one-year survival was merely 59% after major lower limb amputation for PAD. The peri-operative mortality is approximately 10%,^{5, 6} with lower mortality-rates in TTA than in TFA.^{7, 8} These high mortality rates are probably related to a combination of the more progressed arterial disease and other comorbidity, typical of the elderly lower limb amputee. Cardiovascular diseases are one of the most important factors associated with peri-operative^{6, 9} as well as long-term mortality.^{9, 10}

After the acute care in a hospital, patients with lower limb amputation are often referred for rehabilitation. Intensive rehabilitation programs are provided in rehabilitation centers, whereas less intensive rehabilitation programs are provided in skilled nursing facilities (SNF). Patients discharged to SNFs differ from those discharged to rehabilitation centers with respect to amputation level, gender, number of comorbidities, and age.⁴ Yet, little is known about the factors associated with functional outcome of rehabilitation in lower limb amputees, especially when they are referred to an SNF. Only few, mostly retrospective studies, have investigated the outcomes of rehabilitation, while the use of different outcome measures and definitions of success make interpretation of results difficult. Table 1 illustrates the relationship between disease-related factors and outcome, known from existing literature. Age and comorbidity, related to progressed arterial disease, seem to be important in determining outcome, but other uniquely contributing factors cannot be determined because of inconsistency in predicting the outcome. More importantly, most studies were conducted in rehabilitation centers, implicating that the results may have been confounded by selection bias. Factors associated with successful rehabilitation of lower limb amputees in SNFs have not yet been studied. These will probably differ from rehabilitation centers, because of patient group differences (Table 1).

To this end, we have set up a multicenter study in nine SNFs in the Nether-

TABLE 1: Factors (not) associated with outcome after major lower limb amputation in the literature

Outcome	Factors associated with outcome (based on multivariate regression)	Factors not associated with outcome
Prosthetic use	<ul style="list-style-type: none"> - Age >85yrs, stroke, dementia, amputation level.¹¹ - Age, standing balance test.¹² - Non-ambulation/ transfer only status before amputation, amputation level, homebound ambulatory status, age >60yrs, dementia, ESRD, CAD.¹⁰ - Age, LOS, home nurse upon discharge.¹³ 	<ul style="list-style-type: none"> - Age 50-59, history of smoking, nutritional deficiency, prior vascular surgery, and preoperative living status.¹⁰ - Calcium concentration, need for assistive device, hypertension, hours of prosthetic use.¹³
Mobility • RMI	<ul style="list-style-type: none"> - Age, bilateral amputation, homebound ambulatory status, ESRD.¹⁰ - Age, LOS acute care, Doppler features of residual limb, initial BI.¹⁴ 	<ul style="list-style-type: none"> - Amputation level, gender, CAD, and dementia.¹⁰ - Gender, side of amputation, aetiology, presence of comorbidity, and RMI score on admission.¹⁴
ADL • BI	<ul style="list-style-type: none"> - Age, diabetic aetiology.¹⁴ 	<ul style="list-style-type: none"> - Gender, side of amputation, LOS acute care, presence of comorbidity, Doppler features of residual limb, BI score on admission, and RMI score on admission.¹⁴
• GARS	<ul style="list-style-type: none"> - Age, standing balance test, 15 words test.¹² 	<ul style="list-style-type: none"> - Other comorbidity (other than DM or cardiopulmonary disease).¹²

ESRD end-stage renal disease, CAD coronary artery disease, LOS length of stay, RMI Rivermead mobility index, BI Barthel index, GARS Groningen activity restriction scale, DM diabetes mellitus.

lands, with the primary goal to determine the factors that contribute to the success of rehabilitation in lower limb amputees in SNFs. Successful outcome is defined as discharge to an independent living situation. In addition, various functional scales are used as secondary outcome measures.

Methods

Study design

This prospective study is part of the Nijmegen Geriatric Rehabilitation in AMPu-tation and Stroke (GRAMPS) study and comprises three measurements. Baseline data (T0) are collected within two weeks after admission to the SNF. Patients and disease characteristics, functional status, cognition, behavior and caregiver information are registered (table 2). The first follow-up (T1) is at discharge from the SNF, and focuses on functional status and behavior. Successful rehabilitation is defined as discharge from the SNF to an independent living situation within one year after admission. The second follow-up (T2) is at three months after discharge in patients who have been rehabilitated successfully and focuses on functional status, behavior and quality of life.

Data collection has started in January 2008, and will end in July 2010.

Patients

All patients who are consecutively admitted to one of the specialized rehabilitation wards of the nine participating SNFs are eligible to participate in this study. All participating SNFs collaborate in the Nijmegen University Nursing Home Network of the Radboud University Nijmegen Medical Center. After admission patients are provided with oral information from the treating physician or nurse. In addition, all patients and their caregivers receive written information about the study. The patients indicate if they are interested to participate. No other inclusion criteria are applied. Inability to give informed consent is an exclusion criterion. The attending physician judges the legal capacity of his/her patients. In the case of doubt he/she consults the caregivers. The GRAMPS website (www.gramps.nl) provides extra information for interested patients and their caregivers.

Ethical approval

This research protocol was presented to the medical ethics committee of the district Nijmegen- Arnhem, the Netherlands. Ethics approval was not deemed necessary, because the design is observational and because legally incapable patients are excluded.

Instruments

Data are collected by the multidisciplinary teams that are specifically trained to perform the assessments (Table 2). During collective meetings all team members of participating SNFs received the same instructions from the researchers. The outcome measures have been selected based on previously established reliability and validity, and are in accordance with other research in this area.

- ***Patient characteristics***

Patient characteristics as well as disease characteristics, medication use, and information about comorbid diseases, using the Charlson Index (CI), are collected. The CI comprises 19 categories of diagnoses derived from the International Classification of Diseases (9th Revision Clinical Modification ICD-9CM), and is based on a set of risk factors for one-year mortality risk.¹⁵ The CI contains a weighted index for each disease at which the score is a significant predictor of one-year survival. One-year mortality rates for the different scores are: “0” 12%, “1-2” 26%, “3-4” 52% and “>5” 85%.

- ***Functional status***

The Barthel Index (BI), modified by Collin et al. in 1988,¹⁶ measures dependency in activities of daily living (ADL). The BI is a valid and reliable instrument in patients with vascular risk factors, such as stroke.¹⁶⁻¹⁹ The total score ranges from 0-20, with 20 representing complete functional independence. The BI is also used in amputation rehabilitation research.¹⁴ The Frenchay activities index (FAI) is used for assessment of extended ADL. The FAI²⁰ scores the actual activities undertaken by patients and has three domains: domestic housework, indoor activities and outdoor activities. The 15-item questionnaire is a reliable and valid instrument for measuring functional outcome in amputation patients.²¹ Even proxies give reliable information about FAI items.^{22, 23}

The one- leg- standing balance test, first used by Schoppen et al.,¹² is used to assess standing balance on the unaffected leg.

The Functional Ambulation Categories (FAC)²⁴ measures (in)dependency of gait. The FAC is an ordinal six-point scale with 0 indicating total dependency for walking and 5 indicating independent walking on all surfaces. The use of a walking device is allowed.

The Timed up-and-go test (TUG-test) is a valid and reliable instrument, and assesses physical mobility of elderly patients.²⁵ It can also be used for measuring the physical mobility of patients with an amputation of the lower extremity.²⁶ The TUG-test is only performed when FAC score is 3 or higher.

The SIGAM mobility questionnaire is a valid measurement for mobility in lower

TABLE 2: Research instruments

	Instrument	discipline	T0	T1	T2
Patient	Patient characteristics	Physician	X		
	Co-morbidity: Charlson Index	Physician	X		
	Medication list	Physician	X	X	
Caregivers	Social situation	Nurse	X	X	X
	COOP WONCA	Nurse	X		
	Caregiver strain index	Researcher			X
Functional status	Position sense ankle	Physician	X		
	Vibration sense: Rydell Seiffer	Physician	X		
	Barthel index	Nurse	X	X	X
	Social activity: Frenchay activities index	Nurse	X		X
	One leg standing balance	Physio	X	X	X
	Functional Ambulation Categories	Physio	X	X	X
	Timed up and go test	Physio		X	X
	SIGAM mobility questionnaire	Physio		X	X
Cognition	Mini mental state examination	Psychologist	X		
	Clock drawing test	Psychologist	X		
	Hetero anamnestic cognition test	Nurse	X		
Behavior	Neuropsychiatric inventory questionnaire	Nurse	X	X	X
	Neuropsychiatric inventory Nursing Home	Nurse	X	X	
	Global depression scale 8	Psychologist	X	X	X
Quality of life	RAND 36 version 2	Researcher			X

COOP WONCA The Dartmouth COOP Functional Health Assessment Charts / WONCA,
Physio Physiotherapist

limb amputees.²⁷ It also provides information about the use of a prosthesis. In 2008, the SIGAM mobility questionnaire was translated into the Dutch language.²⁸ The inter-rater reliability was 100% in the original study as well as in the translation study, which also included SNF residents.

- **Cognition**

The Mini- Mental- State- Examination (MMSE), developed by Folstein and McHugh,²⁹ is a screening instrument for cognitive impairment, and has a fair reliability and construct validity, with a high sensitivity for moderately-severe cognitive impairment and a lower sensitivity for mild cognitive impairment.³⁰ It comprises items testing orientation, attention, memory, language and constructive abilities. Bottom and ceiling effects have been described.³¹ The Hetero-Anamnestic- Cognition list (HAC list), derived from the MMSE by Meijer in his AMDAS study,³² is used to explore the presence of premorbid cognitive disabilities. The proxy, preferably a partner if present, is asked a few simple 'yes' or 'no' questions concerning orientation, attention and calculation, language, memory, and executive skills. Severity is judged on the basis of need of assistance or professional therapy required.

The Clock Drawing Test (CDT) provides a quick screening for cognitive impairment. In order to correctly draw a clock, the patient needs several domains of cognition: processing language, visualizing, recall, organization, planning and acting. The scoring system of Freedman et al.³³ is used: a score of 9 or less out of 14 items indicates cognitive impairment.

- **Behavior**

The NeuroPsychiatric Inventory (NPI), originally developed for dementia patients,³⁴ gives a global impression of neuropsychiatric symptoms and is applicable in other patient groups as well. The NPI comprises 12 categories of problem behaviors: delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, disinhibition, irritability/lability, apathy, aberrant motor activity, sleeping disorder and eating disorder. If the interviewed person is a nurse, the NPI-NH (nursing home) is used, that measures severity, frequency and distress. If the interviewed person is the partner or a close relative than the NPI-q (questionnaire)³⁵ is used, that measures severity and emotional burden. The NPI is a valid and reliable instrument³⁴ and has been translated into Dutch.

The eight item version of the Geriatric Depression Scale (GDS-8) is a shortened patient-friendly test derived from the GDS-15 version, and has been developed specifically for the nursing home population.³⁶ It is a valid test and indicates the presence of depression at a cut-off of 3 out of 8.

- **Quality of life**

The RAND- 36, developed to measure health related quality of life in chronically ill patients, comprises eight dimensions: physical functioning, role limitations due to physical health problems, bodily pain, general health, vitality, social functioning, role limitations due to emotional problems, and general mental health. It also contains an additional item about perceived health change.³⁷ The item scores of the dimensions need to be recoded according to the RAND health sciences program standards.³⁸ The RAND-36 has been translated into Dutch by van der Zee et al. and was found to be a valid, reliable, and sensitive measurement of general health.³⁹

- **Caregivers**

The Dartmouth COOP Functional Health Assessment Charts/ WONCA subscales⁴⁰⁻⁴² physical fitness, daily activities, feelings and overall health are used to measure proxy's functional status. Each subscale consists of a short title and an illustrated five-point response scale; scores 16 and up are indicative of high strain.³²

The caregiver strain index (CSI) is only used after discharge from the nursing home, when participation level of the patient plays a key role.⁴³ Optimal reintegration reduces the experienced strain of the caregivers. The CSI consists of 13 'yes' and 'no' questions, is an easy-to-use instrument to identify strain, and shows good validity.⁴⁴ A score of 7 or more positive responses indicates a high level of strain.⁴⁵ The CSI has been used caregivers of patients with various types of diseases,⁴⁶⁻⁴⁸ but not yet in proxies of patients with lower limb amputation.

Power

Because only 250 patients per year receive rehabilitation after major lower limb amputation in Dutch SNFs,⁴⁹ it was decided that 50 patients should be an attainable number.¹² As a consequence, the number of factors to be included in the multivariate analysis may not exceed five.

Data analysis

All data is processed using the Statistical Package for Social Science 16.0 (SPSS 16.0). Different techniques will be used to analyze the data, depending on the research question.

- Descriptive analysis will be used for general patient characteristics, disease characteristics, treatment, successful rehabilitation, and functional outcomes.
- Univariate analyses, parametric as well as non-parametric, will be performed for identifying the demographic and clinical factors that are associated with successful rehabilitation.
- Associated factors will then be tested in a multivariate logistic regression analysis to determine their contribution to successful rehabilitation.

Discussion

To our knowledge, this is the first study that focuses on the factors of successful rehabilitation of patients with major lower limb amputation in SNFs. The patients admitted to SNFs differ from patients admitted to rehabilitation centers with respect to age, number of comorbidities, and amputation level. Therefore, factors associated with successful outcome will probably differ as well. By making use of multivariate logistic regression models the independency of associated factors will be established.

All outcome measures have proven to be reliable and valid, or have been selected in accordance with other research in this area.

Because legally incapable patients are excluded from this study, its external validity may be slightly affected. Therefore, general patient characteristics of the excluded patients are registered and compared to those of the included patients. Besides age, length of stay in the SNF, and discharge destination are recorded to compare both groups to test for selection bias. This multicenter study uses multidisciplinary teams to collect the data over a period of two-and-a-half years and, thus, may suffer from some measurement inaccuracies. To minimize these inaccuracies, over 75 persons from all participating SNFs received the same instructions about performing the outcome measures during collective meetings before the start of the study. To ensure the quality of data collection during the study, each SNF has 2 to 3 specially assigned professionals who maintain contact with the main researchers. In addition, a newsletter is provided every 6–8 weeks to keep everybody involved, informed, and motivated with regard to the progress of the study.

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Chapter 4

Is patient-grouping on basis of condition on admission indicative for discharge destination in geriatric stroke patients after rehabilitation in skilled nursing facilities? The results of a cluster analysis.

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Abstract

Background

Geriatric stroke patients are generally frail, have an advanced age and co-morbidity. It is yet unclear whether specific groups of patients might benefit differently from structured multidisciplinary rehabilitation programs. Therefore, the aims of our study are 1) to determine relevant patient characteristics to distinguish groups of patients based on their admission scores in skilled nursing facilities (SNFs), and (2) to study the course of these particular patient-groups in relation to their discharge destination.

Methods

This is a longitudinal, multicenter, observational study. We collected data on patient characteristics, balance, walking ability, arm function, co-morbidity, activities of daily living (ADL), neuropsychiatric symptoms, and depressive complaints of 127 geriatric stroke patients admitted to skilled nursing facilities with specific units for geriatric rehabilitation after stroke.

Results

Cluster analyses revealed two groups: cluster 1 included patients in poor condition upon admission ($n=52$), and cluster 2 included patients in fair/good condition upon admission ($n=75$). Patients in both groups improved in balance, walking abilities, and arm function. Patients in cluster 1 also improved in ADL. Depressive complaints decreased significantly in patients in cluster 1 who were discharged to an independent- or assisted-living situation. Compared to 80% of the patients in cluster 2, a lower proportion (46%) of the patients in cluster 1 were discharged to an independent- or assisted-living situation.

Conclusion

Stroke patients referred for rehabilitation to SNFs could be clustered on the basis of their condition upon admission. Although patients in poor condition on admission were more likely to be referred to a facility for long-term care, this was certainly not the case in all patients. Almost half of them could be discharged to an independent or assisted living situation, which implied that also in patients in poor condition on admission, discharge to an independent or assisted living situation was an attainable goal. It is important to put substantial effort into the rehabilitation of patients in poor condition at admission.

Background

In the past decade, there has been increasing interest in stroke rehabilitation. In 2004, 15 million people suffered a stroke worldwide.¹ The expectation is that the number of patients with stroke will rise in the future, because of the ageing of the population; accordingly, there will be a growing demand for rehabilitation services. In the Netherlands, the incidence of stroke is expected to rise from 1.8 per 1,000 persons in the year 2000 to 2.8 per 1,000 persons in 2020.²

More than a quarter of all patients die after a stroke within one to three months.³ In the Netherlands if the patient survives after the acute phase in the hospital, a stroke patient is referred to either rehabilitation centers or specific geriatric rehabilitation units in skilled nursing facilities (SNFs). Referral depends on the patients' age, general condition and level of impairment. Dutch SNFs provide elderly patients after a stroke with low-intensity multidisciplinary rehabilitation programs, with the objective to discharge them to an independent-living situation. Patients receiving rehabilitation in these SNFs are generally frail, have an advanced age and are suffering from comorbidity. Therefore, the more demanding rehabilitation in rehabilitation centers is not appropriate for these elderly patients.⁴

Rehabilitation in SNFs is provided by a multidisciplinary team consisting of an elderly care physician,⁵ a physiotherapist, an occupational therapist, a speech-language therapist, a psychologist, a dietician, and nursing staff. The overall amount of multidisciplinary treatment in SNFs is approximately 4 hours per week per patient, evenly distributed over 5 working days.⁶ Therapy sessions in SNFs consist of a combination of individual and group therapies, aimed at restoring (functional) abilities. Based on their clinical judgment of the condition at admission, therapists decide on the content of their treatment and tailor the treatment to the needs of the patient. However, rehabilitation could be more efficient if it were possible to refer newly admitted patients to standardized rehabilitation programs with various levels of intensity. Research showed that patients receiving a program of focused stroke rehabilitation performed better than other patients.⁷

In literature, age and disability upon admission are the most important determinants of rehabilitation outcome after stroke.⁷⁻¹¹ However, regardless of the degree of physical impairment at baseline, during the rehabilitation process, which takes from a few weeks to 1 year, several additional factors such as comorbidity,¹² therapy intensity,¹³ early start of therapy following stroke,^{13,14} motivation of the patient, support of relatives, neuropsychiatric symptoms,¹⁵ and environment¹³ can influence rehabilitation outcomes and discharge destination. Therefore, in order to identify meaningful patient groups for developing specific rehabilitation programs in SNFs,

the aims of our study are 1) to determine relevant patient characteristics to distinguish groups of patients based on their admission scores in SNFs, and (2) to study the course of these particular patient-groups in relation to their discharge destination.

Methods

Design

This study is part of the Nijmegen Geriatric Rehabilitation in AMPutation and Stroke study (GRAMPS), which is a longitudinal, multicenter, observational study of geriatric patients admitted to SNFs for rehabilitation. Data were collected from January 2008 until January 2009 in 15 Dutch SNFs, all of which are part of the Nijmegen University Nursing Home Network (UKON: www.uko-n.nl) of the Radboud University Nijmegen Medical Center. All 15 of the SNFs are situated in the southern part of the Netherlands. Data were collected upon admission to the SNF and at discharge to an independent/assisted-living situation or at referral to long-term care in a nursing home. The medical ethical committee of the region Nijmegen-Arnhem approved the research protocol of the GRAMPS study. The research protocol of the GRAMPS stroke-study has been extensively described elsewhere.¹⁶

Patients

All patients admitted to the 15 SNFs for rehabilitation after stroke were asked to participate. Four categories of patients were excluded from participation:

- 1) patients who declined informed consent,
- 2) patients who were legally incapable to give informed consent,
- 3) patients who were expected to be discharged within 2 weeks,
- 4) critically ill patients.

Measurements

From the medical records the following patients' characteristics were collected: age, gender, first stroke or recurrent stroke, stroke subtype (ischemic/non-ischemic) and localization of stroke.

Information about comorbidity was registered using the Charlson Index (CI). The CI comprises 19 categories of diagnoses from the International Classification of Diseases (9th revision Clinical Modification ICD-9CM).¹⁷ We used the adjusted CI, because two items in the original version ("cerebrovascular disease" and "hemiplegia") reflect the stroke itself rather than additional morbidity. The adjusted CI is validated in clinical stroke outcome studies.¹⁸ The CI scores were summed.

We used the Barthel Index (BI), modified by Collin et al. in 1988¹⁹⁻²⁰ for measuring de-

pendency in activities of daily living (ADL). The total score ranges from 0–20. A score of 20 represents complete functional independence.

The Frenchay Arm Test (FAT) was used to evaluate arm function after stroke. The patient is asked to perform five activities with the affected arm, and he or she awards one point for each successfully completed activity.²¹

The patients balance was assessed using the Berg Balance Scale (BBS). This is an ordinal 14-item scale (0–56 points) developed by Berg et al.^{22, 23}

The FAC score assesses a patient's ability to walk independently of other people. It has an ordinal six point scale. Zero indicates total dependency and five indicates fully independent walking. The use of a walking device is permitted during the test.²⁴

To assess neuropsychiatric symptoms, the Neuropsychiatric Inventory: Nursing Home (NPI-NH) version, which is applicable in various patient groups, was used.^{25–27} The NPI comprises 12 symptoms: delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, disinhibition, irritability/lability, apathy, aberrant motor behavior, sleeping disturbances, and eating changes. Symptoms within each domain are rated by the nurse in terms of both frequency (1 to 4) and severity (1 to 3), yielding a composite symptom score (frequency x severity). The 12 composite symptom scores were summed to obtain an NPI total score.

The eight-item version of the Geriatric Depression Scale (GDS-8) was used to screen for depressive complaints. It is a shortened patient-friendly test derived from the GDS-15 version and is developed specifically for the nursing home population.^{28, 29}

All of the measurements described above were performed within 3 weeks after admission to the SNF. Measures of BI, FAT, BBS, FAC, NPI-NH, and GDS-8 were repeated in the two weeks before discharge.

Statistical analysis

To identify meaningful groups of patients, we first performed a Two-step Cluster Analysis to identify variables that discriminate *between groups*. Cluster analysis aims to create groups in which the degree of association between objects is maximal if they belong to the same group and minimal otherwise.

We entered age, gender, information about the stroke (stroke type, localization, first stroke) and measurements on admission of CI, BI, FAT, BBS, FAC, NPI-NH, and GDS-8 in the two-step cluster analysis. Data about cognition, aphasia and swallowing¹⁶ on admission were also entered in the cluster model, but appeared to be not statistically significant and were left out of the final analysis. In the next step, we determined whether patients assigned to each cluster had a different rehabilitation outcome in terms of the percentage of successful rehabilitation (discharge to independent/assisted-living situation within 1 year after admission), change in functional outcomes (BI, FAT, BBS, and FAC), change in neuropsychiatric symptoms

TABLE 1: Description sample and clusters

Variable	Total sample n= 127 Median (IQR)	%	Cluster 1 (poor) Median (IQR) n= 52	%	Cluster 2 (good) Median (IQR) n=75	%	Significant difference between clusters
Berg Balance Scale (range 0-56)	31 (5, 46)		3 (0, 17)		44 (33, 50)		**
Functional Ambulation Categories (range 0-5)	3 (0, 4)		0 (0, 2)		4 (3, 4)		**
Barthel Index (range 0-20)	12 (6, 16)		5 (2, 9)		14 (13, 18)		**
Frenchay Arm Test (range 0-5)	4 (1, 5)		1 (0, 4)		5 (4, 5)		**
Charlson Index (range 0-27)	2 (1, 3)		3 (2, 3)		2 (1, 2)		**
Global Depression Scale (range 0-8)	1 (0, 3)		2 (1, 4)		1 (0, 2)		**
Neuropsychiatric Inventory:							
Nursing Home version (range 0-144)	0 (0, 5)		4 (0, 12)		0 (0, 2)		**
Gender: male		48					
Localization of stroke on right		58					
Ischemic stroke		85					
First stroke		83					
Age (years)	80 (76, 85)		81 (76, 86)		79 (76, 85)		*

Cluster 2 n = 75 (59.1% of the patients)

Cluster 1 n = 52 (40.9% of the patients)

Asterisks indicate significant differences between groups Mann-Whitney-U Test and Chi-squared Test (**p < 0.01, *p < 0.05).

Variables that best separate are at the top of the table and descending.

TABLE 2: Changes in scores between admission and discharge

Variables	Cluster 1 (poor) median (IQR)	Cluster 2 (good) median (IQR)	Cluster 1 (poor) Discharged median (IQR)	Cluster 1 (poor) Long Term Care median (IQR)	Cluster 2 (good) Discharged median (IQR)	Cluster 2 (good) Long Term Care median (IQR)
BI admission (ADL)	n=52 5 (2, 9)	n=75 14 (13, 18)	n=24 6 (3, 10)	n=28 4 (2, 7)	n=60 15 (13, 18)	n=15 13 (11, 17)
BI discharge	n=41 11 (6, 15)**	n=70 18 (16, 20)**	n=23 14 (13, 16)**	n=18 5 (3, 9)	n=60 19 (17, 20)**	n=10 10 (5, 13)
BBS admission (balance)	n=52 3 (0, 17)	n=75 44 (33, 50)	n=24 9 (1, 25)	n=28 2 (0, 4)	n=60 44 (35, 50)	n=15 35 (27, 47)
BBS discharge	n=39 28 (3, 39)**	n=66 48 (41, 52)**	n=22 38 (28, 45)**	n=17 3 (0, 15)*	n=56 49 (44, 52)**	n=10 26 (17, 53)
FAC admission (walking ability)	n=52 0 (0, 2)	n=75 4 (3, 4)	n=24 0 (0, 2)	n=28 0 (0, 1)	n=60 4 (3, 4)	n=15 3 (3, 4)
FAC discharge	n=39 3 (0, 4)**	n=69 5 (4, 5)**	n=22 4 (3, 4)**	n=17 0 (0, 2)	n=58 5 (4, 5)**	n=11 3 (3, 5)
FAT admission (arm function)	n=52 1 (0, 4)	n=75 5 (4, 5)	n=24 1 (0, 3)	n=28 1 (0, 5)	n=60 5 (4, 5)	n=15 5 (4, 5)
FAT discharge	n=38 1 (0, 5)*	n=65 5 (5, 5)	n=21 3 (0, 5)**	n=17 0 (0, 4)	n=57 5 (5, 5)*	n=8 5 (1, 5)
GDS-8 admission (depressive complaints)	n=52 2 (1, 4)	n=75 1 (0, 2)	n=24 1 (0, 4)	n=28 2 (1, 5)	n=60 0 (0, 1)	n=15 1 (0, 2)
GDS-8 discharge	n=35 1 (0, 2)	n=61 0 (0, 1)	n=20 1 (0, 2)**	n=15 1 (0, 4)	n=54 0 (0, 0)	n=7 4 (1, 5)
NPI-NH admission (neu- ropsychiatric symptoms)	n=52 4 (0, 12)	n=75 0 (0, 2)	n=24 2 (0, 8)	n=28 7 (0, 18)	n=60 0 (0, 1)	n=15 0 (0, 4)
NPI-NH discharge	n=40 0 (0, 6)	n=70 0 (0, 1)	n=22 0 (0, 1)**	n=18 4 (0, 15)	n=60 0 (0, 0)	n=10 2 (0, 7)

Asterisks indicate significant changes between admission and discharge within the four groups, Wilcoxon Signed-Rank Test (**p < 0.01, *p < 0.05).

BI: Barthel Index (range 0-20), BBS: Berg balance Scale (range 0-56), FAC: Functional Ambulation Categories (range 0-5), FAT: Frenchay Activities Index (range 0-5)
GDS-8: Geriatric Depression Scale (range 0-8), NPI-NH: Neuropsychiatric Inventory Nursing Home version (range 0-144)

(NPI-NH), and depressive complaints (GDS-8) during the rehabilitation. Differences between the two clusters were evaluated using the Mann-Whitney-U Test and the Chi-squared Test. Changes with respect to the baseline scores and the scores at the end of rehabilitation were tested using the Wilcoxon Signed-Rank Test. The Kruskal-Wallis Test was used to test for differences between groups with reference to the changes between baseline and end of rehabilitation scores. All data were processed using SPSS 18.³⁰

Results

Of the 378 eligible patients, 186 were included in the GRAMPS study. Patients were excluded from the study based on unwillingness to give informed consent ($n = 73$), critical illness ($n = 13$), legal incapacity ($n = 64$), and expected short stay ($n = 7$). In addition, 35 patients were not asked to participate for logistic reasons; e.g. during holidays, every second patient was included to prevent overburdening of the personnel. The excluded patients did not significantly differ from those included in the study in terms of age, gender, or length of stay in the SNF. Patients were admitted to the hospital at day one of the stroke, and stayed a mean 23 days in hospital after stroke (range 9 days - 6 weeks).

In the present study, a complete data set was obtained of 127 patients, these patients were included in the cluster analysis. The admission scores (variables in the cluster analysis) of patients with incomplete data were not different from those included in the analyses, except for age (mean age 76 and 80 years for excluded and included patients respectively; $p < 0.05$).

Table 1 shows the results of the cluster analysis, based on admission data. Patients appeared to cluster in two groups. The groups can be meaningfully described as a cluster with patients in poor condition on admission (cluster 1, “poor cluster”) and a cluster with patients in fair/good condition on admission (cluster 2, “good cluster”).

Table 2 shows the change in scores between admission and discharge of the two clusters. Patients in the poor cluster significantly improved in ADL (BI), balance (BBS), walking ability (FAC) and arm function (FAT). Patients in the good cluster significantly improved in ADL (BI), balance (BBS) and walking ability (FAC).

A total of 84 patients (66%) were discharged to an independent/assisted-living situation, and 43 (34%) were referred for long-term care to a nursing home. Within the poor cluster ($n = 52$), 28 patients (54%) were referred to a nursing home for long-term care after rehabilitation and 24 patients (46%) were discharged to an

independent/assisted-living situation. In the good cluster ($n = 75$), 15 patients (20%) were referred for long-term care to a nursing home and 60 patients (80%) were discharged to an independent/assisted-living situation. The percentage of discharge to an independent/assisted-living situation differed significantly between the good and the poor cluster ($p < 0.0005$).

Patients in the poor cluster who were discharged showed improvement of ADL (BI), balance (BBS), arm function (FAT), walking ability (FAC) and had a decrease of depressive complaints (GDS-8) and neuropsychiatric symptoms (NPI). The discharge scores of patients in the poor cluster who were discharged to an independent/assisted-living situation were almost similar to the on admission scores of the patients in the good cluster who were discharged. Patients in the good cluster who were discharged showed improvement in ADL (BI), balance (BBS), arm function (FAT) and walking ability (FAC).

The poor cluster of which patients were discharged showed the greatest improvement in relation to the other groups. Significant differences between this group and the other groups with reference to changes between admission- and discharge scores appeared for balance (BBS), ADL (BI), walking ability (FAC), arm function (FAT) (Kruskal- Wallis Test $p < 0.01$).

Discussion

Using cluster analysis, with relevant patient characteristics (age, gender, stroke type, first stroke, localization stroke), balance, arm function, walking abilities, activities of daily living, depressive complaints and neuropsychiatric symptoms, we were able to identify two clusters of patients: those in fair/good condition on admission and those in poor condition on admission. Compared to patients in the poor cluster, patients in the good cluster performed significantly better on all assessments. Of the measurements that were used, balance (BBS) was best at separating patients into the poor and good cluster, followed by walking abilities (FAC) and ADL (BI). In this regard, our results were comparable to those of other studies of predictors of functional outcome. Although there is controversy in the field of stroke research regarding predictors of stroke outcome, in most studies age and disability have a stronger association with negative outcome than neuropsychiatric symptoms and depressive complaints.^{9, 11, 31} Interestingly, in our sample, neuropsychiatric symptoms and depressive complaints were significant factors to separate patients into the poor and good cluster, and age was not a significant factor.

In the poor cluster, score changes were more pronounced than in the good cluster. This indicates that patients in poor condition on admission had a greater chance

of further improvement. Within each cluster, a group of patients was discharged to an independent/assisted-living situation and a group was referred to a nursing home for long-term care. Nevertheless, patients in poor condition on admission had a higher risk of being referred to a nursing home for long-term care, although remarkably, half of the patients were discharged to an independent/assisted-living situation. This is in agreement with the findings in previous studies that discharge to an independent/assisted-living situation appears to be difficult to predict on the basis of on admission data for patients in poor condition upon admission. Predictions about discharge can be misleading if therapists and clinicians only take initial functional status as a the basis for discharge,³² since they risk overlooking patients who go on to regain enough functionality to be discharged to an independent/assisted-living situation. Rehabilitation programs that provide algorithms for multidisciplinary collaboration and evaluation on the basis of continuous monitoring of the physical and psychological condition of patients can be helpful in providing optimal individually tailored rehabilitation care.^{33, 34}

Patients in the poor cluster who were discharged to an independent/assisted-living situation had, in general, the same discharge scores as patients in the good cluster on admission. Discharged patients in the poor cluster improved more than discharged patients in the good cluster. In this study, the overall percentage of patients who were discharged to an independent/assisted-living situation approached 70%. To increase this percentage, stroke specific rehabilitation programs can be implemented. These may be effective in improving functional performance,^{14, 35} and need to incorporate high intensity therapy for patients in poor condition. Strikingly, although it has been shown that patients with a poor prognosis benefit more from higher-intensity therapy than patients who are in good condition on admission,³⁶ there is some evidence that patients with severe stroke receive less therapy than patients with mild stroke.¹³ We hypothesize that a more protocolized, comprehensive and intensive multidisciplinary rehabilitation for patients in poor condition on admission may have a positive effect on rehabilitation outcomes and, as a result, the percentage of patients who can be discharged to an independent/assisted-living situation may increase.

Neuropsychiatric symptoms and depressive complaints were significant factors to separate patients into the poor and the good cluster. Rehabilitation programs should, next to balance and functional status, also address neuropsychiatric symptoms and depressive complaints, which may increase during rehabilitation.¹⁵ In addition, rehabilitation programs should define roles for the entire multidisciplinary team, including nursing staff on the rehabilitation ward. For a more comprehensive and intensive rehabilitation program, a therapeutic climate is needed, and nurses are rehabilitators par excellence because of their continuous presence on the reha-

bilitation ward.³⁷ It is important that nurses encourage patients to perform simple exercises, such as reaching for objects and rising from a chair. They should also walk with patients and support them in as many meaningful activities during daily life as possible. Nurses need to determine which activities are therapeutic and contribute positively to rehabilitation. This may lead to an increase of discharge-rates specifically for patients in the poor cluster.

We observed only modest improvements in the patients in the good cluster, raising the question whether these patients might have been better off undergoing rehabilitation in the community or in day-care rehabilitation center rather than in an institution. Directors can organize stroke rehabilitation in a home environment by implementing an ambulatory operating “expert stroke team” comprising multidisciplinary team members from the SNF (including an elderly care physician⁵). Rehabilitation in the homes of patients or in a day-care center would not only be beneficial to patients but is also more cost-effective. Costs of outpatient rehabilitation are less than the costs of an admission to a Dutch SNF: the average costs per person per year are 95.000 euros for institutional SNF care (inclusive intensified therapies) and 5.200 euros for home care (exclusive 65 euros per hour for intensified therapies). Consequently, home-care or day-care could decrease health care costs.^{38, 39}

A limitation of our research is the risk of selection bias due to missing data from patients. However, for all variables except for age, the mean results on admission were not significantly different for patients with incomplete data versus the patients with complete data. Therefore, we believe that our results are applicable to the majority of patients who are admitted to SNFs for rehabilitation.

Research in geriatric rehabilitation is scarce, specifically in those patients who are in poor condition. Therefore, further research is required to identify factors that may contribute to improvement in patients in poor condition upon admission, as well as factors associated with declining scores, which may precede the unsuccessful rehabilitation of patients in good condition on admission. In addition, it is recommended to conduct an intervention-study to investigate therapy-intensity in patients in poor condition. Lastly, there is a need to investigate whether patients can successfully undergo rehabilitation in their home or in a day-care setting to avoid admission to a SNF, and to explore the cost-effectiveness of organizing geriatric rehabilitation in/ from the SNF. The results of such studies will provide more insight into the complex circumstances facing geriatric patients with stroke.

Conclusions

Through cluster analysis, two clusters of patients were identified: patients in fair/good condition on admission and patients in poor condition on admission. Patients in poor condition on admission were more likely to be referred to a facility for long-term care, but this was certainly not the case for all patients. Almost half of these patients were discharged to an independent or assisted living situation, which implied that also in patients in poor condition on admission, discharge to an independent or assisted living situation was an attainable goal. It is important to put substantial effort into the rehabilitation of patients in poor condition at admission. SNFs can develop specific rehabilitation programs for patients in both poor and good condition on admission in order to offer tailored care and support.

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Chapter 5

Time use of stroke patients admitted for rehabilitation in Skilled Nursing Facilities

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Abstract

Purpose

To describe the time use of patients with stroke in five Skilled Nursing Facilities (SNFs) in the Netherlands, focusing on the time spent on therapeutic activities, non-therapeutic activities, interaction with others and the location where the activities took place.

Evidence suggest that task oriented interventions are the most effective for patients with stroke and that some of these interventions are relevant and feasible for use by nurses. The question arises to what extent elderly patients who had a stroke and rehabilitate in a SNF receive therapeutic training and engage in therapeutic activities.

Design

Descriptive, observational design. Therapeutic and non-therapeutic activities of patients were observed at 10 minute intervals during one weekday (8:00 – 16:30) using behavioral mapping.

Findings

Forty-two patients with stroke with a mean age of 76 years participated in the study. The patients spent 56% of the day on therapeutic activities, whereas 44% of the day was spent on non-therapeutic activities. Most therapeutic time was spent on nursing care (9%) and physical therapy (4%). Patients stayed an average 41% of the day in their own room and were alone 49% of the day. Therapeutic time-use was significantly related to improved functional status, patients with higher functional status spent more time on therapeutic activities.

Conclusion

Patients spent more than half of the day on therapeutic activities.

Clinical Relevance

Nurses are faced with the challenge of activating patients with stroke and to assist them to engage in purposeful task-oriented exercises including daily activities. Thereby better rehabilitation results and recovery of patients may be reached.

Background

Geriatric rehabilitation differs from rehabilitation in hospitals and rehabilitation centers.¹ Dutch Skilled Nursing Facilities (SNFs) provide adapted multidisciplinary-rehabilitation programs to elderly patients with stroke, aiming at discharge patients to their own homes or to an assisted living situation. Patients receiving rehabilitation in SNFs are generally aged and frail and in the SNFs the pace of rehabilitation is slower.¹ In these SNFs the multidisciplinary team consists of nurses, physical therapists, occupational therapists, speech language therapists, psychologists, dieticians and elderly care physicians.² These professionals provide multidisciplinary continuous care, support and treatment to elderly patients with stroke.

Substantial evidence supports a multidisciplinary team collaboration of professionals who are specialized in the care and treatment of patients with stroke.³ Good multidisciplinary collaboration between various disciplines improves the rehabilitation outcomes of patients with stroke.⁴ Also, an early start of rehabilitation and more intensive participation in rehabilitation and therapeutic activities has positive effects on recovery.⁵ Some widely accepted principles in rehabilitation are task-oriented and context-specific training, which target the goals that are relevant for the needs of patients.³ Recent reviews have shown that task-oriented training in mobility and activities of daily living are the best way to rehabilitate patients after stroke, leading to a better functional status and a better quality of life.⁵⁻⁸ Task-oriented training includes a wide range of interventions such as treadmill training, walking training, bicycling programs, endurance training and circuit training, sit-to-stand exercises, and reaching tasks for improving balance. In addition, arm training using functional tasks such as grasping objects, constraint-induced (movement) therapy (CIMT) and mental imagery are also task oriented interventions.⁷ Many of these simple task-oriented interventions, especially if tailored to the patients needs, are effective in improving patient outcomes and are highly relevant for nurses to use in the daily care of patients with stroke.⁷ In rehabilitation nurses work in close interaction with patients. Through concrete support the self reliance of patients will be increased.⁹ An Australian study, investigating the experiences and perceptions of nurses in rehabilitation nursing practice, found that carefully and collaboratively designed and sensitively implemented work-based practice development initiatives can change the context and culture of inpatient care resulting in enhancing both the patient's and nurse's engagement in rehabilitation.¹⁰

Several authors investigated the time use of stroke patients in different rehabilitation settings concerning therapeutic and non-therapeutic activities and reported varying results. Therapeutic activities in these studies included all therapeutic treat-

ment and care activities that health care professionals, including nurses, carried out with the patient.¹¹⁻¹⁶ In rehabilitation wards, stroke patients spent 23.4% – 27.5% of the day on therapeutic activities¹⁴ whereas in hospitals, this time varied between 13.7% – 75% of the day.^{11,16} Only one small study investigated the time use of elderly stroke patients in nursing homes and showed that elderly stroke patients spend only a limited amount of time (20%) on therapeutic activities, whereas 80% of the day was spent on non-therapeutic activities. For the largest part of the day (60%), the patients were alone and passive.¹⁵ The large differences in the time spent on therapeutic activities in the before mentioned rehabilitation settings may be explained by differences in observation period, the time since the stroke incidence, the stroke phase, the setting where the study was conducted and the small samples used.

The Study

Aim

The aim of this study was to describe the time use of stroke patients rehabilitating in SNFs focusing on the time spent on therapeutic activities, non-therapeutic activities, social interaction with others, and the location where the activities took place. It was hypothesized that patients with a lower functional status would spend more time on therapeutic activities. Time spent on therapeutic activities was examined in relation to age, gender, functional status, and the specific SNF in which the patient stays.

Design

This observational and descriptive study was part of a larger research study, the Geriatric Rehabilitation in AMPutation and Stroke study (GRAMPS).¹⁷

Sample

The study was conducted in five Dutch SNFs. Included were patients with a clinical diagnosis of stroke as defined by the World Health Organization (WHO)¹⁸ and those who were staying on the participating wards or admitted to the wards during the study. The aim of rehabilitation was discharge to an independent or assisted living situation. Patients who were too ill to participate were excluded.

Data collection

Demographic and illness-related characteristics were collected including: age, gender, marital status, living situation before stroke, length of stay in the hospital and in the SNF as well as health history including diagnosis, comorbidities and the

time and type of stroke.

Time use was measured with behavioral mapping (BM), which is an observation method used for investigating time use.¹³ According to BM, patients are observed at 10 minutes intervals during the day, using an observational plan where activities are divided into several categories; therapeutic activities, non-therapeutic activities, interactions with others and the location where these activities take place. The observational scheme used in this study was based on previous studies.¹³⁻¹⁵ Those previous studies, however, interpreted eating/drinking, transport/travel, communication and activities of daily living as non-therapeutic, whereas in the present study we defined these activities as therapeutic because according to Rousalo and colleagues⁹ they contribute positively to stroke rehabilitation. Therefore, in this study, the following¹⁴ activities were recorded as therapeutic activities: nursing care activities, physical therapy, occupational therapy, speech language therapy (SLT), care by a psychologist, guidance by a dietician, medical care by an elderly care physician, fitness, eating/drinking, transport/travel, communication, independent practice/training, and active leisure activities (for example puzzling). Nursing care included care in activities of daily living as washing, dressing, physical and emotional support including care activities such as wound care, administering injections and medication. Non-therapeutic activities were: sitting, laying or sleeping and passive leisure. Interaction that the patient had with others was registered as interaction with the nurse, elderly care physician, therapist, other patients, visitor(s) or no interaction when the patient was alone. The location where the activities took place was registered in seven categories: patient's bedroom, therapy room/activity room, hall (corridor), dining/living room, lounge, bathroom, outside the ward, outside the institution (outdoor) and other locations. The observations were conducted during the most active part of the day from 8 AM to 4.30 PM.

The functional status of the patients, representing disability and handicap, was measured with the Barthel Index (BI) which is one of the most widely used instruments in stroke rehabilitation.¹⁹ The BI rates 10 functions on a scale from 0 (fully dependent) to 20 (independent), representing the patient's ability to carry out the everyday activities. The total score ranges from 0 – 20. A score of 0 – 9 indicates severe dependency, a score of 10 – 19 indicates moderate independency and a score of 20 indicates total independency.¹⁹⁻²¹ The inter-rater reliability agreement of the BI was found to be 64–99%.²²

Procedure

The researcher and three research assistants conducted all assessments. The observation of patients took place on randomly selected weekdays and was conducted at 10-minute intervals, starting at 8:00 AM and finishing at 4.30 PM. Each patient

was observed during one day. At each time point the observer recorded the patient's activities, his/her interaction with others and the location where the activities took place.

The research assistants were trained in the observation technique, and a manual was provided describing the data collection procedure which ensured standardization of the observations. Rehabilitation staff was informed about the nature of the study, but they were not given information about when observations would take place.

Ethical considerations

Patients were provided with written and verbal information explaining the aims and procedures of the study and were assured of the voluntary character of their participation and of the anonymity of the data. Also, they were given time to think about if they were willing to participate, and if they were willing to participate they were asked for informed consent, which was signed by the patient and the researcher/research assistant. The study was approved by the medical ethics committee of the district Nijmegen–Arnhem, the Netherlands.

Data Analysis

For a comparison of baseline data descriptive statistics were used. Means and medians were calculated for continuous data and percentages were calculated for dichotomous data. Frequencies of observations were calculated to determine the time use of the stroke patients in the participating SNFs. Associations between therapeutic activities and age (< 65 years and ≥65 years), gender, functional status (three categories as described in the measurements section) and the five participating SNFs, were calculated with the Kruskal–Wallis test. This test was used since the data were not normally distributed, more than two unpaired samples were measured and because the test variables were ordinal.²³ The data were analyzed using SPSS 17.

Results

Patient characteristics

A total of 45 patients met the inclusion criteria, of which 42 patients participated in the study. Three patients did not give their informed consent for reasons unknown. The mean age of patients was 76 years (SD ±11.4). Twenty four women (57%) participated in the study as compared to 18 (43%) men. The mean BI score was 11.8 (±5.7). Of the patients 14 (33%) had a score of 0–9 indicating severe dependency, 24 (57%) patients had a BI of 10–19 indicating moderate dependency, and a total of 4

TABLE 1: Baseline characteristics of the included patients

Social demographic characteristics		Patients (n=42) (%)
Age	< 65 years	11 (26%)
	65 year and older	31 (74%)
	Mean years (SD)	76 (11,4)
	Range	53 – 95
Gender	Men	18 (43%)
	Women	24 (57%)
Living Situation	Alone	21 (50%)
	Living together	21 (50%)
Marital status	Married	16 (39%)
	Unmarried	10 (24%)
	Cohabiting	1 (2%)
	Widow(er)	14 (33%)
	Separated	1 (2%)
Children	Yes	35 (83%)
	No	7 (17%)
Stroke type	Hemorrhage	11 (29%)
	Infarct	30 (71%)
First stroke		33 (79%)
Comorbidity		21 (50%)
Type of comorbidity	Heart and lung diseases	8 (19%)
	Diabetes Mellitus	7 (17%)
	Hypertension	6 (14%)
Time since stroke	< 1 month	17 (40,5%)
	1 – 6 months	19 (45,2%)
	> 6 months	6 (14,3%)
Length of stay in SNF	< 1 month	25 (59,5%)
	1 – 6 months	14 (33,4%)
	> 6 months	3 (7,1%)
Functional status	Mean (SD)	11,8 (5,7)
	BI 0 – 9	14 (33%)
	BI 10 – 19	24 (57%)
	BI 20	4 (10%)
Number of patients in SNF's	Skilled Nursing Facility 1	7 (17%)
	Skilled Nursing Facility 2	13 (31%)
	Skilled Nursing Facility 3	11 (26%)
	Skilled Nursing Facility 4	5 (12%)
	Skilled Nursing Facility 5	6 (14%)

(10%) patients were totally independent. The patients had various comorbidities and the most frequently reported were: Diabetes Mellitus, hypertension, heart and lung diseases. The characteristics of the patients are described in Table 1.

Therapeutic activities

On average, the patients spent 56.1% of the day on therapeutic activities, the rest of the day they spent on non-therapeutic activities (Table 2). Of therapeutic activities, eating and drinking took the largest part of the time (14.9%), followed by communication (11.9%). Patients spent 8.5% of the day on active leisure activities and 1.2% of the day on practicing independently. Patients received nursing care for 8.6% of the day and this includes all nursing care and ADL-activities. Patients were engaged in all therapies for 7.6% of the day, in which more time was spent on physical therapy (4.4%) than occupational therapy (1.1%). The time spent on speech language therapy, care by a psychologist, guidance by a dietician and medical care by an elderly care physician was less than one percent of the day for each therapy.

Non-therapeutic activities

Non-therapeutic activities accounted for 43.5% of the day. Patients were sitting passively for 20.3% of the time and laying or sleeping for 19.9% of the time.

Social interaction

The total time spent on interaction with others accounted for 50.7% of the day whereas they spent 49.3% of the day alone. On average they spent 10.7% of the time on interacting with nurses. Patients spent 10.2% of the day on interacting with nurses in SNF number one, 8.3% of the day in SNF number two, 14.2% of the day in SNF number three, 10.8% in SNF number four 10.8% and 9.9% in SNF number five (Table 2).

Location of activity

The patients spent 40.7% of the time in their own room, 38.2% of the time in the living room and they stayed only for a limited part of the day in the therapy room (5.5%).

TABLE 2: Time spent on therapeutic and non-therapeutic activities, location and interaction with others during the day* (* 8.00 am – 16.30 pm)

	Totaal (n = 42) Minutes	%
Therapeutic activities (total)	291.7	56,1%
Nursing care (including-ADL care)	44.7	8,6%
Physical therapy	22.9	4,4%
Occupational therapy	5.7	1,1%
Speech therapy	4.7	0,9%
Psychotherapy	1.0	0,2%
Guidance by dietician	0.5	0,1%
Medical care	1.0	0,2%
Fitness	-	-
Food / Drink	77.5	14,9%
Transport / travel	21.3	4,1%
Communication	61.9	11,9%
Independent practice / training	6.2	1,2%
Active leisure	44.2	8,5%
Other therapeutic activities	-	-
Non-therapeutic activities (total)	226.2	43,5%
Sitting	105.6	20,3%
Laying of sleeping	103.5	19,9%
Passive leisure	9.9	1,9%
Location		
Patient's room	211.6	40,7%
Therapy room / activity room	28.6	5,5%
Corridor	24.4	4,7%
Dining / living room	198.6	38,2%
Lounge	8.3	1,6%
Bathroom	17.7	3,4%
Outside the ward	22.9	4,4%
Outside the institution (outdoor)	4.7	0,9%
Other locations	2.6	0,5%
Social interaction with others		
Nurse	55.6	10,7%
Physician	2.6	0,5%
Therapist	38.5	7,4%
Other patients	84.2	16,2%
Visitor	69.7	13,4%
Other persons	7.8	1,5%
Nobody / no interaction	256.4	49,3%

Functional status and activity

Time use on therapeutic activities was positively associated with functional status (Kruskal-Wallis test $\chi^2 = 13.133$; $df = 2$; $p = 0.001$) (Table 3). Patients with a BI score of 20 spent 63% of the day on therapeutic activities and this was similar for patients with a BI score of 10 – 19 (62%), whereas the patients with a BI score of 0 – 9 spent 45% of the day on therapeutic activities.

TABLE 3: Therapeutic activities: outcomes of subgroup analysis

	Chi ²	p value
Barthel Index	13,133	0,001*
Age	0,023	0,879
Gender	0,246	0,620
Skilled Nursing Facilities	2,397	0,663

* significant difference

Discussion

The findings of this study showed that elderly stroke patients who are rehabilitating in a SNF spent just over half of the day on therapeutic activities, consequently, almost half a day they stayed alone in their own room. Of therapeutic time most of the patients' time was spent on nursing care, followed by physical therapy and occupational therapy. A significant association was found between the level of functioning of the patient and the time used on therapeutic activities. Contrary to expectations, patients with a better functional status spent more time on therapeutic activities than those with lower functional status.

The findings in this study need to be considered in relation to the strengths and limitations. All observational studies have the potential for bias. A limitation of the study is the small sample size and the convenience sample, which may have increased the risk of selection bias. Also, all observations took place on weekdays between 8.00 AM – 4.30 PM. Due to organizational difficulties it was not possible to conduct observations on evenings and weekends. This may have resulted in information bias. Although observation days were randomly selected, sometimes patients did not take

part in therapy every day, which may have resulted in information bias. As inherent in all observational studies, the presence of the observers could have affected behavior of patients and professionals. On the other hand, in order to reduce the risk of affecting behavior of the participants a tight observation scheme was used. Moreover, the observers adhered strictly to the observation scheme and tried to secure not being intrusive when observing the participants in their daily activities. A recent study shows that patients who were discharged had a mean MMSE score of 22 points (22/30). There were no differences in MMSE score between patients who were discharged to home and those who stayed in a nursing home.²⁴

When considering prior studies conducted on the time use of patients with stroke, it is important to point out the difference between this group of stroke patients and the stroke patients in other studies. Similar to the study of Huijben et al.,¹⁵ which was conducted in a nursing home, the patients in our study were about 10 years older than the patients included in other studies. These other studies were conducted in the post acute or acute phase on rehabilitation wards in rehabilitation centre's and hospitals.^{14, 25} Our study showed that age was not associated with therapeutic time. In our study younger patients received an equal portion of therapeutic activities compared to older patients, which is in contrary to the findings of Tinson,¹⁶ who showed that older patients spent more time on therapy. Lang et al.²⁶ studied possible correlates that could influence therapy intensity but found no correlation between age and therapy intensity. It is uncertain if older patients need more therapy, if so; this raises concerns about tailoring activities in SNFs to patient needs. Further insight in therapy-intensity, tailored to patient needs is considered necessary. This study can help design intervention programs specifically for SNFs where patient therapeutic time is much less than for patients residing in hospitals and rehabilitation centers, and research has shown time spent in therapy is an important factor for recovery for all patients regardless of age.^{5, 27}

In this study less time was spent on therapeutic activities than in other studies,^{14, 15} although in our study eating and drinking, communication, travel and ADL activities were registered as therapeutic activities, which was not the case in the other studies. We considered these activities as therapeutic because the therapeutic importance of these activities is endorsed by the geriatric rehabilitation nursing model of Routasalo.⁹ The patients in the present study received physical therapy for only 4% each day, which is equal to the findings of Huijben et al.,¹⁵ but much less than the reported 40% found in the (rehabilitation centre) study conducted by De Wit et al.¹⁴ in four European countries, namely Belgium, Great Britain, Germany and Switzerland. Even time spent on other therapies such as occupational therapy and speech therapy was less in our study than in earlier studies of Huijben et al.¹⁵ and De Wit et al.¹⁴ The lower therapy time we found may partly be explained by the fact that

our study took place in SNFs. The patients in our study had worse functional status, were older and had more comorbidities than patients included in earlier studies in hospitals and rehabilitation centers. Furthermore, distribution of financial resources may differ between countries and health care facilities within countries. However, to date only one study has been conducted on time use of patients with stroke in a nursing home (comparable with SNFs), which makes it difficult to draw conclusions.

The patients in this study did not have much contact with nurses during the day (8.00 AM – 4.30 PM). Only 10% of the day patients had some kind of interaction with nurses, consecutively less than 10% of the day was spent on ADL activities with nurses. Nevertheless, many studies have described the important role that nurses have in rehabilitation of patients with stroke.^{7, 9, 10, 28} Nurses can help to restore functional status, increase well-being and enhance quality of life of patients. Nurses have an important role in motivating patients to comply with their rehabilitation programs and giving emotional support to informal caregivers. Clinical Practice Guidelines (CPGs) such as the Clinical Nursing Rehabilitation Guideline Stroke include recommendations focusing on the daily rehabilitation care and treatment of stroke patients.^{7, 29} During the daily care nurses need to stimulate patients to do simple exercises such as reach for objects,³⁰ standing up from a chair several times during the day³¹ and exercise walking with patients.³² Other studies have shown the importance of involving informal caregivers (partner or family member) in the care and training of patients with stroke.^{33, 34} Based on these studies nurses need to supervise and encourage informal caregivers to conduct simple exercises with the patients, including walking exercises.³⁵ This may contribute to the functional recovery and improve the psychological and social wellbeing of the patients as well as the informal caregiver.³³

It is important to encourage the patient to train in tasks/activities that are important and relevant for him/her and which the patient itself has chosen. This improves the motivation for exercising).³⁰ Based on the findings of this study and CPGs published,^{7, 29} nurses need to select exercises and tailor these to the individual patients' needs and thereby they may contribute in a positive way to the rehabilitation outcome of these patients. Investigation into the origin of the passive nature of patients with stroke and what the best way is to motivate them, is necessary so that nurses and other professionals are better able to encourage them to comply with rehabilitation programs. Also, further research is needed into the role of nurses in the rehabilitation care of stroke patients. Lastly, nurses need to develop intervention programs focusing on improving time use of patients and aiming to improve the functional outcome of patients with stroke. Intervention and training programs may include simple task oriented training exercises that patients can do individually, in groups or with caregivers. Also, intervention programs may include training exerci-

ses focusing on dysphagia, communication problems and fall prevention for patients with stroke. These training programs should occur in therapeutic climates with:

- 1) structured activities which are tailored to patient's needs,
- 2) explicitly formulated goals,
- 3) (mostly) hands-off nursing care (using mainly verbal instructions),
- 4) a supportive climate created by the multidisciplinary team and
- 5) interaction with other patients.

All activities have the focus on discharge of the patient to an independent or assisted living situation. Although it is likely that intervention and training programs may improve various outcomes of patients with stroke, the effects of such programs would need to be investigated, preferably using randomized clinical trials, which may offer information about their effectiveness on various patient outcomes.

Conclusion

Stroke patients spend more than half of the day on therapeutic activities. Patients with a better functional status spend more time on therapeutic activities. Nurses are challenged with how to activate patients and engage them in purposeful task-oriented rehabilitation in daily activities. Nurses need to emphasize the importance of more time for training of patients with worse functional status. This since poor functional recovery has psychological and social consequences and ultimately consequences for discharge from the SNF to an independent or assisted living situation after stroke.

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Chapter 6

Neuropsychiatric symptoms in geriatric patients admitted to skilled nursing facilities in nursing homes for rehabilitation after stroke: a longitudinal multicenter study

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Abstract

Objective

To investigate the prevalence and course of neuropsychiatric symptoms (NPS) in geriatric patients admitted to skilled nursing facilities (SNFs) for rehabilitation after stroke.

Methods

This was a longitudinal multicenter study within fifteen SNFs in the Netherlands. NPS were assessed in one hundred forty five patients with stroke through the Neuropsychiatric Inventory - Nursing Home version (NPI-NH) with measurements on admission and at discharge. The prevalence and course of NPS were described in terms of cumulative prevalence (symptoms either on admission or at discharge), conversion (only symptoms at discharge), remission (only symptoms on admission) and persistence (symptoms both on admission and at discharge) for patients who were discharged to an independent living situation within one year after admission and patients who had to stay in the SNF for long term care.

Results

Eighty percent had had a first-ever stroke and 74% could be successfully discharged. Overall, the most common NPS were depression (33%), eating changes (18%), night-time disturbances (19%), anxiety (15%), irritability (12%) and disinhibition (12%). One year after admission, patients who were still in the SNF showed significantly more hallucinations ($p=0.016$), delusions ($p=0.016$), agitation ($p=0.004$), depression ($p=0.000$), disinhibition ($p=0.004$), irritability ($p=0.018$) and night-time disturbances ($p=0.001$) than those who had been discharged.

Discussion

The overall prevalence of NPS in this study was lower than reported by other studies in different settings. There was a high prevalence of NPS in patients that could not be successfully discharged.

Conclusions

The findings suggests that NPS should be optimally treated to improve outcome of rehabilitation.

Introduction

During the last decade, neuropsychiatric symptoms (NPS) in patients with stroke have received growing attention. NPS are burdensome for patients and have a negative impact on their quality of life.¹ Furthermore, NPS can attenuate functional recovery and independence and, thus, hamper the rehabilitation process.^{2,3} Patients with NPS are at risk for decline in cognitive functioning,⁴ and NPS can also add to the burden on caregivers and proxies, which reduces the possibilities for the patients to be discharged to the home situation.^{5,6}

NPS encompass behavioral problems as well as emotional and mood disorders that are often grouped as psychosis, affective disorders, apathy and agitation/aggression. After stroke, NPS are frequently reported, in particular emotional and mood disorders. In a Swedish study, a prevalence of 31% was found for depression in the acute stage, with a decrease to 16% at one year and an increase up to 29% at 3 years post stroke.⁷ In other studies, 56 to 61% of the patients with stroke had a minor or major depression at some point in time.^{8,9} In a population based cohort, anxiety was found in 28% of the patients in the acute stage of stroke. After three months, 31% suffered from anxiety and after three years only 9% had recovered. Other studies have reported a prevalence of 24 to 27% for anxiety after stroke.^{10,11} Agitation was found in 28 to 43% of the patients,^{8,12} whereas delusions and hallucinations seem to be relatively rare after stroke.^{13,14} The large variety in reported prevalence rates of NPS may be explained by differences in population, rehabilitation setting, assessment scales, and elapsed time after stroke.

The etiology of NPS after stroke is still largely unknown. Several correlates of NPS have been suggested in literature. Left hemisphere stroke has been identified as a risk factor for depression early after stroke,⁷ while vascular burden in frail elderly patients would also predispose to depression.^{15,16} Younger age is a risk factor for irritability⁸ and depression.⁷

Depression itself is related to agitation in geriatric patients,¹⁷ while a variety of physical health problems would be associated with agitation as well.¹⁸ In addition, the prevalence of NPS is varying along the course of stroke. Some NPS occur early after stroke and may, therefore, be the direct result of the neuronal damage, like agitation in response to provoking stimuli.¹² Other NPS occur later after stroke and may, thus, be regarded as phenomena reactive to the stroke and its functional consequences. For instance, patients with acceptance problems are prone to develop depression during their rehabilitation as a result of insufficient coping.^{19,20}

Knowledge about the prevalence and course of NPS in individual patients is important for the planning of rehabilitation services and the provision of adequate

treatment. Furthermore, persistent NPS may negatively affect the rehabilitation process. If so, special attention should be given to the patients with NPS after stroke to optimize functional outcome and limit the length of stay in rehabilitation facilities. Most studies on NPS after stroke have been conducted in rehabilitation centers in patients with relatively low age and good training potential. Only few studies are available that have focused specifically on NPS in elderly rehabilitation inpatients, although such patients may be relatively strongly susceptible to developing NPS due to various co-morbidities. The aim of this study was, to investigate the prevalence and course of NPS in geriatric patients admitted to skilled nursing facilities (SNFs) in nursing homes for rehabilitation after stroke. It was hypothesized that NPS would be particularly prevalent in patients that would show poor functional recovery and, consequently, could not be discharged to an independent living situation within one year after stroke.

Methods

Patients

This study was part of the Nijmegen Geriatric Rehabilitation in AMPutation and Stroke study (GRAMPS), which is a longitudinal, multicenter, observational study of geriatric patients admitted to SNFs for rehabilitation after either stroke or lower-limb amputation. Data were collected from January 2008 until January 2009 in 15 Dutch SNFs, all being part of the Nijmegen University Nursing Home Network of the Radboud University Nijmegen, Medical Center and situated in the Southern part of the Netherlands. All patients admitted for rehabilitation after stroke were asked to participate. Patients who declined informed consent or who were legally incapable to give informed consent, those who were expected to be discharged within two weeks, and critically ill patients were excluded from participation. The medical ethical committee of the region Nijmegen-Arnhem approved the research protocol of the GRAMPS study. The research protocol of the stroke study has been extensively described elsewhere.²¹

Rehabilitation

Rehabilitation in SNFs distinguishes from rehabilitation centers and hospitals as their patients are older and less vital (more frail), and the pace of rehabilitation is slower.²² Each participant was provided with a rehabilitation program by a multidisciplinary team consisting of an elderly care physician,²³ a physiotherapist, an occupational therapist, a speech-language therapist, a psychologist, a dietician, and nursing staff. The overall amount of therapy given was approximately 4 hours per week

(based on the official treatment time in The Dutch Resource Utilization Group ZZP9),²⁴ evenly distributed over 5 working days. Therapy sessions consisted of a combination of individual and group therapies, aimed at restoring functional abilities.

Procedure

NPS were assessed twice with the Neuropsychiatric Inventory – Nursing Home version (NPI-NH);⁵ the first time within three weeks after admission to the SNF ('admission'), and the second time within two weeks before successful discharge to an independent living situation or, at the latest, one year after admission in patients who had to stay in the SNF for long-term care ('discharge'). Discharge to an independent living situation could be either to the patient's own home or to a residential home with or without (in)formal care. When the interval between the two NPI-NH measurements was shorter than 28 days or when patients died during their rehabilitation, the data were excluded post hoc from further analysis. The NPI-NH was administered by qualified nurses who had been specifically trained before the start of the study. In addition, demographic information about previous stroke, stroke location, length of stay, cognition and speech disturbances were collected.

Neuropsychiatric Inventory

Traditionally the NPI-NH has been used in patients with dementia.^{5, 25, 26} Furthermore, the instrument has been proved to be valid and reliable when administered by trained nursing staff.^{5, 25, 26} The NPI-NH identifies 12 neuropsychiatric symptoms: delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria/elation, apathy/indifference, disinhibition, irritability/lability, aberrant motor behavior, night-time disturbances, and appetite/eating changes.

Mini Mental State Examination

Post-stroke cognitive decline was measured with the Mini Mental State Examination (MMSE). The MMSE comprises 11 items concerning orientation, attention, concentration, memory, language, and constructive capacity.^{27, 28}

Stichting Afasie Nederland (SAN) score

The SAN (Dutch Aphasia Foundation) score was used to quantify communicative impairment in stroke patients and is part of the Aachen Aphasia Test (AAT).²⁷⁻³⁰

Analysis

A specific neuropsychiatric symptom was considered to be present when the severity score was greater than 0. Sum of frequency X severity ratings for all NPI-NH domains, on admission and discharge, were calculated. Prevalence rates on admis-

sion and at discharge were determined for all patients together as well as separately for those who were discharged to an independent living situation within one year after admission and those who stayed in the SNF for long term care. The course of NPS was expressed in terms of cumulative prevalence (symptoms either on admission or at discharge), conversion (symptoms only at discharge), remission (symptoms only on admission) and persistence (symptoms both on admission and at discharge). This was done for each group. Differences in prevalence between admission and discharge were tested with the nonparametric McNemar test for repeated samples and differences between groups were analysed using the Fisher's Exact test. All data were processed using SPSS 18.0.

Results

Patients

Of 378 eligible patients, 186 patients met the inclusion criteria for the GRAMPS study. Patients were excluded from the study based on unwillingness to give informed consent ($n=73$), critical illness ($n=13$), legal incapacity ($n=64$), expected short stay ($n=7$). In addition, 35 patients were not asked to participate for logistic reasons, i.e. during holidays merely every second patient was included to prevent too great burden on the personnel. The excluded patients did not significantly differ from those included in the study in terms of age, gender, or length of stay in the SNF. From the 186 included patients, 145 patients underwent two consecutive NPI-NH assessments according to the described protocol. NPS data of 41 patients were incomplete because of untimely death ($n=16$), admission to another nursing home ($n=8$), critical illness during the observation period ($n=2$), an observation period less than 28 days ($n=8$), or loss of data ($n=7$). The 41 patients with incomplete data did not significantly differ from those included in the data analysis ($n=145$) in terms of age, gender, or length of stay in the SNF. Table 1 presents demographic and clinical characteristics of the 145 patients at baseline. Seventy-four percent ($n=108$) of the patients could be successfully discharged within one year, whereas 26% ($n=37$) could not.

Neuropsychiatric symptoms

Depression was the most commonly reported symptom (21% on admission and 20% at discharge), followed by eating changes (13% on admission and 9% at discharge) and nighttime disturbances (12% on admission and 10% at discharge) (Table 2). There were no significant differences in the overall prevalence rates between admission and discharge.

Depressive symptoms either on admission or at discharge were observed in

TABLE 1: Demographic and clinical patient characteristics at baseline (n=145)

Patient characteristics	
Age	79 (sd 8)
Male/female	66/79
Median length of hospital stay [min-max, days]	19 (6-76)
Median length of SNF stay [min-max, days]	119 (29-365)
First time ever stroke	114 (79%)
Stroke location	
left	57 (39%)
right	72 (50%)
other (i.e. cerebellum)	16 (11%)

33% of the cases. Remission was found in 13% of the patients, whereas 12% showed conversion and 8% persistence of symptoms. Anxiety was reported in 15% of the patients. Of these, 6% had anxiety only on admission, whereas 6% had anxiety only at discharge. Persistent anxiety was found in 3% of the patients. Eating changes were found in 19% of the patients. Nine percent showed remission, 5% conversion, and 4% persistence of symptoms. Night-time disturbances were observed in 18% of the patients. In 8% of the cases symptoms were present only on admission and in 6% only at discharge. Changes in other types of NPS were less than 5%, indicating that the symptoms were more or less stable.

Table 3 shows the prevalence on admission and at discharge, and the course of NPS over time for patients who were successfully discharged within one year after admission and for patients who had to stay in the SNF for long-term care. On admission, there was more apathy in patients who could be discharged compared to those who could not ($p=0.002$). Other symptoms on admission did not show significant differences. In contrast, at discharge, patients who were still in the SNF showed a higher prevalence of delusions and hallucinations ($p=0.016$), agitation ($p=0.004$), depression ($p=0.000$), disinhibition ($p=0.004$), irritability ($p=0.018$) and night-time disturbances ($p=0.001$) than those who had been successfully discharged.

Depressive symptoms either on admission or at discharge were present in 24% of the patients who were successfully discharged compared to 59% of the patients who needed long-term care in the SNF. Although symptoms disappeared in an equal proportion in both groups (13%-14%), they appeared during the rehabilitation in 6%

TABLE 2: Prevalence of neuropsychiatric symptoms and neuropsychiatric changes during the observation period (n=145)

Symptoms	Admission n %	Discharge n %	Cumulative %	Conversion n %	Remission n %	Persistence n %
Delusions	3 (2)	3 (2)	3	1 (1)	1 (1)	2 (1)
Hallucinations	4 (3)	3 (2)	4	2 (1)	3 (2)	1 (1)
Agitation/aggression	3 (2)	6 (4)	5	4 (3)	1 (1)	2 (1)
Depression	30 (21)	29 (20)	33	18 (12)	19 (13)	11 (8)
Anxiety	12 (8)	13 (9)	15	9 (6)	8 (6)	4 (3)
Euphoria/elation	2 (1)	3 (2)	3	2 (1)	1 (1)	1 (1)
Apathy/indifference	12 (8)	5 (3)	9	1 (1)	8 (6)	4 (3)
Disinhibition	10 (7)	8 (6)	12	7 (5)	9 (6)	1 (1)
Irritability/lability	11 (8)	10 (7)	12	6 (4)	7 (5)	4 (3)
Abberant motor behavior	1 (1)	2 (1)	1	1 (1)	0 (0)	1 (1)
Night time disturbances	17 (12)	14 (10)	18	9 (6)	12 (8)	5 (3)
Eating changes	19 (13)	13 (9)	19	7 (5)	13 (9)	6 (4)
<i>Minimally one symptom</i>	61 (42)	52 (36)				
<i>NPI F X E total score (mean, SD)</i>	3.5 (7.3) range 54	3.5 (7.8) range 48				

Cumulative = symptoms either on admission or at discharge

Conversion = no symptoms on admission, symptoms at discharge

Remission = symptoms on admission, no symptoms at discharge

Persistence = symptoms on admission and at discharge

of the patients who could be discharged and 32% of the patients who could not. Depressive symptoms were persistent in 6% and 14% of the cases, respectively. Night-time disturbances, either on admission or at discharge, were present in 13% and 32% of the patients, respectively. Remission occurred in 8% of both groups, whereas conversion occurred in 4% and 14%, and persistence was found in 1% and 11% of the cases, respectively. Eating changes were present in 15% of the patients who were successfully discharged and in 27% of the patients who needed long-term care in the SNF. Remission occurred in 7% and 14%, conversion in 4% and 8%,

TABLE 3: Neuropsychiatric changes in successfully (n=108; first row) versus unsuccessfully (n=37; second row) rehabilitated patients

Symptoms	Admission n %	p-value	Discharge n %	p-value	Cumulative %	Conversion n %	Remission n %	Persistence n %
Delusions	1 (1)		0 (0)		1	0 (0)	1 (1)	0 (0)
Delusions	2 (5)		3 (8)	0.016	8	1 (3)	0 (0)	2 (5)
Hallucinations	1 (1)		0 (0)		1	0 (0)	1 (1)	0 (0)
Hallucinations	3 (8)		3 (8)	0.016	14	2 (5)	2 (5)	1 (3)
Agitation/agression	1 (1)		1 (1)		2	1 (1)	1 (1)	0 (0)
Agitation/agression	2 (5)		5 (14)	0.004	14	3 (8)	0 (0)	2 (5)
Depression	20 (19)		12 (11)		24	6 (6)	14 (13)	6 (6)
Depression	10 (27)		17 (46)	0.000	59	12 (32)	5 (14)	5 (14)
Anxiety	8 (7)		6 (6)		11	4 (4)	6 (6)	2 (2)
Anxiety	4 (11)		7 (19)		24	5 (14)	2 (5)	2 (5)
Euphoria/elation	1 (1)		1 (1)		1	0 (0)	0 (0)	1 (1)
Euphoria/elation	1 (3)		2 (5)		8	2 (5)	1 (3)	0 (0)
Apathy/indifference	4 (4)		2 (2)		5	1 (1)	3 (3)	1 (1)
Apathy/indifference	8 (22)	0.002	3 (8)		22	0 (0)	5 (14)	3 (8)
Disinhibition	8 (7)		2 (2)		8	1 (1)	7 (7)	1 (1)
Disinhibition	2 (5)		6 (16)	0.004	22	6 (16)	2 (5)	0 (0)
Irritability/lability	7 (7)		4 (4)		8	2 (2)	5 (5)	2 (2)
Irritability/lability	4 (11)		6 (16)	0.018	22	4 (11)	2 (5)	2 (5)
Abberant motor behavior	1 (1)		1 (1)		1	0 (0)	0 (0)	1 (1)
Abberant motor behavior	0 (0)		1 (3)		3	1 (3)	0 (0)	0 (0)
Night time disturbances	10 (9)		5 (5)		13	4 (4)	9 (8)	1 (1)
Night time disturbances	7 (19)		9 (24)	0.001	32	5 (14)	3 (8)	4 (11)
Eating changes	12 (11)		8 (7)		15	4 (4)	8 (7)	4 (4)
Eating changes	7 (19)		5 (14)		27	3 (8)	5 (14)	2 (5)
<i>Minimally one symptom</i>	41 (37) 20 (52)		38 (25) 24 (65)					

Cumulative = symptoms either on admission or at discharge

Conversion = no symptoms on admission, symptoms at discharge

Remission = symptoms on admission, no symptoms at discharge

Persistence = symptoms on admission and at discharge

and persistence in 4% and 5% of the patients, respectively. On admission, 37% of the patients who could eventually be discharged within one year had minimally one symptom compared to 52% of the patients who needed long-term care in the SNF. At discharge, these percentages were 25% and 65%, respectively.

There were no differences between both patient groups according to cognition and language skills. Patients who were discharged had a mean MMSE score of 22 points (sd 6.0) and those who had to stay in the SNF had a mean MMSE score of 22.3 points (sd 4.9) ($p=0.78$). Patients who were discharged had a mean SAN score of 5.9 points (sd 1.6) and those who stayed in the SNF had a mean SAN score of 5.6 (sd 1.9) ($p=0.37$).

Discussion

The most frequently occurring neuropsychiatric symptoms in patients admitted to skilled nursing facilities for rehabilitation after stroke were depression, night-time disturbances and eating changes, followed by anxiety and irritability. The observed prevalence's of most symptoms were relatively low compared to previous reports in literature. NPS were more or less stable for the entire sample of 145 patients. However, when patients who could be discharged to an independent living situation within one year were compared to those who could not, significant differences in the prevalence and the course of NPS were found. Patients who could be successfully discharged had a consistently low level of NPS, whereas patients who could not be discharged within one year showed an overall and gradual increase in NPS over time. These findings underpin the notion that NPS may be important aspects of rehabilitation outcome in geriatric patients with stroke.

In general, the prevalence of NPS in the present study was low compared to several other studies.^{7, 8, 31} Various reasons might explain this discrepancy, such as differences in cultural or religious background of the patients, differences in rehabilitation services or organizational setting, or differences in demographic and clinical characteristics. Compared to previous studies, the patients in the present study were often two decades older. Hence, the notion that elderly rehabilitation inpatients would be relatively strongly susceptible to NPS could not be supported. Some authors did not find significant effects of age on the prevalence of depression,^{18, 32} whereas other studies have reported that younger patients generally have more post-stroke NPS,⁷ in particular depression.^{8, 31} As for depression, it is possible that elderly patients are better able to accept the functional limitations imposed upon them by the stroke, regarding them as an "inevitable consequence" of ageing, compared to relatively young stroke patients. However, such an explanation may be less likely for other

types of NPS.

In previous studies, the reported prevalence of depression after stroke ranged from 12% to 61%.^{7, 8, 33-38} In the present study, depression was prevalent in 33% of the patients on admission and/or at discharge. Interestingly, this cumulative percentage was much higher (59%) in the patients who could not be successfully discharged within one year, 32% of them developing depressive symptoms during their rehabilitation in the SNF. Astrom⁷ found that half of the patients that were depressed at three months after stroke were still depressed after one year. Depression rates increased again after two and three years. Hence, it appears that patients who are still depressed after one year are at risk of developing chronic depression. Whether depression primarily affects functional outcome or whether patients with a poor functional prognosis have a greater risk of depression is still elusive. The fact that in the present study depression rates increased particularly in those who could not be successfully discharged seems to point towards the latter relationship. On the other hand, depressive symptoms have been associated with a long-term decline in mobility and functional independency after stroke in other studies.³⁹ The causality of the association between functional disability and depression after stroke should, therefore, be an important topic for further research in geriatric patients. In any case, depressive symptoms in elderly stroke survivors need to be adequately recognized and treated at an early stage during the rehabilitation process to optimize quality of life and perhaps rehabilitation outcome as well.

In this study, only 15% of the patients were reported as being anxious on admission and/or at discharge, whereas other studies have found a prevalence of 27-30% in the acute stage of stroke.^{8, 10, 11, 31} We observed such a high (cumulative) prevalence only in those patients who could not be discharged within one year. In several studies an association between anxiety and depression has been reported with a similar prognosis for both conditions.^{10, 11, 31} It might, therefore, be that the relatively low prevalence of anxiety in our study was related to the relatively low prevalence of depression. Clinically, such a relationship might imply that when depression would be adequately treated in an early stage, rates of anxiety would also decrease (or vice versa). Eating changes and night time disturbances showed similar patterns of prevalence as anxiety, both of which might also be related to depressive symptoms. As the NPI-NH only assesses eating changes without further characterization (e.g. in terms of anergia, disinhibition, weight loss or weight gain) and as it does not control for the influence of possible swallowing difficulties, little can be said with regard to underlying mechanisms. According to the literature, sleeping problems may be related to post-stroke depression⁴⁰ as well as to post-stroke fatigue.⁴¹ Thus, it is conceivable that the observed post-stroke eating and sleeping changes as well as anxiety are all symptoms of the same underlying process: a mood disorder.^{9, 42} This notion

would further stress the importance of treating depressive symptoms as early and as adequately as possible during the rehabilitation process to improve both quality of life and possibly functional outcome.

To our knowledge this is the largest multicenter study of neuropsychiatric symptoms focusing on geriatric patients admitted to skilled nursing facilities for rehabilitation after stroke. The results can, therefore, most likely be generalized to other SNFs with similar rehabilitation resources, but not to nursing homes in other countries with fewer facilities.

The prevalence of NPS found in the present study could be an underestimation in relation to the total group of admitted patients ($n=378$), especially because this group included the critical ill and legally incapable patients. Hence, the external validity should therefore be considered with caution. When the interval between the two NPI-NH measurements was shorter than 28 days or when patients died during the rehabilitation, these patients were excluded post hoc from further analysis, which might have caused information bias regarding the admission scores (albeit in opposite directions). Lastly- although we did not test intra-rater reliability of the NPI-NH-, a 2,5 hour training was given to improve reliability of the assessment. Nevertheless, indirect observation by nurses could have been a source of measurement bias.

Conclusion

The overall observed prevalence of NPS in this study was lower than reported by other studies in different settings. There was, however, a high prevalence of NPS in patients that were not successfully discharged compared to those who were discharged to an independent living situation within one year after admission in the SNF. As the prevalence of NPS in the 'unsuccessful' patients was higher mainly at the assessment one year after admission, the observed NPS may be reactive to, rather than the cause of the poor functional outcome (or the direct result of the brain lesion). In particular, reactive depression may be responsible for the occurrence of late NPS. Future research should focus on the course, causation and interrelationship of NPS with functional outcome in geriatric patients with stroke to further substantiate these notions.

Key points

- Most frequently occurring NPS in stroke patients rehabilitating in SNFs in nursing homes are depression, night time disturbances and eating changes.
- Patients who were discharged had less NPS than those who stayed in the SNF.
- NPS should be optimally treated to improve rehabilitation outcome.

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Chapter 7

Determinants of quality of life in geriatric patients with stroke after rehabilitation, and their informal caregivers' burden

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Submitted

Abstract

Objective

Patients' physical disabilities, dependency on care, and possible psychological ill-being may negatively affect both the patient's quality of life and the informal caregiver burden. The objective of this study was to identify determinants of patients' quality of life and informal caregiver burden, focusing on this interrelationship which can be particularly prominent in geriatric patients with stroke.

Methods

This is a prospective, multicenter, cohort study. Data were collected in eighty-four geriatric home-dwelling patients with stroke three months after their rehabilitation period in skilled nursing facilities. We assessed patients' quality of life, depressive complaints, neuropsychiatric symptoms, balance, (instrumental) activities of daily living, and informal caregiver burden. Linear regression models were constructed to study the association between the variables.

Results

For several domains, high quality of life was associated with high functional independence, less neuropsychiatric symptoms, and less depressive complaints. Informal caregiver burden was not associated with patients' quality of life, but patients' neuropsychiatric symptoms were a significant determinant of high informal caregiver burden.

Conclusions

The presence of neuropsychiatric symptoms (more specifically depressive complaints) negatively affects the quality of life of patients. Their neuropsychiatric symptoms also affect caregiver burden. Health-care professionals can play an important role in providing the necessary psychosocial support and after-care.

Introduction

Even after rehabilitation, geriatric patients who live at home after stroke are often dependent on care and social support by professional or informal caregivers. Usually, informal caregivers are aged as well (spouses), or are family members with their own busy household (i.e. children/daughters). Therefore, the patients' physical disabilities, dependency on care, and possible psychological ill-being may negatively affect both the patient's quality of life (QoL) and the informal caregiver burden.^{1,2}

QoL and its determinants in stroke patients have been widely investigated, but most studies predominantly include younger patients in rehabilitation centres. These studies found older age,^{3,4} female gender,⁵⁻⁷ depression,^{3,4,8} lower functional status,^{5,9,10} and caregiver characteristics¹¹ to be associated with lower QoL.

The studies on QoL in geriatric patients mostly focus on the organisation of the care that is delivered in relation to the patients' QoL after rehabilitation. A Norwegian study found that patients who had rehabilitated on a stroke-specific unit were more independent in their activities of daily living and had a better QoL than patients who had rehabilitated on a general ward.¹² In another study, elderly patients who were living at home but who received outreach nursing home care had a lower QoL than patients living in a nursing home after stroke.¹³ This raises concerns about the role of the informal caregiver in the QoL of the patient and, also, the burden that is experienced by the caregiver. Although informal caregiver burden has been investigated in stroke research, literature concerning the characteristics of frail elderly patients after stroke–rehabilitation in relation to informal caregiver burden is lacking. In younger patients, patient characteristics such as male gender, older age, functional disability,¹⁴ depression,^{2,14,15} and lower cognitive functioning^{15,16} were negatively associated with informal caregiver burden.

In the present study, we focus on the interrelationship between patients' QoL, patient characteristics, and informal caregiver burden, which may be particularly prominent in geriatric patients. The study aimed to identify (1) determinants of QoL in home-dwelling geriatric patients with stroke three months after rehabilitation, and (2) patient-related determinants of the burden of their informal caregivers.

Methods

Design

This study is part of the Geriatric Rehabilitation in AMPutation and Stroke (GRAMPS) study, a prospective, multicenter, cohort study primarily aimed at identi-

fying determinants of rehabilitation outcomes in skilled nursing facilities in nursing homes.¹⁷ The current study focuses on the group of stroke patients who were successfully rehabilitated and discharged.

The GRAMPS study was carried out in 15 skilled nursing facilities in the Southern part of the Netherlands, and included patients who were admitted for multidisciplinary rehabilitation after stroke. All admitted patients were asked to participate. Patients who declined informed consent or who were legally incapable of providing informed consent, those who were expected to be discharged within two weeks, and critically ill patients were excluded from participating.

The regional medical ethics committee of the district Arnhem-Nijmegen in the Netherlands approved the study. The research protocol of the GRAMPS study is extensively described elsewhere.¹⁷

Data collection

From January 2008 until March 2010, researchers collected data in the home environment three months after rehabilitation in patients who had been successfully discharged to an independent living situation within one year after rehabilitation. Data were only collected if patients had an informal caregiver.

Measurements: dependent variables

The QoL was assessed in an interview with the patient with the RAND 36 Health Survey (RAND-36),¹⁸ which is developed to measure health-related QoL in chronically ill patients. The RAND-36 comprises eight dimensions: Physical Functioning, Bodily Pain, General Health, Vitality, Social Functioning, Role-Limitations Emotional, Role-Limitations Physical, and Mental Health, each with total scores ranging from 0–100. Higher scores indicate a higher QoL. The RAND was found to be a valid, reliable, and sensitive assessment scale for measuring general health-related QoL.^{18, 19}

The burden of informal caregivers was assessed with the Caregiver Strain Index, which can be used in caregivers of any age who have assumed the role of caregiver for an older adult.^{20, 21} The Caregiver Strain Index is a questionnaire that consists of 13 yes/no questions (range 0–13), is easy to administer, and has shown good validity.²⁰

Measurements: independent variables

Functional status was assessed using the Barthel Index, modified by Collin et al.²² The Barthel Index measures dependency in activities of daily living (ADL) and is reported to be a valid and reliable instrument.²² The total score ranges from 0–20, with 20 representing complete functional independence.

For the measurement of instrumental ADL, the Frenchay Activities Index was used.²³ The Frenchay Activities Index assesses the actual activities undertaken by

patients and has three domains; domestic housework, indoor activities, and outdoor activities. Scores range from 0–45 points. The 15-item questionnaire has been shown to be a reliable and valid instrument for measuring functional outcomes in patients.²³

The Frenchay Arm Test was used to evaluate arm function after stroke. The patient was asked to perform five activities with his affected arm (range 0–5). The Frenchay Arm Test has been found to be applicable in stroke research.²⁴

The Berg Balance Scale is an ordinal 14-item scale (0–56 points) developed by Berg et al. (1995) to assess balance in stroke patients. Reported validity and reliability of the Berg Balance Scale are good.²

To assess neuropsychiatric symptoms, the NeuroPsychiatric Inventory Nursing Home version, which is applicable in various patient groups, was used.²⁶ The Neuro-Psychiatric Inventory comprises 12 symptoms; delusions, hallucinations, agitation/aggression, depression, anxiety, euphoria, disinhibition, irritability/lability, apathy, aberrant motor behaviour, sleeping disturbances, and eating changes. Symptoms within each domain are rated by the nurse in terms of both frequency (1 to 4) and severity (1 to 3), yielding a composite symptom score (frequency X severity). The 12 composite symptom scores can be summed to obtain a NPI total score.

The interview based eight-item version of the Geriatric Depression Scale was used to measure depressive complaints. It is a short, patient-friendly instrument with eight yes/no questions derived from the 15-item Geriatric Depression Scale, and has been developed specifically for the nursing home population.²⁷

Statistical analysis

Nine linear regression models were constructed; eight regression models with patients' QoL (RAND-36 item scores) as the dependent variable and patients' characteristics and informal caregiver burden as independent factors/variables, and one regression model with informal caregiver burden as the dependent variable and the patients' characteristics as independent factors. The variables were considered to be continuous. Multi-collinearity of the variables, and linearity and normality of the data were tested. The data was processed using SPSS 18.0.

Results

One hundred twenty-three patients were successfully discharged to an independent or assisted living situation. After discharge, 5 patients died, 8 patients withdrew informed consent, 13 patients were lost to follow up (5 of whom had a severe recurrent stroke), and 13 patients did not have an informal caregiver. Thus,

TABLE 1: Patient characteristics and measurement instruments

Variable	Mean (sd)	Range
Age	78 (8)	54-95
Frenchay Arm Test	4 (2)	0-5
Berg Balance Scale	43 (13)	0-56
Geriatric Depression Scale	1 (2)	0-8
Caregiver Strain Index	5 (4)	0-13
Barthel Index	17 (4)	4-20
Frenchay Activities Index	16 (9)	0-36
Neuropsychiatric Inventory	10 (14)	0-69
Physical Functioning	48 (30)	0-100
Bodily Pain	85 (22)	0-100
General Health	65 (18)	10-95
Role-Limitations Physical	50 (32)	0-100
Role-Limitations Emotional	71 (29)	0-100
Social Functioning	68 (31)	0-100
Mental Health	75 (22)	0-100
Vitality	61 (21)	0-100

eighty-four patients remained in the final analysis; 36 males and 48 females. In 32%, the caregiver was the patient's partner, 64% were another family member, and 4% were a neighbour or friend.

On the 8 quality of life dimensions, the mean scores varied between 48 and 85 (Table 1).

Determinants of patients' QoL

High (instrumental) ADL scores (BBS, FAI and BI) were significantly associated with higher Physical Functioning scores (Table 2). Gender was associated with Bodily Pain, with lower scores for females for Bodily Pain, indicating lower QoL. Patients who had more depressive complaints experienced lower QoL with regard to Role-Limitations Physical, Role-Limitations Emotional, Mental Health and Vitality. More neuropsychiatric symptoms were significantly associated with lower Mental Health scores. Better arm-function (FAT) was associated with higher scores for Social Functioning. Informal caregiver burden (CSI) was not associated with patients' QoL. In

TABLE 2: Results multivariate linear regression analysis QoL

	Physical Functioning			Bodily Pain			General Health			Role-Limitations Physical			Role-Limitations Emotional			Social Functioning			Mental Health			Vitality		
	B	CI	p	B	CI	p	B	CI	p	B	CI	p	B	CI	p	B	CI	p	B	CI	p	B	CI	p
Age	-0.17	[-0.73-0.39]		0.26	[-0.51-1.03]		0.39	[-0.15-0.93]		0.36	[-0.61-1.34]		-0.20	[-1.08-0.68]		0.10	[0.87-1.07]		0.01	[-0.55-0.57]		0.11	[-0.45-0.67]	
Gender (ref female)	8.10	[-0.51-16.71]	**	12.35	[0.62-24.07]	**	-1.00	[-9.27-7.28]		1.99	[-12.96-16.94]		5.70	[-7.76-19.15]		-6.75	[-21.60-8.09]		2.78	[-5.84-11.40]		-3.82	[-12.39-4.76]	
CSI	0.66	[-0.68-2.01]		0.59	[-1.22-2.39]		0.43	[-0.87-1.72]		-2.19	[-4.52-0.15]		-0.45	[-2.55-1.64]		-1.33	[-3.64-0.99]		0.83	[-0.51-2.18]		-0.16	[-1.50-1.17]	
GDS-8	1.94	[-0.28-4.17]		-0.15	[-3.15-2.85]		-1.58	[-3.73-0.57]		-4.47	[-8.33-0.60]	**	-3.69	[-7.17--0.21]	**	0.51	[-3.33-4.34]		-5.92	[-8.15--3.69]	*	-5.75	[-7.96--3.53]	*
NPI-NH	-0.39	[-0.78--0.00]		-0.18	[-0.70-0.35]		-0.32	[-0.70-0.05]		0.17	[-0.51-0.85]		-0.33	[-0.94--0.28]		-0.40	[-1.07-0.28]		-0.48	[-0.87--0.09]	**	-0.37	[-0.76-0.02]	
BBS	0.72	[0.17-1.26]	*	-0.34	[-1.07-0.39]		-0.25	[-0.79-0.29]		-0.01	[-.95-0.94]		-0.12	[-0.97-.73]		0.46	[-0.48-1.40]		0.25	[-0.30-0.79]		0.42	[-0.12-0.96]	
FAI	1.37	[0.71-2.04]	*	0.48	[-0.42-1.37]		0.07	[-0.57-0.70]		-0.20	[-0.96-1.35]		-0.06	[-1.10-0.98]		0.47	[-0.68-1.61]		-0.32	[-0.99-0.34]		0.10	[-0.56-0.76]	
FAT	0.62	[-2.37-3.60]		-2.00	[-6.01-2.01]		-1.23	[-4.10-1.63]		1.14	[-4.05-6.32]		-1.26	[-5.93-3.41]		-6.76	[-11.91--1.61]	**	0.24	[-2.75-3.23]		-1.60	[-4.58-1.37]	
BI	2.14	[0.13-4.15]	**	2.35	[-0.38-5.07]		2.26	[0.31-4.21]	**	1.96	[-1.53-5.45]		1.97	[-1.17-5.11]		1.65	[-1.82-5.11]		-0.45	[-2.47-1.56]		0.25	[-1.75-2.25]	
R ²	.756			.239			.273			.320		.237			.211			.479			.476			

• p≤ 0.01

** p≤ 0.05

Care Giver Strain Index (CSI)

Geriatric Depression Scale - 8 (GDS-8)

Neuropsychiatric Inventory Nursing Home version (NPI-NH)

Berg Balance scale (BBS)

Frenchay Activities Index (FAI)

Frenchay Arm Test (FAT)

Barthel Index (BI)

the various models, the determinants explained between 21% and 76% of the total variance (Table 2).

For all variables entered in the models the tolerance was >2.5 and the Variance Inflation Factor (VIF) <4.02 , implying that multi-collinearity was of no concern.

Determinants of informal caregiver burden

More neuropsychiatric symptoms were associated with more informal caregiver burden (Table 3). The determinants explained 29% of the total variance.

TABLE 3: Results multivariate regression analysis Informal Caregiver Burden

	Informal Caregiver Burden		
	B	CI	p
Age	-0.07	[-0.17-0.04]	
Gender	0.72	[-0.88-2.32]	
Geriatric Depression Scale	-0.23	[-0.64- 0.19]	
Neuropsychiatric Inventory	0.12	[0.05-0.19] *	
Berg Balance Scale	0.01	[-0.09-0.12]	
Frenchay Activities Index	-0.10	[-0.22-0.03]	
Frenchay Arm Test	-0.32	[-0.88-0.24]	
Barthel Index	-0.13	[-0.51-0.25]	
R ²	0.291		

* $p \leq 0.01$

Discussion

To our knowledge, this is the first study focussing on determinants of patients' QoL and informal caregiver burden in geriatric patients after stroke, shortly after rehabilitation in skilled nursing facilities. Concerning the several domains, the QoL for these geriatric patients was varying between 48-85 (range 0-100). Higher QoL was primarily explained by aspects of good (functional) status and less neuropsychiatric symptoms and depressive complaints. Neuropsychiatric symptoms affected informal caregiver burden. Informal caregiver burden did not affect patient's quality of life.

Geriatric rehabilitation refers to the rehabilitation of older people. Patients are admitted to SNFs when they need low intensity rehabilitation programs, which are usually not provided in rehabilitation centres. Sometimes younger patients are admitted as well, which explains the range of age in this sample.

The relatively high QoL scores (but low Physical Functioning domain score) in geriatric patients with stroke in our study are comparable to those found for younger stroke patients, and for the general population in the Kong and Yang study.⁸ Our older patient group with severe disabilities apparently has a good overall QoL. Indeed, patients with disabilities may experience a good QoL, a phenomenon described earlier as the disability paradox.²⁸ This suggests that QoL is about finding a proper balance between physical, mental, social, and environmental factors, and that this can also be achieved when important life domains are severely affected.

ADL and instrumental ADL were important determinants of QoL. These findings were in line with those of others.^{5, 9, 10} Our findings that neuropsychiatric symptoms and depressive complaints were negatively associated with several aspects of QoL also agreed with the findings of others.^{3, 4, 8, 29} Additionally, neuropsychiatric symptoms were also associated with higher informal caregiver burden. The literature is inconsistent regarding this finding; McCullagh et al.³⁰ found positive correlations for neuropsychiatric symptoms (anxiety and depression) with informal caregiver burden, whereas Ilse et al.²⁰ found functional disability – rather than depression – to be related to higher caregiver burden. Further study, including the characteristics of informal caregivers, may provide more insight.

A limitation of this research may be a possible risk of selection bias regarding our results on determinants of patients QoL, because we did not include patients without an informal caregiver. Next, we did not measure caregiver characteristics as possible determinants of caregiver burden (only patient factors). Furthermore, the results may be subjected to over-fitting of the models due to the relatively small sample size and using relatively many variables, perhaps resulting in false positive findings. Possible over-fitting of the models also made it difficult to test for interaction-effects of all variables with gender (a common effect modifier in literature). We did not find any on a significance level of 0.01, although it might be interesting to study this in a larger sample.

Neuropsychiatric symptoms and depression may be under-diagnosed in patients with stroke, even when these patients are still admitted to the SNF. Therefore, it is very important to observe neuropsychiatric symptoms in general and depression in particular at an early stage. Professionals should use a screening instrument such as the NPI and GDS-8 to screen for neuropsychiatric symptoms and depression. They need to react adequately to neuropsychiatric symptoms and depressive complaints that patients express and discuss these within the multidisciplinary team,

so that psychosocial and pharmacological interventions can be applied. In addition, professionals have to prepare informal caregivers for their changing role during and after the patient's rehabilitation by involving them in the rehabilitation process and provide them tools for coping with neuropsychiatric symptoms. To prevent informal caregiver burden it is important to give after-care and support to both patients and their caregivers in the home situation after rehabilitation 2. This after-care should be organized in close collaboration with health care professionals from the SNF and those in the home situation.

Conclusion

Psychosocial aspects (neuropsychiatric symptoms, depressive complains) are important determinants of both patient's QoL and caregiver burden. This highlights the importance of psychosocial support by professionals, during and after clinical rehabilitation. Multidisciplinary professionals can provide patients and informal caregivers with tools for coping with neuropsychiatric symptoms and in that way contribute to preventing informal caregiver burden.

Key points

- Knowledge about determinants of patients' quality of life and informal caregiver burden is important for giving adequate psychosocial support.
- In elderly people suffering from stroke, neuropsychiatric symptoms are associated with decreased quality of life of patients and increased burden of their caregivers.
- In this study, informal caregiver burden is not associated with patients' quality of life.

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Chapter 8

Determinants of quality of life in older adults after lower limb amputation and rehabilitation in Skilled Nursing Facilities

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Background

The most common causes of lower limb amputation (LLA) are peripheral arterial disease (PAD) and diabetes, which frequently occur in the elderly. LLA and associated co-morbidity cause major problems in daily life such as physical disabilities, psychological ill-being and dependency on care.¹ In literature, of predominantly younger patients, time since amputation,^{1, 2} physical disability,^{1, 3, 4} less social activities,^{1, 3} vascular disease,^{1, 5-6} depression,^{2, 3} gender^{2, 7} and higher age,^{1-3, 6} are factors affecting Quality of Life (QoL).

Our study was aimed at investigating QoL and its determinants in home dwelling geriatric patients with LLA and a history of PAD recently after rehabilitation in a skilled nursing facility (SNF).

Methods

This study is part of the Geriatric Rehabilitation in AMPutation and Stroke (GRAMPS) study,⁸ which is a prospective, multicenter, cohort study aimed at identifying determinants of rehabilitation outcomes.

Three months after discharge, QoL was assessed with the RAND-36 Health Survey (eight subscales) (Table 1). The Geriatric Depression Scale (GDS8), Neuropsychiatric Inventory Nursing Home version (NPI-NH), Frenchay Activities Index (FAI), Barthel Index (BI), One-Leg Standing-Balance test, and Functional Ambulation Categories (FAC), were determinants representing mood, behavioral problems, ADL, IADL, balance and functional status.⁸ The possible determinants of RAND-36/QoL were identified using linear regression analysis.

Results

Of the 48 patients with amputation who were admitted on participating SNFs, 27 patients (18 females) were successfully discharged after rehabilitation. They were on average 75 years old and had a mean elapsed time after amputation of 180 days. Eight patients underwent a trans-femoral amputation, four a knee-disarticulation and 15 a trans-tibial amputation. Eight patients were fitted with a prosthesis for cosmetic reasons or with limited weight-bearing option, 11 patients had a definitive prosthesis which was used for walking short or long walking distances

with a walking device. Two patients were able to walk without a walking device.

Mean QoL scores varied between 22 and 87. Low QoL on Physical functioning – with a low mean score – was correlated positively with FAC (explaining 46% of the total variance). High QoL on Role Limitations Emotional, Social functioning and Mental Health – with relatively high scores – and Vitality was negatively associated with more neuropsychiatric symptoms and/or depressive complaints (NPI-NH & GDS8; explaining 41-69% of the total variance). Vitality was positively correlated with FAI ($R^2 = 16\%$). Bodily Pain was not associated with any of the potential correlates (Table 1).

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Discussion

This study particularly focused on determinants of QoL in geriatric patients with a lower limb amputation and after rehabilitation. It is unique in that QoL was measured shortly after discharge to home. The quality of life for these geriatric patients with LLA was good with the exception of the domain Physical Functioning.

Even in this small sample of 27 successfully rehabilitated patients, high and significant correlations and explained variances were found.

We found a high QoL, in contrast with some other studies^{1,7} but in line with Asano et al.³ In the present study, the elapsed time after LLA was relatively short (on average within a half year). This may imply that geriatric patients adapt rather quickly to the situation of living with LLA. Indeed, patients with disabilities may experience good QoL, a phenomenon earlier described as the disability paradox.⁹ On the other hand, prior to LLA, most patients with PAD are suffering from pain, sleeplessness and other discomfort related to PAD. These aspects may be positively influenced by LLA.

Low scores were found on the Physical Functioning domain. Surprisingly, walking disability (FAC) was the only factor that contributed significantly to explaining the low QoL on this domain. Walking abilities are consequently affected by LLA and

TABLE 1: Results multivariate regression analysis Mental Health related QoL

	Bodily Pain (mean 87, sd 21)			Role Limitations Physical (mean 59, sd 31)			Role Limitations Emotional (mean 85, sd 25)			Social Functioning (mean 81, sd 33)			Mental Health (mean 80, sd 24)			Vitality (mean 68, sd 24)			General Health (mean 73, sd 21)			Physical Functioning (mean 22, sd 23)		
	B	SE	R ² sign	B	SE	R ² sign	B	SE	R ² sign	B	SE	R ² sign	B	SE	R ² sign	B	SE	R ² sign	B	SE	R ² sign	B	SE	R ² sign
NPI (mean 9, sd 13)				-1.61	.37	48**			excluded				-1.02	.33	60**									
FAI (mean 16, sd 8)																1.16	.50	18*						
GDS-8 (mean 1, sd 2)						excluded	-9.90	1.65	63**	-11.34	2.36	48**	-4.72	1.95	9*	-6.63	1.92	29**						
BI (mean 15, sd 4)																								excluded
FAC (mean 2, sd 2)																						7.96	1.76	46**
Balance (mean 2, sd 1)																								excluded
Total R ²			.000			.481			.632			.480			.692			.410			.181			.460

Instruments: Neuropsychiatric Inventory/Nursing Home version (NPI-NH), Frenchay Activities Index (FAI), Geriatric Depression Scale 8 (GDS8), Barthel Index (BI), Functional Ambulation Categories, One-Leg Standing-Balance.

Determinants were only entered in the regression models when they appeared statistically significant in correlation analysis (Spearman's Rho, $p < 0.05$). The variables that were statistically significant in the correlation analysis, but were excluded in the regression analysis were registered.

** $p < 0.01$ * $p < 0.05$

the (none) use of a prosthesis. The older patient often has multiple medical problems that must be considered when being fitted for a prosthesis.¹⁰ Also, some patients do not use it for walking even though it was intended to do so. Given the importance of walking ability for the QoL that is experienced, it is recommended to gain further insight in this matter.

For six QoL domains, neuropsychiatric symptoms (NPI-NH) and/or depressive complaints (GDS8) were independent determinants. It is unclear to which extent depressive complaints in the present study were reactive to LLA. However, it underpins the importance of treating NPS and respond to depressive complaints as early and adequately as possible, during as well as after rehabilitation to improve QoL.

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Chapter 9

Summary and general discussion



Introduction

The main focus of this thesis is on description of the characteristics and course of patients who are admitted to geriatric rehabilitation for stroke and amputation in Skilled Nursing Facilities (SNFs), with specific attention to the (course of) neuropsychiatric symptoms (NPS), their effect on quality of life (QoL) and informal carers after discharge from SNFs, and the role of nurses. In this chapter a summary of the main findings is given, by answering the main research questions of this thesis. Next, the main findings are discussed and interpreted. The methodological issues of the study are discussed, followed by implications for nurses, physicians, psychologists, therapists, medical directors, (nurse) policy makers and (nurse) researchers. Finally, recommendations for future research are given and the thesis ends with a general conclusion.

The research questions in this thesis were:

1. *What are relevant patient characteristics to distinguish groups of patients based on their admission scores in skilled nursing facilities and what is the course of these particular patient-groups in relation to their discharge destination?*
2. *What is the amount of time that stroke patients spend on therapeutic activities, non-therapeutic activities, social interaction with others, and what is the location where the activities take place?*
3. *What are the prevalence and course of neuropsychiatric symptoms in geriatric patients admitted to skilled nursing facilities for rehabilitation after stroke?*
4. *What are the determinants of quality of life in home dwelling geriatric patients with stroke three months after rehabilitation in skilled nursing facilities and what are the patient related determinants of the burden of their informal caregivers?*
5. *What are the determinants of quality of life in home dwelling geriatric patients with lower limb amputation and a history of peripheral arterial disease within a half year after amputation and rehabilitation in skilled nursing facilities?*

Summary of main findings

Research designs GRAMPS

In Chapter two and three the research designs of the GRAMPS study are outlined. The GRAMPS study was a longitudinal, observational, multicenter study in nursing homes in the Southern part of the Netherlands that aimed to include at least 200 patients with stroke in 15 nursing homes and 50 patients with amputation in 11 nursing homes. All participating nursing homes were selected based on the presence of a specialized rehabilitation unit and the provision of dedicated multidisciplinary care. Data were collected within two weeks after admission: patient characteristics, disease characteristics, functional status, cognition, behavior and caregiver information. The first follow-up took place at discharge from the nursing home or at one year after inclusion, and was focused on functional status and behavior. Successful rehabilitation was defined as discharge from the nursing home to an independent living situation within one year after admission. The second follow-up took place three months after discharge in patients who rehabilitated successfully, and focused on functional status, behavior, and quality of life. All instruments have shown to be valid and reliable in rehabilitation research or are recommended by the Netherlands Heart Foundation guidelines for stroke rehabilitation.

The findings

1. *Patients in poor condition upon admission are more likely to be referred to a facility for long-term care, but this is not the case for 50% of these patients.*

The aim of Chapter 4 was to identify meaningful patient groups for developing specific rehabilitation programs in SNFs. In these patient groups, we studied the course of balance, activities of daily living, walking ability, arm function, depressive complaints and neuropsychiatric symptoms after admission, in relation to discharge destination. To identify meaningful groups of patients, we first performed a Two-step Cluster Analysis to identify variables that discriminate *between groups*. Cluster analyses revealed two groups: cluster 1 included patients in poor condition upon admission (n=52), and cluster 2 included patients in fair/good condition upon admission (n=75). Patients in both groups improved in balance, walking abilities, and hand function. Patients in the poor group also improved in ADL. Depressive complaints decreased significantly in patients in the poor group who were discharged to an independent/assisted- living situation. The rates of discharge to an independent or assisted living situation significantly differed between the good (80%) and the poor (46%) group. In both groups, the patients who were discharged improved more on all measurements than those who stayed in the SNF for long-term care. More specifically, patients in the poor group who were discharged improved significantly more

than the other groups on all measurements. Interestingly, although patients in poor condition at baseline were more likely to be referred to a facility for long-term care, this was not the case in 50% of these patients.

2. *Patients in skilled nursing facilities are alone half of the day and are only 10% of the day engaged in social interaction in the presence of nurses.*

After publishing the research design of the GRAMPS study, the question raised to what extent patients with stroke received training by nurses or other professionals in the daily care in SNFs. Therefore, we undertook a complementary study. We aimed to describe the time use of patients with stroke in five SNFs in the Netherlands, focusing on the time patients spent on therapeutic activities, non-therapeutic activities, interaction with others and the location where the activities took place. In this study, therapeutic and non-therapeutic activities of patients were observed from 8 AM to 4.30 PM using behavioral mapping. Patients stayed an average 41% of the day (212 minutes) in their own room and were alone 49% of the day (256 minutes). The patients spent more than half of the day (292 minutes) on therapeutic activities, whereas the remaining time was spent on non-therapeutic activities (226 minutes). Most therapeutic time was spent on nursing care and physical therapy. For 10% of the day (56 minutes), patients with stroke had social interaction and activities of daily living in the presence of nurses. Patients with a higher functional status at baseline spent more time on therapeutic activities.

3. *Neuropsychiatric symptoms in this study were lower than reported by other stroke-studies in different settings (i.e. hospitals, rehabilitation centres and nursing homes), but symptoms are likely to increase in a subgroup of patients that cannot be discharged to an independent living situation.*

The aim of chapter 6 was to investigate the prevalence and course of NPS in geriatric patients admitted to SNFs for rehabilitation after stroke. In this study, NPS were assessed in one hundred forty five patients with stroke by using the Neuropsychiatric Inventory – Nursing Home version (NPI-NH) with assessments on admission and at discharge, for patients who were discharged to an independent living situation within one year after admission and patients who remained in the SNF for long-term care. Eighty percent of all patients had had a first-ever stroke and 74% could be successfully discharged. Overall, the most common NPS were depressive symptoms (33%), eating changes (18%), night-time disturbances (19%), anxiety symptoms (15%), irritability (12%) and disinhibition (12%). One year after admission, patients who were still in the SNF showed significantly more hallucinations, delusions, agitation, depressive symptoms, disinhibition, irritability and night-time disturbances than those who had been discharged.

4. *The presence of neuropsychiatric symptoms is associated with both patient quality of life and caregiver burden in patients with stroke after discharge.*

In chapter 7 we identified QoL determinants of 84 patients and determinants of the burden of their informal caregivers, of patients with stroke being discharged home three months after rehabilitation in SNFs. We focused particularly on the interrelationship between patient and caregiver, which may be specifically relevant in geriatric patients with stroke. We assessed patient QoL with the RAND-36 Health Survey (eight subscales). Mean QoL scores varied between 48 and 85 (theoretical range 0-100). High QoL was primarily associated with high functional independence, less NPS and less depressive complaints. Informal caregiver burden was not associated with patient QoL but with patient NPS.

5. *Walking disabilities and neuropsychiatric symptoms negatively affect quality of life of geriatric patients with a lower limb amputation.*

The aim of this study (chapter 8) was to identify determinants of QoL of home dwelling geriatric patients with amputation, on average within six months after amputation and three months after rehabilitation in an SNF. QoL of 27 patients was assessed with the RAND-36 Health Survey. Mean QoL scores varied between 22 and 87 (theoretical range 0-100). Walking ability was negatively associated with low QoL on Physical functioning – with a low mean score – explaining 46% of the total variance. NPS and depressive complaints were negatively associated with high QoL on Role Limitations Emotional, Social functioning and Mental Health – with relatively high scores – and Vitality, explaining 41-69% of the total variance. Instrumental activities of daily life were positively correlated with Vitality explaining 16% of the variance. Bodily Pain was not associated with any of the potential correlates.

Interpretation of main findings

Patients are referred to rehabilitation programs based on their admission profile. Mostly, only physical functioning is taken into consideration, such as balance and ADL. However, this thesis shows that psychosocial factors also influence the rehabilitation process. Patients who could not be discharged to an independent living situation within one year showed, next to physical decline, an increase of depressive complaints and NPS. Throughout their rehabilitation in the SNF, half of the time patients are alone (between 8 AM and 4.30 PM). During this time, they do not have any social interaction with others and there are no meaningful therapeutic activities, which contribute to an improved and more rapid rehabilitation. Too much time alone may lead to feelings of loneliness and worrying about the impact of stroke or

amputation. Patients may question the possibility of maintaining a way of life as before the event. This may contribute to loss of motivation and increase of NPS and depressive complaints. Moreover, also after rehabilitation, QoL of patients is affected by NPS and depressive complaints, which may consequently put a great burden on informal caregivers. Prevention and treatment of depressive complaints and NPS in an early stage of rehabilitation may result in a more positive rehabilitation outcome and consequently a better QoL for patients and informal caregivers.

Methodological issues

Assessment instruments

In the GRAMPS study many assessment instruments that have been used in previous research on stroke and amputation rehabilitation, were used. However, it can be questioned whether these are feasible for (geriatric) rehabilitation research purposes.

To assess NPS, the NeuroPsychiatric Inventory Nursing Home version, which is applicable in various patient groups, was used. Traditionally the NPI-NH is developed for and used in patients with dementia. The NPI-NH was administered by qualified nurses who had been specifically trained before the start of the GRAMPS study.¹ NPS were rated by the nurses in terms of both frequency (1 to 4) and severity (1 to 3), yielding a composite symptom score (frequency \times severity). Concerning chapter 6, a specific neuropsychiatric symptom was considered to be present when the composite symptom score was greater than 0. This definition includes mild and infrequently occurring NPS and could have caused an overestimation of NPS prevalence, not necessarily meaning that it were clinically relevant NPS. Because previous studies did not provide clear cut-off points for the prevalence of NPS after stroke and amputation, any cut-off point (such as clinically relevant behaviour when FxS >3 , which is often used in dementia research) can be seen as arbitrary for research in stroke and amputation.

The Geriatric Depression Scale-8 (GDS-8)^{2, 3} was used to screen for depressive complaints as expressed by the patient. The results of the GDS-8 gave an indication for a possibly existing problem, without formally establishing a diagnosis of depression.

The observational scheme used in chapter 5 was based on previous studies. Those previous studies interpreted eating/drinking, transport/travel, communication and activities of daily living as non-therapeutic. In the study in chapter 5 we defined these activities as therapeutic, because these generally contribute positively to stroke rehabilitation. However, this may have resulted in overrating the therapeutic

advantage if nurses took over most of the activity in cases where patients were not able to perform the activity independently.

The Behavioral Mapping method comprises the observation and mapping of activities that allowed us to study patient activities in a specific area for a predetermined amount of time.⁴⁻⁶ We performed a systematic observation to track behaviour over space and time. However, observations took place on weekdays between 8.00 AM - 4.30 PM. Extending these observation periods before and after these hours and during the weekends would reduce the possibility of information bias. The expectation is that less therapeutic activities are initiated in weekends and evening hours, probably resulting in an even lower percentage of therapeutic activities.

Study limitations

To our knowledge this is the largest multicenter study focusing on geriatric patients admitted for rehabilitation after stroke and amputation. Data were collected in nursing homes with a specific rehabilitation ward and these were part of the Nijmegen University Nursing Home Network of the Radboud University Nijmegen, Medical Center. This is a selection of nursing homes that already had a specialized rehabilitation ward (SNFs). We choose the term skilled nursing facilities to mark the difference between regular nursing homes and the nursing homes with specialized rehabilitation units: the SNFs. The results of the GRAMPS study⁷ can therefore be generalized to other SNFs and to a lesser extent to rehabilitation patients in nursing homes without a specialized rehabilitation unit.

Although SNFs generally provide rehabilitation for elderly patients, our samples included also younger patients between 54-60 years. In the stroke-sample this was 9% of the excluded patients (17/192) and 5% of the included patients (9/186). In the amputation sample this was 29% of the excluded patients (2/7) and 6% of the included patients (3/48). These patients were in a poor condition before and after stroke and amputation. The pace of rehabilitation in a rehabilitation center would have been too intense and for that reason these patients were admitted for rehabilitation in an SNF. Clearly, age is not the only factor for triage to either rehabilitation center or SNF. Other factors such as frailty and comorbidity (which are not always related to increased age) may play a more important role.

Of 378 eligible patients with stroke, 186 patients met the inclusion criteria for the GRAMPS study. Patients were excluded from the study based on unwillingness to give informed consent ($n=73$), critical illness ($n=13$), legal incapacity ($n=64$), and expected short stay ($n=7$). In addition, 35 patients were not asked to participate for logistic reasons, i.e. during holidays merely every second patient was included to limit the burden of the personnel of the research units. Although the excluded patients did not significantly differ from those included in terms of age, gender, or length of

stay in the SNF, there is neither insight in reasons of unwillingness to give informed consent, nor insight in physical condition, neuropsychiatric symptoms, cognition or caregiver burden of these particular patients. The legally incapable patients were probably in poor physical and/or cognitive condition. Therefore, we consider the results of this study to be generalizable for rehabilitation-patients in SNFs who do not suffer severe cognitive impairments.

Furthermore, the outcome measures are not clustered within SNFs, which underscores the comparability of patient groups, interventions and assessment procedures. For this reason, multilevel models (mix-models) are not necessary.

The data may have been influenced by selection of nursing homes, loss of data, and small sample size in the two studies of chapter 5 and 8. Because of the multi-centre nature of the study, the chance of selection bias is considered to be relatively small.

Implications for nurses

Therapeutic climate

As reported in this thesis patients with stroke have social interaction and activities of daily living in the presence of nurses only 10% of the working day (8.00 AM – 4.30 PM) (chapter 5).⁶ This is true despite the fact that several studies have described the important role of nurses in rehabilitation of patients.⁸⁻¹⁰ Virginia Henderson proclaimed already in 1980 that nurses are rehabilitators par excellence. According to Henderson⁸ the components of nursing care are not only basic but are essential components of a rehabilitation program. In SNFs, various roles of nurses can be identified such as technical and physical care, emotional support and creating a supportive environment for rehabilitation.^{9, 11} Although nurses express a desire to integrate therapy into their care delivery, the actual achievement of this goal is a challenge.¹¹ Thus, these professionals need to be encouraged and empowered by the management team of the facility and the multidisciplinary team for practicing their various roles.

Nurses can be enhancers of a therapeutic climate, because until 2012, the overall amount of time that can be spend on multidisciplinary treatment in SNFs (consultation and reporting included) is restricted and based on the maximum treatment time in The Dutch Resource Utilization Group ZZP9,¹² and amounts to approximately 4 hours per week, evenly distributed over 5 working days.¹³ If nurses exercise with patients they contribute to (functional) recovery. Indeed, they need to determine which activities could be considered as therapeutic for contributing positively to patients' rehabilitation. A therapeutic climate is characterized by a therapeutic program with

structured activities which are tailored to patients needs, explicitly formulated goals, hands-off nursing care (using mostly verbal instructions), a supportive climate created by the multidisciplinary team and interaction with other patients. All these activities focus on discharge of the patient to an independent or assisted living situation. Nurses should use Clinical Practice Guidelines since these multidisciplinary guidelines include recommendations focusing on the daily rehabilitation care and treatment of patients.¹⁴⁻¹⁷ It is important that they stimulate patients to do simple exercises such as reach for objects,¹⁸ stand up from a chair several times a day¹⁹ and walk with the patients.²⁰⁻²² Being an enhancer of a therapeutic climate is in particular a role for nurses, after all, the nurse is the one that takes care of the patient 24 hours/7 days a week and is always present on the rehabilitation ward. In doing so, the nurse is able to detect what the specific needs of patients are, thus attributing to a therapeutic climate.^{23, 24}

Psychosocial influence

Neuropsychiatric symptoms (NPS) and depressive complaints can seriously hinder the rehabilitation process. Prevalence of NPS was higher in patients with stroke who were not successfully discharged compared to those who were discharged to an independent living situation within one year after admission on the SNF (chapter 6). Since the prevalence of NPS in the ‘unsuccessful’ patients was higher at the assessment one year after admission than at baseline, the observed NPS may be reactive to, rather than the cause of the poor functional outcome or the direct result of the brain lesion. This thesis also shows that NPS and depressive complaints influence QoL of patients with stroke or amputation.²⁵⁻²⁹ Therefore, it is very important to observe NPS in general and depression in particular in an early stage, and that is a specific role for nurses. Nurses can use screening instruments such as NPI and GDS-8 to screen for NPS and depression. Nurses need to react adequately to NPS and the depressive complaints that patients express. The information that is collected by nurses needs to be discussed in the multidisciplinary team, so that psychosocial and pharmacological interventions can be applied.^{30, 31}

Caregiver support

As shown in this thesis (chapter 7), informal caregivers are burdened by NPS and depressive complaints. After rehabilitation, patients are (hopefully) discharged to their own homes. The role of the informal caregiver often changes considerably after stroke or amputation. The informal caregiver faces changes in the patient which may have impairments in mobility, balance, mood and social interaction.³²⁻³⁵ Nurses have to prepare informal caregivers for their changing role during the patient’s rehabilitation in the SNF by involving them in the rehabilitation process and give them tools

to cope with for instance NPS. After rehabilitation it is important to give after-care and support to both patients and their caregivers in the home situation, to prevent informal caregiver burden.³³⁻³⁵ This after-care should comprise psychosocial support from a nurse and could well be organized from the SNF.

Implications for physicians, psychologists and therapists

This thesis shows that 50% of the patients in poor condition upon admission are discharged to an independent or assisted living situation. In literature, prediction of outcome after stroke and amputation is based on baseline data.³⁶⁻³⁸ However, prediction models predict outcomes in average patients, which are not necessarily valid for an individual patient. Discharge to an independent/assisted-living situation appears to be difficult to predict on the basis of characteristics of patients in poor condition upon admission.³⁹ Predictions about discharge can be misleading if therapists and clinicians only take initial functional status as a measure for therapy intensity, therapy content, and discharge, since they risk overlooking patients with poor admission status but who go on to regain enough functionality for discharge to an independent/assisted-living situation. Therefore, rehabilitation should be a combination of program-oriented and individually tailored activities.

The elderly care physician is responsible for diagnosis and treatment (functional and psychosocial) and in this role he/she can motivate and guide the multidisciplinary team. Careful monitoring (functional) status during rehabilitation is very important and makes it able to adapt the rehabilitation program to patient needs. It is conceivable that patients in poor condition upon admission need specific rehabilitation in terms of intensity and extended time period: almost 50% of patients in the poor cluster is discharged to an independent/assisted-living situation. Since patients in poor condition upon admission seem capable to recover, it is recommended to increase therapy intensity in these patients.⁴⁰ These patients benefit more from higher therapy intensity than patients in good condition upon admission.^{41, 42} Elderly care physicians and therapists should give patients that time, instead of referring them prematurely to an institution for long-term care where there is no proper and essential therapeutic rehabilitation climate.

New insights about therapy have strongly changed the practice of rehabilitation in the past decennia, and these insights are highly connected with geriatric rehabilitation. Little scientific evidence has been found from different theoretical approaches in stroke rehabilitation such as Neuro Development Training (NDT) (Bobath).^{43, 44} Elaborate scientific insights resulted in a dynamic development in neuro-rehabilitation.^{45, 46} Neuro-rehabilitation exists of re-learning of competences and skills

in (I)ADL in which progression can be achieved, such as in patients with stroke and amputation. Much of the techniques in neuro-rehabilitation are focused on what the patient is able to do and the center of attention lies mainly on compensation techniques.⁴⁵ This is exactly where the geriatric patient finds his/her benefit. The multidisciplinary team should invest neuro-rehabilitation for recovering functional skills,⁴⁷⁻⁴⁹ for example through behavioral compensation strategies.^{47, 50}

In both studies of QoL in this thesis, NPS and depressive complaints are determinants of patient QoL (chapter 7 & 8). Also, NPS rather than functional status of patients are the most important determinants of informal caregiver burden (chapter 7). NPS and depression may be under-diagnosed in patients with amputation or stroke. The elderly care physician and psychologist have to work in close collaboration with each other to diagnose and treat NPS and depression. Psychosocial support to patients and caregivers (next to patients' physical therapy), by a psychologist in particular, is deemed necessary. It can add to QoL of patients and provide informal caregivers with tools for coping with NPS and consequently prevent informal caregiver burden.

Implications for directors of SNFs

This thesis shows that most of the day patients on rehabilitation wards are sitting and waiting and almost half of the day they are alone (chapter 5),⁶ which must be considered ineffective for patients. Patients in poor condition upon admission likely need a higher intensity program and more time to rehabilitate. Half of these patients appear to recover and are ultimately discharged to an independent/assisted living situation. If patients are not given that effort, they are refrained from further – possibly successful- rehabilitation. On the other hand, giving patients more time to rehabilitate is more expensive and may be difficult to pursue, because from the year 2013 rehabilitation is aimed to be short term^{13, 51} due to a new reimbursement system for geriatric rehabilitation in SNFs in the Netherlands. The rehabilitation process is aimed to be short-term and therefore it will fit better in the resource system of the general health insurance (Zorgverzekeringswet, Zvw).⁵¹ Allocation of financial resources on the basis of performance and results in geriatric rehabilitation care will stimulate organizations to increase quality and efficiency of care. Chances for care organizations to improve quality of rehabilitation lie in organizing individual -and group therapies to increase therapy intensity, technological health care innovations and finding new ways of arranging the work that has to be done. The re-allocation of financial resources that is a consequence of the financial transition should not only be distributed between physicians and therapists, but should also support the

nursing team on the rehabilitation ward. Applying various resources for empowerment of nursing teams will be beneficial for patients.^{52, 53} The nurse can be therapist in geriatric rehabilitation!

Directors can cut down on expenses in patients in good condition upon admission. The fact that patient in good condition upon admission show only modest improvement raises the question whether these patients may be better off undergoing rehabilitation in the home environment or in day-care rehabilitation rather in an institution. Management can organize stroke rehabilitation in the home environment by implementing an ambulatory operating “expert stroke team” comprising multidisciplinary team members from the SNF. Rehabilitation in the homes of patients or in day-care would not only be beneficial to patients, but could

- 1) decrease the costs of health care, and
- 2) make it possible to switch financial resources to, for example, intensified institutional rehabilitation for patients in poor condition upon admission.

After rehabilitation, patients and caregivers often have questions about further improvement. They need practical help and information to cope with NPS, changing roles, dependency on care and caregiver burden. Therefore, after-care seems indispensable. Yet most SNFs do not offer after-care. In 2017, improvement of nursing care outside the nursing home will be stimulated by financing home-care from the general health insurance (Zorgverzekeringswet, Zvw).⁵¹ But until then, we recommend the management to utilize financial resources for delivering after-care with a specific role for nurses.

In conclusion, directors should develop specific products that help patients to rehabilitate optimally. The complex situation of geriatric patients (especially because of comorbidity!) demands a specific rehabilitation climate in which treatment strategies to recover daily functioning, with specific awareness of inadequate coping and depression, have a central function. Directors have to design conditions in which multidisciplinary teams can offer optimal and evidence-based geriatric rehabilitation, for example through evidence-based pathways. Expertise should be intensified, acknowledging the transition in reimbursement of chronic- and elderly care. Intensification and differentiation of rehabilitation may in the end result in more optimal functioning and lower care-resource-use after rehabilitation. In that way rehabilitation could be cost-effective, and interesting for health insurances to purchase.

Implications for nurse-policy makers and nurse-researchers in geriatric rehabilitation

The past years, nursing care is more and more based on (recent) scientific insights, and although evidence based guidelines can help to improve quality of care, the implementation hereof is a challenge.^{34, 54} Stimulation programs such as the ZonMw program 'From Knowledge to Action' ('Tussen Weten en Doen') aim to empower the research infrastructure of nursing and aim to increase the quality of nursing care by providing subsidy for research initiatives of collaborating organizations.⁵⁶ Nurse-policy makers in SNFs often have an academic degree and know the necessity of research for nursing practice. They could stimulate participation in such initiatives and motivate directors of the organization they work for to invest in research activities and implementation of the results in geriatric rehabilitation, and to join up with other healthcare organizations in university networks.^{52, 53, 55} The Dutch population is ageing rapidly and nurse-policy makers need to influence the organizations policy and consequently their capital. Academic nurse-policymakers and nurse-researchers need to invest in national and global networks and spread the results of their work (projects and research) at (inter)national conferences for rehabilitation. Research on rehabilitation in SNFs is very scarce and therefore this thesis offers a good starting point for improving the quality of rehabilitation. It is achievable that when money for nursing-research and implementation of guidelines is generated, care for geriatric patients in general and geriatric rehabilitation in particular can be improved.

Suggestions for future research

Nursing research

Research into the role and 'role-perception' of nurses in rehabilitation is desirable. Furthermore, nurses need to develop intervention programs focusing on time use (therapeutic and non-therapeutic activities) of patients with stroke or amputation, and effects of these programs need to be tested, preferably in large randomized clinical trials. And lastly, more nursing research into psycho-social determinants of successful therapy and effectiveness of specific therapeutic interventions is necessary. For example, research into strategies for motivating and encouraging patients to comply with their therapeutic programs, and the nature of the role of informal caregivers during rehabilitation.

Neuropsychiatric symptoms and Quality of life

We have shown in this thesis that knowledge about the prevalence and course of NPS in individual patients is important. This knowledge is necessary for the planning of rehabilitation services such as the provision of adequate treatment and professional- and informal care. Therefore, we need to stimulate research into the causes and course of NPS, the effects of treatment, therapy intensity, motivation of the patient, role of informal caregivers on rehabilitation outcomes and the interrelationship of NPS with functional outcomes in geriatric patients with stroke and amputation to further substantiate these findings. Additionally, future research should focus on differences in NPS and QoL between rehabilitation patients who stay in the SNF and those who have been successfully discharged to an independent living situation after rehabilitation in the SNF. Also, more research is needed at the time after rehabilitation; Next to NPS and depressive complaints, other psychosocial factors, such as quality of the relationship between patient and caregiver, stroke specific phenomena, and prosthesis use after amputation may affect QoL.

Course of rehabilitation

More research is needed into the patterns of geriatric patient outcomes: there is a call for more insight into the course of rehabilitation of geriatric patients in poor and good condition upon admission. Research is needed in the causes of high improvement for patients in poor condition upon admission and what drives the decline in scores for patients in good condition upon admission. In addition, we have to study the possibilities for patients to rehabilitate in their home environment or in day-care to avoid admission to a SNF. Consequently, research is necessary into how rehabilitation services have to be designed to tailor rehabilitation to individual elderly patients. Randomized Controlled Trials, mixed methods designs or other qualitative designs such as participant observation, can offer the opportunity to collect information about the effects of various rehabilitation programs, or effectiveness of rehabilitation wards in SNFs. Results of such studies will give more insight in the complex situation of geriatric patients, especially those with stroke or amputation.

Concluding remarks

All healthcare workers, especially nurses, nurse-researchers and nurse-policy makers, should be encouraged to be the enhancers of a therapeutic climate and patient specific rehabilitation programs, to improve the quality of rehabilitation in SNFs. More therapeutic activities may help to decrease NPS and depressive complaints, which seem to be more prevalent over the course of rehabilitation, since NPS have an enormous impact on patient QoL and consequently on their informal caregivers. A structured, well defined therapeutic climate with multidisciplinary collaboration offers chances for better rehabilitation outcomes.

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Nederlandse samenvatting

Introductie

De focus van dit proefschrift ligt op de beschrijving van de karakteristieken en het beloop van functioneren van patiënten die opgenomen zijn voor geriatrische revalidatie na een beroerte of een beenamputatie op gespecialiseerde revalidatie afdelingen van verpleeghuizen. Hierbij is er speciale aandacht voor (het beloop) van neuropsychiatrische symptomen, hun effect op kwaliteit van leven en de belasting van mantelzorgers na ontslag van de revalidatieafdeling, en de rol die verzorgenden en verpleegkundigen hebben op de revalidatieafdeling in het verpleeghuis. In deze samenvatting wordt antwoord gegeven op de onderzoeksvragen. Verder zijn de belangrijkste implicaties voor de revalidatie samengevat.

De onderzoeksvragen in dit proefschrift zijn:

1. *Wat zijn relevante karakteristieken om groepen patiënten te onderscheiden op basis van hun opname scores op gespecialiseerde revalidatieafdelingen in verpleeghuizen en wat is het beloop van functioneren van deze groepen in relatie tot hun ontslagbestemming?*
2. *Hoeveel tijd besteden patiënten met een beroerte aan therapeutische activiteiten, niet-therapeutische activiteiten, interactie met anderen en wat is de locatie waar deze activiteiten plaatsvinden?*
3. *Wat zijn de prevalentie en het beloop van neuropsychiatrische symptomen bij geriatrische patiënten die na een beroerte opgenomen zijn op gespecialiseerde revalidatieafdelingen van verpleeghuizen?*
4. *Wat zijn de factoren die invloed hebben op de kwaliteit van leven van geriatrische patiënten met een beroerte die drie maanden na ontslag na revalidatie uit het verpleeghuis weer thuis wonen, en wat is de belasting van hun mantelzorger?*
5. *Wat zijn de factoren die invloed hebben op de kwaliteit van leven van patiënten die, met een historie van perifere-arteriële problematiek en gemiddeld een half jaar na beenamputatie, na revalidatie in het verpleeghuis weer zelfstandig wonen?*

Onderzoeksprotocollen GRAMPS

In hoofdstuk twee en drie zijn de onderzoeksprotocollen van de GRAMPS onderzoek beschreven. De GRAMPS studie was een longitudinale, observationele, multicenter studie waarin 15 verpleeghuizen in het zuidelijke deel van Nederland participeerden. Deze studie had tot doel 200 patiënten met een beroerte en 50 patiënten met een beenamputatie te includeren. De verpleeghuizen werden geselecteerd op basis van het beschikken over een gespecialiseerde revalidatie unit waarop multidisciplinaire zorg en behandeling geboden wordt. De data werden verzameld binnen twee weken na opname in het verpleeghuis. De patiëntkarakteristieken, ziektekarakteristieken, functionele status, cognitie, gedrag en informatie over de mantelzorger werden in kaart gebracht. De eerste nameting vond plaats bij ontslag van de revalidatieafdeling of één jaar na opname en was gericht op functionele status en gedrag. Succesvolle revalidatie was gedefinieerd als ontslag uit het verpleeghuis naar huis óf verzorgingshuis binnen een jaar na opname. De tweede nameting vond plaats drie maanden na ontslag bij patiënten die succesvol waren gerevalideerd. Deze meting richtte zich op functionele status, gedrag en kwaliteit van leven. Alle gebruikte instrumenten zijn als betrouwbaar en valide te beschouwen. Ze zijn eerder gebruikt in revalidatie onderzoek en worden aanbevolen in de richtlijnen van de Nederlandse hartstichting.

Samenvatting van de belangrijkste bevindingen

- 1. Bij patiënten in een ongunstige conditie bij opname is vaak de verwachting dat zij permanent opgenomen zullen worden in het verpleeghuis, maar dit is niet het geval bij 46% van deze patiënten.**

Het doel van de studie in hoofdstuk vier was het identificeren van patiëntengroepen, om specifieke revalidatieprogramma's te kunnen ontwikkelen voor revalidatieafdelingen in verpleeghuizen. In deze patiëntengroepen onderzochten we het beloop van balans, ADL, loopvermogen, armfunctie, depressieve klachten en neuropsychiatrische symptomen, in relatie tot de ontslagbestemming. Om deze groepen te identificeren voerden we een twee-staps cluster-analyse uit waarin de variabelen werden geïdentificeerd die op verschillen tussen groepen wijzen. Deze cluster-analyse resulteerde in twee groepen: in cluster 1 bevonden zich de patiënten in ongunstige conditie bij opname (n=52), en in cluster 2 bevonden zich de patiënten in redelijke tot goede conditie bij opname (n=75). De patiënten in beide groepen verbeterden in balans, loopvermogen en armfunctie. Patiënten in de groep met een ongunstige conditie vertoonden eveneens een groter herstel in ADL. In cluster 1 en cluster 2 be-

vonden zich een subgroep patiënten die wel en niet met ontslag gingen. Depressieve klachten namen significant af bij de sub-groep van patiënten in een ongunstige conditie die uiteindelijk wel ontslagen werd uit het verpleeghuis. De ontslagpercentages verschilden significant tussen de subgroepen: 80% van de patiënten in goede conditie en 46% van de patiënten in ongunstige conditie werden ontslagen uit het verpleeghuis. In beide clusters herstelden degenen die ontslagen werden beter op alle kenmerken dan degenen die permanent werden opgenomen in het verpleeghuis. Meer specifiek, de sub-groep van patiënten in ongunstige conditie die ontslagen werd, herstelde significant beter op alle variabelen in vergelijking met de andere subgroepen. Aangezien op revalidatieafdelingen meestal de verwachting is dat patiënten in ongunstige conditie bij opname permanent opgenomen zullen worden in het verpleeghuis, was het zeer opmerkelijk om te zien dat dit voor bijna de helft van die patiënten niet het geval was.

2. Patiënten op revalidatieafdelingen van verpleeghuizen zijn bijna de helft van de dag alleen en hebben slechts 10% van de dag interactie met de verzorgenden en verpleegkundigen.

In een aanvullende studie in hoofdstuk 5 was het doel de tijdsbesteding te beschrijven van patiënten met een beroerte op vijf revalidatieafdelingen, waarbij de aandacht uitging naar tijdsbesteding aan therapeutische activiteiten, niet-therapeutische activiteiten, interactie met anderen, en de locatie waar deze activiteiten plaatsvinden. De patiënten werden tussen 8.00 uur 's morgens en 16.30 uur 's middags volgens de methode "behavioral mapping" geobserveerd. Patiënten bleken overdag gemiddeld 41% van de tijd in hun kamer te verblijven (212 minuten) en 49% alleen te zijn (256 minuten). De patiënten besteedden overdag iets meer dan de helft van de tijd aan therapeutische activiteiten (292 minuten) en het resterende deel werd besteed aan niet-therapeutische activiteiten (226 minuten). De meeste therapeutische tijd werd gebruikt voor verpleegkundige zorg en fysiotherapie. Er was overdag slechts 10% van de tijd sprake van interactie (inclusief hulp bij ADL) met verzorgenden en verpleegkundigen (56 minuten). Opvallend was dat patiënten met een hogere functionele status meer tijd besteedden aan therapeutische activiteiten.

3. De prevalentie van neuropsychiatrische symptomen in de GRAMPS studie was lager dan in andere CVA-studies in verschillende settingen (zoals ziekenhuizen, revalidatiecentra en verpleeghuizen). De symptomen bleken tijdens revalidatie echter toe te nemen in een subgroep van patiënten die uiteindelijk permanent moest worden opgenomen in het verpleeghuis.

In hoofdstuk 6 was het doel te beschrijven wat de prevalentie en het beloop van neuropsychiatrische symptomen was bij geriatrische patiënten met een beroerte

die waren opgenomen op specifieke revalidatieafdelingen in verpleeghuizen. In deze studie werden neuropsychiatrische symptomen gemeten met de Neuropsychiatric Inventory-Nursing Home version (NPI-NH) bij 145 patiënten. De metingen vonden plaats bij opname en ontslag. Patiënten werden ingedeeld in patiënten die ontslagen werden uit het verpleeghuis en een groep die permanent werd opgenomen. Bij 80% van alle patiënten was het de eerste beroerte en 74% kon succesvol worden ontslagen. Voor de gehele groep waren de meest voorkomende symptomen depressieve klachten (33%), eetveranderingen (18%), nachtelijke onrust (19%), angst (15%), irritatie (12%) en ontremd gedrag (12%). Patiënten die permanent werden opgenomen in een verpleeghuis bleken gedurende de revalidatie significant meer hallucinaties, wanen, agitatie, depressieve klachten, irritatie en nachtelijke onrust te hebben in vergelijking met degenen die met ontslag konden.

4. De kwaliteit van leven van patiënten met een beroerte na revalidatie én de belasting van de mantelzorger is afhankelijk van aanwezigheid van neuropsychiatrische symptomen bij de patiënt.

In hoofdstuk 7 was het doel te beschrijven welke factoren de kwaliteit van leven beïnvloeden bij 84 patiënten met een beroerte drie maanden na ontslag van revalidatieafdeling in het verpleeghuis. Ook onderscheidden we de met de patiënt samenhangende factoren die invloed hadden op de belasting van hun mantelzorgers. De aandacht ging uit naar de eventuele samenhang tussen kenmerken van patiënt en mantelzorger, omdat deze samenhang mogelijk specifiek aanwezig is bij oudere patiënten met een beroerte. Kwaliteit van leven werd gemeten met de RAND-36 Health Survey (acht subschalen). De gemiddelde kwaliteit van leven scores varieerden tussen 48 and 85 (theoretische range 0-100). Hoge kwaliteit van leven hing vooral samen met hoge functionele onafhankelijkheid, minder neuropsychiatrische symptomen en minder depressieve klachten. De belasting van de mantelzorger was niet van invloed op de kwaliteit van leven van de patiënt, maar neuropsychiatrische symptomen van de patiënt waren wel van invloed op een hogere mantelzorgbelasting.

5. Een slechte loopfunctie en neuropsychiatrische symptomen beïnvloeden de kwaliteit van leven negatief bij oudere patiënten met een beenamputatie.

Het doel van de studie in hoofdstuk 8 was het beschrijven van de factoren die kwaliteit van leven beïnvloeden bij oudere patiënten, gemiddeld zes maanden na amputatie en drie maanden na ontslag van de revalidatieafdeling in het verpleeghuis. De kwaliteit van leven van 27 patiënten is gemeten met de RAND-36 Health Survey. De gemiddelde kwaliteit van leven scores varieerden tussen 22 en 87 (theoretische range 0-100). Een slechtere loopfunctie hing samen met een lagere kwaliteit van leven op het domein Fysiek Functioneren (met een lage gemiddelde score). Neuro-

psychiatrische symptomen en depressieve klachten waren negatief van invloed op een goede kwaliteit van leven op de domeinen Rol Beperkingen Emotioneel, Sociaal Functioneren, Mentale Gezondheid en Vitaliteit. Goede scores op Instrumentele Activiteiten van het Dagelijks Leven (IADL) hadden een positieve invloed op het domein Vitaliteit.

Interpretatie van de belangrijkste bevindingen

Patiënten van een revalidatieafdeling in een verpleeghuis krijgen een behandelprogramma op basis van hun profiel bij opname. Vaak wordt dan hoofdzakelijk het fysiek functioneren in beschouwing genomen, zoals balans en ADL. Dit proefschrift toont echter aan dat ook psychosociale factoren het revalidatie proces beïnvloeden. Patiënten die permanent moesten worden opgenomen in het verpleeghuis, bleken namelijk naast fysieke achteruitgang ook een toename te vertonen van neuropsychiatrische symptomen en depressieve klachten. Tijdens de revalidatie op de revalidatieafdeling in het verpleeghuis waren de patiënten overdag de helft van de tijd alleen (tussen 8.00 uur en 16.30 uur). Gedurende deze tijd hadden ze geen interactie met anderen en geen zinvolle therapeutische activiteiten die konden bijdragen aan een meer spoedige revalidatie. Te veel tijd alleen kan leiden tot gevoelens van eenzaamheid, en piekeren over de impact die een beroerte of amputatie heeft. Dit kan mogelijk bijdragen aan verlies van motivatie en een toename van neuropsychiatrische symptomen en depressieve klachten. Verder kunnen neuropsychiatrische symptomen en depressieve klachten na de revalidatie leiden tot een verminderde kwaliteit van leven, met de mogelijke consequentie van een hogere mantelzorgbelasting. De preventie en behandeling van neuropsychiatrische symptomen en depressieve klachten in een vroeg stadium van de revalidatie resulteert mogelijk in een betere revalidatie-uitkomst en als resultaat daarvan een betere kwaliteit van leven voor patiënten en hun mantelzorgers.

Implicaties voor de revalidatie

Verzorgenden en verpleegkundigen

Ondanks dat verzorgenden en verpleegkundigen het verlangen uitspreken om therapie meer te integreren in hun dagelijkse werk, is het bereiken van dat doel een ware uitdaging. Deze professionals dienen dus in hun diverse rollen aangemoedigd en 'empowered' worden door het managementteam en het multidisciplinaire team van het verpleeghuis. Verzorgenden en verpleegkundigen kunnen de kar-trekkers

zijn van een therapeutisch klimaat op de afdeling. Wanneer zij dagelijks oefenen met patiënten, dragen zij significant bij aan het (functioneel) herstel van de patiënt. Het therapeutisch klimaat karakteriseert zich door gestructureerde evidence based revalidatieprogramma's die op maat gesneden zijn voor de patiënt, gebruik maken van richtlijnen, expliciet geformuleerde doelen, handen-op-de-rug-verpleging, een motiverend klimaat en interactie met andere patiënten. Al deze activiteiten hebben een constante focus op ontslag van de patiënt naar huis. Verzorgenden en verpleegkundigen kunnen vaker korte oefeningen doen met de patiënten, bijvoorbeeld reiken naar dingen op tafel en een stukje lopen. De kar trekken voor de realisatie van een therapeutisch klimaat is bij uitstek een rol voor verzorgenden en verpleegkundigen omdat zij 24 uur per dag aanwezig zijn op de revalidatieafdeling! Het is belangrijk dat verzorgenden en verpleegkundigen de patiënt goed te observeren en adequaat te reageren bij een vermoeden op neuropsychiatrische symptomen en depressieve klachten. Neuropsychiatrische symptomen en depressieve klachten kunnen het revalidatieproces behoorlijk negatief beïnvloeden. De door verzorgenden en verpleegkundigen verzamelde informatie, bij voorkeur verzameld met specifiek voor dat doel ontwikkelde instrumenten, moet besproken worden in het multidisciplinaire team. Vervolgens kan onmiddellijk actie worden ondernomen om deze klachten te behandelen. Omdat de mantelzorgbelasting toeneemt bij neuropsychiatrische symptomen en depressieve klachten, is het zinvol dat verzorgenden en verpleegkundigen de mantelzorgers betrekken bij de revalidatie. Zij kunnen dan handvatten bieden om zich hun mogelijk nieuwe rol als mantelzorger eigen te maken. Ook kan de verzorgende/verpleegkundige vanuit het verpleeghuis nazorg bieden op psychosociaal gebied.

Behandelaren

Voorspellende modellen voorspellen de uitkomsten van revalidatie voor de gemiddelde patiënt. Deze zijn echter niet per se valide voor elke individuele patiënt. Het kan daarom moeilijk zijn voor behandelaren om ontslag naar huis te voorspellen, omdat zoveel verschillende factoren een succesvolle revalidatie beïnvloeden. Wanneer dan alleen functionele status in ogenschouw wordt genomen, bestaat het risico dat ze patiënten in een ongunstige conditie te weinig aandacht geven terwijl zij, zoals blijkt uit dit proefschrift, vaak voldoende potentieel hebben om met ontslag naar huis te kunnen. Daarom zou revalidatie een combinatie moeten zijn van specifieke zorgprogramma's en individueel op maat gesneden activiteiten. Patiënten in een ongunstige conditie bij opname zijn gebaat bij een hogere therapie intensiteit, met een opbouw gedurende een langere tijd. Zij moeten die tijd echter wel kunnen krijgen van behandelaren en niet prematuur worden overgeplaatst naar een afdeling voor langdurige zorg waar veel minder een essentieel therapeutisch revalidatie klimaat heerst.

Bestuurders en managers

Dit proefschrift toont aan dat patiënten op een revalidatie afdeling vaak alleen zijn en soms weinig therapeutische activiteiten ondernemen en krijgen aangeboden. Dat kan als ineffectief worden beschouwd. Hier liggen kansen voor het verbeteren van de kwaliteit en intensiteit van revalidatie, bijvoorbeeld door een combinatie van individuele- en groepstherapieën, door toepassing van technologische ontwikkelingen en door nieuwe manieren om het werk slimmer te organiseren. De inzet van verpleegkundigen en verzorgenden als behandelaar in de revalidatie is daar ook een voorbeeld van. Verder kan de inzet van gespecialiseerde ambulante revalidatie teams mogelijk de opnameduur verkorten of voorkomen dat mensen voor revalidatie opgenomen moeten worden in het verpleeghuis. Dit kan stijgende kosten in de zorg helpen voorkomen. Het is aan bestuurders en managers om de omstandigheden te creëren waarin het multidisciplinaire team een optimale evidence based geriatrische revalidatie kan bieden, met aandacht voor de complexe fysieke en psychosociale toestand van de oudere revalidant.

Verpleegkundige beleidsmakers en- onderzoekers

Verpleegkundige beleidsmakers en- onderzoekers kunnen organisaties stimuleren om gebruik te maken van evidence based richtlijnen. Het is belangrijk om innovaties te implementeren, onderzoeksactiviteiten te ontplooiën en om bestuurders te motiveren om deel te nemen aan universitaire kennisnetwerken. Deze beleidsmakers en onderzoekers kunnen (inter)nationaal een podium zoeken om hun projecten- en onderzoeksresultaten te presenteren. Daarnaast is meer onderzoek nodig naar geriatrische revalidatie. Bijvoorbeeld door het ontwikkelen van interventieprogramma's en deze uit te testen in randomized clinical trials. Verder is er meer onderzoek nodig naar de invloed van psychosociale factoren op succesvolle revalidatie. Tevens is verder onderzoek nodig naar de rol van mantelzorgers tijdens en na de revalidatie. En als laatste is het essentieel om onderzoek te doen naar de organisatie van revalidatie binnen verpleeghuizen om een betere kwaliteit van revalidatie aan de individuele geriatrische patiënt te kunnen bieden.



Dankwoord

Uiteindelijk valt alles op zijn plaats. Soms gaan daar vele jaren overheen. En laat het leven zijn sporen na. Ik heb het gevoel dat ik de afgelopen 12 jaar in dubbel tempo heb geleefd, de schade heb ingehaald. Mijn grootste hoogtepunten zitten in die afgelopen 12 jaar. Al hebben ook alle beleefde gebeurtenissen voor die tijd mij gevormd tot wie ik ben. De hoogtepunten doen de dieptepunten verbleken. Op het omslag vind je een schilderij dat mijn nichtje Iris heeft gemaakt. Het laat wat van mijzelf zien: onafhankelijk, trots, doorzetter, vechtlustig, vrouwelijk, liefdevol, loyaal, contemplatief. Er zijn wellicht nog meer eigenschappen in te zien, maar die mogen jullie zelf invullen. Ik ben tevreden met wie ik ben.

Veel van deze eigenschappen zijn ook nodig om een promotieonderzoek af te kunnen ronden. Door de jaren heen heb ik verschillende metaforen gehoord: het is net als een kind krijgen, een lang en pijnlijk proces (zo waar). Het is een levenswerk (ja, in ieder geval iets dat een aantal jaren van je leven beheerst). Het is het beklimmen van de Alpe d'Huez of het lopen van een marathon (veel trainen voor het uiteindelijke resultaat). Bij deze metaforen blijf je na de gebeurtenis uitgeput achter. Ik hoop dat ik nieuwe energie van het promoveren krijg.

Hernieuwde energie om verder te werken aan empowering van de sector Verzorging & Verpleging (V&V), de mensen die er werken en degenen die er noodgedwongen verblijven. Deze mensen zijn de eersten die ik ga bedanken: de patiënten die toestemden om mee te doen met het onderzoek. Zonder jullie zou er geen onderzoek naar geriatrische revalidatie zijn. Revalideren vraagt moed, kracht, motivatie en wilskracht. Veel dank ben ik verschuldigd aan de multidisciplinaire teams van de 15 verpleeghuizen die hebben geparticipeerd in het GRAMPS onderzoek: De Zorgboog (St. Josefsheil), SVRZ zorgt in Zeeland ('t Gasthuis & Ter Valcke), Pantein (Madeleine), De Zorggroep (Martinushof), Vitalis (Brunswijck & Peppelrode), Vivent (Mariaoord), ZZG Zorggroep (Margriet), Archipel (Dommelhof), Careyn (De Plantage), Curamus (De Blaauwe Hoeve), De Riethorst Stroomland (De Riethorst), De Wever (Jozefszorg & De Hazelaar). Wat hebben wij jullie een hoop werk gegeven! Wat hebben jullie veel data moeten verzamelen voor ons. Vooral verzorgenden en verpleegkundigen van de revalidatieafdelingen zijn met taken belast die zij van nature niet gewend zijn om te doen. Jullie zijn allemaal kanjers!

Een bijzondere plek in dit dankwoord neemt het begeleidingsteam van GRAMPS in. Op de eerste plaats promotor Raymond Koopmans. Je moest in dit promotieonderzoek een specialist ouderengeneeskunde inruilen voor een verpleegkundige.

Onze belangen zijn echter niet tegenstrijdig: empoweren van de V&V sector in het algemeen, en specialisten ouderengeneeskunde en verpleegkundigen in het bijzonder. Promotieonderzoeken van verpleegkundigen en specialisten ouderengeneeskunde dragen in mijn opinie bij aan empowerment. In het GRAMPS onderzoek dus dubbel succes! Wat ik heel fijn vond, was je punctualiteit. Altijd precies op tijd voor je afspraken. Bedankt voor je aanmoediging en je vertrouwen. Copromotor Sytse Zuidema, het was boeiend en plezierig om steeds weer de discussie met je aan te gaan over methodologische en statistische vraagstukken. Ik heb veel van je geleerd! Ik wens jou heel veel succes in je toekomstige loopbaan als hoogleraar. Co-promotor Debby Gerritsen, op mijn verzoek in een later stadium toegevoegd aan het begeleidings-team. En ik ben heel erg blij met jou! Door jouw aanvullingen werden mijn artikelen rijper, volwassener, meer doordacht. Ik vond het erg fijn om met jou te werken. San-der Geurts, je moet weten dat ik graag naar je luister. Je beschouwingen over revalidatie zijn verhelderend en laten voor mij steeds weer stukjes op zijn plaats vallen. Harmen van der Linde, bedankt voor je humor en relativiseringsvermogen. Hans Bor, ik heb de nodige uren met jou aan de computer gezeten voor het vinden van de beste analyses om mijn onderzoeksvragen te beantwoorden. Je was altijd bereid met me mee te denken.

Ook hier een plekje voor de man die het initiatief heeft genomen om het GRAMPS onderzoek te starten: Frans Voncken. Je hebt een belangrijke rol gespeeld in mijn promotieonderzoek. Ik nam het stokje van jou over toen het voor jou niet langer mogelijk bleek om het onderzoek voort te zetten. Ik hoop dat je de beide promoties in het GRAMPS onderzoek ook als jouw succes kan zien. Ik beschouw dat in ieder geval zo. Ik bedank ook voormalig bestuurder van de Zorgboog Hans van den Bosch. Jouw keuzen voor voortzetting van het GRAMPS onderzoek waren beperkt. Je moest een specialist ouderengeneeskunde inruilen voor een verpleegkundige. Maar...mis-sie volbracht! Stichting De Zorgboog kende daarna een woelige periode waarin de nodige mensen de organisatie bestuurden. Ton Borghs bleef. Bedankt dat ik op koers kon blijven en mijn promotieonderzoek verder af kon ronden.

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sistente aan de slag te gaan. Al heel snel bleek dat ik als volwaardig onderzoeker aan de slag moest. Ik vond dat spannend. Met niet heel veel onderzoekservaring was ik bezorgd dat het mis kon gaan tijdens jouw verlof. Maar je werkte mij in een paar weken goed in en onze samenwerking verliep plezierig. We zaten op hetzelfde level en vulden elkaar prima aan. Jouw kinderwens ging net als mijn kinderwens in vervulling tijdens het promotieonderzoek. Dát hadden we niet vastgelegd bij ons arbeidsvoorwaardengesprek.... We weten nog niet wat de toekomst brengt, maar ik hoop dat we in de toekomst samen verder onderzoek kunnen doen in de geriatrische revalidatie. Mijn andere paranimf is Mirelle Magni. Ik leerde jou ken tijdens de studietijd in Utrecht. Ik ben er trots op dat ik jouw vriendin mag zijn. New York bestendigde onze vriendschap (het had ook anders kunnen lopen...: “sssh, Bianca, het is 5.00 uur in de ochtend. Het is nog geen tijd om te praten...”). Ik heb vreugde en verdriet met je gedeeld. Je bent een warm mens. Je hebt dezelfde dromen als ik. En ik wens vurig dat ze voor jou ook in vervulling mogen gaan en dat ik er deel van uit mag maken.

In de loop der jaren hebben heel wat mensen mijn werk-pad gekruist. Zij verdienen een plekje in mijn dankwoord omdat ze mij gesteund hebben, of mij geholpen hebben met de belangrijke keuzen in mijn leven. Chantal Vermeulen, ik werkte mee aan jouw eerste artikel “Time use of stroke patients”. Dit artikel verdient een plaatsje in mijn proefschrift. We hebben gezellige momenten beleefd en ik hoop vaker met je te kunnen samenwerken in de toekomst. Collega’s van afdeling Albatros en Dubbelzorg, bedankt voor jullie steun tijdens mijn kruistochten. Misschien heb ik het nooit zo benoemd, maar jullie steun heeft ontzettend veel voor mij betekend. Ik zal dat nooit vergeten. Anneke, Joyce en Corina ik hoop dat er nog veel etentjes mogen volgen. André Merks, jouw naam is een plaatsje waard in mijn dankwoord. Je hebt een belangrijke rol gespeeld bij mijn keuzen in de afgelopen 12 jaar. Op de een of andere manier blijf ik jou tegenkomen. Je hebt me gemotiveerd om te groeien. Collega’s van Atlant Zorggroep, fijn dat ik mijn kennis en ervaringen met jullie heb kunnen delen. Veel voorspoed gewenst met onderzoek in het algemeen en Topcare in het bijzonder. Unieke zorg voor unieke mensen. Nelleke Vogel, Topcare is een uniek initiatief! Ineke, Monique en Sascha, succes gewenst met jullie promotieonderzoek. Medebestuurleden van Rho Chi Chapter at Large: Thóra, Roelof, Marlou, Pieter, Ada en Saskia, Irina. Marie-Louise in het bijzonder, bedankt voor het taalkundig bewerken van mijn laatste artikel dat nodig was om te kunnen promoveren. Het is mooi om binnen Rho Chi goede dingen te doen voor de verpleegkunde en verpleegkundig onderzoek. Jullie weten als geen ander wat het is om promotieonderzoek te doen. Een aantal van jullie zullen kort na mij volgen, dus ook heel veel succes gewenst! Docenten van de diverse opleidingen; bedankt voor alles wat jullie mij hebben bijgebracht. Medestudenten Eline, Eric en Margreet, ik vond het fijn om met jullie te studeren en projecten te doen. UKON medewerkers Els, Anke en Betsie, het was erg leuk om met jullie te

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Mauro, mijn hart, mijn alles. Ik vertel je dagelijks hoeveel ik van je hou. Jij bent het meest bijzondere wat me is overkomen:

*Ik wens je in het leven liefde en geluk,
zodat het je goed gaat,
beproevingen om sterk te worden,
tranen om menselijk te blijven,
en de hoop je dromen te vervullen.*

Bianca

*moeder, vrouw, echtgenote, dochter, kleindochter, schoondochter, vriendin,
collega en... workaholic.*

Terneuzen, mei 2013.



Curriculum Vitae

Bianca Ivonne Buijck zag op 8 mei 1970 het levenslicht in het ziekenhuis van Oostburg, Zeeuws-Vlaanderen. Als vroeger gevraagd werd wat ze later wilde worden, dan zei ze steevast “zuster”. Ze groeide op in een stabiele en liefdevolle omgeving, omringd door familie, vrienden en dieren. Paarden en honden speelden een belangrijke rol in haar leven. Leren ging haar gemakkelijk af, maar in het eerste jaar op een grote scholengemeenschap voor MAVO/HAVO/VWO kon ze haar plekje niet vinden. Bianca startte in het 2^e jaar van het Lager Huishoud- en Nijverheidsonderwijs (LHNO) kortweg de huishoudschool.....Ze had daar een prima tijd! Omdat ze altijd erg creatief bezig was, ging ze daarna de opleiding MDGO activiteitenbegeleiding volgen. Uiteindelijk startte ze met de inservice-opleiding ziekenverzorging: werken en leren.

Ze begon haar loopbaan in 1988 bij Stichting Voor Regionale Zorgverlening (SVRZ) als leerling verzorgende in verpleeghuis Ter Schorre. Vanaf het begin voelde de zich op haar plek in het verpleeghuis. Hoewel in haar privéleven haar vleugels gebonden waren, participeerde zij door de jaren heen in verschillende commissies en projecten, in verschillende rollen. Daarmee diende ze het belang van de organisatie waar ze werkte, maar dat betekende ook een rijke aanvulling op persoonlijk vlak. Dit was echter niet genoeg om de honger naar kennis en uitdaging te stillen. Ze ontworstelde zich aan haar moeilijke privéleven, maakte een nieuwe start en studeerde in 2003 af als HBO verpleegkundige met een onderzoek naar “klanttevredenheid op de afdeling infectieziekten” van de GGD. Ze startte vervolgens met de studie gezondheidswetenschap in Utrecht (afstudeerrichting verplegingswetenschap). Tijdens deze studie ontdekte ze dat ze met het doen van onderzoek en het schrijven van artikelen haar creativiteit kwijt kon. Het afstudeeronderzoek “de relatie tussen teamleren en implementatie-effect van het Neuman Systems Model” was daarvan een voorbeeld. Het bleek een uitdaging om een bijdrage te leveren aan de wetenschappelijke theorievorming en praktijk.

In het afstudeerjaar 2008 verving Bianca in het GRAMPS onderzoek haar SVRZ collega Monica tijdens haar zwangerschapsverlof. Door omstandigheden moest Frans, de onderzoeker van Stichting de Zorgboog, kort daarop afscheid nemen van het GRAMPS onderzoek. Bianca kreeg van de Zorgboog de kans om te blijven en het onderzoek voort te zetten. Zij onderzocht in haar promotieonderzoek de multidimensionale aspecten van de geriatrische revalidatie. In het laatste jaar van de studie gezondheidswetenschap ging ze ook aan de slag als organisatiebrede kwaliteits- en beleidsmedewerker bij SVRZ. Daarnaast werd ze auditor van Perspekt keurmerk.

Verder trad ze toe tot de externe klachtencommissie van Emergis (Geestelijke Gezondheidszorg) en tot het bestuur van Rho Chi Chapter at Large (Honor Society of Nursing Sigma Theta Tau International), een vereniging van hoog (wetenschappelijk) opgeleide verpleegkundigen. Deze activiteiten dragen bij aan het empoweren van de Verzorging- & Verpleeghuissector in het algemeen en verpleegkundigen in het bijzonder. De patiënt centraal en doelen op steeds betere zorgverlening zijn altijd haar uitgangspunten. Handelen volgens de laatste wetenschappelijke inzichten (evidence based), aangevuld met inzichten vanuit de praktijk (practice based) en wensen van de patiënt (patient based).

Begin 2012 veranderde ze van functie bij SVRZ en maakte ze bij Atlant Zorggroep kennis met twee nieuwe specifieke doelgroepen: patiënten met het syndroom van Korsakov en patiënten met de ziekte van Huntington. Haar huidige opdracht is om als wetenschappelijk onderzoeker samen met multidisciplinaire professionals een wetenschappelijk klimaat te creëren binnen de verpleeghuissector.

