Summary

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, their effect on quality of life 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 on admission are more likely to be referred to a facility for long-term care, but this is not the case for 46% of these patients.**

The aim of Chapter 4 was to identify meaningful patient groups for developing specific rehabilitation programs in skilled nursing facilities (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 ADL. Patients in the poor group also improved in armfunction. 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 almost 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 skilled nursing facilities (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 neuropsychiatric symptoms (NPS) in geriatric patients admitted to skilled nursing facilities (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 Quality of Life (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 skilled nursing facilities (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 neuropsychiatric symptoms and less depressive complaints. Informal caregiver burden was not associated with patient QoL but with patient neuropsychiatric symptoms.

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 indentify determinants of Quality of life (QoL) of home dwelling geriatric patients with amputation, on average within six months after amputation and three months after rehabilitation in an skilled nursing facilitie (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 neuropsychiatric symptoms. 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 neuropsychiatric symptoms and depressive complaints. Moreover, also after rehabilitation, quality of life of patients is affected by neuropsychiatric symptoms and depressive complaints, which may consequently put a great burden on informal caregivers. Prevention and treatment of depressive complaints and neuropsychiatric symptoms in an early stage of rehabilitation may result in a more positive rehabilitation outcome and consequently a better quality of life for patients and informal caregivers.