The impact of emotional and cognitive changes after stroke

a longitudinal community-based study

Annemarie C. Visser - Keizer
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The impact of emotional and cognitive changes after stroke
a longitudinal community-based study

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Stroke epidemiology

Stroke is a clinical diagnosis defined as a focal neurological impairment of sudden onset and lasting more than 24 hours (or leading to death) and of presumed vascular origin (Hatano, 1976). Most strokes are ischemic in nature and according to population-based studies constitute 67 to 80 percent of all strokes (Feigin et al., 2003). In the Netherlands, annually approximately 30,000 people are afflicted by a stroke. It is estimated that 120,000 to 140,000 people in the Netherlands have suffered one or more strokes (Van Oers, 2002). The incidence rate of stroke increases with age, with rates between 1.7 in 1000 for men aged 55 to 59 years and 69.8 in 1000 for men aged 95 years and over. Corresponding figures for women in a recent Dutch population-based study were 1.2 and 33.1 in 1000 respectively. Although the incidence rate of stroke is higher in men than women, the lifetime risk was found to be similar for both sexes (Hollander et al., 2003). Due to ageing of the population, it is estimated that the incidence of stroke will increase with 30% in 2015 (RIVM, 1997). Mortality rates after stroke have dropped in recent decades, but appear to have levelled off in the Netherlands since the end of the 1980’s (Reitsma et al., 1998). Twenty to 30 percent mortality rates are found within the first months after stroke, of which 12 to 16 percent involve ischemic strokes (Feigin et al., 2003, Hollander et al., 2003). In 1999, stroke was the third leading cause of death in the Netherlands and was responsible for 2.9% of the total health care costs (CBS, 2001).

Stroke care

Since the introduction of thrombolytic therapy in the Netherlands, the treatment of acute stroke is slowly changing from ‘wait and see’ to crisis management with referral
to a hospital stroke unit within 3 hours. Recent Dutch population-based studies performed before the widespread availability of thrombolytic therapy showed that approximately 55 to 60 percent of patients was hospitalised after stroke, with the proportion decreasing with age (Looman et al., 1996, Bots et al., 1996, Hollander et al., 2003). Stroke patients admitted to a hospital might constitute a special group of patients. First of all, they survived the time until hospitalisation and must have been referred to a hospital by their General Practitioner. If stroke patients directly check into the emergency department of a hospital without prior consultation of a physician, they must have been able to identify the signs of a stroke. A recent study showed that delayed hospital admission was related to the inability of patients to recognise the symptoms of stroke (Meijer et al., 2004). In 2001, the mean duration of hospitalisation after stroke in the Netherlands was 21 days, although regional differences were present (Kloek & Bots, 2003, Huijsman et al., 2001). After hospitalisation, of all stroke survivors, 40 to 60 percent is discharged home, 20 to 30 percent is transferred to a nursing home and only 10 to 15 percent is transferred to a rehabilitation centre (van Exel et al., 2003, Faber et al., 2002). Combining the percentages of patients who are not admitted to a hospital with those who are directly sent home after hospital admission shows that roughly three quarters of all patients will be at home several weeks after stroke. These groups of non-fatal non-hospitalised strokes and non-fatal hospitalised strokes without further institutional care will generally incorporate the physically less severe strokes.

**Emotion and cognition following stroke**

When patients continue their daily life after stroke, they may experience a variety of dysfunctions. Although in past research most attention has been directed at the physical consequences of stroke, one becomes increasingly aware that a range of emotional and cognitive changes can occur in the acute and chronic phases after stroke (Bogousslavsky, 2003, Hochstenbach, 1999, Ghika-Smid et al., 1999, Stolker, 1999). It is assumed that the emotional consequences of stroke are the result of a complex interaction between premorbid personality, damage to the brain and the emotional reaction of the patient to the consequences of stroke (Visser, 2002). In recent studies, the impact of the emotional and cognitive sequelae on the long-term adaptation to stroke has been stressed (Pohjasvaara et al., 2002, Gauggel, Peleska & Bode, 2000, Tatemichi et al., 1994). Furthermore, emotional disturbances and cognitive disabilities after stroke have
been described as causing most strain on the patient’s social system (van den Heuvel et al., 2001, Anderson, Linto & Stewart-Wynne, 1995).

So far, most studies on the consequences after stroke have been conducted in samples derived from hospitals and rehabilitation centres. As outlined above, these cohorts represent only a small and selected proportion of the total stroke group, which is biased towards the physically more disabled patients. Although some data have been gathered on cognitive disabilities and depression in community-dwelling stroke patients, little is known about the impact of changes in emotion and cognition on stroke patients living in the community.

**Aim and outline of this thesis**

The aim of this thesis is to discuss the impact of emotional and cognitive changes after stroke on the lives of stroke patients and their partners. The emotional and cognitive consequences of stroke are investigated at three and fifteen months post-stroke in a community-based sample of first-ever, ischemic stroke patients. The extent and course of the emotional and cognitive sequelae of stroke are surveyed. In addition, the relationships between the emotional and cognitive consequences of stroke and several aspects relevant to the quality of life and well-being of stroke patients and partners are investigated.

Most patients in the present study were enrolled into the study by General Practitioners (GPs) from the northern part of the Netherlands. As samples derived from institutions may be biased towards the more disabled patients, it may well be that the group of patients included by their GP in the present study is biased towards the least disabled patients. This question of representativeness of the health status of the study sample is addressed in chapter 1. In this chapter the stroke-related comorbidity of the study sample is compared to comorbidity of a large stroke sample derived from the Morbidity Registration Network Groningen (RNG).

In chapter 2, the changes in emotion and cognition as experienced by patients and partners at three months after the stroke event are described. When these changes are investigated, one can only rely on reports of the patient and on accounts of those
who knew the patient before and observed the patient after the stroke. This poses the question whether patients and partners can accurately report on the changes that have occurred. This issue is investigated with an emphasis on the factors that influence differences between the accounts of patients and partners.

In addition, chapter 3 describes the course of the patient’s awareness of changes in emotion and cognition after stroke. The factors that appeared to influence disagreement between patients and partners at three months post-stroke are now longitudinally related to the awareness of the patient. These factors include the level of unilateral neglect and the amount of distress of the patient and partner.

In chapter 4, the course of anxious and depressive mood after stroke is analysed. A comparison is made with mood of elderly controls. An attempt is made to distinguish mood affected by stroke from mood affected by other factors that play a role in the lives of elderly patients. Furthermore, the influence of neurological variables, demographic factors, disabilities and life events on mood at fifteen months post-stroke is examined.

In chapter 5, the relationship between depressive mood and cognitive disturbances after stroke is investigated. Patients with and without depressive mood, as assessed with a self-rated and observer-rated scale, are compared across time on speed of information processing, memory functioning, reasoning abilities and subjectively rated cognitive change.

Chapter 6 focuses on an important, but neglected issue after stroke. In this chapter, the course of fatigue after stroke is investigated. The longitudinal influence of comorbid disorders, mood and post-stroke disabilities on fatigue is analysed, with an emphasis on the relationship with attentional disorders.

Chapter 7 addresses the impact of disabilities and changes in emotion and cognition in the patient on the well-being of the partner. Well-being of the partner is analysed within the framework of the Social Production Functions (SPF) theory.

In chapter 8, this same theory is used to discuss the impact of cognitive disabilities and activity restriction on the subjective well-being of stroke patients at fifteen months post-stroke.
Finally, the last chapter summarises the main findings and discusses the limitations of the present study and the implications for future research and clinical practice.
References


Huijsman, R. et al. (2001). *Beroerte, beroering en borging in de keten*. ZonMW.


Abstract
Stroke-related comorbidity in the study sample was compared to comorbidity in a large dataset of stroke patients collected through the Morbidity Registration Network Groningen (RNG). Most stroke patients in the study sample were collected by GPs, while a small part was recruited at a hospital stroke unit. Aim of this comparison was to gain insight into the possibility of an inclusion bias of patients recruited by GPs towards those with a better health status and a lower risk profile. The results showed that stroke-related comorbidity in the study sample was very similar to comorbidity in the RNG sample. However, within the study sample, risk profiles and stroke characteristics differed between patients recruited by GPs and those collected at the hospital. Some comorbid disorders appeared to be more prevalent in the control study sample than in the RNG controls, which was attributed to inclusion of subjects in the study sample residing in a region characterised by multiple risk factors for cardiovascular disease. It was concluded that comorbidity of the stroke patients in the study sample was representative for comorbidity of community-dwelling stroke subjects living in the same region. Furthermore, the present study stressed the need to include community-based samples in stroke research as hospital-based samples might differ in stroke type and risk profiles.
Chapter 1

Introduction

The present study on the impact of emotional and cognitive changes after stroke was conducted in a community-based stroke sample. Previous studies on the outcome after stroke have most often used samples recruited by hospitals or rehabilitation centres, which can be biased towards patients with a higher risk profile (Schulz & Rothwell, 2003). Furthermore, samples derived from hospitals or rehabilitation centres only represent a small proportion of patients suffering from a stroke. In the Netherlands, approximately 60 percent of patients are hospitalised after stroke, with the proportion decreasing with age (Hollander et al., 2003). A recent Dutch study showed that 6 months after stroke, fifty percent of patients had returned home after hospitalisation, while only 9 percent had been referred to a rehabilitation centre (van Exel, et al., 2003). In the present study, most patients were collected through the aid of General Practitioners (GPs). During the study, the question arose whether the inclusion of stroke patients in the study sample might have been biased towards the less disabled patients and patients with a lower risk profile. As data collection was dependent on GPs, a selection bias could have occurred, when GPs protected severely disabled patients or patients with greater comorbidity from participation in the possibly straining measurement procedures. To be able to gain more insight into the health status of stroke patients in the study sample, the presence of comorbid disorders is compared to comorbidity in a large dataset of stroke patients.

Comorbidity refers to one or more other diseases among patients with an index-disease, such as cerebrovascular disease. A study in a rural municipality in the northern region of the Netherlands showed 84 percent of stroke patients suffering from more than one other chronic disease (Buis, 1998). Comorbid diseases can be distinguished into diseases that constitute a risk factor and diseases unrelated to the index-disease. Only stroke-related comorbidity will be investigated in the present chapter. Comorbid diseases that have been found to increase the risk of stroke include cardiovascular disease, peripheral vascular disease, hypertension, diabetes and migraine (Rodgers et al., 2004, Welch, 2003, Grau et al., 2001, Buis, 1998).

In sum, the aim of the present study is to examine whether stroke-related comorbidity in the present study sample is representative for comorbidity in a large dataset of stroke patients living in the same region in the Netherlands. This dataset is derived from the
Morbidity Registration Network Groningen (RNG). The RNG was founded in 1989 by the Department of General Practice of the University of Groningen. The objective of the RNG is to provide access to data from general practice on morbidity, medication, and referrals to be used for educational, research and planning purposes. Since 1992, 17 GPs have been collecting data on 30,000 patients. Morbidity is recorded in an episode-oriented way and classified in accordance with the International Classification of Primary Care (ICPC); medication and referrals are indication-related.

This chapter first describes the procedures used to include patients and controls in the study sample. Furthermore, the stroke characteristics of patients in the study sample are presented and, within the study sample, comorbidity is compared between patients and controls. Second, the construction of the RNG dataset is described. Within the RNG dataset, differences between comorbidity of patients and controls are also analysed. Finally, comorbidity of patients and controls in the study sample is compared to comorbidity of subjects in the RNG dataset.

Methods

Study sample

Inclusion of stroke patients
Of all General Practitioners (GPs) from the three northern provinces of the Netherlands who were asked to participate in the present study, 300 were willing to report stroke patients. Stroke was defined as an acute focal neurological deficit, with symptoms lasting more than 24 hours, as shown by CT scan or of presumed vascular nature after appropriate clinical and neuroradiological diagnosis (WHO, 1989). Patients were included if they had suffered a clinically first-ever ischemic stroke. Furthermore, the infarction should be restricted to one hemisphere. Preceding the stroke, patients should not have been diagnosed or treated for neurological diseases, psychiatric disturbances or substance abuse. Stroke patients had to be reported before the first time of measurement at three months post-stroke. During a period of 2 years, GPs could put patients forward. Furthermore, during a period of 1 year, patients were collected at the Stroke Unit (SU) of the University Hospital Groningen. A total of 235 stroke patients were recruited, 194 patients by 137 GPs and 41 patients through the aid of the SU. After recruitment, stroke
patients were sent detailed information about the study and were asked to give permission to their GP to provide medical information. All GPs filled in a questionnaire concerning the exclusion criteria. Of the 235 patients, 46 did not meet the inclusion criteria (see Table 1 for details).

Table 1. Number of stroke patients included at different times of measurements for interview and neuropsychological assessment (NPA).

<table>
<thead>
<tr>
<th>Admitted by GP, Stroke Unit</th>
<th>235</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exclusion criteria</td>
<td></td>
</tr>
<tr>
<td>- no clinically first, ischemic stroke &lt; 3 months</td>
<td>33</td>
</tr>
<tr>
<td>- history of psychiatric or neurologic disturbance or substance abuse</td>
<td>13</td>
</tr>
<tr>
<td>Meet inclusion criteria</td>
<td>189</td>
</tr>
<tr>
<td>Not able to be interviewed T1</td>
<td>26</td>
</tr>
<tr>
<td>Could not be reached or did not want to be interviewed T1</td>
<td>36</td>
</tr>
<tr>
<td>Died before interview T1</td>
<td>5</td>
</tr>
<tr>
<td>Interview T1</td>
<td>122</td>
</tr>
<tr>
<td>Not able for NPA T1</td>
<td>11</td>
</tr>
<tr>
<td>Could not be reached or did not want NPA T1</td>
<td>7</td>
</tr>
<tr>
<td>Died before NPA T1</td>
<td>4</td>
</tr>
<tr>
<td>Neuropsychological assessment (NPA)T1</td>
<td>100</td>
</tr>
<tr>
<td>Not able to be interviewed T2</td>
<td>6</td>
</tr>
<tr>
<td>Could not be reached or did not want to be interviewed T2</td>
<td>9</td>
</tr>
<tr>
<td>Died before interview T2</td>
<td>6</td>
</tr>
<tr>
<td>Interview T2</td>
<td>101</td>
</tr>
<tr>
<td>Not able for NPA T2</td>
<td>6</td>
</tr>
<tr>
<td>Did not want to NPA T2</td>
<td>11</td>
</tr>
<tr>
<td>Died before NPA T2</td>
<td>3</td>
</tr>
<tr>
<td>Neuropsychological assessment (NPA)T2</td>
<td>80</td>
</tr>
</tbody>
</table>

The 189 stroke patients who did meet criteria for inclusion were contacted and, if willing to participate, an appointment was made at their residence. 148 patients were willing to participate in the first assessment at three months post-stroke, of whom 26 stroke patients could not be assessed because of severe physical disabilities, severe aphasia or severe cognitive impairment. During the study, patients were assessed at three and fifteen months post-stroke. Informed consent was obtained from all patients after the
nature of the assessment procedures had been fully explained. Assessment at each time of measurement consisted of an interview of one session and a neuropsychological assessment (NPA) divided into two sessions. Table 1 provides detailed information concerning patient inclusion and drop-out during the study.

**Inclusion of control subjects**

Control subjects were recruited among the population of 4 practices of GPs in the northern part of the Netherlands. Two practices reside in the largest city of the northern region (Groningen) and two practices are set up in more rural villages (Winsum, Scheemda). Control subjects were successively included after inclusion of stroke patients. A stratified randomisation procedure was performed to match the patient group to the control group with regard to age and gender. After randomised selection, the list of selected controls was returned to their GPs in order to check on the exclusion criteria. Control subjects were excluded if they had been diagnosed or treated for neurological diseases, psychiatric disturbances or substance abuse. A total of 80 controls were included at T1. Two subjects were excluded because of previous neurological damage and a history of psychiatric disturbances. At T2 the control group consisted of 70 subjects, 8 subjects had dropped out because they did not want to participate again (n=4), were too busy (n=2) or had moved (n=2). Of these 70 controls, 23 resided in the south of the city of Groningen, 7 in the central part of this city, 21 resided in Winsum and 19 in Scheemda.

**Stroke characteristics**

All patients in the study sample approved of the fact that medical data were collected. Neurological data were collected by a senior student supervised by a neurologist. All patients underwent CT-scanning, a minority was also analysed through MRI-scanning (8%). Neurological and radiological reports were investigated concerning the type, site and number of lesions. If sufficient data was available, the Oxfordshire Community Stroke Project (OCSP) classification for the overt stroke was made retrospectively on the basis of neurological reports. (Bamford et al., 1991; Johansson, Norrving, and Lindgren, 2000).

**Registration of comorbidity**

After informed consent of stroke patients and control subjects, their GPs were asked to fill in a Comorbidity Index at T2. In this index, the presence of several comorbid disor-
ders could be indicated. Only stroke-related comorbidity was included in the present analyses. The presence of several heart conditions and peripheral vascular diseases was clustered into two categories (see Table 2 for ICPC codes). Furthermore, the presence of diabetes, hypertension and migraine were recorded. GPs were asked to indicate if comorbidity was present at the time of stroke.

Table 2. ICPC codes of comorbidity and exclusion criteria in RNG data.

<table>
<thead>
<tr>
<th>Comorbidity</th>
<th>Description</th>
<th>ICPC code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td></td>
<td>K86 / K87</td>
</tr>
<tr>
<td>Heart disease</td>
<td></td>
<td>K74 - K84</td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td>T90</td>
</tr>
<tr>
<td>Peripheral vascular disease</td>
<td></td>
<td>K91 / K92</td>
</tr>
<tr>
<td>Migraine</td>
<td></td>
<td>N89</td>
</tr>
</tbody>
</table>

Exclusion Criteria

<table>
<thead>
<tr>
<th>Psychiatric and psychological comorbidity</th>
<th>Chronic alcoholism</th>
<th>P15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Substance abuse</td>
<td></td>
<td>P19</td>
</tr>
<tr>
<td>Memory disorders</td>
<td></td>
<td>P20</td>
</tr>
<tr>
<td>Dementia</td>
<td></td>
<td>P70</td>
</tr>
<tr>
<td>Organic psychosis</td>
<td></td>
<td>P71</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td></td>
<td>P72</td>
</tr>
<tr>
<td>Affective psychosis</td>
<td></td>
<td>P73</td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td>P76</td>
</tr>
<tr>
<td>Coma</td>
<td></td>
<td>A07</td>
</tr>
<tr>
<td>Encephalitis</td>
<td></td>
<td>N71</td>
</tr>
<tr>
<td>Parkinson's disease</td>
<td></td>
<td>N87</td>
</tr>
<tr>
<td>Epilepsy</td>
<td></td>
<td>N88</td>
</tr>
</tbody>
</table>

RNG sample

Data collection

Patients were included in the RNG dataset when, during a period of three years, GPs registered a clinically first stroke with ICPC code K90. Stroke patients could have contacted their GP for either a consultation, prescription of medication or reference to a specialist. To each individual patient, a control subject was matched based on age, gender and duration of the period of investigation. During the 3-year period, first episodes of K90 were recorded in 247 patients, therefore a database of 247 matching control subjects was formed. The dataset of the stroke patients was screened for neurological and psychiatric comorbidity preceding the stroke. The same exclusion criteria were applied to the dataset of the controls. A total of 41 patients and controls were excluded, so the
total dataset consisted of 206 matched pairs. Table 2 shows those ICPC codes that were present in the datasets and based on which patients and controls were excluded.

**Registration of comorbidity**
Comorbidity in the RNG dataset was investigated using the same criteria and clusters as in the study sample. Table 2 shows the ICPC codes that were included to assess comorbidity. Comorbidity before and after the first consultation for stroke was recorded.

**Results**

**Study sample**

**Demographical characteristics of study sample**
Table 3 describes the demographical characteristics of the controls and patients included in the study sample at T1 and T2. The control and stroke group did not differ significantly in age, gender or professional level. Stroke patients included by the aid of GPs (n=84) did not differ significantly in age or professional level from those included by the aid of the Stroke Unit (SU) (n=17). However, the hospital-based SU sample consisted of significantly more male patients than the sample included through GPs (SU 88% male vs GP 42% male, $X^2=5.4$, $p=.02$).

Table 3. Comparison of age, gender and professional level (SES) between control and patient group in study sample.

<table>
<thead>
<tr>
<th></th>
<th>Controls n=70</th>
<th>Stroke n=101</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age, M (SD)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>range</td>
<td>66.9 (11.8)</td>
<td>65.4 (11.9)</td>
<td>$t=0.8$</td>
</tr>
<tr>
<td><strong>Gender, % male</strong></td>
<td>42-86</td>
<td>32-93</td>
<td></td>
</tr>
<tr>
<td><strong>SES, M (SD)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>range</td>
<td>56%</td>
<td>63%</td>
<td>$X^2=1.0$</td>
</tr>
<tr>
<td></td>
<td>4.2 (1.3)</td>
<td>3.9 (1.3)</td>
<td>$Z=-1.0$</td>
</tr>
</tbody>
</table>

*Classification Verhage, 1964

**Stroke characteristics**
Of the 122 stroke patients with a clinically first-ever stroke included at the first interview, brain imaging data could be collected for 110 patients. CT-scans were performed at a mean of 8 days post-stroke (range 0-291 days), 58% of scans was performed within
48 hours and 84% within the first week after stroke. On 31 scans (27%), the majority made within 48 hours after stroke, no lesions were visible. All strokes appeared to be ischemic in nature, 4 patients appeared to have bilateral damage and 5 patients an infarction of brain stem or cerebellum. Although all patients had suffered a clinically first stroke, 31 scans (28%) demonstrated one or more old silent brain infarctions (SBI). Based on all available data, the side of lesion could be classified for the remaining 119 stroke patients. Table 4 presents the neurological data, including lesion characteristics and OCSP classification. Patients who dropped out from T1 to T2 did not differ significantly in side of lesion, OCSP classification or in the presence of silent brain infarctions from patients who stayed in the study. However, drop-out appeared to be related to higher age (t=2.2, p=.03) and female gender (X²=3.8, p=.05).

Table 4. Lesion characteristics of stroke patients included at T1

<table>
<thead>
<tr>
<th>Age (n=122) M (SD)</th>
<th>Male (n=122) No. (%)</th>
<th>Side of lesion (n=119) No. (%)</th>
<th>SBI (n=110) No. (%)</th>
<th>OCSP (n=92) No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>66.5 (12.5) range 32-93</td>
<td>73 (60%)</td>
<td>Right 54 (46%)</td>
<td>0 79 (72%)</td>
<td>Laci 43 (47%)</td>
</tr>
<tr>
<td></td>
<td>Left 56 (47%)</td>
<td>1 15 (14%)</td>
<td>Paci 30 (33%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Bilateral 4 (3%)</td>
<td>&gt;1 16 (15%)</td>
<td>Taci 10 (11%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Other 5 (4%)</td>
<td>9 (10%)</td>
<td>Poci</td>
<td></td>
</tr>
</tbody>
</table>

It appeared that SBI were more often present in patients derived from the SU (46%) versus patients recruited by GPs (26%), although statistics did not reach significance (X²=3.3, p=.07). Stroke patients collected through the SU and the GPs did not differ in the proportions in each OCSP category or in the distribution of the side of lesion.

Comparison of comorbidity between patients and controls

Comorbidity was compared between patients and controls included at both T1 and T2. Patients who dropped out from T1 to T2 had a significantly higher percentage of peripheral vascular disease (PVD) than patients who stayed in the study (X²=5.0, p=.03). Drop-out of control subjects was not related to the presence of comorbidity. As presented in Table 5, within the study sample, diabetes and PVD were significantly more often present in stroke patients than in controls. When comorbidity of stroke patients collected by GPs (n=84) was compared to comorbidity of the hospital-based SU sample (n=17), a significant difference emerged with regard to the prevalence of PVD. PVD was present in 13 percent of stroke patients collected by GPs, versus 43 percent of patients recruited by the SU (X²=7.6, p=.006). Furthermore, PVD was more often present in pa-
tients with SBI than in patients without SBI (25% versus 4%, $X^2=4.4$, $p=.04$). In patients without SBI, diabetes occurred more often than in patients with SBI (16% versus 0%, $X^2=4.3$, $p=.04$).

**RNG sample**

*Demographical characteristics*

As the result of the matching procedure, age of stroke patients and controls in the RNG sample was very similar (Stroke: $M=69.2$, $SD=15.2$, range 19-94, Control: $M=69.2$, $SD=15.2$, range 20-94, $t=-0.1$, $p=.94$), while the distribution of gender was exactly the same (53% male).

*Comparison of comorbidity in matched pairs*

Table 5 presents the stroke-related comorbidity for the matched pairs of the RNG dataset preceding and after the incident stroke. Preceding the stroke, all comorbidity, except for migraine, was significantly more prevalent in patients than controls. Comparison of comorbidity after stroke showed that hypertension, heart disease and diabetes were more prevalent in RNG stroke patients than in matched controls.

Table 5. Comorbidity in percentages before and after stroke of incident stroke patients 1999-2001 (n=206) and controls (n=206) in RNG population and stroke patients (n=101) and controls (n=70) of study sample.

<table>
<thead>
<tr>
<th>Comorbidity</th>
<th>Pre-stroke RNG</th>
<th>Post-stroke RNG</th>
<th>Study sample</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Stroke</td>
<td>Control</td>
<td>$t$</td>
</tr>
<tr>
<td>Hypertension</td>
<td>40.8</td>
<td>29.1</td>
<td>2.6*</td>
</tr>
<tr>
<td>Heart disease</td>
<td>35.0</td>
<td>24.3</td>
<td>2.5*</td>
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<tr>
<td>Diabetes</td>
<td>17.5</td>
<td>9.2</td>
<td>2.5*</td>
</tr>
<tr>
<td>PVD</td>
<td>6.3</td>
<td>2.0</td>
<td>2.2*</td>
</tr>
<tr>
<td>Migraine</td>
<td>1.0</td>
<td>3.4</td>
<td>-1.7</td>
</tr>
</tbody>
</table>

*Comparison between RNG data and study sample*

The distribution of gender did not differ significantly between stroke patients in the study sample and patients in the RNG sample, although the RNG sample contained relatively more female patients (Study 63% male, RNG 53% male, $X^2=2.7$, $p=.10$). The age of male patients in both groups did not differ significantly (Study: $M=65.5$, $SD=10.8$, RNG: $M=69.2$, $SD=15.2$).
However, female patients in the RNG group were significantly older than female patients in the study sample (Study: M=65.3, SD=13.7, RNG: M=72.6, SD=14.7, t=-2.6, p=.01).

Inspection of the prevalences of post-stroke comorbidity in RNG stroke patients and in stroke patients of the study sample as presented in Table 5 showed that prevalences were quite similar for hypertension (44% in both groups), heart disease (31% vs. 30%) diabetes (16% vs 12%) and migraine (1% in both groups). PVD, however, seemed to be more prevalent in the study sample than in the RNG-sample (3% vs. 20%).

Inspection of comorbidity of controls in both groups, showed that prevalences of hypertension seemed less prevalent in the RNG-sample than in the study sample (28% vs 42%). The same trend was visible for the prevalence of heart disease (20% vs 34%).

**Discussion**

*Comparison of stroke-related comorbidity between study sample and RNG sample*

Most important aim of this chapter was to gain more insight into the comorbidity of the stroke patients in the study sample. Stroke-related comorbidity of patients referred to the study by their GP was compared to comorbidity of all stroke patients registered by GPs participating in the RNG. It appeared that comorbidity in the stroke group of the study sample was very similar to comorbidity of stroke patients in the RNG dataset. Only peripheral vascular disease was more often present in the study sample, which can partly be attributed to a high prevalence in the hospital-based stroke sample. Once patients are admitted to the hospital stroke unit they are thoroughly examined with regard to risk factors for stroke, so one of the explanations for the higher prevalence of PVD in this group might be a registration bias. Although comorbidity was similar in the study sample and RNG sample, drop-out in the study sample was selective and concerned mostly elderly female patients and patients with a relatively high incidence of PVD. The RNG sample therefore contained slightly more female patients, who were older than the female patients in the study sample. Furthermore, the most severe stroke patients had to be excluded from participation in the present study. The stroke patients in the study sample are therefore somewhat biased towards those less affected after stroke.
It can be concluded that, with regard to comorbidity, patients in the study sample are comparable to stroke patients living in the community in the northern part of the Netherlands. GPs did not seem to have withheld patients from the present study based on the presence of comorbid diseases at the time of stroke. Although patients in the study sample can only be compared to the RNG sample on comorbidity and not on the outcome after stroke, the presence of comorbid diseases such as heart disease and diabetes have been related to the stroke severity and to poorer outcome after stroke (Megherbi et al., 2003, Appelros et al., 2002, Baird et al., 2002).

Differences in comorbidity and stroke types within study sample
The present study confirmed the idea that community-based stroke samples differ from stroke patients derived from hospitals. The relatively small hospital-based group of the study sample consisted mostly of male patients with a relatively great incidence of silent brain infarctions and with a high prevalence of PVD. Although the stroke sample collected by GPs did not differ in age from the hospital-based sample, this can probably be attributed to the lack of elderly females in the hospital-based sample. Female stroke patients in average suffer from stroke on a higher age than male patients, while the chances of being referred to a hospital after stroke declines with higher age (Hollander et al., 2003). The present study evokes the question whether stroke types and risk factors differ between community-based and hospital-based stroke samples. Schulz and Rothwell (2003), for example, found more cardio-embolic strokes, higher blood pressure and higher cholesterol levels in hospitalised versus non-hospitalised stroke patients. The differences between hospital-based and community-based stroke samples with regard to comorbidity, risk factors and stroke types should receive more attention in stroke research.

Stroke characteristics in study and RNG sample
Although prevalences of comorbid disorders were similar, stroke types included in the study sample differed partly from those included in the RNG sample. The study sample only included ischemic strokes, while the ICPC code K90 used in the RNG-dataset covers all stroke types. Unfortunately, data on stroke types were not available for the RNG sample. Although 70 to 80 percent of all strokes are of ischemic nature, the remaining part consists of strokes of a different nature and with different risk profiles (Feigin et al., 2003, Schmal et al., 1998). In the study sample, ischemic stroke was defined on the basis of neurological and radiological findings, in which neuroimaging data play an
important role to distinguish ischemic infarctions from haemorrhages. Most CT-scans in the present patient group were made shortly after stroke, with 27 percent showing no ischemic lesions at all. The lack of ischemic signs on early CT after clinically evident stroke is a well-known finding, with similar percentages of negative CT’s found in other stroke studies (Saur, Kucinski et al., 2003; Horowitz et al., 1991). Although all strokes were clinically first-ever strokes, 28 percent of scans showed silent brain infarctions preceding the stroke. A similar percentage of 27 percent silent brain infarctions has been described in Danish patients with acute stroke (Jorgensen et al., 1994). Silent brain infarctions are also frequently found on imaging data of brains of healthy elderly persons and constitute a risk factor for stroke (Vermeer et al., 2003).

**Comorbidity in control samples**

The construction of the control groups differs between the study sample and the RNG sample. The control group in the study sample was successively formed by a stratified group matching procedure, while in the RNG sample each patient had a unique match in the control group.

When comparing comorbidity in the study sample to comorbidity in the RNG sample, the presence of heart disease and hypertension seemed more prevalent in the study sample. This can partly be explained by the inclusion of subjects in the study sample residing in the eastern part of the province of Groningen. The inhabitants of this region of Groningen have previously been described as a group with multiple risk factors for cardiovascular disease and with a high mortality caused by coronary heart disease (Bemelmans et al., 2002, Broer, 2000).

**Risk factors for stroke**

In both the study sample and the RNG sample diabetes and peripheral vascular disease were significantly more prevalent in stroke patients than in controls. In the RNG sample heart disease and hypertension were also significantly more often present in stroke patients than in controls. These findings support previous studies on the risk factors of stroke (Rodgers et al., 2004, Grau et al., 2001, Buis, 1998). Contrary to the expectations, the prevalence of migraine was not higher in stroke patients compared to controls. An explanation might be that, among the comorbid diseases, migraine is most likely not always recorded by GPs. Furthermore, although migraine has been described as a risk factor for stroke, migraine-induced stroke is rare (Welch, 2003). Quite unexpectedly,
stroke patients in the study sample did not differ from control subjects with regard to the prevalence of heart disease and hypertension. This can be attributed to the relatively high prevalence of these disorders in the control group, as has been described in the previous paragraph. However, the resemblance of stroke-related comorbidity between patients and controls in the study sample can be an advantage. It gives an opportunity to study the effects of stroke on top of the presence of several risk factors. In other words, a part of the control group is very similar to the stroke group, except for the occurrence of a stroke.
References


Stroke-related comorbidity


Abstract
The presence and severity of changes in emotion and cognition experienced by left and right-sided stroke patients and observed by their partners were compared at three months post-stroke. The results showed that, regardless of the side of stroke, several changes were reported by half of the stroke patients and their partners. It appeared that while left hemisphere stroke patients agreed with their partners on the number and severity of most changes, partners of right hemisphere patients reported more frequent and more severe changes than the patients themselves. The level of observability of the altered behaviour influenced the amount of agreement between patients and partners. Distress of partners and patients was related to disagreement scores in the left sided group, while only distress of partners but not of patients was associated with disagreement in the right sided group. In addition, the level of hemispatial neglect was related to a greater number and more severe changes in emotion and cognition reported by partners compared to the reports of right-sided stroke patients themselves.
Introduction

A cerebrovascular accident (CVA) or stroke can, in addition to causing physical and cognitive impairments, change the way stroke patients express, experience or comprehend emotions. An emotional state has many components, including overt behavioural expression, cognitive processes and physiological changes. In neuropsychological literature, there have been many clinical reports on changes in emotion, cognition and behaviour after left and right sided brain injury. Recently, Hochstenbach (1999) has made an inventory of emotional and cognitive changes reported by patients and proxies nine months after stroke onset. She concluded that emotional and cognitive changes following stroke are experienced by fifty percent of stroke patients and their relatives. Most frequently mentioned changes by patients and partners, irrespective of side of lesion, were mental slowness, memory disabilities, less initiative and hyperemotionality (Hochstenbach et al., 1997). However, agreement between patients and relatives on the presence of symptoms was low. Most studies showed greater problems reported by relatives than by stroke patients themselves (Teasdale et al, 1997; Hochstenbach et al., 1997).

Until now, little attention has been paid to factors that can affect the discrepancies in changes reported by patients and relatives. One of the relevant patient-related factors is the amount of awareness of deficits. Awareness of deficits is not a unitary phenomenon: the awareness of changes after brain injury can be inconsistent across physical, cognitive and affective domains (Hibbard et al., 1992). McKinlay & Brooks (1984) demonstrated large discrepancies between relatives and head-injured patients on emotional disturbances of the patient. In contrast, close agreement was found on items related to sensory-motor impairments, memory and concentration. Several studies found that impaired awareness of deficits after brain injury is more commonly observed after right sided stroke, however others failed to find lateralized differences in the level of awareness (Hibbard et al., 1992).

Giacino and colleagues (1998) suggest that three factors may underlie patients’ lack of awareness of deficits after brain injury. First, diminished awareness can be a secondary effect of impaired cognition, such as memory and reasoning deficits. In order to be aware of changes, patients have to remember pre- and post-injury states and compare the two. Trudel and colleagues (1998) did find a relationship between memory...
impairment and diminished awareness of disability. Prigatano, (1990) however, failed to find differences between traumatic brain injury patients who overestimated their behavioural competencies and patients who underestimated themselves, using tests of memory and abstract reasoning. McKinlay & Brooks (1984) also found no relation between patient-partner discrepancies concerning reported problems and several neuropsychological tests of intelligence, recall, verbal fluency and comprehension. A finding more consistently demonstrated, is the association between impaired awareness of deficits and hemispatial neglect (Heilman et al. 1998; McGlynn & Schacter, 1989; Motomura et al., 1988; Starkstein et al., 1992; Willanger et al., 1981).

A second hypothesis concerning impaired awareness suggests that it is a psychological defensive mechanism by which the consequences of brain damage are denied (Giacino, 1998). The denial hypothesis, like the cognition hypothesis, however, does not account for hemispheric asymmetries often associated with awareness of deficits. It also does not explain the differences in awareness across physical, cognitive and emotional domains.

Finally, Giacino and colleagues mention that the unawareness of deficits can be a relatively 'pure' inability directly caused by the brain injury. Research on anosognosia of motor and visual deficits in stroke patients supports this hypothesis, in finding a greater number of right hemisphere lesions and bilateral subcortical atrophy among anosognostic stroke patients (Starkstein et al., 1992). In addition to the association between right-sided brain injury and impaired awareness of deficits, McGlynn & Schacter (1989) suggest that unawareness of perceptual and motor deficits involves parietal damage, while unawareness of complex deficits such as cognitive and behavioural changes involves frontal damage. Besides its role in the awareness of deficits, right hemisphere damage is thought to have a greater effect on emotional perception and expression than left hemisphere damage (Borod et al, 1998; Rolls, 1999). Gainotti (1993), after reviewing recent literature, suggests that right hemisphere damage disrupts the autonomic components of the emotional response much more than the ability to comprehend or express emotions. According to him, the right hemisphere is more concerned with the basic levels of emotional arousal, while the left hemisphere is more involved in inhibiting and controlling emotions.

Besides these factors related to awareness of disability in the patient, the presence and severity of depressive mood of both patient and relative might affect the number and
severity of reported changes in emotion and cognition. McKinlay & Brooks (1984) propose that the disagreement between patients’ and relatives’ reports may in part be attributable to a distorted perception on the part of the relatives. These authors found that the amount of post injury changes reported by relatives was positively related to their neuroticism scores. Knapp and Hewison (1999) showed that disagreement between patient and partner concerning the functional abilities of the patient after stroke was significantly associated with greater carer strain, however, they failed to find a relationship between disagreement and patient or carer mood.

The aim of the present study is first to describe the presence and severity of emotional and cognitive changes reported by left and right-sided stroke patients and their relatives at three months post-stroke. Furthermore, a comparison will be made of both frequency and severity of reported changes between left and right hemisphere patients and between patients and partners. After that, factors that could be related to discrepancies between patient and partner will be examined. For the patients, these factors are side of damage, cognitive impairments and distressed mood. The contribution of distress of the partner to disagreement scores is also evaluated. Finally, literature on agreement between observers suggests that the degree of agreement is affected by the level of observability of the behaviour. To examine this effect, patient and partners are also compared on reported changes in the level of activity of the patient.

Methods

Subjects

Patients were recruited through the aid of 300 General Practitioners (GPs) from the northern part of the Netherlands and in co-operation with the Stroke Unit of the University Hospital Groningen. Patients were included if they met the following criteria: (1) a first-ever, unilateral, ischemic stroke within the previous three months, (2) no neurologic or psychiatric history, (3) no history of alcohol or drug abuse, (4) sufficient language and cognitive abilities to allow assessment. Side of damage was checked with CT-scan findings and neurological reports. The GP, with permission of the patient, reported on the medical history of the patient.
A total of 235 stroke patients were recruited over a period of two years. Patients who did not meet the criteria of having a first-ever, unilateral, ischemic stroke within the previous three months were excluded from the study (n=33). Patients with a history of neurologic (n=8) or psychiatric disturbances (n=2) were excluded as well as subjects who were known as alcohol abusers (n=3). Stroke patients who could not be assessed because of very severe aphasia (n=7), physical or cognitive impairments (n=19) were also excluded. Another 36 patients could not be included in the study because they did not want to participate (n=30) or could not be reached within three months (n=6). Finally, 5 patients died before the first measurement at three months post-stroke.

The group of patients included in the present study consisted of 113 first-ever unilateral ischemic stroke patients of whom 55 subjects had right-sided damage (RH) and 58 subjects left-sided damage (LH). Mean age for the left hemisphere group (M=67.1, SD =12.7) did not differ from mean age in the right hemisphere group (M=66.0, SD=11.5; t=-.49, p=.63). Neither did left or right hemisphere patients differ in educational level (U=-0.4, p=.66). The majority of the patients in both hemisphere groups was male (RH 60% vs LH 59%; X² =.02, p =.88). Both patient groups did not differ in severity of impairments of basic activities as measured by the Barthel Index (RH: M=17.8, SD=4.0, LH: M =18.7, SD=2.2; t =-1.2 , p =.22). Of the right and left sided stroke patients, respectively 36 (65%) and 38 (66%) had partners with whom they lived; these partners were interviewed as well. Patient and partners were interviewed at a mean of 115 days (SD=31) post-stroke. Left and right hemisphere patients with partner did not differ in age (t=1.1, p=.30), level of education (U=-.42, p=.68), gender (X²=.33, p=.57), Barthel Index (t=-1.3, p=.19) or in time between stroke and interview (t=1.1, p=.26).

Materials en procedure

After signing an informed consent, stroke patients and partners were interviewed by a trained interviewer at their own place of residence at three months post-stroke. Because of living arrangements and physical handicaps not all patients and partners could be interviewed independently. Patients were always interviewed first, followed by their partners. A series of questionnaires concerning physical impairments and mood were administered. Within the following two weeks the cognitive functions of the stroke patients were assessed neuropsychologically. All patients and partners will be followed up at 15 months post-stroke.
**Physical functioning**

The Barthel Index (BI) was used to measure the patient’s performance on ten basic functions of daily living (Mahoney & Barthel, 1965). The scale is scored 0 to 20 with higher scores indicating greater independence in functional ability. The BI was scored by the interviewer based on observations and information provided by the patient and the partner. The instrumental activities of daily life were assessed with ten items based on the Frenchay Activities Index (FAI) (Holbrook & Skilbeck, 1983). These ten items concerning the frequency of a variety of activities were complemented with questions concerning the change in activity after stroke. Patients and partners could indicate whether the patients had maintained (1), had increased (2) or had decreased (0) their pre-stroke level of certain activities. Scores range from 0 to 30, with scores below 10 indicating a decrease in level of activity.

**Emotion and mood**

Emotional and cognitive changes were assessed using 20 questions. These questions are based upon clinical relevance according to both neuropsychological literature and interviews with partners of stroke patients (Schure, 1995). Both patients and partners were asked to rate the amount of emotional and cognitive change in the stroke patient on a 4-point scale running from ‘not changed’ (0) to ‘very much changed’ (3). The internal consistency of all items was assessed by calculating Cronbach’s alpha. The partner’s form demonstrated high internal consistency (alpha=.94) while the patient’s form showed less but still moderate consistency (alpha=.80). Discrepancy in judgement of emotional and cognitive changes after stroke was measured by subtracting partner scores from patient scores.

Depressive and anxious mood of both patients and partners was screened using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The HADS has anxiety and depression subscales both containing 7 items (scored 0 to 21). Higher scores indicate a greater likelihood of anxiety or depression. According to Johnson et al. (1995), when examining a community based stroke group, best cut-off scores for the HADS are 5 for the depression scale and 6 for the anxiety scale. Although several studies found a two factor solution for the HADS using principal component analysis, both subscales correlate highly and can together be seen as an indication of the amount of general distress (Johnson et al., 1995; Spinhoven et al., 1997). In the present study, after a confirmative answer on an item of the HADS, subjects were asked if the depressive or
anxious mood could be attributed to the stroke event. These scores were summed to a total stroke impact score (range 0-14).

**Neuropsychological examination**

After the interview, the presence and severity of expressive speech disturbances and receptive language difficulties were rated by the interviewer. Both expressive and receptive difficulties were rated as (0) non-existent, (1) mild or (2) severe. The neuropsychological assessment consisted of many tests aimed at measuring a variety of neuropsychological functions. Only those tests relevant for the research questions posed in this article are described here.

Both verbal and non-verbal memory capabilities of the patient as well as overall cognitive functioning were measured. To measure immediate verbal memory, a Dutch version of the Auditory Verbal Learning Test (AVLT) was used (Department of Neuropsychology, 1986; Van den Burg & Kingma, 1999). A non-verbal memory task was designed to measure immediate retention of non-verbal material. In this task, subjects had to match pairs of faces. A verbal version of this memory task consisted of matching pairs of names (Gerritsen et al., 2000). The mean of the percentages correct in each completed memory test renders a total memory score, higher scores indicating better performance. The SON, a non-verbal intelligence test, was administered to measure reasoning (Snijders et al., 1988). The SON was originally designed for deaf children, but appeared also to be a valuable instrument for assessing reasoning in the elderly (Gerritsen et al., 2001). The total sumscore of the three subtests Categories, Stories and Mosaics was used in the present study, higher scores indicate better reasoning abilities. The Star Cancellation task, a subtest of the Behavioural Inattention Test (BIT) was used as a measure of hemispatial neglect (Wilson et al., 1987). The total number of stars cancelled is used in the present analyses, higher scores indicate better performance.

**Statistical analysis**

Left and right sided stroke patients were compared on the frequency (Chi-square analyses) and severity of changes (Mann-Whitney U test). Kappa scores were calculated to compare the answers of patients and partners. The Kappa coefficient expresses the proportion of agreement beyond chance. Agreement based on Kappa scores can be interpreted as slight (.01-.20), fair (.21-.40), moderate (.41-.60), substantial
(.61-.80) to almost perfect (.81-1.00) (Landis & Koch, 1977). The McNemar Test for two related dichotomous variables was used to compare the reported presence of emotional and cognitive changes for left-sided and right-sided stroke patients and their partners. To compare the severity of reported changes between patients and partners, the Wilcoxon signed ranks test for two related samples was used. When total scores of emotional changes and activity levels are compared between patients and partners, the Paired t-test was calculated. If multiple analyses were carried out simultaneously, the level of alpha (.05) was divided by the number of analyses (Bonferroni adjustment).

**Results**

*Comparison of right and left sided stroke patients on cognitive and emotional changes*

First, the presence of emotional changes as well as the severity of change reported by left and right-sided stroke patients were analysed. The left sided stroke patients reported changes on a mean of 5 items, (SD=4), while right-sided stroke patients mentioned change on 6 items (SD=5). These mean numbers of changes did not differ significantly between the two groups (t=1.4, p=.71).

Table 1 shows that within the right sided stroke group, hyperemotionality was the most frequently mentioned change, followed by being more listless and being more self-centred. Within the left hemisphere group, the most frequently mentioned changes were impairments in memory, mental slowness and hyperemotionality. The frequencies of different cognitive and emotional changes after stroke reported by left and right sided stroke patients were generally similar. After Bonferroni correction, no significant differences were found at alpha=.003. The rank order of the reported frequency of changes in both hemisphere groups correlated significantly (rs=0.71, p=.00).

When comparing the severity of reported emotional and cognitive changes, right hemisphere stroke patients tended to report greater changes than left hemisphere patients did (RH: M=8.4 (SD=7.3) vs LH: M= 6.5 (SD=5.6); T=-1.3, p=.20). These differences were not significant, however.
Subjective changes in emotion and cognition

Table 1. Percentages and rank orders of the presence of emotional and cognitive changes reported by left and right sided stroke patients (N=113)

<table>
<thead>
<tr>
<th>Emotional and cognitive change</th>
<th>Side of stroke</th>
<th>Left n=58</th>
<th>%</th>
<th>rank</th>
<th>Right n=55</th>
<th>%</th>
<th>rank</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperemotional</td>
<td></td>
<td></td>
<td>41</td>
<td>3</td>
<td>55</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>More listless</td>
<td></td>
<td></td>
<td>23</td>
<td>8</td>
<td>44</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>More self-centred</td>
<td></td>
<td></td>
<td>26</td>
<td>7</td>
<td>40</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Mentally slower</td>
<td></td>
<td></td>
<td>46</td>
<td>2</td>
<td>38</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Less initiative</td>
<td></td>
<td></td>
<td>39</td>
<td>4</td>
<td>38</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Impaired memory</td>
<td></td>
<td></td>
<td>49</td>
<td>1</td>
<td>36</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>More sad, depressive mood</td>
<td></td>
<td></td>
<td>16</td>
<td>14</td>
<td>35</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Presenting oneself more positively</td>
<td></td>
<td></td>
<td>20</td>
<td>11</td>
<td>33</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>More easily irritated</td>
<td></td>
<td></td>
<td>20</td>
<td>12</td>
<td>33</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Overrating oneself</td>
<td></td>
<td></td>
<td>29</td>
<td>6</td>
<td>31</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>More impatient</td>
<td></td>
<td></td>
<td>16</td>
<td>15</td>
<td>29</td>
<td>11</td>
<td></td>
</tr>
<tr>
<td>Less concentration</td>
<td></td>
<td></td>
<td>29</td>
<td>5</td>
<td>29</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>More anxious</td>
<td></td>
<td></td>
<td>19</td>
<td>13</td>
<td>27</td>
<td>13</td>
<td></td>
</tr>
<tr>
<td>More restless</td>
<td></td>
<td></td>
<td>6</td>
<td>18</td>
<td>20</td>
<td>14</td>
<td></td>
</tr>
<tr>
<td>Overdependent</td>
<td></td>
<td></td>
<td>14</td>
<td>16</td>
<td>20</td>
<td>15</td>
<td></td>
</tr>
<tr>
<td>Less orientation time/place</td>
<td></td>
<td></td>
<td>7</td>
<td>17</td>
<td>16</td>
<td>16</td>
<td></td>
</tr>
<tr>
<td>Less interest in others</td>
<td></td>
<td></td>
<td>23</td>
<td>9</td>
<td>15</td>
<td>17</td>
<td></td>
</tr>
<tr>
<td>Less planning abilities</td>
<td></td>
<td></td>
<td>22</td>
<td>10</td>
<td>13</td>
<td>18</td>
<td></td>
</tr>
<tr>
<td>More demanding</td>
<td></td>
<td></td>
<td>5</td>
<td>19</td>
<td>11</td>
<td>19</td>
<td></td>
</tr>
<tr>
<td>More impulsive</td>
<td></td>
<td></td>
<td>5</td>
<td>20</td>
<td>4</td>
<td>20</td>
<td></td>
</tr>
<tr>
<td>No changes</td>
<td></td>
<td></td>
<td>14</td>
<td></td>
<td>9</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Comparison of reported emotional and cognitive changes between left and right hemisphere stroke patients with and without partner.

Table 2 shows that the group of patients without partner was significantly older and consisted of more females than the group of patients with partner. This pattern seems generally consistent with demographical data of the Netherlands. When comparing patients with partner to patients without partner on the total mean frequency and severity of reported changes, no significant differences emerged.
Table 2. Comparison of demographic data, severity of basic impairment and number and severity of emotional changes between patients with and without a partner

* p < .05, ** p < .01, *** p < .001 (two tailed)

<table>
<thead>
<tr>
<th></th>
<th>Patients without partner n=40</th>
<th>Patients with partner n=74</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>M (SD)</td>
<td>M (SD)</td>
<td>t=2.6*</td>
</tr>
<tr>
<td></td>
<td>70.5 (13.5)</td>
<td>64.4 (10.7)</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>Male n=12 (30%)</td>
<td>Male n=55 (75%)</td>
<td>X²=22.0***</td>
</tr>
<tr>
<td></td>
<td>Female n=28 (70%)</td>
<td>Female n=18 (25%)</td>
<td></td>
</tr>
<tr>
<td><strong>Barthel Index</strong></td>
<td>17.0 (4.9)</td>
<td>18.3 (3.2)</td>
<td>t=-1.6</td>
</tr>
<tr>
<td><strong>Emotional changes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Frequency</strong></td>
<td>5.4 (4.7)</td>
<td>5.6 (4.1)</td>
<td>t=-0.3</td>
</tr>
<tr>
<td><strong>Severity</strong></td>
<td>7.7 (7.9)</td>
<td>7.3 (5.8)</td>
<td>T=-0.3</td>
</tr>
</tbody>
</table>

Table 3 presents the percentages of the reported changes in emotion and cognition by left and right hemisphere stroke patients with a partner. As in the total stroke group, the frequency and severity of cognitive and emotional changes after stroke reported by left and right sided stroke patients were generally similar. The rank order of the reported frequency of changes of both hemisphere groups correlated significantly (rs=.55, p=.01). As in the total stroke group, the change most frequently reported by right hemisphere stroke patients with partner was hyperemotionality. Within the left hemisphere stroke group with partner, now the first most frequently mentioned change was mental slowness, which was the second complaint in the total left hemisphere group. After Bonferroni correction, left sided stroke patients only reported significantly more often having reduced interest in others than right sided stroke patients (X²=7.3, p=.00).

**Comparison of patient and partner: presence of emotional and cognitive changes**

Next, the presence or absence of changes in emotion and cognition stated by stroke patients was compared with the answers of their partners. Left hemisphere patients reported change on 6 items (SD=4), while their partners reported change on 7 items (SD=4), a non-significant difference (t=-1.2, p=.18). Partners of right hemisphere patients mentioned change on significantly more items than the patients themselves did. While right hemisphere stroke patients also reported change on 6 items (SD=4), their partners observed change on 9 items (SD=6.0, t=-3.5, p=.01).
Table 3. Percentages and rank orders of the presence of emotional and cognitive changes reported by left and right sided stroke patients and partners

<table>
<thead>
<tr>
<th>Emotional or cognitive change</th>
<th>Patient Left n=38</th>
<th>Patient Right n=36</th>
<th>Partner Left n=38</th>
<th>Partner Right n=36</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hyperemotional</td>
<td>42%</td>
<td>3%</td>
<td>50%</td>
<td>1%</td>
</tr>
<tr>
<td>More listless</td>
<td>26%</td>
<td>7%</td>
<td>33%</td>
<td>4%</td>
</tr>
<tr>
<td>More self-centred</td>
<td>32%</td>
<td>26%</td>
<td>10%</td>
<td>5%</td>
</tr>
<tr>
<td>Mentally slower</td>
<td>47%</td>
<td>1%</td>
<td>39%</td>
<td>3%</td>
</tr>
<tr>
<td>Less initiative</td>
<td>47%</td>
<td>2%</td>
<td>25%</td>
<td>3%</td>
</tr>
<tr>
<td>Impaired memory</td>
<td>45%</td>
<td>66%</td>
<td>28%</td>
<td>6%</td>
</tr>
<tr>
<td>More sad, depressive mood</td>
<td>16%</td>
<td>26%</td>
<td>31%</td>
<td>6%</td>
</tr>
<tr>
<td>Presenting oneself more positively</td>
<td>24%</td>
<td>12%</td>
<td>42%</td>
<td>2%</td>
</tr>
<tr>
<td>More easily irritated</td>
<td>26%</td>
<td>11%</td>
<td>28%</td>
<td>10%</td>
</tr>
<tr>
<td>Overrating oneself</td>
<td>32%</td>
<td>8%</td>
<td>31%</td>
<td>7%</td>
</tr>
<tr>
<td>More impatient</td>
<td>21%</td>
<td>14%</td>
<td>25%</td>
<td>13%</td>
</tr>
<tr>
<td>Less concentration</td>
<td>34%</td>
<td>5%</td>
<td>31%</td>
<td>8%</td>
</tr>
<tr>
<td>More anxious</td>
<td>24%</td>
<td>13%</td>
<td>28%</td>
<td>11%</td>
</tr>
<tr>
<td>More restless</td>
<td>5%</td>
<td>19%</td>
<td>17%</td>
<td>15%</td>
</tr>
<tr>
<td>Overdependent</td>
<td>13%</td>
<td>16%</td>
<td>19%</td>
<td>14%</td>
</tr>
<tr>
<td>Less orientation time/place</td>
<td>5%</td>
<td>20%</td>
<td>18%</td>
<td>17%</td>
</tr>
<tr>
<td>Less interest in others</td>
<td>34%</td>
<td>6%</td>
<td>8%</td>
<td>18%</td>
</tr>
<tr>
<td>Less planning abilities</td>
<td>29%</td>
<td>9%</td>
<td>11%</td>
<td>17%</td>
</tr>
<tr>
<td>More demanding/forceful</td>
<td>8%</td>
<td>17%</td>
<td>6%</td>
<td>19%</td>
</tr>
<tr>
<td>More impulsive</td>
<td>8%</td>
<td>18%</td>
<td>3%</td>
<td>20%</td>
</tr>
<tr>
<td>No changes</td>
<td>13%</td>
<td>3%</td>
<td>11%</td>
<td>6%</td>
</tr>
</tbody>
</table>

Table 4. Comparison of the number of emotional and cognitive items on which patients and partners disagreed concerning the presence of change.

*p < .05, ** p < .01, *** p < .001 (two tailed)

<table>
<thead>
<tr>
<th>Side of stroke</th>
<th>Left n = 38</th>
<th>Right n = 36</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Items disagreed</td>
<td>5.1 (2.8)</td>
<td>6.4 (3.9)</td>
<td>t=1.6</td>
</tr>
<tr>
<td>Partner &gt; Patient*</td>
<td>3.0 (3.0)</td>
<td>4.9 (4.5)</td>
<td>t=2.0*</td>
</tr>
<tr>
<td>Patient &gt; Partner**</td>
<td>2.0 (2.2)</td>
<td>1.5 (2.2)</td>
<td>t=-1.0</td>
</tr>
</tbody>
</table>

* Change reported by partner, but not by patient
** Change reported by patient, but not by partner
As can be seen from Table 4, disagreement between patient and partner on the presence of change involved the same number of items in the right-sided group compared to the left-sided group. However, changes present according to partners, but not according to patients concerned more items within the right-sided group compared to the left-sided group.

Table 3 shows percentages of stroke patients and their partners who reported changes on each aspect of behaviour and cognition. When looking at the separate items after Bonferroni correction, the results showed that partners of right hemisphere stroke patients reported more often changes in mental slowness (p=.00) and irritability (p=.00) than did the patients. The rank order of the frequency of emotional and cognitive changes correlated significantly between left hemisphere patients and their partners (rs=.76, p=.00) and right hemisphere stroke patients and partners (rs=.77, p=.00).

Table 5. Comparison of the severity of emotional and cognitive change on separate items reported by patient and partner for whole (Kappa) and both hemisphere groups (Wilcoxon). ** p < .003 (two tailed)
Comparison of patient and partner: severity of emotional and cognitive changes

Besides the presence of emotional and cognitive changes, the severity of changes reported by 36 right-sided and 38 left-sided stroke patients were compared with the answers of their partners. While left-sided patients did not differ significantly on the total amount of reported change, again, partners of right-sided stroke patients reported significantly greater emotional and cognitive change than did the patients (LH: patients M=7.3 (SD=5.6), partners M=7.9 (SD=6.2), T=-0.6, p=.45; RH: patients M= 7.1 (SD=5.9), partners M=13.5 (SD=12.9), T=-3.0, p=.01).

Kappa coefficients for the total stroke and partner groups and Wilcoxon Z-scores for both hemisphere groups are provided in Table 5, comparing the severity of changes reported by patients and their partners on the different emotional and cognitive items. The proportion of agreement measured with Kappa ranged from .10 to .48. The results show that, in general, partners tended to report greater changes than patients did. After Bonferroni-correction, no differences existed between left-sided stroke patients and their partners on the severity of cognitive and emotional changes. Within the right-sided stroke group, partners reported significantly greater changes than the patients on the items mental slowness, planning ability, the ability to rate oneself and the irritability of the patient.

Disagreement between patient and partner: related factors

I. Observability of change

To compare the agreement scores across more and less observable domains of investigation, both stroke patients and partners were also asked to judge the change in the level of activities of the stroke patient. In general, 50 percent of the stroke patients and partners reported a drop in activities, 45 percent reported an equal level of activities and 5 percent reported a higher level of activities after stroke (see Table 6 for the different activities). Right and left hemisphere patients did not differ in reported change in the level of activities (t=0.5, p=.63). The most frequently mentioned reduction of activity by patients and partners was driving a car (62%). The least reported reduction in activity was watching television (22%), which 20 percent of the patients reported doing more frequently. In general, patients reported a higher post-stroke level of activities than their partners did. Mean scores did not differ significantly between left hemisphere stroke patients and their partners (M=6.6 (SD=5.6) vs M=6.4 (SD=6.2), t=0.60, p=.55). There was,
however, a small, but significant difference in activities reported by right hemisphere stroke patients and partners (M=6.8 (SD=3.9) vs M=6.0 (SD=4.0), t=2.3, p=.03).

As can be seen from Table 6, Kappa coefficients ranged from .52 to .77. After Bonferroni correction, patients did not report significantly more change in any of the activities than partners did.

Table 6. Comparison of the amount of change in the level of activities reported by patient and partner for whole (Kappa) and both hemisphere groups (Wilcoxon).

<table>
<thead>
<tr>
<th>Changes in</th>
<th>Kappa</th>
<th>Z-score</th>
<th>Left stroke n=38</th>
<th>Right stroke n=36</th>
</tr>
</thead>
<tbody>
<tr>
<td>shopping for groceries</td>
<td>.75</td>
<td>-1.9</td>
<td>-0.4</td>
<td></td>
</tr>
<tr>
<td>social activities</td>
<td>.58</td>
<td>0.0</td>
<td>-0.9</td>
<td></td>
</tr>
<tr>
<td>walking</td>
<td>.56</td>
<td>-0.8</td>
<td>-1.5</td>
<td></td>
</tr>
<tr>
<td>active leisure activities</td>
<td>.70</td>
<td>0.0</td>
<td>-0.4</td>
<td></td>
</tr>
<tr>
<td>driving</td>
<td>.77</td>
<td>-0.6</td>
<td>-2.2</td>
<td></td>
</tr>
<tr>
<td>making trips</td>
<td>.56</td>
<td>-1.1</td>
<td>-0.8</td>
<td></td>
</tr>
<tr>
<td>gardening</td>
<td>.52</td>
<td>-1.3</td>
<td>-1.1</td>
<td></td>
</tr>
<tr>
<td>fixing things</td>
<td>.55</td>
<td>-0.4</td>
<td>-0.5</td>
<td></td>
</tr>
<tr>
<td>reading books</td>
<td>.59</td>
<td>-2.0</td>
<td>0.0</td>
<td></td>
</tr>
<tr>
<td>watching television</td>
<td>.70</td>
<td>-1.2</td>
<td>-2.2</td>
<td></td>
</tr>
</tbody>
</table>

II. Cognitive functioning of the patient
Left and right hemisphere patients did not differ significantly in reasoning abilities (t=0.6, p=.54), verbal memory (t=-0.4, p=.70), memory for paired faces (t=0.3, p=.81) or in memory for paired names (t=0.0, p=.98). Right hemisphere patients, however, had significant more omissions on the test measuring neglect (t=-2.1, p=.04). Left and right hemisphere patient did not differ in severity of receptive language disturbances (LH: mild n=6, severe n=1, RH: mild n=3, severe n=1, I=0.1, p=.42). Left hemisphere patients, on the other hand, were significantly more disturbed in speech (LH: mild n=18, severe n=7, RH: mild n=7, severe n=0, I=0.5, p=.00).

As Table 7 shows, no significant correlations were found between disagreement scores on the presence of changes on the one hand and memory and reasoning scores on the other. Also, expressive speech or receptive language disturbances on part of the patient were not significantly related to disagreement scores (range of correlations
Disagreement between right sided stroke patients and partners on the presence and severity of change was significantly associated with the total number of stars cancelled on the Star Cancellation task ($r_s=-.41, p=.02$). Significant disagreement between patient and partner on the severity of emotional and cognitive changes was only seen in the right hemisphere group, therefore correlations between disagreement on severity of change and cognition and mood were only performed in the right hemisphere group.

Table 7. Correlations ($r_s$) between measures of cognition and mood and disagreement between stroke patients and partners.

<table>
<thead>
<tr>
<th>Subjective changes in emotion and cognition</th>
<th>Left (n=36) Presence change</th>
<th>Right (n=34) Presence change</th>
<th>Severity change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total disagreed</td>
<td>partner $&gt;$ patient $^a$</td>
<td>patient $&gt;$ partner $^b$</td>
<td>Total disagreed</td>
</tr>
<tr>
<td>Cognitive tests</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td>.16</td>
<td>-.09</td>
<td>.32</td>
</tr>
<tr>
<td>Reasoning</td>
<td>.13</td>
<td>-.09</td>
<td>.25</td>
</tr>
<tr>
<td>Neglect</td>
<td>.10</td>
<td>.08</td>
<td>.07</td>
</tr>
<tr>
<td>Mood</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>General distress patient</td>
<td>.59**</td>
<td>.08</td>
<td>.60**</td>
</tr>
<tr>
<td>Stroke Impact score patient</td>
<td>.48**</td>
<td>-.01</td>
<td>.62**</td>
</tr>
<tr>
<td>General distress partner</td>
<td>.38*</td>
<td>.37*</td>
<td>.02</td>
</tr>
<tr>
<td>Stroke Impact score partner</td>
<td>.28</td>
<td>.32</td>
<td>-.02</td>
</tr>
</tbody>
</table>

$^a$ Change reported by partner, but not by patient

$^b$ Change reported by patient, but not by partner

III. Mood of patient and partner

Before correlating mood of stroke patients and mood of partners with disagreement scores, it is important to see if the amount of distress in the right hemisphere group differs from the amount of distress in left hemisphere patients and partners. There appeared to be no significant differences in total HADS score between left and right hemisphere patients or between partners in both hemisphere groups. On the depres-
sion subscale, 22% of the right-sided stroke patients and 26% of the left-sided stroke patients scored above cut-off (>5). These percentages were not significantly different ($X^2 = 0.17$, $p=.50$). On the anxiety subscale, percentages above cut-off (>6) were similar for both hemisphere groups: 14 % for the right hemisphere stroke patients and 13% for the left hemisphere stroke patients ($X^2=0.00$, $p=.92$). For both the anxiety and depression scale, 24% of the partners of left sided stroke patients and 31% of the partners of right sided stroke scored above cut-off ($X^2=0.45$, $p=.50$).

The difference on the reported presence of emotional and cognitive changes was correlated with the HADS total score and the HADS stroke impact score of patients and partners. Table 7 shows significant correlations between distress of the partner and the number of changes acknowledged by the partner, but not by the patient (LH, $r_s=.37$, $p=.03$ ;RH $r_s=.51$, $p=.00$). On the opposite, for both left and right hemisphere patients, a significant relation was found between distress of the patient, attributed to the stroke event, and the number of changes reported by the patient, but not by the partner (LH, $r_s=.62$, $p=.00$ ;RH $r_s=.36$, $p=.04$). Within the left hemisphere group, this correlation with distress of the patient was also visible in the total disagreement scores ($r_s=.59$, $p=.00$). However, within the right hemisphere group, no significant relation was found between distress of the patient and general disagreement on the presence and severity of changes.

**Discussion and conclusions**

**Presence and severity of emotional and cognitive changes**

Most studies on emotional changes after brain injury examine patients in the chronic phase after injury, perhaps in line with the idea that within the first months most attention is directed at physical recovery. This study shows that even at three months after stroke, both patients and partners reported a substantial number of cognitive and emotional changes. Only 12 percent of patients and 5 percent of partners reported no changes in the investigated emotions and cognitive functions. Cognitive changes that were reported by half of the patients and partners were mental slowness and impairments in memory. With regard to emotional changes, hyperemotionality, lowered initiative and heightened irritability were mentioned most frequently. The rank order of changes at three months post-stroke is in line with findings from a study of Hochstenbach (1999) nine months after the stroke event, although she found a higher percent-
Perceived emotional and cognitive change and side of damage

In the present study, based on the patients’ accounts, no substantial differences emerged between right-sided and left-sided stroke patients in the number and the severity of emotional and cognitive changes. On the basis of existing literature, one could have expected a different emotional reaction for left and right-sided stroke patients or a greater impact on emotional perception and expression in right-sided stroke patients (Borod et al., 1998; Gainotti, 1993). The rank order of changes reported by left and right hemisphere patients, although significantly related, nevertheless left room for a great proportion of variability between the order of changes in both hemisphere groups.

The agreement on emotional and cognitive changes between the patient group and partner group was only slight to fair. When comparing the perception of change between patients and partners, a difference appeared for the two hemisphere groups. While left hemisphere stroke patients generally agreed with their partners on the presence of symptoms, partners of right-sided stroke patients reported a greater number of changes than patients themselves. They reported twice as often changes in mental slowness and irritability than patients did. A similar result was found when comparing the severity of emotional and cognitive changes. Left hemisphere stroke patients also tended to agree with their partners on the severity of emotional and cognitive changes, while partners of right hemisphere stroke patient reported a greater amount of change than the patient. This was most pronounced on the items concerning change in mental slowness, irritability, the ability to rate oneself and planning abilities.

Factors related to disagreement between patient and partner

Level of observability

Several factors might contribute to the disagreement between stroke patients and their partners. In general, agreement between observers is greater when the level of
observability increases. Also in the present study, agreement between the total patient and partner group was far greater for the more observable changes in activities (Kappa .52 -.77) than for changes in emotion and cognition (Kappa .10 -.48). No significant disagreement was present for change in each activity of the patient, but when examining overall change in level of activity, again right hemisphere stroke patients reported less change than their partners, while left hemisphere patients agreed with their partners.

**Perception of change related to cognitive functioning**

Disagreement between patient and partner could also originate in an impaired ability of the patient to have insight into the changes that occurred after stroke. As previous studies suggest, impaired awareness is more commonly observed after right-sided stroke (Hibbard et al., 1992). Impaired awareness on the part of the stroke patient could be caused by several factors, including impairments in cognition. In the present study, disagreement scores between patients and partners were used to approach the concept of impaired insight. The present results showed no significant relation between disagreement scores and performance on tasks of memory and reasoning abilities. This lack of correspondence was also found in research on agreement between patients with severe head injury and their relatives (McKinlay & Brooks, 1984). Although severe aphasic patients were excluded from the present study, it could be that either receptive language disturbances or expressive speech difficulties in the patient influenced disagreement scores. The results showed that aphasic disturbances were not significantly related to disagreement between patient and partner. Several studies demonstrated that impaired awareness is often accompanied by hemispatial neglect (McGlynn & Schacter, 1989). Also in the present study, disagreement between right-sided stroke patients and partners on emotional changes was significantly related to the severity of unilateral neglect.

**Perception of change related to mood**

It was proposed that changes in mood could affect the observation and reporting of changes in both stroke patients and their partners. The present results confirmed that greater distress in both left and right hemisphere patients was related to a greater number of changes reported by the patients compared to their partners. Vice versa, greater distress in partners of both left and right hemisphere patients was related to a greater number of changes reported by the partners compared to the patients. When investigating total disagreement scores, it appeared that distress of the partner was also
related to the total number of items on which the presence of change was disagreed. However, for patients, distress was only associated with the total number of items disagreed in the left hemisphere group. The association between total disagreement and distress was not present in right hemisphere patients.

McKinlay & Brooks (1984) suggested that disagreement between patient’s and relative’s report of post injury changes could partly be caused by a distorted perception of a neurotic partner. In the present study, distress of the partner was measured which reflects both underlying personality traits as well as the present emotional state of the partner. Partners were also asked to indicate if their distress could be attributed to the stroke event. In the present study, it seems unlikely that the distress of partners of right sided stroke patients was the cause of the disagreement between patient and partner. First, distress of the partner was related to greater disagreement in both left and right hemisphere groups. Second, in partners of right hemisphere stroke patients, only distress attributed to the stroke event was significantly related to total disagreement scores. It seems therefore far more likely that partners experience distress in response to the stroke event and the following changes in the stroke patient. One of these changes after stroke can be a reduced ability to reflect on one's behaviour.

Awareness of deficits: psychological defensive mechanism or neurological impairment?

In sum, the present results showed that almost all patients and their partners reported several changes in emotion and cognition after stroke. Partners of right hemisphere stroke patient did mention more and greater changes in emotion and cognition than patients themselves did. For all partners and for left hemisphere patients it appeared that a greater level of disagreement was related to a greater level of distress. However total disagreement scores were not associated with distress in right hemisphere patients. It could therefore be argued that the underreporting of changes in right hemisphere patients is a psychological defensive mechanism to successfully reduce distress. However, the level of anxiety and depression did not differ between left and right hemisphere patients. Moreover, the underreporting of changes in emotion and cognition by right hemisphere patients was related to the level of hemispatial neglect. The right hemisphere is thought to be involved in the representation of emotion as well as the higher level of representation of body state, therefore a right hemisphere stroke might impair both, when the integration of somatosensory information is disrupted (Damasio, 1999). McGlynn & Schacter (1989) propose that unawareness of complex deficits,
such as changes in cognition or behaviour involves frontal damage. A limitation of the present study is that extensive neuro-imaging data on the presence and extent of neurological damage in our patient group is not available, so no conclusions can be drawn about the involvement of frontal damage in the awareness of changes in behaviour and cognition. The present results do offer support for impaired awareness of emotional and cognitive change as a result of neurological damage within the right hemisphere and its effect on attentional mechanisms.

The implication for a neurological model of impairments in awareness might be, that it can be hard, if sometimes impossible, to enhance awareness in the patient. Impairments in awareness of changes after stroke can have great impact on the lives of patients and partners. It can, for example, seriously affect the motivation of the patient to participate in rehabilitation. Therefore, changes in emotion and cognition after stroke and the mechanisms involved in awareness of changes deserve great attention in both clinical practice and research. The present study underlines that changes in emotion and cognition after stroke can only be studied appropriately when the perception of close relatives is taken into account.
Subjective changes in emotion and cognition

References


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Subjective changes in emotion and cognition


Chapter 3

Longitudinal analysis of patients’ awareness of emotional and cognitive changes after stroke

Abstract

Aims of the present study were to investigate the time course of patients’ awareness of changes in emotion and cognition after stroke and to analyse the longitudinal relationship between lesion characteristics, neglect, mood and awareness. In addition, the longitudinal influence of awareness of the patients on their activity level was investigated. A sample of 57 first-ever ischemic stroke patients and partners were assessed at three (T1) and fifteen months (T2) post-stroke. The amount of awareness was measured by calculating the number of changes in emotion and cognition reported by partners, but not by patients. The results showed that changes in emotion and cognition were reported slightly more often by patients at T2 than at T1. At T2, only 10 to 15 percent of patients reported no changes at all. The number of changes reported by partners, but not by patients did not differ between left and right hemisphere groups. However, partners of right hemisphere patients reported a greater total number and severity of changes than patients themselves at both T1 and T2. The presence of silent brain infarctions and the level of neglect were related to greater unawareness in right hemisphere patients. In partners, distress was longitudinally related to the amount of unawareness in the patient, a relationship that strengthened in time for partners of right hemisphere patients. In left, but not right hemisphere patients, greater distress appeared to be longitudinally related to a greater awareness of changes. Finally, not the level of awareness, but greater disturbances in mood and more severe neglect were longitudinally related to a lower activity level in left and right hemisphere patients. The present results showed that less awareness of changes in emotion and cognition than one’s partner is not a temporarily phenomenon after stroke and supported the neurological basis of impaired awareness in right hemisphere patients.

Introduction

Although impairments in the awareness of disabilities are generally considered to impede rehabilitation after brain injury, relatively few studies have been conducted on this phenomenon in a stroke population. Awareness can be described as the capacity to perceive a situation, object, or interaction in a manner similar to other persons’ perceptions, while at the same time maintaining the sense of a private, subjective, or unique interpretation of an experience (Prigatano and Schacter, 1991). Awareness of deficits is not a unitary phenomenon: the awareness of changes after stroke can be inconsistent across physical, cognitive and affective domains (Jehkonen et al., 2000, Hibbard et al., 1992). Despite the fact that unawareness of deficits in behaviour and cognition is considered to be more prevalent and more persistent than unawareness of motor deficits, so far, the majority of studies on impairments in awareness have focused on the insight of patients with regard to the physical consequences of stroke (Hartman-Maeir et al., 2002, Wagner & Cushman, 1994, Hibbard et al., 1992, Anderson & Tranel, 1989).

Impairments in the awareness of cognitive or behavioural deficits after brain injury have been measured by comparing patients’ ratings of deficits to the ratings of relatives or professionals. Another methodology used to measure awareness of cognitive deficits is to compare patients’ reports of deficits to the outcome of cognitive tests. With regard to the ratings by patients, underestimation of disabilities after stroke can involve a failure to perceive changes as a consequence of neurological damage, but can also be considered a coping mechanism (Giacino & Cicerone, 1998). Another possibility for patients’ reports to deviate from reports of others or from the outcome of tests might be that, shortly after stroke, patients have not been able to experience the full extent of their deficits. A study on the development of awareness after brain injury showed that, according to patients describing this process retrospectively, awareness emerged when they had been able to compare current performance of activities to pre-morbid performance (Dirette, 2002).

The capacity to be aware of oneself has been described as a higher order cerebral function (Stuss & Benson, 1986). In stroke patients, poorer overall cognitive functioning has been related to greater unawareness (Marcel et al., 2004, Jehkonen et al., 2002, Wagner & Cushman, 1994). On the other hand, it was demonstrated that unawareness of deficits
could exist without impaired cognitive functioning or without cognition being more impaired than in patients with intact awareness (Marcel et al., 2004, Venneri & Shanks, 2004, Starkstein et al., 1992). In the present patient group, we showed that the level of unawareness was not related to memory or reasoning capacities at three months post-stroke (Visser-Keizer et al., 2002). The association between impaired awareness of deficits and hemispatial neglect has been demonstrated in several studies (Visser-Keizer et al., 2002, Heilman et al. 1998; McGlynn & Schacter, 1989; Motomura et al., 1988; Starkstein et al., 1992; Willanger et al., 1981).

The neuro-anatomical correlates of impairments in awareness after stroke are still subject of debate. Although some studies did not find greater overestimation of functioning in right compared to left hemisphere patients (Wagner & Cushman, 1994, Hibbard et al., 1992), most studies on patients with cerebrovascular lesions showed that awareness of deficits was more impaired in right hemisphere patients (Marcel et al., 2004, Hartman-Maeir, 2003, Visser-Keizer, 2002, Starkstein et al., 1992, Anderson & Tranel, 1989). Moreover, less awareness of deficits in the right hemisphere group was correlated with several lesion variables and with the presence of unilateral neglect (Hartman-Maeir, 2003, Visser-Keizer, 2002, Starkstein et al., 1992). In addition, unawareness of hemiparesis after stroke has been related to a high incidence of pre-existing subcortical atrophy (Ellis & Small, 1997, Starkstein et al., 1992).

The hypothesis that impaired awareness of one’s disabilities after brain injury is primarily a coping mechanism has not received much support so far. Greater distress in patients and partners has been related to greater post injury changes reported by both groups (McKinlay & Brooks, 1984, Visser-Keizer et al., 2002). However, less awareness of deficits neither protected patients from distress nor showed a clear relationship with mood of the patient (Starkstein et al., 1992, Visser-Keizer et al., 2002). Another point of view is to regard the discrepancy between patients and partners as caused by over-exaggeration of the extent of deficits by the partners. This view, however, does not account for the hemispheric differences and the relationship between impaired awareness and attentional deficits in stroke patients (Visser-Keizer et al., 2002).

Most studies on impaired awareness after brain injury compared patients’ ratings with ratings of others on only one occasion, neglecting it’s interactional nature. Hartman-Maeir and colleagues (2003) found awareness of functional disabilities to improve with-
in the first year after stroke. At admission to rehabilitation, right hemisphere patients significantly overestimated their functional abilities compared to a therapist rating. At discharge, their overall rating did not differ from the therapists’ rating. Similarly, Jehkonen et al. (2000) reported that awareness of illness and hemiparesis improved in right hemisphere stroke patients within the first year after stroke. Unawareness of neglect, however, was still present in some patients after one year. In both studies, less awareness of disabilities at onset or at discharge was related to poorer functional outcome (Hartman-Maeir et al., 2002, Hartman-Maeir et al., 2003; Jehkonen et al., 2000).

In the present study, the time course of awareness of cognitive and emotional changes after stroke will be analysed in a community based stroke group. Patients’ subjective reports of change will be compared to the reports of their partners at three and fifteen months post-stroke. The description of the course of awareness of the cognitive and emotional sequelae of stroke will be preceded by a description of the time course of the presence and severity of these changes as experienced by patients and partners separately. Both patients and partners can be increasingly confronted with changes in emotion and cognition within the first year post-stroke. Within this perspective, an increasing number or more severe changes reported by both patients and partners could be expected. On the other hand, it would be possible that less or less severe changes will be reported at fifteen than at three months post-stroke. Patients and partners might be able to cope better with the consequences of stroke, which might diminish emotional reactions of the patient. Furthermore, several functions could show recovery within the first year after stroke. As was described in the previous chapter, analyses within the present patient group at three months post-stroke showed significant disagreement on the presence and severity of cognitive and emotional changes between right hemisphere patients and partners. Furthermore, greater unawareness in the right hemisphere patient correlated significantly with more severe neglect. On the other hand, greater disturbances in mood of left hemisphere patients and of partners in both hemisphere groups correlated with greater total disagreement between patients and partners (Visser-Keizer, 2002). The longitudinal influence of these factors on the awareness of changes will be investigated in the present study. Attention will be directed at the impact of lesion side and the presence of silent brain infarctions preceding the stroke on the level of unawareness of patients. To investigate the longitudinal influence of impaired awareness on functional recovery, disagreement scores will be related to the activity level of patients.
In sum, the following questions will be addressed in the present study 1] what is the course of changes in emotion and cognition as experienced by left and right hemisphere patients and partners? 2] what is the course of the patient’s awareness of changes in emotion and cognition? 3] to what extent do lesion characteristics, neglect and mood of the patient and partner longitudinally relate to awareness of changes in emotion and cognition? 4] to what extent does the level of awareness longitudinally relate to activity level after stroke?

Methods

Subjects

Stroke patients were recruited by 100 General Practitioners from the northern part of the Netherlands and by the Stroke Unit of the University Hospital Groningen. Stroke was defined as an acute focal neurological deficit, with the symptoms lasting more than 24 hours, as shown by CT scan or of presumed vascular nature after appropriate clinical and neuroradiological diagnosis (WHO, 1989). At T1, data of 113 unilateral ischemic stroke patients were collected: 58 left hemisphere and 55 right hemisphere stroke patients (Visser-Keizer et al., 2002). At T2, a year later, 5 stroke patients had died, 10 were either physically or mentally not capable of participating again and 9 patients refused further participation. So at T2, 89 unilateral stroke patients were assessed again, 41 right hemisphere and 48 left hemisphere patients. It appeared that patients who dropped out of the study were significantly older and were more often of female gender. Drop-out mostly concerned patients without partner. Attrition was also related to the variables of interest: patients who dropped out of the study reported both a significantly greater number and a greater severity of changes in emotion and cognition at T1 than patients who stayed in the study.

At T1, data of 76 partners were collected, 42 partners of left hemisphere stroke patients and 34 partners of right hemisphere stroke patients. At T2, 65 partners were interviewed again, 29 of right hemisphere patients and 36 of left hemisphere patients. Non-participation of the partner at T2 was most often related to non-participation of the patient: 2 patients had died, 1 was not able to participate again and 4 patients refused further participation. Another 2 partners refused to be interviewed at T2. Partners
or patients who participated at T1 but no longer at T2 did not differ significantly from those couples who stayed in the study with regard to disagreement on the changes in emotion and cognition reported at T1.

A total of 57 couples were assessed twice: 26 right hemisphere patients and partners and 31 left hemisphere patients and partners. Left and right hemisphere patients did not differ significantly in age (LH, M=63.8, SD=11.4, RH, M=62.3, SD=8.6, t=-0.5, p=.59) educational level (LH, M=3.9, SD=1.4, RH, M=4.1, SD=1.6, Z=-0.4, p=.67) or basic independence in ADL as measured with the Barthel Index (LH, M=19.0, SD=2.1, RH, M=17.8, SD=4.2, Z=-1.1, p=.26). The majority of patients in both groups was male (LH 69%, RH 76%, X²=0.3, p=.57).

Data concerning silent brain infarctions were collected from the patient’s medical records, all patients underwent CT or MRI (8%) scanning. Silent brain infarctions were classified as such when infarct-like lesions or white matter lesions were visible on CT or MRI, without known history of stroke according to both the patient and the GP. Of the 57 stroke patients with partner who were assessed twice, data concerning silent brain infarctions were present for 25 left hemisphere and 25 right hemisphere patients. Scans of 7 left hemisphere patients (28%) and 8 right hemisphere patients (32%) showed silent brain infarctions in addition to a recent infarction of the brain.

**Materials**

**Changes in emotion and cognition**

Emotional and cognitive changes since the occurrence of the stroke were assessed at T1 and T2 using a 20-item questionnaire (see Table 3 for items). The questions are based upon clinical relevance according to both neuropsychological literature and interviews with partners of stroke patients (Schure, 1995). Both patients and partners were asked to rate the amount of emotional and cognitive change in the stroke patient on a 4-point scale running from ‘not changed’ (0) to ‘very much changed’ (3). The internal consistency of all items, assessed at three months post-stroke, was high in the partner’s form and moderate in the patient’s form (Visser-Keizer et al., 2002). Two total scores were calculated, a total score of all items on which change is present (range 0-20) and a total score of the severity of changes (range 0-60).
Unawareness of changes in emotion and cognition

Stroke patients and partners were compared on their judgement of the presence and severity of changes in emotion and cognition in the patient. With regard to the presence of change, three scores were calculated, (1) an overall disagreement score, indicating the total number of items on which the patient and the partner disagreed concerning the presence of change. This total score can be divided into (2) items on which the patient reported change, but the partner did not and (3) items on which the partner reported change and the patient did not. This last score will be used as a measure of unawareness of the patient.

Neglect

To measure unilateral neglect after stroke, the Star Cancellation Task, a subtest of the Behavioural Inattention Test (BIT) was administered (Wilson et al., 1987). The total number of stars encircled was summed (range 0-56). A dichotomous score indicating ‘neglect’ or ‘no neglect’ was also calculated. Patients who scored above the cut-off score presented in the BIT-manual, were given the score of (1). Stars omitted had to be in the field contralateral to the lesion, moreover the number of stars omitted in the contralateral field had to be greater than the number of stars omitted in the field lateral to the lesion. Independently of test scores, neglect was clinically diagnosed as (0) absent, (1) mild or (2) severe by a neuropsychologist during the interview. The combination of performance on the Star Cancellation Task and the clinical observation led to a score from 0 to 3. Patients with a combined score of 2 or more were diagnosed with neglect.

Mood

Depressive and anxious mood of both patients and partners was screened using the Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983). The HADS has anxiety and depression subscales both containing 7 items (scored 0 to 21). Higher scores indicate a greater likelihood of anxiety or depression. Although several studies found a two factor solution for the HADS using principal component analysis, both subscales correlate highly and can together be seen as an indication of the amount of general distress (Johnson et al., 1995; Spinhoven et al., 1997). The HADS has been well validated and showed sufficient internal reliability in different groups of Dutch subjects (Spinhoven et al., 1997).
Activities

The instrumental activities of daily life were assessed with ten items based on the Frenchay Activities Index (FAI) (Holbrook & Skilbeck, 1983). The 15 items of the original FAI can be divided into three subscales, ‘domestic activities’, ‘outdoor activities’ and ‘leisure activities’ (Sveen et al., 1999; Cockburn et al., 1990). In the present study, we included the subscales ‘outdoor activities’ and ‘leisure activities’. We omitted the item ‘gainful work’ to improve the reliability of the scale (Schuling et al., 1993). The total activity score was used in the statistical analyses (range 0-28).

Statistical analyses

To analyse the course from T1 to T2 of the total number and total severity of changes in emotion and cognition reported by patients, GLM Repeated Measures analyses followed by post-hoc LSD tests were performed. The comparison of frequencies per item between T1 and T2 was performed by McNemar’s Test for two related dichotomous variables, while the severity of changes was compared between T1 and T2 using Wilcoxon’s signed-rank test. Because multiple analyses were carried out simultaneously, the level of alpha (.05) was divided by the number of analyses (Bonferroni adjustment). These analyses were first performed in the total patient group and repeated in patients without partner and partners themselves. In all analyses, possible effects of lateralization of lesion were taken into account. Next, patients’ accounts of the number and severity of changes were compared to the accounts of their partners at T1 and T2 using Paired-Samples T-tests. The course of the disagreement scores from T1 to T2 was analysed using GLM Repeated Measures analyses, with side of lesion as between-subjects factor. Right and left hemisphere groups with or without silent brain infarctions were compared on the number of items reported by partners, but not by patients, using Independent-Samples T-tests. These analyses were performed in SPSS 10.0 for Windows.

Finally, Generalized Estimated Equations (GEE) were used to analyze the longitudinal relationship between neglect, mood and awareness of changes in emotion and cognition (Zeger & Liang, 1986). The advantage of GEE is that the dependency of repeated observations within persons is taken into account. An exchangeable correlation structure was chosen. GEE were also used to analyse the longitudinal influence of unawareness of changes in emotion and cognition, neglect and mood on the activity level of the patient. GEE-analyses were performed in SPIDA version 6.05.
Results

Course of changes in emotion and cognition reported by total stroke group

Number of changes

GLM Repeated Measures analyses show a slight increment from T1 to T2 in the total number of changes in emotion and cognition reported by patients (F=4.1, p=.05). The time course of these changes did not differ between right and left hemisphere stroke patients (Time*side, F=0.8, p=.36). Neither age nor gender was related to the course of the number of changes in emotion and cognition from T1 to T2.

After correction for multiple analyses, changes on separate items were not significantly mentioned more often at T2 than at T1. At both times of measurement, right and left hemisphere patients did not differ with regard to the frequency of changes. Changes most frequently reported by left hemisphere patients at T1 and T2 were impairments in memory (T1 44%, T2 63%), mental speed (T1 40%, T2 44%) and hyperemotionality (T1 38%, T2 37%). At T1, right hemisphere patients reported being hyperemotional (51%), more self-centred (37%) and more listless (34%) as most frequent changes after stroke. At T2, the three most frequently reported changes were impairments in memory (54%), mental speed (44%) and hyperemotionality (42%), the same as those reported by left hemisphere patients.

Severity of change

GLM Repeated Measures analyses showed that, overall, stroke patients reported slightly more severe changes in emotion and cognition at T2 compared to T1 (F=6.0, p=.02). The time course of these changes did not differ between right and left hemisphere patients (F=.04, p=.53).

With regard to the severity of change reported on individual items, after Bonferroni correction, right hemisphere patients reported more severe changes in hyperemotionality (Z=-3.2, p=.002) and memory (Z=-3.1, p=.002) at T2 compared to T1. Left hemisphere patients did not report more severe changes on individual items at T2 than at T1 when an alpha of .003 was applied. At both times of measurement, right and left hemisphere patients neither differed significantly on the total severity of change in emotion and cognition, nor on the severity of change reported on individual items.
Course of changes in emotion and cognition reported by patients and partners

As Table 1 shows, the group of patients without partner included at T1 and T2 appeared to be significantly older and consisted of more females than patients with partner. This pattern is consistent with demographical data of the Netherlands. Table 1 also shows that at T1 patients with partner reported significantly more severe and more frequent changes in emotion and cognition than patients without partner. At T2, the same trend was visible, although differences did not reach significance. The course of the total number and severity of changes did not differ between patients with and without partner.

Table 1. Comparison of demographic data, the number and the severity of emotional changes between patients with and without a partner at T1.
* p < .05, ** p < .01, *** p < .001 (two tailed)

<table>
<thead>
<tr>
<th></th>
<th>Patients without partner n=23</th>
<th>Patients with partner n=66</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>69.7 (13.1)</td>
<td>63.4 (10.4)</td>
<td>T=2.3*</td>
</tr>
<tr>
<td>Gender</td>
<td>Male n=7 (30%) Female n=16 (70%)</td>
<td>Male n=51 (77%) Female n=15 (23%)</td>
</tr>
<tr>
<td>Emotional changes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frequency</td>
<td>2.9 (3.1)</td>
<td>5.6 (4.1)</td>
</tr>
<tr>
<td>Severity</td>
<td>4.1 (3.7)</td>
<td>7.2 (6.0)</td>
</tr>
</tbody>
</table>

Number of changes

Different from the total patient group, neither patients with partner nor partners themselves reported a significantly greater number of changes at T2 than at T1 (F=1.4, p=.23, F=0.8, p=.37). The course of changes did not differ for partners of right and left hemisphere stroke patients (Time*Side, F=.04, p=.84). Further analyses showed that 47 percent of partners reported a greater number of changes at T2 than at T1, 16 percent reported a similar percentage, while 37 percent reported less changes at T2 than at T1. In the patient group, these percentages were respectively 51 percent, 12 percent and 37 percent.

Next, patients and partners were compared on their account of the number of changes at T1 and T2. Table 2 and Figure 1 show that left hemisphere patients did not differ...
significantly from their partners on the total number of changes at both times of measurement. Partners of right hemisphere patients, however, reported significantly more frequent changes than the patients themselves at both T1 and T2.

Figure 1. Number and severity of emotional and cognitive change reported by left (LH) and right hemisphere (RH) stroke patients and partners.

Table 2. Comparison of total number and severity of changes in emotion and cognition between left and right hemisphere patients and partners at T1 and T2.

<table>
<thead>
<tr>
<th></th>
<th>Left n=31</th>
<th>Right n=26</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number</td>
<td>Severity</td>
</tr>
<tr>
<td></td>
<td>T1 M (SD)</td>
<td>T2 M (SD)</td>
</tr>
<tr>
<td>Patient</td>
<td>4.6 (4.0)</td>
<td>5.6 (4.8)</td>
</tr>
<tr>
<td></td>
<td>5.7 (3.9)</td>
<td>6.3 (4.7)</td>
</tr>
<tr>
<td>Partner</td>
<td>5.9 (4.8)</td>
<td>6.6 (4.4)</td>
</tr>
<tr>
<td></td>
<td>9.0 (5.5)</td>
<td>9.5 (6.3)</td>
</tr>
<tr>
<td>T-value</td>
<td>1.8</td>
<td>1.0</td>
</tr>
<tr>
<td></td>
<td>3.6***</td>
<td>3.0**</td>
</tr>
</tbody>
</table>

* p < .05, ** p < .01, *** p < .001 (two tailed)
Table 3 shows the percentages change on individual items reported by patients and partners at T1 and T2. No significant differences were found between T1 and T2 when an alpha of .003 was applied. Although partners generally reported changes more frequently than patients, after Bonferroni correction, percentages of change on individual items did not differ significantly between patients and partners at both times of measurement.

Table 3. Percentages of emotional and cognitive changes as reported by left and right hemisphere patients and partners at T1 and T2.

<table>
<thead>
<tr>
<th>Emotional and cognitive change</th>
<th>Left (n=31)</th>
<th></th>
<th></th>
<th>Right (n=26)</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Patient</td>
<td>Partner</td>
<td>Patient</td>
<td>Partner</td>
<td>Patient</td>
<td>Partner</td>
</tr>
<tr>
<td>Hyperemotional</td>
<td>39</td>
<td>48</td>
<td>39</td>
<td>65</td>
<td>50</td>
<td>65</td>
</tr>
<tr>
<td>More listless</td>
<td>19</td>
<td>26</td>
<td>23</td>
<td>23</td>
<td>38</td>
<td>38</td>
</tr>
<tr>
<td>More self-centred</td>
<td>26</td>
<td>26</td>
<td>39</td>
<td>29</td>
<td>38</td>
<td>50</td>
</tr>
<tr>
<td>Mentally slower</td>
<td>39</td>
<td>68</td>
<td>39</td>
<td>71</td>
<td>38</td>
<td>65</td>
</tr>
<tr>
<td>Less initiative</td>
<td>39</td>
<td>35</td>
<td>32</td>
<td>29</td>
<td>27</td>
<td>54</td>
</tr>
<tr>
<td>Impaired memory</td>
<td>45</td>
<td>65</td>
<td>65</td>
<td>55</td>
<td>27</td>
<td>54</td>
</tr>
<tr>
<td>More sad, depressive mood</td>
<td>16</td>
<td>26</td>
<td>29</td>
<td>35</td>
<td>35</td>
<td>46</td>
</tr>
<tr>
<td>Presenting oneself more positively</td>
<td>23</td>
<td>23</td>
<td>19</td>
<td>19</td>
<td>50</td>
<td>58</td>
</tr>
<tr>
<td>More easily irritated</td>
<td>23</td>
<td>48</td>
<td>29</td>
<td>45</td>
<td>38</td>
<td>65</td>
</tr>
<tr>
<td>Overrating oneself</td>
<td>32</td>
<td>32</td>
<td>26</td>
<td>42</td>
<td>38</td>
<td>62</td>
</tr>
<tr>
<td>More impatient</td>
<td>23</td>
<td>42</td>
<td>35</td>
<td>39</td>
<td>27</td>
<td>42</td>
</tr>
<tr>
<td>Less concentration</td>
<td>32</td>
<td>29</td>
<td>39</td>
<td>52</td>
<td>31</td>
<td>69</td>
</tr>
<tr>
<td>More anxious</td>
<td>23</td>
<td>19</td>
<td>19</td>
<td>26</td>
<td>31</td>
<td>38</td>
</tr>
<tr>
<td>More restless</td>
<td>6</td>
<td>6</td>
<td>16</td>
<td>16</td>
<td>19</td>
<td>23</td>
</tr>
<tr>
<td>Overdependent</td>
<td>10</td>
<td>13</td>
<td>10</td>
<td>16</td>
<td>23</td>
<td>35</td>
</tr>
<tr>
<td>Less orientation time/place</td>
<td>3</td>
<td>16</td>
<td>13</td>
<td>10</td>
<td>23</td>
<td>27</td>
</tr>
<tr>
<td>Less interest in others</td>
<td>32</td>
<td>26</td>
<td>32</td>
<td>23</td>
<td>12</td>
<td>31</td>
</tr>
<tr>
<td>Less planning abilities</td>
<td>23</td>
<td>16</td>
<td>29</td>
<td>23</td>
<td>12</td>
<td>42</td>
</tr>
<tr>
<td>More demanding</td>
<td>3</td>
<td>23</td>
<td>13</td>
<td>32</td>
<td>8</td>
<td>27</td>
</tr>
<tr>
<td>More impulsive</td>
<td>6</td>
<td>6</td>
<td>13</td>
<td>13</td>
<td>0</td>
<td>27</td>
</tr>
<tr>
<td>No changes</td>
<td>19</td>
<td>3</td>
<td>10</td>
<td>10</td>
<td>11</td>
<td>0</td>
</tr>
</tbody>
</table>
Severity of change
The total severity of changes in emotion and cognition reported by patients with partners did not differ significantly from T1 to T2, although the level of significance was nearly reached (F=3.3, p=.07). As in the total patient group, the time course of changes did not differ between left and right hemisphere stroke patients (Time*Side, F=.03, p=.86). Partners of both right and left hemisphere stroke patients did not report significantly more severe changes at T2 compared to T1 (Time, F=2.1, p=.15, Time*Side, F=.08, p=.79). Table 2 and Figure 1 show that, again, ratings of left hemisphere patients did not differ from the ratings of their partners at both times of measurement, while partners of right hemisphere patients reported significantly greater changes than the patients at both T1 and T2.

When analysing the course of ratings of the severity of change on individual items from T1 to T2, no significant differences were found for partners or for stroke patients. In general, at both T1 and T2, partners reported more severe changes in emotion and cognition than patients themselves. After Bonferroni-correction, the only significant difference concerned partners of right hemisphere patients reporting greater changes in memory functioning than patients themselves at T2 (Z=-3.1, p=.002).

Course of awareness of changes in emotion and cognition

Disagreement on number of changes
GLM Repeated Measures analyses showed that the total number of items on which patients and partners disagreed increased significantly from T1 to T2 (F=4.2, p=.05), but this course did not differ for left and right hemisphere groups (time*side, F=0.4, p=.52). The level of awareness, the total number of items on which partners reported change but patients did not, did not differ from T1 to T2 (F=0.6, p=.45). Lateralization of lesion did not affect the time course of this variable (Time*Side, F=.08, p=.78). The number of items on which patients reported change, but their partners did not, showed a slight but non-significant increase from T1 to T2 (F=3.8, p=.06).

Table 4 shows that no significant differences were found on the number of items disagreed upon between both hemisphere groups at T1 or T2.
Table 4. Comparison between the right and left hemisphere group concerning the number of items disagreed between patient and partner.

<table>
<thead>
<tr>
<th></th>
<th>T1 Left (M, SD)</th>
<th>T1 Right (M, SD)</th>
<th>T-value</th>
<th>T2 Left (M, SD)</th>
<th>T2 Right (M, SD)</th>
<th>T-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Items disagreed</td>
<td>4.8 (2.8)</td>
<td>5.7 (3.2)</td>
<td>1.2</td>
<td>6.2 (3.1)</td>
<td>6.5 (4.0)</td>
<td>0.3</td>
</tr>
<tr>
<td>Partner &gt; patient</td>
<td>3.0 (2.9)</td>
<td>4.5 (3.6)</td>
<td>1.8</td>
<td>3.6 (3.3)</td>
<td>4.8 (4.1)</td>
<td>1.2</td>
</tr>
<tr>
<td>Patient &gt; partner</td>
<td>1.7 (2.1)</td>
<td>1.2 (1.9)</td>
<td>-1.0</td>
<td>2.6 (3.2)</td>
<td>1.7 (2.3)</td>
<td>-1.3</td>
</tr>
</tbody>
</table>

# Change reported by partner, but not by patient
## Change reported by patient, but not by partner

**Silent brain infarctions and awareness of changes in emotion and cognition**

Next, the impact of the presence of silent brain infarctions on awareness, the number of items reported by partners, but not by patients, was analysed. As Figure 2 illustrates, unawareness of the presence of changes in emotion and cognition was greatest in right hemisphere patients with silent brain infarctions. The difference between right hemisphere patients with and without silent brain infarctions reached significance at the second time of measurement (t=-2.6, p=.02). Within the left hemisphere group, the presence of silent brain infarctions did not influence the number of changes acknowledged by partners, but not by patients.

Figure 2. Number of changes in emotion and cognition reported by partners, but not by patients at T1 and T2 for left and right hemisphere patients with (RH/LH SBI) and without silent brain infarctions (RH/LH).
Longitudinal relationship between neglect, mood and awareness of changes

Neglect
At T1, 7 right hemisphere patients (23% of RH group) and 2 left hemisphere patients (5% of LH group) had unilateral neglect. From T1 to T2, 1 patient in each hemisphere group recovered from neglect. At T1, right hemisphere patients omitted significantly more items on a measure of neglect than left hemisphere stroke patients, at T2 this difference was no longer significant. Right hemisphere patients showed a slight and non-significant improvement on this task, while performance of left hemisphere remained on a similar level. Improvement in neglect scores showed a small, but significant correlation with an increasing number of changes reported at T2 than T1 by left hemisphere patients (rs=.40, p=.02). In right hemisphere patients, changes in neglect scores were not significantly related to differences in the number of changes reported at T2 compared to T1 (rs=-.29, p=.12).

The longitudinal relationship between neglect and awareness of changes in emotion and cognition was analysed with GEE. Table 5 shows a significant negative longitudinal relationship between neglect and the amount of awareness in right hemisphere patients. Worse performance on a measure of neglect, at any time of measurement, was significantly related to more items reported by partners but not by patients. Table 5 also shows an interaction between neglect and time, indicating that the relationship between neglect and unawareness of changes in the right hemisphere group strengthens at T2 compared to T1. In the left hemisphere group, no significant longitudinal relationship was found between neglect and awareness of changes in emotion and cognition.

Mood of patient
Right and left hemisphere patients with partner did not differ significantly in mood at T1 or T2. Mood of stroke patients with partner showed improvement in time (F=11.8, p=.001). The course of mood did not differ significantly for right and left hemisphere stroke patients (F=1.6, p=.21). More interestingly, patients with neglect at T1 showed a greater improvement in mood than patients without neglect at the first time of measurement (Neglect * Time, F=5.1, p=.03). In both hemisphere groups, improvement in mood was significantly related to improvement in the experienced changes in emotion and cognition (RH, rs=.38, p=.04; LH, rs=.48, p=.003).
Table 5 shows the significant results of the GEE-analyses concerning the longitudinal relationship between mood of the patient and awareness of changes in emotion and cognition. As was also demonstrated at three months post-stroke, greater disturbances in mood in the left hemisphere patients were significantly related to more items reported by patients that were not mentioned by partners. The strength of this relationship did not differ in time. There appeared to be no longitudinal relationship between mood of right hemisphere patients and awareness of changes in emotion and cognition.

Mood of partner
Mood of partners of right and left hemisphere stroke patients did not differ significantly. Mood of the partners also did not change significantly in time. In both hemisphere groups, improvement in mood of partners was significantly related to improvement in the changes emotion and cognition reported at T2 compared to T1 (RH rs=.63, p=.001; LH rs=.71, p=.000). As Table 5 shows, mood of partners of right hemisphere stroke pa-
tients was, at both times of measurement, significantly related to more changes reported by partners than by patients. Furthermore, this relationship strengthened in time. Mood of left hemisphere partners was also related to greater changes perceived by partners compared to patients at both T1 and T2, but the strength of this relationship did not differ in time.

**Longitudinal relationship between awareness of changes in emotion and cognition, neglect, mood and activity level**

Finally, the longitudinal relationship between awareness of changes in emotion and cognition, neglect, mood and activity level was analysed. Right and left hemisphere patients with partner did not differ in activity level at T1 or T2. Activity level of both left and right hemisphere patients increased significantly from T1 to T2 (Time, F=6.3, p=0.01; Time*Side, F=0.4, p=.54).

Table 6. Longitudinal relationship between neglect, mood of patient, awareness (partner>patient) and activity level for right and left hemisphere patients.

<table>
<thead>
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<td>0.2</td>
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<td>Partner&gt;Patient</td>
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Table 6 shows a significant negative longitudinal relationship between neglect, mood of the patient and the level of activity of the right hemisphere patient. The relationship between mood and activities differed for right hemisphere patients with and without neglect. Further analysis showed first that right hemisphere patients with neglect performed significantly fewer activities than patients without neglect at both T1 and T2. Second, within the group of right hemisphere patients with neglect, mood was negatively related to activity level at T1, but showed a positive relationship with activity level at T2. In right hemisphere patients, no longitudinal relationship was found between the awareness of changes in emotion and cognition and their activity level. In left hemi-
sphere patients, mood of the patient and a measure of neglect also showed a negative longitudinal relationship with the level of activities. Again, less awareness of changes in emotion and cognition was not significantly related to the activity level.

Discussion

Critical remarks

In the present study, the awareness of changes in emotion and cognition and its course after stroke were studied. Awareness was measured by comparing subjective reports of patients to subjective reports of partners. Obviously, one can argue about the question if reports of patients and partners are accurate. Furthermore, it has been demonstrated that agreement on the less visible aspects of behaviour is often low (Visser-Keizer et al., 2002, Hochstenbach, 1999, Dorman et al., 1997). The difficulty is that, in order to study change, one can only rely on reports of patients themselves or on reports of those who are able to compare current behaviour with behaviour preceding the stroke. The investigation of changes in emotion and cognition has great clinical value, as complaints of patients and partners are often the start of an intervention programme. Patients and partners generally experience most grief and burden with regard to functions that have diminished or qualities that are lost.

Awareness of deficits after brain injury has also been measured by comparing subjective ratings of deficits to the performance on tests. It can be questioned, however, if this is a valid and clinically appropriate way to measure unawareness of deficits. What is actually demanded of patients, often shortly after stroke, is to predict their performance on a test they have never carried out before. It has previously been described that, according to patients, they could gain awareness of deficits in comparing current performance to their premorbid performance (Dirette, 2002).

A limitation of the present study from a clinical point of view, is that awareness is measured with a questionnaire only. Previous studies have shown that, when investigating unawareness of deficits, patients’ personal reports should also be taken into account. While a patient could deny deficits on a questionnaire, ‘tacit’ or distorted knowledge of the deficit could be present during conversation (Marcel et al., 2004, Berti et al., 1998)
Course of changes in emotion and cognition

The present results showed that, on group level, stroke patients reported a slightly greater number and a greater severity of changes in emotion and cognition at T2 than at T1. When a correction for multiple analyses had been made, the percentages of patients and partners reporting change on individual items did not change significantly from first to second time of measurement. When the analyses of the time course of changes in emotion and cognition was repeated in the smaller group of patients with partner and partners themselves, a non-significant increment of the number and severity of changes was found.

Furthermore, it appeared that, within the group of patients assessed twice, stroke patients without partner reported fewer changes in emotion and cognition than patients with partner at T1. At T2, this difference was still present, but did not reach levels of significance. These findings can partly be attributed to the selective drop-out of patients. Patients who dropped out were mostly older female stroke patients without partner. Furthermore, patients who dropped out reported greater changes in emotion and cognition than those who stayed in the study. Another explanation for the greater number and severity of changes reported by patients with partner, might be that the presence of a partner influences the expression or the early awareness of these changes.

Further analyses showed that half of the stroke patients and partners reported a greater number of changes at T2 compared to T1. Previous analysis in the current patient group has shown that an increase in subjective changes in cognition was not related to the actual course of cognitive functioning after stroke (Visser-Keizer et al., 2003). Within the first year after stroke, patients and partners might become more aware of existing deficits, most likely caused by an increasing confrontation with these changes. This confrontation, in turn, might strengthen or induce emotional reactions. The confrontation in daily life might be of a self-discovering nature, but patients might also acquire knowledge through interaction with others. The question in which way brain injured patients learn from experiences and gain awareness is of the utmost importance for clinical practice. The present results further showed that one third of patients and partners reported fewer changes in emotion and cognition at T2 compared to T1. In both right and left hemisphere patients and in partners, the improvement in mood was related to fewer changes reported at T2 than at T1. This improvement might reflect a suc-
cessful coping with the consequences of the stroke, although improvement in both variables might also be caused by a recovery of function.

Although improvement can take place, the presents study showed that changes in emotion and cognition after stroke are common and cannot be regarded as temporarily phenomena. At fifteen months post-stroke, only 10 to 15 percent of patients and an even lower percentage of partners reported no changes in emotion and cognition at all. Right and left hemisphere patients did not differ with regard to the frequency of change on individual items. Most frequently mentioned changes at fifteen months post-stroke, reported by approximately half of the right and left hemisphere patients, were changes in memory, mental speed and emotionality. Overall, partners reported slightly greater percentages of change. These findings are in line with a Dutch study on changes in cognition and emotion in a group of stroke patients nine months after the stroke event (Hochstenbach, 1999).

**Awareness of changes in emotion and cognition**

Comparable to previous findings at three months post-stroke, at fifteen months post-stroke, right hemisphere stroke patients still reported a significantly lower number and less severe changes in emotion and cognition than their partners (Visser-Keizer et al., 2002). At both times of measurement, left hemisphere patients did not differ from their partners in ratings on the total number and severity of changes. The awareness of the patient was further investigated by comparing the agreement between patient and partner on the presence of change per item. The number of items reported by partners but not by patients did not change significantly in time. While research at three months post-stroke had shown that right hemisphere patients and partners disagreed on a significantly greater number of items than left hemisphere, this difference was not found at fifteen months post-stroke (Visser-Keizer et al., 2002). As the level of disagreement between right hemisphere patients and partners concerning the total severity of changes did not diminish, these findings are in line with a previous study on the awareness of physical disabilities (Hartman-Maeir et al., 2003) In this study, no significant differences were found between the two hemisphere groups in the incidence of overestimation, but more severe unawareness was found in right hemisphere stroke patients. The present study further showed that, within the group of right hemisphere patients, unawareness of the presence of changes was, at fifteen months post-stroke, significant-
ly greater in patients with silent infarctions to the brain preceding the clinically overt stroke. In left hemisphere patients, silent brain infarctions did not affect the awareness of changes. These data correspond to previous findings that showed a higher incidence of pre-existing atrophy in patients unaware of motor deficits (Ellis & Small, 1997, Starkstein et al., 1992). Detailed information concerning the neuro-anatomical structures lesioned lacks for a part of the current patient group, so no further conclusion can be drawn on the neural circuits involved in the awareness of deficits.

Both left and right hemisphere patients reported a slightly greater total number and greater severity of changes in emotion and cognition at fifteen compared to three months post-stroke. In line with studies that demonstrated improvement in awareness with regard to functional disability and hemiparesis, these results might suggest that stroke patients can become increasingly aware of changes in emotion and cognition (Hartman-Maeir et al., 2003; Jehkonen et al., 2000). Comparison with ratings of their partners suggests, however, that awareness concerning the total extent of these changes in emotion and cognition was incomplete in right hemisphere stroke patients. These results support the notion that unawareness of changes in emotion and cognition can be a persistent phenomenon (Hartman-Maeir et al., 2002, Wagner & Cushman, 1994, Hibbard et al., 1992, Anderson & Tranel, 1989)

**Longitudinal correlates of awareness of changes in emotion and cognition**

Mood of the patient and the partner and the severity of neglect were analysed with regard to their longitudinal relationship with awareness of changes in emotion and cognition after stroke. The correlational findings at three months post-stroke were replicated using the more robust method for analysing longitudinal relationships. In partners of both right and left hemisphere stroke patients, greater distress was longitudinally related to more changes perceived by partners than by patients themselves. It is likely that the mood of the partners colours their perception of the changes they perceive in the patient, while changes in the patient influence mood of the partner. In partners of right hemisphere patients, however, the relationship between mood and awareness strengthened as time after stroke passed. This can imply that impaired awareness of changes in right hemisphere stroke patients might cause increasing distress on partners in the chronic phase after stroke. In left hemisphere patients, greater distress was longitudinally related to more changes perceived by patients than by their partners.
This relationship between the awareness of changes and mood lacked in right hemisphere stroke patients. This finding has also recently been demonstrated in a study on the course of unilateral neglect after stroke (Appelros et al., 2004).

In line with previous studies, the level of unilateral neglect of right hemisphere stroke patients was longitudinally related to less awareness of changes in emotion and cognition compared to their partners’ account (Heilman et al. 1998; McGlynn & Schacter, 1989; Motomura et al., 1988; Starkstein et al., 1992; Willanger et al., 1981). Neglect did not improve significantly after three months post-stroke, but the relationship between the level of neglect and less awareness of changes after stroke strengthened in time. Quite interesting is the finding that in patients with neglect at three months post-stroke, mood showed greater improvement than in patients without neglect. Patients with persistent neglect and impaired awareness might emotionally not be affected by their deficits. However, as the assessment of mood was based on subjective reports of patients themselves, it may be that these reports are biased towards a more favourable account.

Longitudinal relationship between awareness of changes in emotion and cognition and activity level after stroke

The present study showed that not the level of awareness of changes in emotion and cognition, but the severity of neglect and the level of mood longitudinally predicted activities after stroke. This finding was found in both left and right hemisphere stroke patients. A remark that can be made is that, again, activity level is reported by patients themselves and might be biased. However, in order to rule out errors as much as possible, patients were not asked to evaluate their performance, but to estimate the frequency of activities. The present results correspond to several other studies that have described neglect as a negative predictor of outcome after stroke (Buxbaum et al., 2004, Appelros et al., 2003, Katz et al., 1999). Appelros et al. also found neglect but not anosognosia to be related to disability one year after stroke. They suggested that anosognosia more often occurs in patients who are cognitively impaired before the stroke (Appelros et al., 2003). This hypothesis seems interesting in the light of the recent results that patients with greater unawareness more often had pre-morbid silent brain infarctions. On the other hand, not the presence of silent brain infarctions perse, but the combination of silent infarctions and a lesion to the right hemisphere was related to greater unawareness.
Conclusions

Less awareness of changes in emotion and cognition than one's partner is not a temporary phenomenon and still existed in right hemisphere patients at fifteen months post-stroke. Although in comparison with their partners, left hemisphere patients sometimes underestimated changes in emotion and cognition after stroke, total reports of left hemisphere patients did not differ significantly from reports of their partner. In right hemisphere patients, the presence of silent brain infarctions and the severity of neglect were longitudinally related to impaired awareness. The relationship with neglect strengthened at fifteen months post-stroke, although mood of patients improved. These findings indicate a neurological basis of impairments of awareness after right hemisphere stroke. Not less awareness itself, but neglect showed a negative longitudinal relationship with activity level after stroke. However, continuous impaired awareness of changes in emotion and cognition can be related to increasing distress in partners of right hemisphere stroke patients. In clinical practice, attention must be directed at this small group of patients that remain less aware of their cognitive and behavioural deficits. So far, it has not been assessed systematically what methods can be used to improve awareness in those patients. If awareness cannot be improved, those surrounding the patient must be supported to be able to cope with these changes in the patient.
References


Awareness of changes in emotion and cognition


Chapter 4
Depressive and anxious mood after stroke

Abstract
Aims of the present study were describe the level and course of anxious and depressive mood from three to fifteen months post-stroke and to evaluate the effects of neurological variables, demographic factors, disabilities and life events on mood at fifteen months post-stroke. Mood was divided into late life and post-stroke mood by attribution of patients themselves. A group of 101 first-ever ischemic stroke patients was assessed at three and fifteen months post-stroke using self-report questionnaires. A control group consisting of 70 elderly subjects was also assessed with the same time interval. The results showed that late life anxious and depressive mood remained constant from three to fifteen months post-stroke, whereas post-stroke mood improved significantly. While disabilities not related to stroke were associated with late life mood, post-stroke disabilities were associated with post-stroke mood. Psychosocial disabilities best predicted post-stroke anxious and depressive mood at fifteen months post-stroke. For post-stroke anxiety, the experience of life events and younger age were also predictive of higher anxiety at follow-up.

Introduction

Post-stroke and late life depression

Estimates of the prevalence of major depression are 10 to 15 percent within the first few months after stroke in a community-based population (Burvill et al., 1995, House et al., 1991). Minor depression has been diagnosed in an additional 8 to 14 percent of community-dwelling stroke patients (Burvill et al., 1995, Pohjasvaara et al., 1998). The course of depression after stroke remains unclear as some researchers reported little diagnosable depression after one year (House et al., 1991), whether others mentioned one third of patients developing depressive symptoms within the first year after stroke (Herrmann et al., 1998). For several years, researchers have investigated the nature of depression after stroke, but have not reached similar conclusions (Aben et al., 2001). While some researchers stress the importance of neurological factors in post-stroke depression, others consider it primarily to be a psychological reaction to the consequences of stroke (Robinson et al., 1994; Gainotti et al., 1999). Recently, one recognizes that there is no definite evidence to accept or refute a solely neurological or psychological mechanism in the occurrence of depression following stroke (Whyte & Mulsant, 2002). Depression after stroke is multifactorial and might be regarded within a biopsychosocial model or stress-vulnerability model. (Oldehinkel et al., 2003, Whyte & Mulsant, 2002).

Neurological factors that have been associated with depression after stroke include stroke severity, vascular risk factors and silent brain infarctions (Dennis et al., 2000, Alexopoulos et al., 1997, Fujikawa et al., 1993). A relationship between depressive symptoms and lesion location has not been consistently demonstrated and seems, in part, dependent on the time of measurement since stroke onset (Carson et al., 2000, Robinson et al., 1984). Variables which can be viewed in terms of vulnerability are increasing age, female sex or psychiatric disorder prior to stroke (Dennis et al., 2000, Burvill et al., 1995, Herrmann et al., 1998). Stressors or psychosocial risk factors that have been found to influence depression after stroke were functional disability and other life events that occurred after stroke. (Bisschop et al., 2004, Singh et al., 2000, Herrmann et al., 1998, Bush, 1999, Burvill et al., 1997).

Some factors associated with post-stroke depression, have also been related to depression in a group of elderly people without brain damage. Prevalences of late life depression in a population based study lay around 15 percent (Schoevers et al., 2003a,
Depressive and anxious mood

Beekman et al., 2001). Recent studies showed older age, female gender, marital status, stressful life events and a history of anxiety or depression to be related to a higher incidence of depression in late life (Schoevers at al., 2003a, Schoevers at al., 2003b, Oldehinkel et al., 2003, Beekman et al., 2001; Palsson et al. 2001). Also, a mutual relationship between disability and depression has been established in both clinical and community dwelling elderly (Lenze et al., 2001).

Post-stroke and late life anxiety
In comparison to studies on depression, little studies have investigated anxiety after stroke, although in both stroke patients and elderly subjects without brain damage, the presence of depression is often associated with the presence of anxiety (Lenze et al., 2001; Castillo et al., 1995). A community-based stroke study showed that anxiety as measured with the Hospital Anxiety and Depression scale (HADS) occurred in 23 percent of patients 4 months post-stroke (Johnson et al., 1995). While physical disability is often found to be related to depression, a less strong relationship seems to exists between disability and anxiety after stroke (Dennis et al., 1999; Lenze et al., 2001). As for depression, a history of psychiatric disorders has also been related to the occurrence of early-onset anxiety after stroke (Castillo et al., 1995). The relationship between anxiety and lesion location has not been consistent across different studies (Castillo et al., 1993; Starkstein et al., 1990).

In studies on anxiety in community dwelling older persons, 10 percent of subjects scored above cut-off of the HADS anxiety scale, while 3 percent was diagnosed with generalized anxiety (Schoevers et al., 2003a, Beekman et al., 1998). In the few longitudinal studies that have been conducted on anxiety of elderly subjects, best predictors for becoming anxious were older age, being female and the occurrence of stressful life events, especially death of one’s partner (Schoevers et al., 2003a, de Beurs et al., 2000).

Aims of present study
To sum up, depressive and anxious mood are quite prevalent among older persons and raise to affect approximately one third of community-dwelling subjects after a stroke. Depression and anxiety often co-occur after stroke and are influenced by multiple factors, of which some can be viewed in terms of vulnerability and others as stress-inducing factors. Several of these factors related to post-stroke depression and anxiety seem to be the same as those found to affect late life depression and anxiety. In the
present study, the level and course of depressive and anxious mood of stroke patients will be compared to mood of age-matched controls. An attempt is made to distinguish post-stroke depression from late life depression by asking stroke patients themselves if their mood can be attributed to the stroke event. Furthermore, the predictive value of several factors for late life and post-stroke depressive and anxious at fifteen months post-stroke will be analysed. Vulnerability factors included are age, gender, marital status and lesion characteristics. In addition, the impact of physical and psychosocial disabilities and stressful life events after stroke will be investigated, the presence of which might induce stress.

**Methods**

**Stroke patients**

To obtain a sample not solely biased by admission to hospital or rehabilitation centres, 235 stroke subjects were recruited through the aid of 100 general practitioners (GPs) from the northern part of the Netherlands and the stroke unit of the University Hospital Groningen. All subjects approved of the fact that their medical history was provided by the GP. At T1, 122 patients met inclusion criteria and were willing and able to participate, while 101 patients could be included at T2. See Chapter 1 for a detailed prescription of patient exclusion and drop-out. Mean age of these patients was 65.4 (SD=11.9) at the start of the study, ranging from 32 to 93 years. The group consisted of 64 men and 37 women. Of these patients, 90 lived independently, 4 semi-independently and 7 lived in a nursing home. At T1, medication was recorded of 85 patients of whom 12 used sedative and 10 used antidepressive medication. At T2, medication as prescribed by the GP was collected of 99 patients. Sedative medication was now used by 9 patients and antidepressive medication by 10 patients. Non-participation at T2 was related to higher late life depression scores at T1. Patients who did and who did not participate at T2 did not differ in anxiety scores at T1.

**Control subjects**

Control subjects were recruited among the population of four general practices from the northern part of the Netherlands. A stratified randomisation procedure was used to match the control subjects to patients on age and gender. Control subjects with a history of psychiatric disturbances, neurological conditions or alcohol abuse were
excluded from the study. At T1 80 control subjects were interviewed. It appeared afterwards that one subject had suffered previous neurological damage, another subject had a history of psychiatric disturbances. Both were excluded from the study. At T2, the control group consisted of 70 subjects, 8 subjects had dropped out because they did not want to participate again (n=4), were too busy (n=2) or had moved (n=2). The level of anxious or depressive mood at T1 did not affect the participation at T2. Mean age of the control subjects at the start of the study was 66.9 (SD=11.9) which did not differ significantly from the age of the stroke subjects (t=0.8, p=.42). Within the control group, 39 men and 31 women participated, the ratio of gender did not differ significantly from the patient group (X²=1.0, p=.32). Neither did the percentage of subjects with or without a partner differ between patients and control subjects (79 % vs. 74 % with partner, X²=0.6, p=.45). Mean level of education was also comparable between patients and control subjects (Z=-0.2, p=.82). Next, control subjects did not differ from stroke patients in the use of antidepressive or sedative medication at T1 or T2 (T1, sedatives X²=0.3, p=.62; antidepressants X²=2.8, p=.10; T2 sedatives X²=0.4, p=.55; antidepressants X²=1.4, p=.24).

Lesion characteristics
Classification of the side of ischemic damage was based on neurological data. Of 91 patients CT-scan findings were present, mean time between onset of stroke and CT-scan was 10 days (SD=36 days) with a range of 0 to 291 days. On the basis of all neurological data, lateralization of lesion of 98 patient could be classified: 41 had right-sided damage, 48 left-sided damage, 4 bilateral lesions and 5 had lesions affecting brain stem or cerebellum. As has been well documented, a stroke can be preceded by transient ischemic attacks or silent brain infarctions. In our study, one third of CT-scans of patients demonstrated one or more silent infarctions of the brain, localised either unilaterally or bilaterally. To be able to analyse the effect of silent brain infarctions on mood, patients are divided into three groups a) subjects with no silent brain infarctions, b) subjects with one silent brain infarction and c) subject with multiple silent brain infarctions.

Procedure and Measures
All subjects were assessed twice at their own place of residence by trained interviewers with an interval of approximately one year. After signing an informed consent, several questionnaires concerning functional ability, mood, changes in emotion and cognition...
and quality of life were administered. Only those instruments relevant for the current research question will be described.

**Depression and anxiety**
The Hospital Anxiety and Depression Scale (HADS) was used to measure anxious and depressive mood (Zigmond & Snaith, 1983). The HADS has an anxiety and a depression sub-scale both containing 7 items (scored 0 to 21). Higher scores indicate a greater likelihood of anxiety or depression. According to Johnson et al. (1995), when examining a community based stroke group, best cut-off scores for the HADS are 5 for the depression scale and 6 for the anxiety scale. Following de Beurs et al. (2000), when measuring change in HADS scores from T1 to T2, only scores who exceed the cut-off and have changed with 3 or more scale points are considered to be changed reliably. Both sub-scales of the HADS correlate highly, although principal component analysis demonstrated a two factor solution for the HADS in several studies (Johnson et al., 1995; Spinhoven et al., 1997).

In the present study, after a confirmative answer on an item of the HADS, stroke patients were asked if they attributed the depressive or anxious mood questioned in this item to the stroke event. Total anxiety and depression scores can thus both be divided into a stroke related score, the addition of scores attributed to the stroke event, and into a total of scores not attributed to the stroke event. Both stroke related and non-stroke related scores are divided by the number of items to obtain a mean score. The non-stroke related depression and anxiety of stroke patients and the depression and anxiety of control subjects will be further referred to as respectively late life depression and late life anxiety.

**Physical and psychosocial disabilities**
The Stroke Adapted –Sickness Impact Profile (SA-SIP) is a 30-item stroke-adapted version of the original SIP (van Straten et al., 1997; Bergner et al., 1981). The SA-SIP measures functional health status on 8 subscales. All items are scored ‘yes’ (1) or ‘no’ (0); scores range from 0-30 with higher scores indicating poorer functional health. Principal component analysis has shown that a physical dimension can be formed by the scales Body care and movement, Mobility, Household management and Ambulation. A psychosocial dimension can be formed by the scales Social Interaction, Communication, Emotional Behaviour and Alertness Behaviour. Internal reliability proved to be
high for both the physical scale (alpha=.82) and the psychosocial scale (alpha=.78) (van Straten, 1997). In the present study, after each item of the SA-SIP, stroke patients were asked if the disability is seen as a consequence of stroke. All items on which impairment is attributed to stroke were summed, as well as the items that were not related to stroke.

Life events
The Social Readjustment Rating Scale was adapted to assess the number and impact of life events experienced within the year between measurements (Holmes & Rahe, 1967). Only the ten items ranked most highly on their estimated influence on life changes were presented to the stroke patients and the control subjects. Next, subjects could report other life events that were not covered by these ten items. Subjects could indicate how they experienced the impact of the life event with scores ranging from (0) none to (5) very much. Both the number of life events and their impact scores were calculated to overall scores. When examining the effect of separate life events, only those events reported by at least 10 percent of subjects will be analysed.

Statistical analysis
Mood of stroke patients and control subjects was compared by using independent samples T-tests. Chi-square analyses were used to compare the number of patients and controls scoring above depression and anxiety cut-offs. To measure change in the level of mood from T1 to T2, paired samples T-tests were performed, while changes in cut-off scores were analysed using Mc Nemar’s test for two dichotomous related variables.

The evaluation of factors predictive of mood at T2 was performed in two steps. First the association between demographic variables, physical and psychosocial disabilities and life events on the one hand and late life and post-stroke mood on the other was evaluated by investigating correlations and by comparing means. Next, the combined predictive value of the investigated variables was analysed using the GLM univariate procedure. Continuous predictor variables were entered into the regression model as covariates, while dichotomous variables were entered as fixed factors. All statistical analyses were performed in SPSS 9.0.
Results

Late life and post-stroke anxiety and depression for stroke patients and control subjects at T1 and T2

Investigation of correlations
At T1, 75 percent of depression scores and 64 percent of anxiety scores of stroke patients were attributed to the stroke event. At T2, patients attributed 67 percent of depression scores and 50 percent of anxiety scores to the stroke.

For control subjects, at both times of measurement, depression scores were significantly related to anxiety scores (T1, r=.48, p=.00; T2 r=.42, p=.00). For stroke patients, post-stroke depression scores correlated significantly with post-stroke anxiety scores (T1 r=.52, p=.00; T2 r=.42, p=.00) as was also the case for late life depression and anxiety scores (T1 r=.26, p=.01; T2 r=.22, p=.03). There were no significant correlations between post-stroke anxiety scores and late life anxiety (T1 r=.04, p=.69; T2 r=.05, p=.59) or between both depression scores (T1, r=-.19, p=.06; T2 r=-.11 p=.29).

Comparison of anxiety and depression scores between patients and controls
Comparison of the total HADS anxiety scores of stroke patients and control subjects at T1 and T2 showed that anxiety scores did not differ significantly between the two groups (T1, Stroke: M=2.7, SD=3.1, Control: M=2.0, SD=3.0 t=-1.6, p=.11; T2, Stroke: M=2.0, SD=2.7, Control: M=1.4, SD=2.3, t=-1.5, p=.13). Comparison of late life anxiety scores also showed no significant differences between the two groups at T1 and T2 (T1: t=1.2, p=.22; T2: t=0.6, p=.57). Total depression scores were significantly higher for patients than controls at both times of measurement (T1, Stroke: M=3.4, SD=3.2, Control: M=1.1, SD=1.5, t=-6.3, p=.000; T2, Stroke: M=2.5, SD=3.3, Control: M=1.4, SD=2.0, t=-2.7, p=.008). Further analysis showed that late life depression scores did not differ significantly between the two groups (T1, t=0.1, p=.96; T2, t=1.5, p=.13).

Impact of lesion characteristics on late life and post-stroke anxiety and depression
When comparing unilateral right and left hemisphere stroke patients at T1 and T2, neither post-stroke nor late life mood scores differed between the two groups (Late life anxiety: T1, t=0.2, p=.82; T2, t=0.1, p=.91; Post-stroke anxiety: T1, t=0.7, p=.50; T2, t=0.1, p=.50).
Depressive and anxious mood

$p=.93$; Late life depression: $T1, t=-0.3, p=.76$; $T2, t=1.9, p=.07$; Post-stroke depression: $T1, t=-0.1, p=.92$; $T2, t=-1.0, p=.34$). The presence of silent brain infarctions also did not significantly affect late life or post-stroke mood at three or fifteen months post-stroke (Late life anxiety: $T1, F=1.3, p=.29$; $T2, F=2.7, p=.07$; Post-stroke anxiety: $T1, F=0.5, p=.60$; $T2, F=1.5, p=.23$; Late life depression: $T1, F=0.4, p=.67$; $T2, F=2.1, p=.13$; Post-stroke depression: $T1, F=0.2, p=.81$; $T2, F=1.8, p=.17$).

Course of anxiety and depression scores

Figure 1 and Table 1 show that post-stroke depression and anxiety improved significantly from $T1$ to $T2$. For both patients and controls, late life anxiety and depression remained at the same level between $T1$ and $T2$.

GLM Repeated Measures analyses showed significant improvement from $T1$ to $T2$ in post-stroke anxiety ($T1$, $F=16.4, p=.000$, $T2$, $F=0.6, p=.43$) and post-stroke depression ($T1$, $F=10.7, p=.002$, $T2$, $F=0.5, p=.50$) for both right hemisphere and left hemisphere stroke patients. Furthermore, the presence of silent brain infarctions did not affect the course of post-stroke depression ($T1$, $F=1.2, p=.28$) or post-stroke anxiety scores ($T1$, $F=.07, p=.80$).

Figure 1. Course of mean late life (LL) and post-stroke anxiety and depression scores from $T1$ to $T2$ for stroke patients and control subjects.
Table 1. Paired-samples t-test of post-stroke and late life anxiety and depression between T1 and T2 for patients (n=100) and control subjects (n=70).
* p <.05; ** p < .01, *** p <.001 (two-tailed)

<table>
<thead>
<tr>
<th>HADS scores</th>
<th>Patient T1 M (SD)</th>
<th>Patient T2 M (SD)</th>
<th>Paired t-value</th>
<th>Control T1 M (SD)</th>
<th>Control T2 M (SD)</th>
<th>Paired t-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Late Life Depression</td>
<td>0.2 (0.3)</td>
<td>0.1 (0.3)</td>
<td>0.5</td>
<td>0.2 (0.2)</td>
<td>0.2 (0.3)</td>
<td>-1.9</td>
</tr>
<tr>
<td>Post-stroke Depression</td>
<td>1.1 (1.0)</td>
<td>0.7 (0.8)</td>
<td>3.8***</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late Life Anxiety</td>
<td>0.2 (0.4)</td>
<td>0.2 (0.3)</td>
<td>1.1</td>
<td>0.3 (0.4)</td>
<td>0.2 (0.3)</td>
<td>2.0</td>
</tr>
<tr>
<td>Post-stroke Anxiety</td>
<td>0.8 (0.9)</td>
<td>0.4 (0.7)</td>
<td>4.8***</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Prevalences of total anxiety and depression

As Table 2 presents, at both times of measurement, significantly more patients scored above depression cut-off than controls. Patients did not differ from controls, however, in the proportion of subjects scoring above anxiety cut-off or in the number of new anxiety or depression cases. Unilateral right and left hemisphere stroke patients did not differ in the number of subjects scoring above cut-off at T1 or T2 for anxiety or depression.

Table 2. Number and percentages of patients (n=100) and control subjects (n=70) scoring above HADS depression and anxiety cut-off at T1 and T2 and number and percentages of subjects scoring above HADS depression and anxiety cut-off at T2, but not at T1 (new cases).
* p < .05, ** p < .005, *** p <.001 (two-tailed)

<table>
<thead>
<tr>
<th></th>
<th>T1 stroke n (%)</th>
<th>Control n (%)</th>
<th>X²</th>
<th>T2 stroke n (%)</th>
<th>Control n (%)</th>
<th>X²</th>
<th>New cases stroke n (%)</th>
<th>Control n (%)</th>
<th>X²</th>
</tr>
</thead>
<tbody>
<tr>
<td>HADS dep</td>
<td>28 (28)</td>
<td>3 (10)</td>
<td>16.2***</td>
<td>17 (17)</td>
<td>3 (4)</td>
<td>6.4 *</td>
<td>6 (6)</td>
<td>2 (3)</td>
<td>0.9</td>
</tr>
<tr>
<td>HADS anx</td>
<td>14 (14)</td>
<td>7 (10)</td>
<td>0.6</td>
<td>12 (12)</td>
<td>5 (7)</td>
<td>1.1</td>
<td>5 (5)</td>
<td>2 (3)</td>
<td>0.5</td>
</tr>
</tbody>
</table>

At T1, 8 patients (29% of depressed cases and 57% of anxious cases) were both anxious and depressed, at T2 this occurred in 7 patients (41% of depressed cases, 58% of anxious cases). In the control group, 1 subject was both depressed and anxious at T1 and T2. Statistical analyses showed significantly less depression cases on T2 compared to T1 for patients, but not for controls. Anxiety cases did not differ significantly from T1 to T2 for both patients and controls.
Factors related to late life and post-stroke depression and anxiety at T2

Age
In the control group, age was positively related to depression scores ($r=.35$, $p=.003$) but not to anxiety scores ($r=-.00$, $p=.95$). For stroke patients, there was a small, nonsignificant, relation between age and late life depression scores at T2 ($r=.16$, $p=.11$). There appeared to be no significant relation between age of the patients and post-stroke depression scores ($r=.11$, $p=.30$). Age of the patients, however, correlated negatively with post-stroke anxiety scores, indicating greater anxiety among younger stroke patients ($r=-.28$, $p=.005$). No relationship was present between age and late life anxiety for stroke patients ($r=-.07$, $p=.52$).

Gender
Male control subjects did not differ from female subjects on depression or anxiety scores at T2 (Depression: Male, $M=1.0$, SD=1.4; Female, $M=1.7$, SD=2.5, $t=-1.3$, $p=.20$, Anxiety: Male, $M=1.5$, SD=2.2, Female, $M=1.4$, SD=2.5, $t=0.1$, $p=.94$). In the stroke group, gender had neither an effect on mean post-stroke depression scores nor on mean post-stroke anxiety scores (Depression: Male, $M=0.8$, SD=0.9; Female, $M=0.6$, SD=0.7, $t=0.9$, $p=.37$, Anxiety: Male, $M=0.4$, SD=0.7, Female, $M=0.4$, SD=0.8, $t=0.3$, $p=.78$). Female stroke patients, however, had significantly higher mean late life anxiety scores than male stroke patients (Depression: Male, $M=0.1$, SD=0.2; Female, $M=0.2$, SD=0.3, $t=-1.2$, $p=.22$, Anxiety: Male, $M=0.1$ SD=0.2, Female, $M=0.3$, SD=0.4, $t=-2.4$, $p=.02$).

Marital status
The presence of a partner did not seem to affect mood at the second time of measurement, although depression scores tended to be somewhat higher for both control subjects and stroke patients who did not have a partner compared to subjects with partner (Controls: $M=2.0$, SD=2.4 vs $M=1.1$, SD=1.8, $t=-1.7$, $p=.09$, Patients: $M=1.4$, SD=2.7 vs $M=0.7$, SD=1.3, $t=-1.3$, $p=.21$).

Physical and psychosocial disabilities
At T2, physical and psychosocial disability scores were higher for patients than for controls. (Physical disability: $M=4.4$, SD=4.3 vs $M=1.5$, SD=2.2, $t=-5.7$, $p=.00$; Psychosocial disabilities: $M=3.7$, SD=3.2 vs $M=1.5$, SD=2.3, $t=-5.3$, $p=.00$).
Table 3 shows correlations between non stroke related and post-stroke physical and psychosocial disabilities at T2 and late life and post-stroke mood at T2. In the control group, a significant relationship was found between physical disabilities and psychosocial disabilities on the one hand and depression and anxiety scores on the other. For stroke patients as well, a significant relationship was found between psychosocial disabilities not related to stroke and late life depression and anxiety. Physical disabilities not related to stroke were, however, only significantly associated with late life depression but not with late life anxiety. Post-stroke physical and psychosocial disabilities were significantly related to both post-stroke depression and post-stroke anxiety.

Table 3. Bivariate Pearson’s correlations between late life and post-stroke mood and non stroke related (NS-) and post-stroke (PS-) physical (PHYS) and psychosocial (PSYCHO) disabilities for patients (n =100) and control subjects (n=70) at T2. * p <.05; ** p <.01; *** p <.001 (two-tailed)

<table>
<thead>
<tr>
<th></th>
<th>Control PHYS</th>
<th>Control PSYCHO</th>
<th>Patient NSPHYS</th>
<th>Patient NSPSYCHO</th>
<th>Patient PSPHYS</th>
<th>Patient PSPSYCHO</th>
</tr>
</thead>
<tbody>
<tr>
<td>Late Life Depression</td>
<td>.52***</td>
<td>.37**</td>
<td>.40***</td>
<td>.27**</td>
<td>-.10</td>
<td>-.13</td>
</tr>
<tr>
<td>Post-stroke Depression</td>
<td>.02</td>
<td>.10</td>
<td>.46***</td>
<td>.47***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Late Life Anxiety</td>
<td>.26*</td>
<td>.30*</td>
<td>-.01</td>
<td>.24*</td>
<td>.08</td>
<td>.11</td>
</tr>
<tr>
<td>Post-stroke Anxiety</td>
<td>-.18</td>
<td>.03</td>
<td>.34**</td>
<td>.51***</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Life events

Patients (n=82) and controls (n=70) retrospectively reported a mean of one life event within the previous year. The mean impact of life events did not differ between patient and control group (M=2.4 vs M=3.0, Z=-.8, p=.41). The most frequently mentioned life event was ‘death of a family member or friend’, reported more often by control subjects (n=31) than by patients (n=22) (X²=5.1, p=.02). This life event was also ranked most highly concerning the impact score. Eleven control subjects mentioned an illness of themselves within the last year and 21 patients mentioned an illness other than the stroke within the year after stroke (X²=2.2, p=.14). The third frequent life event was ‘illness of a family member’, reported by 17 control subjects and 15 stroke patients (X²=0.8, p=.37). Table 4 shows that life events within the previous year were significantly related to late life anxiety for control subjects, but to post-stroke anxiety for stroke patients. In stroke patients, the impact of personal illness was related to higher post-stroke anxiety (rs=.32, p=.004). Within the control group, no relationship was found between the impact of individual life events and mood.
Table 4. Spearman’s correlations between number and impact of Life events (LE) and late life depression (LLDEP), post-stroke depression (PSDEP), late life anxiety (LLANX) and post-stroke anxiety (PSANX) for control subjects (n=70) and stroke patients (n=82) at T2.

* p <.05; ** p <.01; *** p <.001 (two-tailed)

<table>
<thead>
<tr>
<th></th>
<th>Control LLDEP</th>
<th>LLANX</th>
<th>Patients LLDEP</th>
<th>PSDEP</th>
<th>LLANX</th>
<th>PSANX</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number LE</td>
<td>.11</td>
<td>.22</td>
<td>.19</td>
<td>.13</td>
<td>.00</td>
<td>.32**</td>
</tr>
<tr>
<td>Total impact LE</td>
<td>.13</td>
<td>.31**</td>
<td>.21</td>
<td>.04</td>
<td>.06</td>
<td>.15</td>
</tr>
</tbody>
</table>

Multivariate prediction of late life and post-stroke anxiety

In correlational analyses, several factors were found to influence anxiety and depression in both control subjects and stroke patients at T2. All variables showing a significant relation to either anxiety or depression at T2 were entered into the General Linear Model. For late life depression and anxiety these included age, gender, non stroke related disabilities, and number and impact of life events. The same variables were used to predict post-stroke mood, except now post-stroke disabilities were entered as covariates.

Table 5. GLM multivariate prediction of late life (LLANX) and post-stroke anxiety (PSANX) in patient group and late life anxiety scores (LLANX) of control subjects at T2.

<table>
<thead>
<tr>
<th></th>
<th>Control LLANX</th>
<th>Patient LLANX</th>
<th>PSANX</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F</td>
<td>p</td>
<td>F</td>
</tr>
<tr>
<td>Age</td>
<td>0.8</td>
<td>.38</td>
<td>0.1</td>
</tr>
<tr>
<td>Gender</td>
<td>0.3</td>
<td>.61</td>
<td>8.4</td>
</tr>
<tr>
<td>Post-stroke physical disabilities</td>
<td>1.0</td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>Post-stroke psychosocial disabilities</td>
<td>12.4</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td>Non stroke related physical disabilities</td>
<td>3.8</td>
<td>.06</td>
<td>2.1</td>
</tr>
<tr>
<td>Non stroke related psychosocial disabilities</td>
<td>1.3</td>
<td>.26</td>
<td>8.7</td>
</tr>
<tr>
<td>Total number of life events</td>
<td>1.6</td>
<td>.21</td>
<td>1.4</td>
</tr>
<tr>
<td>Total impact of life events</td>
<td>3.9</td>
<td>.05</td>
<td>1.1</td>
</tr>
<tr>
<td>Corrected model (including intercept)</td>
<td>2.6</td>
<td>.03</td>
<td>3.3</td>
</tr>
</tbody>
</table>

As Table 5 shows, 6 percent of the variance of anxiety in the control group could be explained by the impact of life events (Corrected model, R²=.21). Gender predicted 10 percent of the variance of late life anxiety for stroke patients, while non-stroke related psychosocial disabilities explained another 11 percent (Corrected model, R²=.21). For
post-stroke anxiety several predictors could be found among which impairments in psychosocial functioning after stroke had the greatest impact. Younger age and the experience of a greater number of life events also predicted worse anxiety scores at fifteen months post-stroke (Corrected model, $R^2=.34$).

**Multivariate prediction of late life and post-stroke depression**

Table 6 presents the outcome of the GLM analyses used to predict depression scores at T2. Within the control group, 12 percent of the variance of depression could be explained by physical disabilities. Age did not appear to explain variances in depression independently from disabilities (Corrected model, $R^2=.34$). Late life depression in stroke patients at T2 could not be predicted by the model used in the analyses (Corrected model, $R^2=.14$). Of post-stroke depression, 25 percent of variance could be explained by age of the patient and psychosocial disabilities after stroke, while physical disabilities did not appear to be an independent significant predictor (Corrected model, $R^2=.34$).

**Table 6. GLM multivariate prediction of late life (LLDEP) and post-stroke depression (PSDEP) in patient group and late life depression scores (LLDEP) of control subjects at T2.**

<table>
<thead>
<tr>
<th></th>
<th>Control LLDEP</th>
<th>Patient LLDEP</th>
<th>PSDEP</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F</td>
<td>p</td>
<td>F</td>
</tr>
<tr>
<td>Age</td>
<td>1.5</td>
<td>.22</td>
<td>0.2</td>
</tr>
<tr>
<td>Gender</td>
<td>0.0</td>
<td>.89</td>
<td>0.0</td>
</tr>
<tr>
<td>Post-stroke physical disabilities</td>
<td>0.0</td>
<td>.98</td>
<td>1.6</td>
</tr>
<tr>
<td>Post-stroke psychosocial disabilities</td>
<td>17.1</td>
<td>.00</td>
<td>8.3</td>
</tr>
<tr>
<td>Non stroke related physical disabilities</td>
<td>0.3</td>
<td>.62</td>
<td>0.0</td>
</tr>
<tr>
<td>Total number of life events</td>
<td>0.7</td>
<td>.11</td>
<td>1.8</td>
</tr>
<tr>
<td>Total impact of life events</td>
<td>5.3</td>
<td>.00</td>
<td>2.0</td>
</tr>
<tr>
<td>Corrected Model (including intercept)</td>
<td>5.3</td>
<td>.00</td>
<td>2.0</td>
</tr>
</tbody>
</table>

**Discussion**

**Late life and post-stroke mood**

In the present study, late life and post-stroke mood was distinguished by stroke patients themselves. This process of attribution of mood to different causes could, however, be distorted, for example by impairments in cognition or emotion after stroke. Also, the
emotional impact of the stroke event itself can bias patients to attribute all existing disturbances in mood to the impact of stroke. Besides, when both stroke-related and non-stroke related factors affect mood in the same individual, it can be hard to disentangle the two. Despite these possible biases, several findings in the present study support the distinction between late life mood disturbances and post-stroke changes in mood based on the perception of patients. First, post-stroke mood was not related to late life mood. Second, the level of late life depression and anxiety did not differ between stroke patients and elderly control subjects without cerebral pathology. Moreover, in both groups, mean level of late life anxious and depressive mood did not change significantly over time. In contrast, post-stroke anxious and depressive mood improved between three and fifteen months post-stroke. Next, while disabilities not related to stroke were associated with late life mood, disabilities after stroke were associated with post-stroke mood.

Course of late life and post-stroke mood
An important aim of this study was to describe the course of mood between three and fifteen months post-stroke. During this time interval, 21 percent of patients dropped out. Non-participation of stroke patients was in part selective: it appeared to be related to a higher level of late life depression at three months post-stroke. Stroke patients lost from T1 to T2 were also older and physically more severely disabled than subjects who stayed in the study. The results therefore concern the less depressed, less disabled and somewhat younger stroke patients.

Between three and fifteen months post-stroke, the percentage of depressive stroke patients decreased significantly, but remained significantly higher than the percentage of control subjects scoring above cut-off. The depression cases in the stroke group, 28 percent at T1 and 17 percent at T2, are similar to other community based stroke studies (House et al., 1991; Johnson et al., 1995). Because of the relative low number of subjects who scored above cut-off, depression and anxiety cases have not been further divided into stroke related or non-stroke related, which can be interesting for studies using larger samples. The percentage of depressive control subjects (4%) is similar to another study on late life depression in the Netherlands (de Beurs et al., 2001), but is quite low. This might partly be caused by the exclusion of subjects who had gone through depressive episodes prior to participation in the study. The new incident depression cases, 6 percent for patients and 2 percent for control subjects are similar to those found in
the prospective study of Andersen and colleagues (1994). It is important to note that the incidence of new depression cases between three and fifteen months post-stroke did not differ from the incidence of new cases in elderly controls.

In both the stroke and control group, the level of anxiety was related to the level of depression. Analyses of double cases within the stroke group showed that anxiety was more strongly related to depression than vice versa. In contrast to depression, neither anxiety scores nor the number of anxious subjects differed between stroke patients and elderly control subjects. Also, the number of anxiety cases in the stroke group did not decrease between T1 and T2. The percentage of stroke patients scoring as anxious, 14 percent at three and 12 percent at fifteen months post-stroke, is quite low in comparison to another community based study (Johnson et al., 1995). Again, the selection criteria used in this study could be partly responsible for the relative low number of anxious patients. Stroke patients with previous psychiatric disorders were excluded, the occurrence of which has been related to early-onset anxiety after stroke. The proportion of elderly control subjects with anxiety scores above cut-off, 10 percent at T1 and 7 percent at T2, are in line with another study of community dwelling older persons (Beekman et al., 1998).

Prediction of late life and post-stroke mood
Another important aim of the present study was to evaluate the role of different contributing factors for late life and post-stroke depression and anxiety at fifteen months post-stroke. In the present study, only those patients and controls were included who were not diagnosed or treated for previous psychiatric disorders. It might be that in this group a different risk profile is related to the onset of depression or anxiety than in subjects with previous psychiatric disorders. Vulnerability and stress-inducing factors included in the present study were neurological factors, demographical variables, disability measures and stressful life events.

It appeared that late life depression in stroke patients could not be predicted adequately by the current model. Of post-stroke mood at fifteen months post-stroke, 25 to 30 percent of variance could be explained. This indicates that several other factors not included in this study mediate the occurrence of depression or anxiety. One of them could be personality characteristics such as neuroticism (de Beurs et al., 2001) or individual coping styles.
Multivariate prediction of late life and post-stroke anxiety

In stroke patients, the experience of psychosocial disabilities was predictive of both late life and post-stroke anxiety. As has also been found in previous research, physical disabilities were less strongly related to anxiety and did not emerge as a significant predictor for late life or post-stroke anxiety (Dennis et al., 2000). Besides psychosocial disabilities, female gender predicted higher late life anxiety in stroke patients, while younger stroke patients experienced greater post-stroke anxiety. These findings are in line with those from a study of anxiety up to two years after stroke (Schultz et al., 1997). An explanation for these findings might be that the impact of disabilities after stroke might be greater in younger stroke patients. Analyses of the cognitive functions of the present patient group, for example, showed that older stroke patients did not differ from the control subjects on a diversity of cognitive tasks, while stroke patients below the age of 65 were significantly more impaired than control subjects similar in age (Gerritsen, 2004). In the present study, psychosocial disabilities were not predictive of anxiety in the control group. Psychosocial disabilities include a diversity of cognitive, social and emotional disabilities, some of them specifically affected after stroke. They should be further analysed to gain insight into those factors that have greatest impact on anxiety after stroke.

In both patients and controls, a greater number or a higher impact of life events was related to a greater level of anxiety, but not to higher depression scores. Contrary to a recent longitudinal study in the Netherlands, individual stressful life events did not appear to be related to late life anxiety scores in elderly community dwelling subjects (de Beurs et al., 2001). Possibly, serious life events occurred too infrequently to be able to measure significant effects, for example only three control subjects reported the loss of one’s partner. In stroke patients, however, the personal life event of illness to oneself was associated with anxiety after stroke. This is in line with the ideas of Finley-Jones and Brown (1981) who suggested that life events involving threat can lead to anxiety. The finding that individual threatful life events do relate to anxiety in stroke patients, contrary to control subjects, indicates that patients may have become more vulnerable after stroke.

Late life and post-stroke depression

In univariate analyses, the side of lesion and the presence of silent brain infarctions did not affect the level or course of mood after stroke. These findings fit with recent
reviews that could not find consistent replications concerning the impact of specific lesion sites on depressive mood after stroke (Carson et al., 2000, Whyte & Mulsant, 2002). Furthermore, in studies that did find an association between specific lesion locations and depression, the impact was quite small and seemed restricted to the acute phase after stroke (Whyte & Mulsant, 2002). In line with previous studies, physical disabilities appeared as most predictive for depression in elderly controls (Lenze et al., 2001). However, in stroke patients not physical but psychosocial disabilities after stroke most strongly predicted post-stroke depression. While older age was not associated with post-stroke depression in single correlational analysis, it emerged as a predictor in multivariate prediction. This last finding is most likely confounded by the association between older age and greater physical disabilities. A great number of previous studies have investigated the impact of physical disabilities on depression after stroke. The present study indicates that the broad range of psychosocial disabilities should also be subject of investigation.

A biopsychosocial model of post-stroke mood?

At first glance, the importance of the experience of psychosocial disabilities for post-stroke mood and the lack of influence of lesion characteristics seem to offer support for a psychological rather than a neurological model of mood in the chronic phase after stroke. However, extensive neuro-imaging data lacked for a part of the stroke patients, so a proper investigation of the impact of specific lesion sites on mood after stroke could not be performed. On the other hand, the association between psychosocial disabilities and mood does not preclude any effect of the lesion location on mood after stroke. Psychosocial disabilities include a diversity of cognitive, social and emotional disabilities which could be both a direct and an indirect effect of stroke. The present study showed that slightly different factors increased the vulnerability for post-stroke anxious and depressive mood. In addition to greater disabilities that predicted both post-stroke depressive and anxious mood, younger age and the experience of life events after the occurrence of a stroke influenced anxiety at fifteen months post-stroke.
References


Depressive and anxious mood


Chapter 5

Depressive mood and cognitive functioning after stroke

Abstract

Little consensus exists on the relationship between depressive mood and cognitive functioning after first-ever ischemic stroke. In the present community-based study 99 patients were examined at three months post-stroke and 80 of them at fifteen months after stroke onset. An observer-rated (PSDRS) and a self-rated (HADS) depression scale, cognitive tests and a questionnaire for subjective cognitive changes were administered. Although patients with depressive mood had increasingly more cognitive complaints than those without, the patients did not differ in cognitive test scores when mood was self-rated. Moreover, change in mood was not related to change in cognitive performance. When the PSDRS criteria were applied, patients with depressive mood appeared to be mentally slower than those without. The frequently suggested relationship between post-stroke depression and cognitive impairments was confirmed for the subjectively experienced cognitive changes, but only few relations between objectively measured cognitive impairment and depressive mood were found in this study. Moreover, the data demonstrated the decisive role of the instruments that are used to assess depressive mood and cognitive performance after stroke.

Chapter 5

Introduction

Both cognitive disorders and depressive symptoms are common sequelae of stroke. Their relation, however, is still unclear (Gainotti & Marra, 2002). Several studies have found depression and cognitive disorders after stroke to be related (Andersen et al., 1996; Bolla-Wilson et al., 1989; Desmond et al., 2003; Kauhanen, Korpelainen, & Hiltunen, 1999; Robinson, Bolla-Wilson, & Kaplan, 1986; Murata, Kimura, & Robinson, 2000; Spalletta et al., 2002), while others did not (Dam, 2001; Kase, et al., 1998; Madureira, Guerreiro, & Ferro, 2001). It has been suggested that a relationship between post-stroke depression and cognitive disorders only exists in a selection of patients, like in stroke patients with a major depression (Robinson et al., 1986), or in left hemisphere stroke patients (Bolla-Wilson et al., 1989; Spalletta et al., 2002). According to Kauhanen and co-workers (2000), especially stroke patients with aphasia are at risk for developing post-stroke depression, but within their group of aphasic patients no differences between patients with and without depression were found in neuropsychological test scores.

Several hypotheses about the nature of the relationship between post-stroke depression and cognition have been postulated. Robinson and colleagues (1986) suggested a theory that relates to ‘dementia of depression,’ in which major depression is thought to cause cognitive disorders. In subsequent longitudinal and depression treatment studies they reported an association between the improvement in mood of depressed stroke patients and an improvement in cognitive functioning as measured with the Mini-Mental State Examination (MMSE) (Kimura, Robinson, & Kosier, 2000; Murata, et al., 2000; Narushima et al., 2003). The authors argue that if ‘dementia’ was primarily due to structural brain damage it would remain unchanged irrespective of improvement in mood. House and co-workers (1990) on the other hand did not confirm this hypothesis; they did not find major depression to be associated with a different intellectual outcome after stroke. Moreover, Andersen and colleagues (1996) did not find an improvement in intellectual functioning in depressive stroke patient, despite improvement in mood. Based on their results they even suggested the opposite hypothesis ‘depression of dementia.’ Finally, depression and cognitive disorders might be concomitant but independent consequences of stroke as one might conclude from the fact that several studies did not find post-stroke depression and cognition to be related.
In the stroke studies that investigated the relation between post-stroke depression and cognitive functioning rather different measures were applied. Often a dementia screening instrument, like the MMSE, was used as the only tool to assess cognitive functioning, or even dementia (Anderson et al., 1996; House et al., 1990; Kase et al., 1998; Kimura et al., 2000; Murata et al., 2000; Narushima et al., 2003; Robinson et al., 1986; Spalletta et al., 2002), while some others used a more extensive neuropsychological test battery (Bolla-Wilson et al., 1989; Dam, 2001; Desmond et al. 2003; Kauhanen et al., 1999; Madureira et al, 2001). Using a neuropsychological test battery Bolla-Wilson and co-workers (1989) found that depressed left hemisphere patients, without language disorders, performed worse on tasks for language and fluency, orientation, and Luria motor sequences, than left and right hemisphere patients without depression or right hemisphere depressive patients. No significant correlations were found between depression and memory performance and visuoconstructive functions. Kauhanen and colleagues (1999), on the other hand, showed that memory, psychomotor speed, problem solving, and attention were the cognitive domains that were most likely to be defective in depressed stroke patients.

For the assessment of depression too, a wide variety of measures has been used that may lead to different results (Schramke et al., 1998). Pohjasvaara and colleagues (2002) for example found that a higher score on a self-rated depression scale (Beck) was related to executive dysfunction, but an observer-rated scale (MADRS) and a clinical psychiatric evaluation were not. Some authors favour the use of semi-structured interviews to diagnose depression based on DSM-III-R or DSM-IV criteria (Robinson, & Starkstein, 1997). This method has been found to be valid by some authors (Federoff et al., 1991, Paradiso & Robinson, 1999; Starkstein & Lischinsky, 2002), while others recommend caution because of the physical symptoms included in the diagnosis of depression that could be due to the brain lesion and not the depression (Desmond et al., 2003; Gainotti, et al., 1997; Schramke et al., 1998). Gainotti and colleagues (1997) compared stroke patients with and without depression and non-brain damaged patients with functional depression, using the Post-Stroke Depression Rating Scale (PSDRS). They concluded that post stroke depression was mainly caused by exogenic factors related to the consequences of the stroke.

The goal of the present study is to investigate the relationship between depressive mood and cognitive functioning after first-ever ischemic stroke in a community based
population. Depressive mood was assessed with both an observer-rated and a self-rated depression scale. In this study ‘depression’ was always considered in terms of depressive mood, since the used scales are not designed to diagnose depressive disorder. Besides a dementia screening instrument, tests of memory, speed of information processing, and reasoning were administered, using at least three instruments for each cognitive domain. Moreover, subjective cognitive changes as experienced by the patients themselves and by their partners were registered as well.

To gain more insight into the causal relations between cognition and depression, the course of cognitive functioning and depressive mood was assessed with a one-year time interval between three and fifteen months after stroke onset. In sum, the main questions in this study are 1] is cognitive functioning in the three cognitive domains speed of information processing, memory, and reasoning, related to depressive mood according to an observer-rated and/or a self-rated depression scale? 2] is the course of cognitive functioning related to the course of depressive mood after stroke? 3] does cognitive functioning differ between left and right hemisphere stroke patients with depressive mood?

**Methods**

**Subjects**

Patients who were clinically diagnosed as having a unilateral, first-ever, ischemic stroke were recruited from 100 general practitioners (GPs) in the northern part of the Netherlands, and from the stroke unit of the University Hospital Groningen. The GPs and the stroke unit presented 235 stroke patients. Neurological and GPs’ reports were checked, and 47 patients did not meet the stroke-related inclusion criteria (unilateral, first-ever, and ischemic). Moreover, other neurological disorders, psychiatric diseases, or alcohol abuse were criteria to exclude patients from the study (n=13). Finally, patients had to be able to keep up the testing procedures for at least half an hour, which appeared to be impossible for 17 patients. Aphasic patients were included in this study, unless they were unable to understand even the simplest test-instructions (n=7). Nine patients died before the neuropsychological test-procedure. Eventually, a group of 142 patients met all criteria, and 99 of them were willing to participate in the interview and neuropsychological test-procedure at three months post stroke (T1). One year after the first
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assessment (T2) 80 of the 99 patients again participated in the study (3 had died, 3 were too ill, 2 had suffered a second stroke, and 11 did not want to co-operate any longer). To compose a comparable control group, control subjects (n=72) were also recruited by four of the GPs. The controls were matched to the patients on age and gender. They had no history of stroke, had no other neurological or psychiatric disorders, and no history of alcohol abuse. One year after the first assessment 64 control subjects were examined again (4 were too ill to participate any longer, 3 didn't feel like it, and 1 moved abroad).

Materials

Mood
The Hospital Anxiety and Depression Scale (HADS) is a self-rating scale with a depression and an anxiety scale; in this study the depression scale was used (Zigmond & Snaith, 1983). The scores range from zero to 21, higher scores indicating more depressive mood. According to Johnson and colleagues (1995) the cut-off score for the HADS-depression scale should be 5 when a community based stroke group is studied. In the present study, change from T1 to T2 had to be at least 3 points to be considered reliable (Vermeer et al., 2002). This scoring leads to four subgroups: subjects who did not show a depressive mood at either T1 or T2 (non-depressive cases: NONDEP), individuals who had a depressive mood at both T1 and T2 (depressive cases: DEP), people with a depressive mood at T1 but no longer at T2 (recovered cases: REC), and finally those who had a depressive mood at T2 but not yet at T1 (new cases: NEW).

A neuropsychologist also rated mood of 99 patients and 71 control subjects after a structured interview. The neuropsychologist was blind for the cognitive data, but not for the HADS-questionnaire. The first section of the Post Stroke Depression Rating Scale (PSDRS) (Gainotti et al., 1997) was used to rate the level of depressive mood, ranging from ‘well balanced mood’ (0) to ‘gloomy black mood’ (5). The cut-off for depressive mood was set at 2: ‘mood clearly more oriented toward sadness and pessimism than before illness’. Change from T1 to T2 on the PSDRS led again to four subgroups (non-depressive, depressive, recovered and new cases).

Cognitive functioning
A Dutch dementia screening test, the Cognitive Screening Test (CST-20) was administered to all subjects (De Graaf & Deelman, 1992). The CST-20 is comparable to the MMSE
with respect to the reliability and validity, while the CST-20 is less sensitive to the influence of age, education, depression and premorbid intelligence (Schmand, Deelman, Hooijer, Jonker, & Lindeboom, 1996). The maximum score is 20 points, higher scores indicate better performance. The cut-off for possible dementia is 12 points.

To assess memory, a paired-associate learning task (the Couples Test) and the Rey Auditory Verbal Learning Test (AVLT) were used. The Couples Test is a paired-associate learning task with a verbal (Names) and non-verbal (Faces) subtest. Subjects had to memorise 10 couples of male and female first names or male and female faces, in five successive trials. In each trial all stimuli, the couples, are presented, and immediate recall is measured by asking the subjects to match the females with the males (forced guessing). To reduce the chance for guessing five distracters, not previously presented female names or faces, were added when the recall was tested. The Dutch version of the AVLT is a test in which subjects have to learn 15 one-syllable words in five successive trials (Saan & Deelman, 1986). The sum score of the free recalls on the 5 trials was used. The mean of the percentages correct in each completed memory tests renders a total memory score, higher scores indicating better performance.

Speed of information processing was measured using a reaction time apparatus that registered both movement and decision times. In this study only the decision times, measured in four tasks, were used. Decision times were measured in milliseconds. The visuomotor decision time is the mean of the median decision times on a simple and an eight choice reaction time task (Van Zomeren & Deelman, 1976). The cognitive decision time represents the mean of the median decision times on two semantic categorisation tasks, one verbal (words) and one non-verbal (pictures) (Gerritsen et al., 2003).

Reasoning was assessed using the Snijders Oomen Non-verbal Intelligence Test (SON-R 5 ½ -17). Originally the SON-R 5 ½ -17 was constructed for deaf children (Snijders, Telegen, & Laros, 1989), but the test appeared to be reliable and valid to be used in older adults as well (Gerritsen, Berg, & Deelman, 2001; Lezak, 1995). Based on pilot studies three subtests were selected for the present study: Categories (abstract reasoning), Stories (concrete reasoning) and Mosaics (visuospatial abilities). The reasoning score represents the mean of the percentages correct in each of the completed subtests, therefore higher scores indicate better reasoning abilities.
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Subjective cognitive change
Subjective emotional and cognitive changes were assessed using a 20-item questionnaire. The questions are based upon clinical relevance according to both neuropsychological literature and interviews with partners of stroke patients (Schure, 1995). Both patients and their partners (n=73 at T1, n=69 at T2) were asked to rate the amount of emotional and cognitive change they attributed to the stroke on a 4-point scale ranging from ‘not changed’ (0) to ‘very much changed’ (3). For this study only the 5 questions concerning cognitive change were used: memory, slowness, orientation in time and place, planning, and concentration.

Procedure
The interview, in which several (neuro)psychological and health questionnaires were administered, and the neuropsychological assessment took place in three sessions of about two hours each. The first two sessions took place at the participant’s home; the third at the University Hospital Groningen. Participants who were not able to come to the hospital were again visited at home. The patients and the control subjects signed informed consent preceding the interview, and the study was approved of by the medical ethics committee of the University Hospital Groningen. The same procedure was followed at both T1 and T2.

Statistical analyses
The alpha level was fixed at 0.05, and all tests were two-tailed. First, the left and right hemisphere patients and control subjects were compared on age, gender and educational level with respectively the Student’s t-test, Mann-Whitney-U and Chi-square test. Moreover the relationship between these demographic variables and the mood scales were assessed with Spearman’s rho correlation coefficient and Chi-square tests. Second, the number of patients with depressive mood according to both scales are presented and compared to the number of control subjects with depressive mood using Chi-square tests. The number of patients who had depressive mood at both times (DEP), at T1 only (REC), at T2 only (NEW) and at neither T1 or T2 (NONDEP) are presented for the patients only, considering the very small numbers of control subjects with depressive mood. Third, the differences between the patients and the control subjects with respect to the neuropsychological test performances are analysed at both T1
and T2 using Student’s t-tests. This could not be done for the subjectively experienced cognitive change, as cognitive change due to stroke cannot be experienced by control subjects. Moreover, both groups were checked for the presence of dementia according to the CST. Fourth, the relationship between depressive mood and cognitive function was analysed comparing cognition of patients with and without depressive mood according to the HADS and according to the PSDRS at both T1 and T2. ANOVA was used for the objective neuropsychological test scores, Mann Whitney-U tests for the subjective data. To gain insight into the relationship over time, GLM repeated measures were used to analyse the interaction between Time, T1 versus T2, and Group: DEP, REC, NEW and NONDEP. This was done for the test scores, the subjective data according to the patients, and the subjective data according to the partners. Finally, the effect of the side of stroke was analysed. The number of left and right hemisphere patients with and without depressive mood were compared using Chi-square analysis. Within the patient groups with depressive mood, left and right hemisphere patients were compared using ANOVA for the test scores, and Mann Whitney-U tests for the subjective data. The course of mood between the subgroups (DEP, REC, NEW, NONDEP) could not be analysed due to the small sample sizes.

**Results**

*Sample and depression scale characteristics*

The subject characteristics are presented in Table 1. There were no differences in age, gender and education between the left and right hemisphere patients and the control subjects.

**Table 1. Comparison of demographical variables between left and right hemisphere patients and controls.**

<table>
<thead>
<tr>
<th>Group</th>
<th>T1 n</th>
<th>Age M (SD)</th>
<th>Gender</th>
<th>Education M (SD)</th>
<th>T2 n</th>
<th>Age M (SD)</th>
<th>Gender</th>
<th>Education M (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>RH-patients</td>
<td>47</td>
<td>66.5 (11.0)</td>
<td>male 62%</td>
<td>3.9 (1.5)</td>
<td>39</td>
<td>67.1 (10.8)</td>
<td>male 62%</td>
<td>3.9 (1.5)</td>
</tr>
<tr>
<td>LH-patients</td>
<td>53</td>
<td>66.6 (12.7)</td>
<td>male 66%</td>
<td>3.8 (1.2)</td>
<td>42</td>
<td>65.4 (11.6)</td>
<td>male 64%</td>
<td>3.9 (1.2)</td>
</tr>
<tr>
<td>Controls</td>
<td>72</td>
<td>66.0 (11.9)</td>
<td>male 54%</td>
<td>4.0 (1.4)</td>
<td>64</td>
<td>67.8 (11.94)</td>
<td>male 56%</td>
<td>4.2 (1.38)</td>
</tr>
<tr>
<td><strong>Group comparison</strong></td>
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<tr>
<td>Anova</td>
<td>F = 0.03</td>
<td>p = .97</td>
<td></td>
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<tr>
<td>Chi-square</td>
<td>$\chi^2 = 1.88$</td>
<td>p = .39</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>Kruskal-Wallis</td>
<td>H = 1.44</td>
<td>p = .49</td>
<td></td>
<td></td>
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<tr>
<td>Anova</td>
<td>F = 0.57</td>
<td>p = .57</td>
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<tr>
<td>Chi-square</td>
<td>$\chi^2 = 0.74$</td>
<td>p = .69</td>
<td></td>
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<td></td>
<td></td>
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<tr>
<td>Kruskal-Wallis</td>
<td>H = 1.57</td>
<td>p = .56</td>
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</tbody>
</table>
At T1, neither the HADS nor the PSDRS depression scores were significantly correlated with age or education in either patients or control subjects (rho max=.21). Female control subjects had higher PSDRS-scores than male control subjects (Z=-2.21, p=.01), no other gender differences were found (control-HADS: Z=-.24, p=.81; patient-HADS: Z=-0.74, p=.46; patient-PSDRS: Z=-0.80, p=.43).

Depressive mood
At both T1 and T2, a higher frequency of stroke patients than control subjects had depressive mood, according to the HADS (T1: X²=21.13, p < .001; T2: X²=8.00, p < .01) as well as the PSDRS (T1: X²=5.56, p=.02; T2: X²=8.33, p < .01). The number of individuals with depressive mood according to both measurements are presented in Table 2.

Table 2. Number of patients and control subjects with (-DEP) and without (NON-DEP) depressive mood according to the HADS and the PSDRS.

<table>
<thead>
<tr>
<th></th>
<th>Patient</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HADS-DEP</td>
<td>NON-DEP</td>
</tr>
<tr>
<td>T1</td>
<td></td>
<td></td>
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<tr>
<td>PSDRS-DEP</td>
<td>7</td>
<td>22</td>
</tr>
<tr>
<td>NON-DEP</td>
<td>7</td>
<td>63</td>
</tr>
<tr>
<td>Total</td>
<td>14 (14%)</td>
<td>85</td>
</tr>
<tr>
<td>HADS-DEP</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td>NON-DEP</td>
<td>7</td>
<td>59</td>
</tr>
<tr>
<td>Total</td>
<td>11 (14%)</td>
<td>70</td>
</tr>
</tbody>
</table>

As is shown in Table 2, there is some, but certainly no complete overlap between the two ratings of depressive mood.

From the patients who participated at both times of measurement, 13 (16%) recovered from depressive mood (REC), 10 (12%) had depressive mood at both times (DEP), 5 (6%) patients became depressive (NEW), and finally 53 (65%) patients had no depressive mood at both times (NONDEP) according to the HADS. Following the PSDRS criteria this were respectively, 5 (6%), 5 (6%), 6 (8%), and 64 (80%) patients.

Cognitive test performance
At T1, the stroke patients had significantly lower memory scores (t=3.64, p < .001), reasoning abilities (t=4.90, p < .001), and were slower on both visuomotor (t=-3.48, p < .01) and cognitive (t=-2.42 p=.02) decision times than the control subjects. All subjects
scored above cut off on the dementia screening test (CST). At T2, the patients still performed worse than the controls with respect to memory ($t=3.31$, $p < .01$), reasoning ($t=3.33$, $p < .01$), and cognitive decision times ($t=-2.08$, $p=.04$), but they did not differ on visuomotor decision times ($t=-1.68$, $p=.10$). At T2, still none of the participants scored below cut-off on the CST.

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**Objective cognitive test performance**

In Table 3 the objective cognitive test scores and ANOVA statistics for the patients with and without depressive mood are presented.

<table>
<thead>
<tr>
<th></th>
<th>HADS-D M (SD)</th>
<th>HADS-ND M (SD)</th>
<th>(df)</th>
<th>$F$</th>
<th>$p$</th>
<th>PSDRS-D M (SD)</th>
<th>PSDRS-ND M (SD)</th>
<th>(df)</th>
<th>$F$</th>
<th>$p$</th>
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</thead>
<tbody>
<tr>
<td><strong>Visu-DT</strong></td>
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<tr>
<td>T1</td>
<td>455 (180)</td>
<td>417 (93)</td>
<td>1.61</td>
<td>.55</td>
<td></td>
<td>557 (229)</td>
<td>408 (86)</td>
<td>1.64</td>
<td>&lt;.001</td>
<td></td>
</tr>
<tr>
<td>T2</td>
<td>407 (85)</td>
<td>422 (103)</td>
<td>0.27</td>
<td>.60</td>
<td></td>
<td>500 (152)</td>
<td>405 (81)</td>
<td>0.60</td>
<td>.60</td>
<td></td>
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<tr>
<td><strong>Cogn-DT</strong></td>
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<tr>
<td>T1</td>
<td>1069 (321)</td>
<td>1019 (321)</td>
<td>0.36</td>
<td>.22</td>
<td></td>
<td>1154 (383)</td>
<td>1014 (375)</td>
<td>1.77</td>
<td>.02</td>
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<tr>
<td>T2</td>
<td>969 (280)</td>
<td>1067 (522)</td>
<td>0.49</td>
<td>.49</td>
<td></td>
<td>1290 (561)</td>
<td>1001 (462)</td>
<td>1.72</td>
<td>.09</td>
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<tr>
<td><strong>Memory</strong></td>
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<tr>
<td>T1</td>
<td>38.3 (17.4)</td>
<td>32.7 (12.0)</td>
<td>2.95</td>
<td>.09</td>
<td></td>
<td>29.3 (11.1)</td>
<td>35.0 (14.8)</td>
<td>1.89</td>
<td>.13</td>
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<tr>
<td>T2</td>
<td>38.8 (17.0)</td>
<td>36.8 (16.4)</td>
<td>0.17</td>
<td>.68</td>
<td></td>
<td>30.0 (20.1)</td>
<td>38.3 (15.6)</td>
<td>1.79</td>
<td>.24</td>
<td></td>
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<tr>
<td><strong>Reasoning</strong></td>
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<td></td>
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<tr>
<td>T1</td>
<td>40.2 (18.9)</td>
<td>44.8 (19.5)</td>
<td>1.12</td>
<td>.29</td>
<td></td>
<td>37.5 (21.0)</td>
<td>44.4 (20.7)</td>
<td>1.94</td>
<td>.14</td>
<td></td>
</tr>
<tr>
<td>T2</td>
<td>55.4 (18.9)</td>
<td>46.8 (21.9)</td>
<td>2.00</td>
<td>.16</td>
<td></td>
<td>30.6 (18.4)</td>
<td>51.2 (20.7)</td>
<td>1.80</td>
<td>.14</td>
<td>&lt;.01</td>
</tr>
</tbody>
</table>

At both T1 and T2 there were no differences in cognitive functioning between patients with and without depressive mood according to the HADS. The patients with depressive mood as measured with the PSDRS, on the other hand, had slower visuomotor decision times than the non-depressive patients at both T1 and T2. Moreover, at T2 the patients with PSDRS depressive mood showed worse reasoning performance than the patients without PSDRS depressive mood.

GLM repeated measures for the cognitive test performance in the four patient subgroups according to the change in depressive mood (NONDEP, DEP, REC, NEW) re-
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revealed no significant Time x Group interactions when the patient groups were compared according to the HADS (memory F (3,72) = 1.83, p=.15; reasoning F (3,74) = 1.19, p=.32; visuomotor decision time F (3,67) = 0.18, p=.91; cognitive decision time F (3,62) = 0.84, p=.48). The same was true for the four subgroups according to the PSDRS (memory F (3,71) = 1.12, p=.35; reasoning F (3,73) = 2.19, p=.10; visuomotor decision time F (3,66) = 0.68, p=.57; cognitive decision time F (3,61) = 0.52, p=.67). So, the course of cognitive performance and the course of depressive mood were not related significantly.

Subjective cognitive change according to patients

With respect to the subjective cognitive data, the patients with HADS-depressive mood experienced significantly more cognitive changes than patients without depressive mood at both T1 (Z=-3.04, p < .01), and T2 (Z=-2.55, p=.01). Analyses of the 5 cognitive items separately revealed significant differences at T1 and T2 in experienced mental slowness (T1: Z=-2.46, p=.01; T2: Z=-2.59, p < .01) and concentration (T1: Z=-2.48, p=.01; T2: Z=-2.73, p=.01), and only at T1 in orientation in time and place (Z=-2.67, p=.01).

The difference in experienced cognitive change between patients with and without PSDRS-depressive mood, on the other hand, failed to reach significance at T1 (Z=-1.76, p=.08). At the level of the separate items, the patients with depressive mood according to the PSDRS complained more about changes in concentration (Z=-2.03, p=.04) and orientation (Z=-3.15, p < .01). Moreover at T2, the difference was significant for the sum score (Z=-4.60, p < .001), and all five items separately (p < .01).

To measure the course of cognitive complaints in the four groups according to the change in mood (NONDEP, DEP, REC, NEW), GLM Repeated Measure analyses were performed. The results showed no significant interactions Time x Group for the HADS depressive patients, but did show a significant interaction for the PSDRS-depressive patients (F (3, 76) = 4.75, p < .01) as is illustrated in Figure 1.

Figure 1 shows that the reported cognitive complaints increased disproportionally in the depressive stable (change = 2.4 points) and new cases (change = 2.2 points) as compared to the recovered (change = 0 points) and non-depressive stable (change = 0.5 points) cases.
Figure 1. Course of subjective cognitive functioning according to the patients. Patients are classified according to the PSDRS: NDEP = not depressive at both T1 and T2, REC = depressive at T1 but not at T2, NEW = depressive at T2 but not at T1, DEP = depressive at both T1 and T2.

Subjective cognitive change according to partners
At T1, the partners of the patients with depressive mood did not report more cognitive changes in the patients than the partners of the patients without depressive mood. This was true for both depression scales (HADS: Z=-1.08, p=.28, PSDRS: Z=-1.39, p=.17). No differences were found on item level either. The same was true at T2 (HADS: Z=-0.90, p=.37, PSDRS: Z=-1.37, p=.17). Moreover, GLM Repeated measures revealed no significant interaction of Time by Group for either depression scale (HADS F (3,53) = 0.02, p=.99; PSDRS F (3,53) = 0.54, p=.66).

Side of stroke

Mood
Side of stroke was not significantly related to mood at both T1 and T2: there were no significant differences in the number of left and right hemisphere patients with depressive mood according to the HADS (T1: X²=0.31, p=.58; T2: X²=0.07, p=.80), and the PSDRS (T1: X²=2.57, p=.11; T2: X²=0.09, p=.76). According to the HADS-criteria at T1 13
(28%) right hemisphere and 16 (30%) left hemisphere patients had depressive mood, at T2 these were respectively 7 (18%) and 8 (19%) patients. According to the PSDRS 10 (22%) right hemisphere patients, and 4 (7.5%) left hemisphere patients had depressive mood at T1. At T2 respectively 6 (16%) and 5 (12%) patients had depressive mood according to the PSDRS.

Mood and cognition
Within the patient group with depressive mood according to the HADS, there were no differences in cognitive functioning between left and right hemisphere patients at T1 (reasoning \(p=0.57\), memory \(p=0.79\), visuomotor DT \(p=0.12\), cognitive DT \(p=0.81\), subjective cognition according to the patient \(p=0.91\), subjective cognitive change according to the partner \(p=0.23\)). The same was true for the PSDRS depressive patients (reasoning \(p=0.42\), memory \(p=0.06\), visuomotor DT \(p=0.68\), cognitive DT \(p=0.07\), subjective cognition according to the patient \(p=0.54\), subjective cognitive change according to the partner \(p=0.71\)). At T2 too, there were no differences with respect to lateralisation in any of the cognitive measures for both the HADS and the PSDRS-depressive patients (data not presented).

Discussion
The objective of the present study was to examine the relationship between depressive mood and cognitive functioning at three and fifteen months post stroke in a community-based patient group with a first-ever unilateral ischemic stroke. Three cognitive domains: memory, speed of information processing and reasoning, were studied with at least three measurements each. Moreover, depressive mood was examined with both a self-rated (HADS) and an observer-rated (PSDRS) scale. In addition a dementia screening test (CST) was applied. Two major restrictions need to be considered when interpreting the presented data. First, though the size of the patient group (\(n=99\)) can be considered adequate, the subgroups of patients with depressive mood were small. Second, we could not systematically control for the use of anti-depressants. Two patients with HADS-depressive mood and three with PSDRS-depressive mood used anti-depressive medication. However, in the groups without depressive mood there were also patients (respectively 7 and 6) who used anti-depressants. Therefore we assume that use of these drugs did not strongly contaminate our data.
Depressive mood and cognitive test performance

Remarkably, the present results with regard to the relationship between depressive mood and cognitive functioning were, to some extend, contradictory. Patients with depressive mood according to the HADS did not perform worse on any of the cognitive measures than patients without depressive mood at three and fifteen months post-stroke. Moreover, course of depressive mood was not related to course of cognitive performance. Patients with depressive mood according to the observer-rated scale (PSDRS), on the other hand, showed slower visuomotor decision times than patients without depressive mood at three months post stroke. One year later, the patients with PSDRS depressive mood still had slower visuomotor decision times than patients without depressive mood. Moreover, they showed worse reasoning performance than the non-depressive patients. However, there were no interactions between course of cognitive performance and course of depressive mood according to the PSDRS criteria either. Cognitive decision times and memory performance were not related to either of the depressive mood measurements.

The finding that different measures of depressive mood revealed differences with respect to the relationship with cognitive functioning is in line with a study recently presented by Pohjasvaraa and colleagues (2002). In contrast to the present data, however, they found that a relation was present only when a self-rated depression scale was used and not with the observer-rated methods. We cannot rule out the possibility that in the present study the self-rated scale overrated the presence of depressive mood compared to the observer-rated method, thus including more patients with relatively mild depressive mood. The HADS has been shown to have a misdiagnosis rate of 20%, which even was the lowest percentage of three self-rating scales (Aben, Verhey, Lousberg, Lodder, & Honig, 2002). In fact our results do show nearly twice as many patients with depressive mood according to the HADS (29%) than patients with depressive mood according to the PSDRS (14%). The latter amount is comparable to a cohort study by Desmond and colleagues (2003) who found a comparable observer-rated (Structured Interview Guide for the Hamilton Depression Rating Scale) percentage of depressive stroke patients, and like our study, excluded patients with a history of depression.

The few studies that found a relationship between depressive mood and cognitive functioning while using a neuropsychological test battery, showed a rather broad range of cognitive domains to be impaired in depressed patients (Bolla-Wilson et al.,
1989; Kauhanen et al., 1999). In non-stroke studies focussing on major depressive disorder speed of information processing has been suggested to be the central cognitive impairment (Den Hartog, 2002; Nebes, 2000). This is in line with the present findings that mainly speed of information processing is more impaired in patients with (observer-rated) depressive mood than in patients without depressive mood. Moreover, reasoning was more impaired in this group, but only at fifteen months post-stroke. A possibility that needs consideration is that, for as far as the mental slowness can be observed, this might have been interpreted as a sign of depressive mood by the observer. Kauhanen et al. (1999) too found stronger relations between depressive mood and cognitive functions at one year after stroke than at three months after stroke onset. The opposite was shown by House et al. (1990), though, they found weak, but significant, correlations between the MMSE and depression at one and at six months post-stroke, but not at twelve months after stroke. For further longitudinal examination of the relationship between change in mood and cognition, our patients were divided into four subgroups according to their change in mood. No relation between change in mood and change in cognitive function was found, however, for either of the mood measurements. Hence, these data cannot confirm either the theory of ‘dementia of depression’ (Kimura et al., 2000; Murata et al., 2000) or ‘depression of dementia’ (Andersen et al., 1996) after stroke.

Depressive mood and subjective cognitive change

Not only objective measures of cognitive functioning were used in this study, but the patients were also asked to what extent they experienced cognitive changes due to the stroke. Like Dam (2001) we found that patients with depressive mood reported more cognitive change due to their stroke than patients without depressive mood did. At T1, both PSDRS and HADS-depressive mood patients felt that they had more trouble concentrating and orientating than patients without depressive mood. In addition, the patients with depressive mood according to the HADS had more complaints about mental slowness. At T2, patients with depressive mood according to the HADS still had more complaints about decline in mental speed and concentration. The patients with depressive mood according to the PSDRS felt more decline in cognitive function than the patients without depressive mood in all five domains at T2. So, the cognitive complaints increased with time and, according to the PSDRS classification of depressive mood, this appeared to be related to change in mood. Especially the patients with depressive mood at both T1 and T2 and the patients who’s mood became depressed
between T1 and T2, experienced more cognitive changes at T2 compared to T1. So the present findings are, to some extent, in line with the conclusion by Gainotti et al. (1997) that depressive mood is related to the experienced impairments due to stroke even though this was not confirmed by the objective cognitive data. The patients who’s mood recovered, on the other hand, did not show a decrease in cognitive complaints, but they had a very low level of complaints to begin with at three months after stroke. The partners of the patients with, versus the partners of the patients without depressive mood (according to both the self-rated and the observer-rated scale) did not differ with respect to the cognitive changes they perceived in the patients. Nor was there a relationship between course of mood and course of cognitive functioning as perceived by the partners.

**Depressive mood and side of stroke**

Carson and colleagues (2000) systematically reviewed the literature and could not confirm the hypothesis that the occurrence of depression after stroke is related to the side of the stroke. Our findings are in line with this conclusion. With respect to the relationship between cognitive dysfunction and depression it has been suggested that this relation is specific for left hemisphere patients (Bolla-Wilson et al., 1989; Spalletta et al. 2002). The present study did not confirm these findings. No significant differences in cognitive functioning between left and right hemisphere patients with depressive mood were found.

**Conclusions**

In sum, the results show that a relationship between depressive mood and cognitive functioning after stroke is clearly present when subjective cognitive changes according to the patients are considered. Objective cognitive test scores and partners’ reports, on the other hand, could not confirm this relation. With one exception though: observer-rated depressive mood appeared to be related to speed of information processing at both times of measurement, and to reasoning at fifteen months post-stroke.

Considering the lack of significant relations between (course of) cognitive test performance and (course of) depressive mood after stroke, this study suggests that these are two entities that can independently occur after stroke. Still, like suggested by Gainotti
Depressive mood and cognitive functioning

and co-workers, post-stroke depression can be a reaction to the experienced changes, among which the perceived cognitive changes. Finally, the present results emphasise the decisive role of the choice of measures that are used to assess both depression and cognitive functioning.
References


Depressive mood and cognitive functioning


Depressive mood and cognitive functioning


Chapter 6
Longitudinal analysis of fatigue after stroke

Abstract
The objective of the present study was to describe the course of fatigue in stroke patients between three and fifteen months post-stroke and to analyse the longitudinal determinants of fatigue. A community-based group of 101 first-ever, unilateral, ischemic stroke patients and a group of 70 elderly controls were assessed twice. Fatigue was measured with the energy/fatigue subscale of the Rand-36. The influence of comorbid disorders on fatigue was analysed in both patients and controls. Furthermore, the longitudinal influence of mood, physical disability, changes in emotion and cognition and performance on tests of mental speed and neglect on fatigue was investigated in the stroke group. The results showed that although stroke patients improved in fatigue, they remained more often fatigued than controls at fifteen months post-stroke. In both groups fatigue could be predicted by the presence of heart disease and musculoskeletal diseases. In stroke patients, poorer post-stroke mood, greater changes in emotion and cognition and greater physical disabilities were longitudinally related to a greater frequency of fatigue. In right hemisphere patients, slower complex mental speed was also related to more frequent fatigue. The implications of the present findings for the treatment of fatigue after stroke are discussed.

Introduction

Fatigue after stroke is a frequent complaint, even late after stroke (Glader, Stegmayer & Asplund, 2002, Ingles, Gail &Phillips, 1999, van der Werf et al., 2001). Sometimes, fatigue is the only remaining complaint in stroke patients (Staub & Bogousslavsky, 2001). Fatigue can be defined as the reversible decrease or loss of abilities associated with a heightened sensation of physical and mental strain, which leads to inability or difficulty to sustain even routine activities (Staub & Bogousslavsky, 2001). Furthermore, fatigue after stroke may be pathological in nature, experienced as chronic, excessive or not ameliorated by rest (de Groot et al., 2003). Staub & Bogousslavsky (2001) propose that several subtypes of fatigue could develop after stroke. Besides fatigue developing in connection with activities requiring sustained effort, fatigue could also be a primary state in which motivation is preserved, but effectiveness has decreased. This ‘primary fatigue’ is thought to be the effect of attentional disorders after stroke. Fatigue associated with loss of interest would be more closely related to depression.

Fatigue, as one of the components of vitality, has been analysed in studies on functional impairments and quality of life after stroke (Kauhanen et al., 2000, Bugge, Hagen & Alexander, 2001). Nevertheless, post-stroke fatigue has hardly been studied as a separate outcome measure. Besides, little is known about the course and determinants of fatigue after stroke. One of the factors that complicates research of fatigue after stroke is that fatigue is a common symptom in several conditions such as heart disease, endocrine disorders, lung diseases, cancer and musculoskeletal diseases (Buis, 1998, de Rijk, 1999). Cerebrovascular disease, especially in elderly patients, is often accompanied by one or more of these disorders (Buis, 1998, Loor, 1998). Besides, loss of energy and increased fatigue are also main symptoms of depression. Depression often occurs after stroke, but is also often present in patients with other chronic diseases (Bisschop et al., 2004). Although depression and fatigue are both common after stroke and show considerable overlap, they have also been found to be independent sequelae of stroke (Ingles, Gail & Phillips, 1999, Staub & Bogousslavsky, 2001, van der Werf et al., 2001).

One of the questions that has remained unanswered is the impact of cognitive impairments after stroke on the experience of fatigue. Recent studies have linked fatigue to lesions in structures involving attentional systems (Staub & Bogousslavsky, 2001, Chaudhuri & Behan, 2000). Others have described the impact of fatigue on cognitive...
functioning (Ingles, Gail & Phillips, 1999). Alternatively, fatigue after stroke could be a consequence of cognitive disorders in attention or mental speed. Van Zandvoort et al. (1998) describe deficits in attention and mental effort after a single lacunar infarction, which could play a role in the subjective experience of fatigue or the experience that ‘things are not going as they used to’. Finally, cognitive impairments and fatigue could be independent sequelae of stroke.

Fatigue after stroke can thus be regarded as multi-dimensional, and might be influenced by neurological, physical, psychological and cognitive factors. The main aim of the present study is to analyse the course and longitudinal determinants of fatigue in stroke patients. First, at three months post-stroke, factors that can be regarded as comorbid conditions will be analysed in both stroke patients and elderly controls. It is expected that in both groups fatigue will be influenced by physical comorbid disorders. Furthermore, the impact of these comorbid disorders on the course of fatigue is investigated in patients and controls. Next, it is hypothesized that fatigue after stroke will be longitudinally related to the physical, emotional and cognitive sequelae of stroke. A special emphasis will be placed on the influence of disorders of attention and mental speed after stroke. Attention is a broad concept, which cannot be measured by a single test (van Zomeren & Brouwer, 1994). In this study, three measures of attention and mental speed will be related to fatigue: a measure of unilateral neglect, a measure of simple mental decision time and a measure of complex mental decision time.

Methods

Subjects

Stroke patients
First-ever, unilateral, ischemic stroke patients were recruited by 100 general practitioners (GPs) from the northern part of the Netherlands and by the Stroke Unit of the University Hospital Groningen. Stroke was defined as an acute disruption of blood circulation in the brain with clinically visible symptoms lasting more than 24 hours. A total of 235 patients were admitted of whom 33 were excluded because they did not meet the inclusion criteria of having a first-ever, ischemic stroke within the previous three months; 13 patients were excluded because of a history of neurologic disturbances,
psychiatric disturbances or substance abuse; 26 patients could not be assessed because of very severe aphasic, physical or cognitive impairments; another 36 patients could not be included in the study because they did not want to participate or could not be reached within three months. Finally, 5 patients died before the first measurement at three months post-stroke (T1). So, the group of patients included at T1 consisted of 122 first-ever ischemic stroke patients. From the first to the second measurement at fifteen months post-stroke (T2), 6 patients died, 6 were either physically or mentally not capable of participating again, 8 patients refused to participate again and 1 had moved to another part of the country. This means that at T2 101 stroke patients were interviewed again. Mean age of these patients was 65.4 (SD=11.9) at the start of the study, ranging from 32 to 93 years. This group consisted of 64 men and 37 women.

All subjects approved of the fact that their medical history and lesion characteristics were provided by GP and neurologist. On the basis of all neurological data, lateralisation of lesion could be classified for 98 patients: 41 had a right hemisphere infarction, 48 a left sided infarction, 4 bilateral lesions and 5 patients had lesions affecting brain stem or cerebellum.

Control subjects
Control subjects were recruited among the population of four general practices from the northern part of the Netherlands. A stratified randomisation procedure was used to match the control subjects to patients on age and gender. Control subjects with a history of psychiatric disturbances, neurological conditions or alcohol abuse were excluded from the study. At T1 80 control subjects were interviewed. Two subjects were excluded because of previous neurological damage and a history of psychiatric disturbances. At T2 the control group consisted of 70 subjects, 8 subjects had dropped out because they did not want to participate again (n=4), were too busy (n=2) or had moved (n=2). Mean age of the control subjects at the start of the study was 66.9 (SD=11.9) which did not differ significantly from the age of the stroke patients (t=0.8, p=.42). Within the control group, 39 men and 31 women participated, the ratio of gender did not differ significantly from the patient group (X²=1.0, p=.32). Mean level of education was also comparable for patients and control subjects (Z=-0.2, p=.82). Consumption of medication with a possible side effect of fatigue: heart medication, anti-hypertensive medication, antidepressants and sedative medication, did not differ between stroke and control group.
Procedure and Measures

All subjects were assessed twice at their own place of residence by trained interviewers with an interval of approximately one year. After signing an informed consent, several questionnaires concerning functional ability, mood, changes in emotion and cognition and quality of life were administered. Within two weeks after the interview, the cognitive functions of the subjects were assessed using several neuropsychological tests. Only those instruments relevant for the current research question will be described.

Comorbid disorders

After informed consent of stroke patients and control subjects, their GP’s were asked to fill in a Comorbidity Index at T2. In this index, the presence of several comorbid disorders at T1 and T2 could be indicated. Diseases were divided into 6 categories: heart disease, peripheral vascular disease, sensory deficits, musculoskeletal disease, cancer and respiratory disease. Besides, the presence of hypertension, diabetes and migraine were recorded. In the present study, single conditions that might be associated with fatigue and that occurred in at least ten percent of patients or controls were used to predict fatigue. These conditions were heart disease, musculoskeletal disease, respiratory disease and diabetes mellitus.

Previous research has shown that the functional status of patients deteriorated as the number of chronic conditions increased (Buis, 1998). Therefore, in the present study, the concurrent effect of two disorders on fatigue was also analysed if approximately ten percent of subjects experienced their combined occurrence.

Questionnaires

Fatigue

Fatigue was measured in stroke patients and control subjects using the energy/fatigue subscale of Dutch version of the Rand 36-item Health Survey 1.0 (Ware & Sherbourne, 1992, Van der Zee & Sanderman, 1993). The subscale contains 4 items questioning how often a subject (1) feels full of pep (2) has a lot of energy (3) feels worn out and (4) feels tired. Scores ranging from (1) all of the time to (6) none of the time are converted into a percentage of the maximum score (range 0 to 100). Internal consistency of the energy/fatigue subscale measured by Cronbach’s alpha was .82 in a Dutch commu-
nity based population (Van der Zee & Sanderman, 1993). In order to investigate the co-occurrence of fatigue after stroke and post-stroke impairments in attention, cut-off scores for two separate items were calculated: tiredness present ‘all of the time’, ‘most of the time’ or ‘a good bit of the time’ was scored as frequent tiredness, while energy present ‘none of the time’, ‘a little of the time’ or ‘some of the time’ was rated as frequent lack of energy.

**Mood**
Depressive and anxious mood was assessed in stroke patients and control subjects using the Hospital Anxiety and Depression scale (HADS) (Zigmond & Snaith, 1983, Johnson et al., 1995). The HADS has an anxiety and a depression sub-scale both containing 7 items (scored 0 to 21). Higher scores indicate a greater likelihood of anxiety or depression. The HADS has been well validated and showed sufficient internal reliability in different groups of Dutch subjects (Spinhoven et al., 1997).

**Physical disabilities**
The Stroke Adapted –Sickness Impact Profile (SA-SIP) is a 30-item stroke-adapted version of the original SIP (Van Straten et al., 1997). The SA-SIP measures functional health status on 8 subscales. All items are scored ‘yes’ (1) or ‘no’ (0); scores range from 0-30 with higher scores indicating poorer functional health. Principal component analysis has shown that a physical dimension can be formed by the scales Body care and movement, Mobility, Household management and Ambulation. This physical scale was used in the present study.

**Emotional and cognitive changes after stroke**
Emotional and cognitive changes in the patient were assessed by asking them to rate the amount of change after stroke on 20 items. These items are based upon clinical relevance according to both neuropsychological literature and interviews with partners of stroke patients (Schure, 1995). Patients could indicate change on a 4-point scale running from ‘not changed’ (0) to ‘very much changed’ (3). The internal consistency of all items was assessed by calculating Cronbach’s alpha. The cognitive scale showed acceptable consistency ($\alpha=.84$) as well as the behavioural scale ($\alpha=.90$).
Neuropsychological measurement of attention

Mental decision time

Reaction times were measured using an apparatus developed by van Zomeren (1981). The reaction time was recorded by a computer and can be divided into a decision component and a motor component. In this study only decision times of two conditions were used. The first condition in which subjects react to light stimuli is called visuomotor reaction time task. To measure more complex mental speed, a cognitive reaction time task, was designed (Gerritsen et al., 2003). A computer screen was placed behind the reaction time apparatus on which words (Text task) or landscapes (Picture task) emerged. In the Text task, a category word (e.g. flowers) was presented on the upper half of the screen, while a stimulus word (e.g. rose) appeared in the lower half of the screen. Subjects were required to decide if a word fitted in the category. In the Picture task, a landscape was presented (e.g. beach) and a picture (e.g. kite) which did or did not fit into the landscape. Previous factor analysis on the reaction time components showed that visuomotor decision times and cognitive decision times were identified as two separate factors (Gerritsen et al., 2003). Cut-off scores for the decision times of patients were calculated on the basis of the decision times of the control subjects. Patients whose decision times were equal to or slower than the 10 percent slowest controls, were regarded as impaired in mental decision time.

Neglect

To measure unilateral neglect after stroke, the Star Cancellation Task, a subtest of the Behavioural Inattention Test (BIT) was administered (Wilson, Cockburn & Halligan, 1987). Two continuous scores, the number of omissions on the left and right side of the paper, were used for analysis in respectively the right and left hemisphere group.

Statistical analyses

First, fatigue was compared between patients and controls at T1 and T2 using independent-samples T-tests. Differences between both groups on individual items of the fatigue scale was analysed using Mann-Whitney U tests. To investigate the course of fatigue in both groups from T1 to T2, GLM Repeated Measures analyses were performed. The course of individual items was analysed using Wilcoxon signed-rank test. Next, the
impact of physical comorbid disorders on fatigue of patients and controls was investigated at T1 by GLM univariate analyses. Comorbid disorders were entered into the model as fixed factors, while depressive and anxious mood were entered as covariates. The impact of comorbid disorders at T1 on the course of fatigue from T1 to T2 was analysed by GLM Repeated Measure analyses. These analyses were performed in SPSS 10.0. The longitudinal relationship between post-stroke disabilities and fatigue was investigated with Generalized Estimated Equations (GEE) (Zeger & Liang, 1986). An exchangeable correlation structure between the repeated measures of fatigue was chosen. An advantage of GEE is that all subjects are included in the analyses, regardless of missing values. This reduces the bias from loss of the more impaired stroke patients. GEE-analyses were performed in SPIDA 6.05.

Results

Level of fatigue in patient and control group at T1 and T2
Only patients and controls who were assessed at both T1 and T2 were used in these analyses. Patients who participated at T1, but no longer at T2 appeared to be significantly older and were more often fatigued than patients who stayed in the study (Age: t=3.0, p=.00, Fatigue: t=-3.2, p=.00). Twice as much female stroke patients dropped out, compared to male stroke patients (F 30% vs M 15%, Χ²=4.5, p=.03). Drop-out of control subjects was not significantly related to demographic variables or to fatigue.

Table 1 shows that stroke patients were significantly more often fatigued than control subjects at both T1 and T2. Left and right hemisphere stroke patients did not differ in fatigue at either times of measurement (T1: t=-0.26, p=.80; T2: t=0.24, p=.80). Age was not significantly related to fatigue in stroke patients at T1 or T2 (T1: r=-.04, p=.67; T2: r=.02, p=.84). At T1, in both patient and control group, women reported fatigue more frequently than men (Stroke: t=2.5, p=.02; Control: t=2.6, p=.01). At T2, only in the control group, women were significantly more often fatigued than men (Stroke: t=1.2, p=.22; Control: t=2.7, p=.01). Comparison between the stroke and control group showed that male stroke patients were significantly more often fatigued compared to male control subjects at T1 and T2. For female stroke patients this difference was only significant at T1, but no longer at T2. With regard to individual items of the fatigue scale, Table 1 shows that at T1 stroke patients reported significantly less often having ‘a lot of energy’,
and more frequently feeling ‘worn out’ and ‘tired’ than control subjects. At T2, patients only reported significantly less frequently ‘having a lot of energy’.

Table 1. Comparison of fatigue between stroke patients (n=99) and controls (n=70) at T1 and T2. * p <.05, ** p < .01, *** p < .001 (two-tailed).

<table>
<thead>
<tr>
<th>Item</th>
<th>T1 Stroke Mean (SD)</th>
<th>Control Mean (SD)</th>
<th>Z-score</th>
<th>T2 Stroke Mean (SD)</th>
<th>Control Mean (SD)</th>
<th>Z-score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full of pep</td>
<td>77.3 (29.6)</td>
<td>81.4 (22.4)</td>
<td>-0.21</td>
<td>84.2 (23.1)</td>
<td>85.4 (20.7)</td>
<td>-0.12</td>
</tr>
<tr>
<td>Lot of energy</td>
<td>46.1 (28.6)</td>
<td>72.3 (25.1)</td>
<td>-5.5***</td>
<td>52.9 (29.7)</td>
<td>76.6 (23.8)</td>
<td>-5.1***</td>
</tr>
<tr>
<td>Worn out</td>
<td>73.1 (26.2)</td>
<td>86.3 (16.9)</td>
<td>-3.3***</td>
<td>78.2 (25.9)</td>
<td>85.5 (20.0)</td>
<td>-1.6</td>
</tr>
<tr>
<td>Tired</td>
<td>56.8 (25.2)</td>
<td>73.4 (24.7)</td>
<td>-4.3***</td>
<td>62.8 (22.7)</td>
<td>67.4 (25.1)</td>
<td>-1.4</td>
</tr>
<tr>
<td>Total energy/fatigue</td>
<td>63.3 (19.5)</td>
<td>78.4 (16.7)</td>
<td>-4.9***</td>
<td>69.6 (18.6)</td>
<td>79.1 (17.1)</td>
<td>-3.5***</td>
</tr>
<tr>
<td>Male</td>
<td>67.0 (19.5)</td>
<td>82.8 (13.3)</td>
<td>4.4***</td>
<td>71.3 (17.0)</td>
<td>84.0 (12.6)</td>
<td>4.0***</td>
</tr>
<tr>
<td>Female</td>
<td>57.2 (18.2)</td>
<td>72.7 (19.0)</td>
<td>3.4**</td>
<td>66.5 (20.1)</td>
<td>72.7 (20.1)</td>
<td>1.2</td>
</tr>
</tbody>
</table>

Course of fatigue in stroke and control group

GLM repeated measures analyses on fatigue scores showed a significant effect of time of measurement (F=5.0, p=.03), a significant effect of group (F=24.4, p=.00) and a significant interaction between time and group (F=4.1, p=.05). Stroke patients felt less fatigued at fifteen months than at three months post-stroke (t=-3.4, p=.001), while the total level of fatigue in control subjects remained similar from T1 to T2 (t=-0.1, p=.89). The course of fatigue did not differ for male or female patients (F=0.5, p=.49) or for left and right hemisphere patients (F=0.5, p=.48). Age also appeared to be unrelated to the course of fatigue in stroke patients (r=-.06, p=.56).

When analysing the course of the individual items of the energy/fatigue scale, it appeared that stroke patients significantly improved in their frequency of feeling ‘full of pep’ (Z=-2.2, p=.02), while the other items of energy and fatigue did not improve significantly. Control subjects only differed in tiredness, which they reported significantly more often at T2 compared to T1 (Z=-2.0, p=.04).

Impact of physical comorbid conditions on fatigue in stroke patients and controls

Before the predictive value of comorbid conditions for fatigue was analysed, all stroke patients and control subjects were compared on the presence of several comorbid conditions. Table 2 shows that stroke patients and control subjects did not differ in the
occurrence of most disorders, except for diabetes which was significantly more often present in stroke patients. Stroke patients and control subjects did not differ significantly on the total number of comorbid disorders (Stroke $M=1.6$, $SD=1.2$ (range 0-6), Control $M=1.9$, $SD=1.5$ (range 0-6), $t=1.2$, $p=.23$).

Table 2. Percentage of stroke patients ($n=101$) and control subjects ($n=70$) with comorbid conditions.
* $p <.05$ (two-tailed)

<table>
<thead>
<tr>
<th>Comorbidity</th>
<th>Stroke %</th>
<th>Control %</th>
<th>$X^2$</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td>43.5</td>
<td>41.8</td>
<td>0.0</td>
</tr>
<tr>
<td>Heart disease</td>
<td>29.8</td>
<td>34.3</td>
<td>0.4</td>
</tr>
<tr>
<td>Muscle/Skelet</td>
<td>23.9</td>
<td>36.4</td>
<td>2.0</td>
</tr>
<tr>
<td>COPD</td>
<td>13.8</td>
<td>18.2</td>
<td>0.6</td>
</tr>
<tr>
<td>Diabetes</td>
<td>11.8</td>
<td>3.0</td>
<td>4.0*</td>
</tr>
<tr>
<td>Heart disease * COPD</td>
<td>9.0</td>
<td>8.5</td>
<td>0.1</td>
</tr>
<tr>
<td>Heart disease * Muscle/Skelet</td>
<td>8.6</td>
<td>16.4</td>
<td>2.3</td>
</tr>
<tr>
<td>Hypertension * Muscle/Skelet</td>
<td>9.8</td>
<td>18.2</td>
<td>2.4</td>
</tr>
<tr>
<td>Heart disease * Hypertension</td>
<td>10.8</td>
<td>19.4</td>
<td>2.4</td>
</tr>
</tbody>
</table>

Based on the criteria described in the method section, heart disease, diabetes, musculoskeletal disease and respiratory disease were selected to predict the level of fatigue in control subjects and in patients at three months post-stroke. The level of mood was considered a covariate. Table 3 shows that fatigue at three months post-stroke could be predicted by the presence of heart disease and the combination of heart disease and musculoskeletal diseases. Most variance of fatigue after stroke, however, was predicted by the covariate depressive mood. Anxious mood also explained a proportion of variance in fatigue after stroke. In control subjects, most variance of fatigue was predicted by the concurrence of heart disease and COPD, and next by the single occurrence of heart disease and musculoskeletal diseases. Depressive mood also proved predictive of fatigue in control subjects.

The impact of comorbid disorders at T1 on the course of fatigue from T1 to T2 was subsequently investigated. In stroke patients, physical comorbid disorders at T1 did not affect the course of fatigue after stroke. In control subjects, the presence of heart disease at the first time of measurement did affect the course of fatigue from T1 to T2 ($Time \times HD$, $F=5.3$, $p=.02$). Although in the total control group fatigue did not differ from T1 to
T2, control subjects with a heart disease showed a slight increase in fatigue from first to second time of measurement.

Table 3. GLM-univariate prediction of fatigue by comorbid diseases in control subjects (n=70) and stroke patients at T1 (n=74).

<table>
<thead>
<tr>
<th>Comorbid disease</th>
<th>Patient F</th>
<th>Patient Beta</th>
<th>Control F</th>
<th>Control Beta</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart disease</td>
<td>4.0*</td>
<td>5.3*</td>
<td>3.8*</td>
<td>27.1**</td>
</tr>
<tr>
<td>Diabetes</td>
<td>0.1</td>
<td>-0.4</td>
<td>0.2</td>
<td>4.6</td>
</tr>
<tr>
<td>Muscle/Skelet</td>
<td>1.0</td>
<td>2.8*</td>
<td>5.6*</td>
<td>11.2*</td>
</tr>
<tr>
<td>COPD</td>
<td>0.2</td>
<td>0.3</td>
<td>0.2</td>
<td>13.2</td>
</tr>
<tr>
<td>Hd * Muscle</td>
<td>6.0*</td>
<td>-4.0*</td>
<td>0.1</td>
<td>-2.6</td>
</tr>
<tr>
<td>Hd * COPD</td>
<td>0.4</td>
<td>-1.5</td>
<td>7.6**</td>
<td>-31.0**</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.6*</td>
<td>-0.3*</td>
<td>0.1</td>
<td>0.2</td>
</tr>
<tr>
<td>Depression</td>
<td>23.7***</td>
<td>-0.6***</td>
<td>7.1*</td>
<td>-3.2*</td>
</tr>
<tr>
<td>Intercept</td>
<td>527.0***</td>
<td>17.0***</td>
<td>188.0***</td>
<td>61.5***</td>
</tr>
<tr>
<td>Corrected model</td>
<td>7.3***</td>
<td>R²=.47</td>
<td>6.4***</td>
<td>R²=.48</td>
</tr>
</tbody>
</table>

Longitudinal prediction of fatigue in stroke patients

Influence of post-stroke emotional and cognitive changes, mood and physical disabilities

Next, the hypothesis that physical disabilities, subjective changes in cognition and emotion after stroke and mood are longitudinally related to fatigue, was examined using GEE-analysis. At both T1 and T2, left and right hemisphere stroke patients did not differ significantly with regard to post-stroke mood, subjective changes in behaviour and cognition and physical disabilities.

Table 4 shows that all measures significantly related to fatigue in the stroke group. Higher anxious and depressive mood, greater physical disabilities and greater changes in emotion and cognition all independently related to more frequent fatigue after stroke.

Influence of attentional disorders: neglect and mental speed

Three measures of attention, visuomotor and cognitive speed of information processing and a measure of neglect, were investigated concerning their longitudinal relationship with fatigue in stroke patients. At both T1 and T2, right hemisphere patient were
significantly slower on the visuomotor decision times than left hemisphere patients (T1: t=2.3, p=.02; T2: t=2.0, p=.05). At T1 and T2, right-sided stroke patients were significantly slower than controls on visuomotor decision times (T1: t=-3.6, p=.001; T2: t=-2.2, p=.03), while left-sided stroke patients were significantly slower than controls on more complex, cognitive decision times (T1: t=-2.1, p=.04; T2: t=-2.0, p=.05). With regard to the Star Cancellation task, right hemisphere patients had significantly more omissions than left sided stroke patients at T1 (t=-2.9, p=.006), but not at T2 (t=-1.4, p=.16). Left hemisphere stroke patients had significantly more omissions than controls at T1 (t=-7.5, p=.000), but no longer at T2 (t=1.3, p=.19). Right hemisphere patients had significantly more omissions than controls at both times of measurement (T1: t=2.0, p=.05, T2: t=2.3, p=.03).

Table 4. Longitudinal relationship between mood, physical disabilities, emotional and cognitive changes after stroke and fatigue for the total stroke group (n=110).

<table>
<thead>
<tr>
<th></th>
<th>Beta</th>
<th>Fatigue Error</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>18.2</td>
<td>0.7</td>
<td>0.000</td>
</tr>
<tr>
<td>Time</td>
<td>1.2</td>
<td>0.3</td>
<td>0.001</td>
</tr>
<tr>
<td>Anxious mood</td>
<td>-0.3</td>
<td>0.1</td>
<td>0.008</td>
</tr>
<tr>
<td>Depressive mood</td>
<td>-0.3</td>
<td>0.1</td>
<td>0.000</td>
</tr>
<tr>
<td>Physical disabilities</td>
<td>-0.1</td>
<td>0.1</td>
<td>0.05</td>
</tr>
<tr>
<td>Emotional and cognitive changes</td>
<td>-0.1</td>
<td>0.0</td>
<td>0.003</td>
</tr>
</tbody>
</table>

The longitudinal relationship between attention and fatigue was analysed for left and right hemisphere patients separately. As Table 5 shows, complex cognitive mental speed was longitudinally related to fatigue in right hemisphere stroke patients. In this group, slower cognitive mental speed was related to more frequent fatigue. Neglect and visuomotor mental speed were not independently related to fatigue. Within the group of left hemisphere patients, neglect and mental speed were not longitudinally related to fatigue.

Based on these results, the concurrence of impaired cognitive mental speed and fatigue was further inspected in the right hemisphere stroke group at T2. Of the 9 right hemisphere patients that were tired and the 18 patients that lacked energy, 3 patients had cognitive decision times below cut-off. Of the 4 right hemisphere stroke patients with cognitive mental speed below cut-off, 3 lacked energy and were tired.
Table 5. Longitudinal relationship between measures of neglect (SC), visuo-motor mental speed, cognitive mental speed and fatigue in left and right hemisphere stroke patients (n=110).

<table>
<thead>
<tr>
<th></th>
<th>Beta Right (n=55)</th>
<th>P-value</th>
<th>Beta Left (n=55)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constant</td>
<td>14.6</td>
<td>0.000</td>
<td>18.0</td>
<td>0.000</td>
</tr>
<tr>
<td>Time</td>
<td>0.7</td>
<td>0.02</td>
<td>1.3</td>
<td>0.02</td>
</tr>
<tr>
<td>SC Right</td>
<td>-0.4</td>
<td>0.76</td>
<td>-0.04</td>
<td>0.76</td>
</tr>
<tr>
<td>SC Left</td>
<td>0.003</td>
<td>0.33</td>
<td>0.000</td>
<td>0.001</td>
</tr>
<tr>
<td>Visual motor RT</td>
<td>0.000</td>
<td>0.69</td>
<td>-0.003</td>
<td>0.04</td>
</tr>
<tr>
<td>Cognitive RT</td>
<td>0.000</td>
<td>0.001</td>
<td>0.001</td>
<td>0.001</td>
</tr>
</tbody>
</table>

Discussion and conclusions

**Level and course of fatigue in stroke patients**

A remark that must be made first, is that attrition in the stroke group was selective. Patients who dropped out from T1 to T2 were mostly female, were older and showed more frequent fatigue at T1 compared to patients who stayed in the study. It is therefore likely that the occurrence of fatigue after stroke was underestimated in the present study. Three months after stroke onset, patients were significantly more often fatigued than control subjects similar in age, gender and most physical comorbid conditions. At fifteen months after stroke, patients were less often fatigued than at three months post-stroke. However, in comparison with control subjects, stroke patients still reported fatigue more often, in particular a more frequent lack of energy. The results further showed that male patients remained more often fatigued compared to male control subjects. The lack of difference between female patients and controls might be attributed to the drop-out of female stroke patients with a relatively high frequency of fatigue. Within the stroke group, the side of lesion did not affect the occurrence of fatigue after stroke.

**Comorbid disorders and fatigue**

The present study demonstrated that fatigue cannot only be regarded as a consequence of the stroke event. In both stroke patients and controls, a proportion of variance in fatigue could be predicted by the presence of heart disease and diseases of the musculoskeletal system. In control subjects, the concurrence of heart disease and respiratory disease also proved predictive of fatigue. Furthermore, the occurrence of heart disease in control subjects negatively affected the course of fatigue over a one-year pe-
period. In a large community based study on chronic diseases in the northern part of the Netherlands, back pain and rheumatism also appeared as most important predictors of fatigue, followed by lung diseases and the occurrence of a heart attack (Buis, 1998). The present findings are also in agreement with a recent Dutch study that found decreased energy to be a risk factor for stroke (Schuitemaker et al., 2004). It seems likely that stroke patients with pre-existing comorbid conditions such as heart disease may have experienced fatigue preceding the stroke. Nevertheless, the present study showed that in comparison with control subjects with similar comorbidity, fatigue is more frequent after the stroke event. A prospective study in subjects with a high risk for cerebrovascular disease that measures fatigue on several occasions, might give more insight into the course of fatigue from time preceding stroke to time after stroke.

Longitudinal relationship between physical disabilities, changes in emotion and cognition, mood and fatigue

The present results clearly showed a longitudinal relationship between the physical, cognitive and emotional effects of stroke and fatigue after stroke. The relationship between post-stroke anxious and depressive mood, subjective changes in emotion and cognition and fatigue seems quite complex. First, changes in emotion and cognition might influence fatigue in stroke patients. Activities in daily life could require more effort, which causes fatigue to develop faster. Even patients who report subtle changes in emotion an cognition may experience a decreased level of competence in everyday life (Van Zandvoort et al., 1998). Vice versa, in subjects who are fatigued, mental performance could decrease. In addition, the experience of fatigue and a reduced competence in daily life can have an impact on mood, and can influence changes in emotion and behaviour. Another explanation for the relationship between post-stroke anxious and depressive mood and fatigue might be the co-occurrence of sleep disorders (Staub & Bogousslavsky, 2001, Leppavuori et al., 2002).

Longitudinal relationship between attention and fatigue

While side of lesion did not affect the occurrence of post-stroke fatigue, the influence of attention on fatigue, however, appeared to be different for right and left hemisphere stroke patients. In right but not left hemisphere patients, slower complex mental speed was related to more frequent fatigue after stroke. Visuomotor decision speed and visual attention were also more severely affected in right compared to left hemisphere patients. This is in line with the theory that the right hemisphere directs attention to both
sides of the visual field, while the left hemisphere mainly shifts attention to the right side of the visual field. Injury to the right hemisphere would cause greater disturbances in attention, because compensation could not be provided by the intact left hemisphere (Mesulam, 2000). The lack of a significant longitudinal relationship between mental speed and fatigue within the left hemisphere group, however, does not rule out an effect of changes in mental speed on the experience of fatigue in individual left hemisphere stroke patients. After all, complex mental speed of left hemisphere stroke patients was significantly slower than mental speed of age-matched controls.

De Rijk (1999), in a study on fatigue in general practice patients, describes that external stimulation that was either too high or low was related to fatigue. When this theory is applied to right hemisphere patients with impairments in speed of information processing, one could argue that fatigue develops in those patients as the result of over-stimulation. Staying alert and orienting oneself in an external world that goes too fast and for some patients even contains a side that does not exist, will often demand increased effort.

As has previously been demonstrated with disturbances in mood, it appeared in the present study that right hemisphere patients could experience fatigue without being impaired in complex mental speed (Ingles, Gail & Phillips, 1999, Staub & Bogousslavksy, 2001). On the other hand, of all patients who were impaired in complex mental speed most experienced tiredness and a lack of energy. However, the number of patients in these groups were quite small, so no definite conclusions can be made about the independence of complex mental slowness and fatigue after stroke.

Implications for future research
Further research is needed to clarify the relationship between post-stroke fatigue and the emotional and cognitive sequelae of stroke. A fatigue scale specifically designed to capture the dimensions of fatigue should be used for this purpose, which has not been included in the present study. With more detailed analyses of fatigue and its contributing factors, more insight can be gained into the existence of different subtypes of fatigue after stroke. Furthermore, the impact of fatigue on daily functioning after stroke has not been clear so far and deserves further investigation. The nature of the relationship between activities and fatigue might take on different forms, as has been demonstrated in patients with Chronic Fatigue Syndrome (CFS). Active and passive CFS
patients could be distinguished, which different treatment methods developed for each group (Bazelmans, Prins & Bleijenberg, 2002). So far, the effectiveness of therapeutic strategies used to treat fatigue in other patient groups have not been investigated in stroke patients. Nevertheless, several suggestions for the treatment of fatigue after stroke based on it’s contributing factors will be made in the next paragraph.

Implications for clinical practice
The results of the present study supported the multi-dimensionality of fatigue in stroke patients. It also showed that especially levels of energy were impaired till at least fifteen months post-stroke. If a stroke patient experiences fatigue, both physical and mental aspects of fatigue need to be evaluated. It is necessary to evaluate the presence of comorbid diseases, especially heart disease, musculoskeletal disorders, anxious and depressive mood. An inventory of the use of medication with possible side effects of fatigue should also be made. Furthermore, the presence and extent of cognitive disabilities and changes in emotion and behaviour need to be investigated. In addition, it is valuable to gain insight into the relationship between activity level and fatigue after stroke.

Dependent on the most important contributing factors in an individual patient, the psychological treatment of fatigue could be roughly divided into three main domains. First, the anxious or depressive mood of the patient and the emotional sequelae of stroke could be the focus of attention. Leegaard (1983), in comparing patients with cerebral infarction to patients with myocardial infarction, states that changes in emotion can be caused by brain damage, but can also be the manifestations of a stress response. One of the possibilities for intervention is to direct attention to the way the patient is coping with the consequences of stroke. Second, interventions can also be directed at the management of fatigue. Merely the presence of fatigue forces a patient to change it’s activity level. A patient could learn to use levels of energy more efficiently by, for example, finding a better balance between activities and rest. If speed of information processing is impaired, an adapted speed of performing activities could slow the development of fatigue. A third possibility for intervention which has proven useful in other patient groups, is a cognitive behavioural approach directed at the (inaccurate) cognitions with regard to fatigue (Prins et al., 2002). A complicating factor in patients with brain injury, however, might be that the recognition of physical or mental signs of fatigue might be disturbed. Furthermore, this approach may only be used in patients
who are able to reflect on one's cognitions and behaviour. As has been made clear, these different treatments of fatigue have not been systematically evaluated in stroke patients so far and future research is needed to establish their effectiveness.
References


Fatigue


Van Zomeren, A.H. (1981). Reaction time and attention after closed head injury [dissertation], University of Groningen, the Netherlands.


Abstract
In this paper the impact of post-stroke impairments on strain and life satisfaction of the partner is examined within the framework of social production function theory (SPF-theory). A community based sample of 70 partners of first-ever ischemic stroke patients was assessed twice, at T1 and T2 which corresponds respectively to three and fifteen months post-stroke. One quarter of partners experienced considerable strain at both T1 and T2, whereas life satisfaction decreased from the time preceding stroke to three months after stroke. Predictive factors for the physical strain on the partners were the physical disabilities and behavioural and cognitive changes in the patient; the latter also explained most of the variance in the emotional strain experienced by the partners. SPF-theory was supported as the disabilities of the patient did not directly affect the life satisfaction of the partner, but were mediated by strain on the partner. Female partners of stroke patients experienced greater emotional strain than male partners at T2. In female partners, life satisfaction was predicted by both physical and emotional strain, whereas in male partners, only physical strain proved to be predictive. The impact of the patients’ disabilities on the strain and life satisfaction experienced by the partner was explained by their restricting influence on comfort, activities, affection, and behavioural confirmation of the partner which are described in SPF-theory as instrumental goals to achieve well-being. Gender differences in strain were explained by the greater number of care tasks and the restriction of activity seen in female partners. To provide the best support to partners in clinical practice, gender differences with respect to strain should be taken into consideration.

Introduction

The quality of life of the caregivers of stroke patients has received increasing attention during recent decades. Two important, but distinct concepts in recent research on the quality of life of caregivers are ‘burden of care’ and ‘well-being’. Burden of care refers to the consequences of caring for the patient, whereas well-being is a broader concept referring to the emotional and cognitive evaluation of one’s life, on a global level and concerning different life domains (Diener, 1984). An important aspect relevant to subjective well-being is satisfaction with life (Lucas et al., 1996; Bush, 1984).

One of the factors that has been related to burden of care and the well-being of caregivers is the severity of disabilities after stroke. Physical disabilities have been associated with burden of care after stroke in several studies (Blake & Lincoln, 2000; Bugge, Alexander & Hagen, 1999; Scholte op Reimer et al., 1998). In non-institutionalised patients, the cognitive and behavioural disturbances seen in the patient appeared to be most predictive for the burden of care (van den Heuvel et al., 2001; Draper et al., 1992). It is not yet clear, however, what the direct impact of patient characteristics is on the broader concept of the well-being of the stroke caregiver. While some studies showed a negative relationship between the physical disabilities of the patient and the well-being of the caregiver, others have not (Forsberg-Warleby, Moller, & Blomstrand, 2001; Wyller et al., 2003; Wade, Lengh-Smith & Hewer, 1986). Several studies have described a relationship between the cognitive and behavioural changes following a stroke and the well-being of the caregiver (van den Heuvel et al., 2001; Schure, van Dreumel & Groenier, 1992; Anderson, Linto & Stewart-Wynne, 1995). It has been proposed, however, that the subjective well-being of caregivers is more closely related to the perceived burden of care than to individual patient characteristics (Scholte op Reimer et al., 1998; Wyller et al., 2003).

A theoretical account of the mechanisms by which patient disabilities influence caregiver strain and well-being is lacking in most studies. In one study which examined depression in caregivers, the restriction on engaging in their own activities was shown to affect the well-being of spousal caregivers (Nieboer et al., 1998). This study used the framework of the Social Production Functions (SPF)-theory to explain the impact of caregiving on the well-being of the caregivers. SPF-theory states that subjects actively produce their own psychological well-being by trying to optimize physical and social
well-being through individual instrumental goals (Ormel et al., 1997; Steverink, Lindenberg & Ormel, 1998).

Disturbances in the relationship between partners and their spouses as a consequence of stroke, could temporarily influence the partners’ psychological well-being if their goals in the areas of physical and social well-being are not realised. Additional long-term effects of life events on the partner’s well-being are expected if he or she is unable to substitute goals or compensate for losses (Ormel et al., 1996). SPF-theory states that the presence of internal comfort is important to well-being. This includes an absence of pain and fatigue, the presence of stimulation and activation, and engaging in physical or mental activities. Hypothetically, the severity of the patient’s physical disability predicts the partner’s level of physical well-being. Caregivers who provide large amounts of physical help can secure less internal comfort and are less able to engage in their own activities.

According to SPF-theory, behavioural confirmation and affection are important to social well-being. The extent of cognitive, behavioural, and emotional disturbances in the patient is hypothetically an accurate predictor of the partner’s level of social well-being, because behavioural confirmation and affection might be diminished within the patient-caregiver relationship. Emotional, cognitive, and behavioural changes may also influence physical well-being. These changes may increase the demands on the partner, thereby restricting his or her own activities.

In the present study, the concepts of physical and social well-being are examined by measuring the strain on the partner. Life satisfaction of the partner is used as a measure of psychological well-being. In line with SPF-theory, it is hypothesized that caregiver strain mediates the relationship between patient disturbances and the partner’s life satisfaction. The influence of physical disabilities, cognitive and behavioural changes, and the patient’s mood on short and long-term strain and the well-being of the caregivers will be analysed in a community-based sample of first-ever ischemic stroke patients and their partners at three and fifteen months post-stroke.


Methods

Subjects

Stroke patients and their partners
Stroke patients were admitted by 100 general practitioners from the northern part of the Netherlands and by the Stroke Unit of the University Hospital Groningen. At three months post-stroke (T1), 122 first-ever, ischemic stroke patients were included in the study. Patients were included if they had not suffered previous neurological damage, psychiatric disorders, or alcohol addiction. The side of the brain in which the stroke had occurred was determined through CT-scanning and neurological reports. 83 (68%) of the 122 patients had a partner, who was subsequently interviewed. At fifteen months post-stroke (T2), 13 partners were unavailable for re-interview. In 7 cases this was due to the non-participation of the stroke patients because the patient had either died (n=2), was unable (n=1), or unwilling to continue it’s participation in the study (n=4). Another 6 partners could not be followed up because of divorce (n=1), death of the partner (n=1), or refusal (n=4). Drop-out of partners was not related to the age or gender of the partner or to the partner variables of interest. Partners did not differ in level of strain, or in pre-stroke and post-stroke life satisfaction at T1, regardless of their participation at T2. The drop-out of partners was not related to the severity of the patients’ disabilities. 70 partners were interviewed at T2. Their mean age was 60.7 years ranging from 35 to 81 years. The majority of the partners was female (n=51, 73%). All partners lived independently following the stroke. Five stroke patients lived in a nursing home while their partners remained at home. The mean score of the patients on the Barthel Index (BI) was 18.4 (SD=3.4) at T1 and 18.7 (SD=3.2) at T2. Of the 70 patients whose partners were included at T1 and T2, 29 had a right hemisphere stroke, 36 had a left hemisphere stroke, 3 had bilateral damage, and 2 had strokes which affected the brain stem or cerebellum. The analyses in the present study only include those 65 patients with unilateral cortical strokes.

Materials

Life satisfaction of the partner
Global and domain specific satisfaction with life was measured using the Life Satisfaction Scale (Viitanen et al., 1988). The partners of stroke patients were asked to rate
their satisfaction with life in general, leisure, togetherness with friends, togetherness with family, marriage, and sexuality on a numerical scale including “1” for very dissatisfied, “2” for dissatisfied, “3” for mostly dissatisfied, “4” for mostly satisfied, “5” for satisfied, and “6” for very satisfied. At T1 the satisfaction preceding the stroke (recorded as satisfaction at T0) and at three months after the stroke was rated. At T2, the satisfaction at fifteen months post-stroke was assessed. Cut-off scores were calculated for all items. Partners who rated their level of satisfaction as very dissatisfied, dissatisfied, or mostly dissatisfied were regarded as being dissatisfied with the investigated item.

**Strain on the partner**
To measure caregiver strain at T1 and T2, the Caregiver Strain Index (CSI) was used (Robinson, 1983). This questionnaire was originally developed to measure the strain on the caregivers of elderly patients who were hospitalised with hip and heart disease, but has since been used for caregivers of stroke patients as well (Bugge, Alexander & Hagen, 1999; Schure, 1995; van den Heuvel et al., 2001). It appeared to be a feasible and valid instrument for the assessment of the burden of care experienced by stroke caregivers in the Netherlands (van Exel et al., 2004). The CSI consists of 13 items concerning strain and can be answered with yes (1) or no (0). The original cut-off of 7 or more as an indication of increased strain was used.

**Physical disabilities of stroke patients**
The SA-SIP, a 30-item stroke-adapted version of the original Sickness Impact Profile, was used to measure the functional impairments of stroke patients (van Straten et al., 1997; Bergner et al., 1981). The scale was administered to patients at T1 and T2. A principal component analysis with Varimax rotation has shown that a physical disability scale could be formed by adding up the scales Body Care and Movement, Mobility, Household Management, and Ambulation (Eigen Value = 3.6; 44.6% Explained Variance). The physical scale was used in the present study, and it proved to have good reliability (alpha = .91) (van Straten et al., 1997).

**Cognitive, emotional, and behavioural changes in stroke patients**
Cognitive, emotional, and behavioural changes in the stroke patients were assessed at T1 and T2 by asking the patients and the partners to indicate the presence of change on 20 items. These items were based on clinical relevance according to both neuropsycho-
logical literature and interviews with the partners of stroke patients (Schure, 1995). The partners’ forms demonstrated a high internal consistency (alpha = 0.94), whereas the patients’ forms showed a lesser but still moderate internal consistency (alpha = .80). All items on which both patient and partner agreed were summed. This score of the total number of changes in cognition, emotion, and behaviour mentioned by both patient and partner was used for the statistical analyses.

**Anxiety and depression in stroke patients**

The Hospital Anxiety and Depression scale (HADS) was used to measure anxiety and depression in the stroke patients at T1 and T2 (Zigmond & Snaith, 1983). The depression and anxiety subscales each contain 7 items (scored 0 to 21), with higher scores indicating a greater likelihood of anxiety or depression. Although several studies found a two factor solution for the HADS using principal component analysis, both subscales correlate highly and can together be seen as an indication of the amount of general distress experienced by the patient (Johnson et al., 1995; Spinhoven et al., 1997). The total HADS score was used in the present study. The HADS has been well validated and showed sufficient internal reliability in different groups of Dutch subjects (Spinhoven et al., 1997).

**Statistical analysis**

To examine whether strain could be subdivided into strain associated with achieving physical well-being and strain associated with achieving social well-being, a Principal Component analysis with Varimax rotation was performed on the items of the CSI at T2. Factors with an Eigen Value greater than 1 were extracted. To analyse the time course of the strain on partners, a paired-samples T-test was calculated. GLM repeated measure analyses, followed by LSD post-hoc analyses were performed to examine the course of total life satisfaction from T0 to T2. The course of satisfaction with respect to life domains was calculated with Friedman's test using several related variables. The multiple prediction of strain at T1 and T2 by disabilities of the patient at T1 and T2 was examined by GLM univariate analyses. To analyse the mediating influence of strain between patient disabilities and the life satisfaction experienced by the partner, two GLM univariate models were compared. First, a multiple prediction of life satisfaction at T1 and T2 by patient disabilities was performed. Second, the analysis was repeated using the patient variables that predicted life satisfaction in the previous analysis, but now with the
inclusion of the partner’s strain. Finally, a multiple prediction of strain and gender on life satisfaction at T1 and T2 was assessed using GLM univariate analysis. All statistical analyses were performed in SPSS 10.0 for Windows.

**Results**

**Course of strain on stroke partners**
As Table 1 shows, factor analysis revealed two factors for strain, the first explaining 38% of variance, while factor 2 explained an additional 12%. Factor 1 is termed Physical Strain, as it contains items that indicate physical effort in caring for patients and changes or restrictions in the activities of the partner. Factor 2 is termed Emotional Strain as the items mostly involve behavioural changes in the patient, the relationship with the patient, and worries of the partner. The internal reliability of the physical strain scale was good (alpha = .88) while the reliability of the emotional strain scale was moderate (alpha = .70).

**Table 1. Factor loadings on items of CSI, PCA, after Varimax rotation.**

<table>
<thead>
<tr>
<th>Items of CSI</th>
<th>Factor 1 EV=5.0</th>
<th>Factor 2 EV=1.6</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical strain</td>
<td>.77</td>
<td>.17</td>
</tr>
<tr>
<td>Other time demands</td>
<td>.76</td>
<td>.21</td>
</tr>
<tr>
<td>Inconvenient</td>
<td>.73</td>
<td>.00</td>
</tr>
<tr>
<td>Family changes</td>
<td>.73</td>
<td>.00</td>
</tr>
<tr>
<td>Feeling overwhelmed</td>
<td>.71</td>
<td>.41</td>
</tr>
<tr>
<td>Confining</td>
<td>.70</td>
<td>.36</td>
</tr>
<tr>
<td>Changes to plans</td>
<td>.70</td>
<td>.00</td>
</tr>
<tr>
<td>Work changes</td>
<td>.43</td>
<td>.18</td>
</tr>
<tr>
<td>Behaviour upsetting</td>
<td>.00</td>
<td>.78</td>
</tr>
<tr>
<td>Financial strain</td>
<td>-.23</td>
<td>.66</td>
</tr>
<tr>
<td>Emotional adjustment</td>
<td>.25</td>
<td>.57</td>
</tr>
<tr>
<td>Person has changed</td>
<td>.45</td>
<td>.56</td>
</tr>
<tr>
<td>Sleep is disturbed</td>
<td>.25</td>
<td>.44</td>
</tr>
</tbody>
</table>

On a group level, the total strain on the partners of stroke patients did not change significantly between T1 and T2 (T1 M=3.9, SD=3.6, T2 M=3.7, SD=3.3, t=0.6, p=.57). Neither physical strain (t=1.0, p=.31) nor emotional strain (t=-0.3, p=.80) changed signifi-
significantly from T1 to T2. The gender of the partner did not affect physical strain at either T1 (t=-0.5, p=.62) or T2 (t=-0.9, p=.39). While emotional strain did not differ between male and female partners at T1 (t=-0.4, p=.66), female partners did experience significantly greater emotional strain than male partners at T2 (t=-2.2, p=.03). The age of the partner and the side of the lesion were not related to strain at either T1 or T2.

14 partners at T1 (23%) and 13 partners at T2 (22%) scored above CSI cut-off. The percentage of male or female partners scoring above cut-off did not differ at T1 ($X^2=0.1$, p=.81) or T2 ($X^2=0.2$, p=.67). There was no age difference in partners scoring above or below the cut-off at T1 and T2.

**Course of life satisfaction**

GLM Repeated measures analysis showed a significant overall change in total life satisfaction for the partners of stroke patients ($F=5.8$, p=.01). Post-hoc tests showed a significant deterioration from T0 to T1 ($F=11.5$, p=.00) but no difference in life satisfaction from T1 to T2 ($F=0.2$, p=.66).

**Figure 1. Life satisfaction on all seven domains at T0, T1 and T2 for partners of stroke patients.**
Neither the side of the ischemic lesion, gender, nor the age of the partner influenced the total life satisfaction at each time of measurement.

As Table 2 and Figure 1 show, it appeared that in the partners of stroke patients, satisfaction with life in general ($X^2=6.5$, $p=.04$), satisfaction with leisure ($X^2=6.6$, $p=.04$), and satisfaction with sexuality ($X^2=6.5$, $p=.04$) changed significantly from the time before stroke to three months post-stroke, and remained at an overall diminished level at T2. Table 2 also describes the percentage of partners dissatisfied with life domains. At T0, T1, and T2, the highest proportion of dissatisfaction concerned sexual life. The percentage of partners dissatisfied with life domains did not differ significantly from T0 to T1 to T2.

Table 2. Mean level of satisfaction and percentages dissatisfied (DIS) with life domains in partners of stroke patients rated pre-stroke (T0) and at three (T1) and fifteen months (T2) post-stroke (n=60).

<table>
<thead>
<tr>
<th>Satisfaction with</th>
<th>T0 M (SD)</th>
<th>% DIS</th>
<th>T1 M (SD)</th>
<th>% DIS</th>
<th>T2 M (SD)</th>
<th>% DIS</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Life in general</td>
<td>5.1 (0.7)</td>
<td>2</td>
<td>4.8 (0.7)</td>
<td>2</td>
<td>4.9 (0.7)</td>
<td>2</td>
<td>6.5*</td>
</tr>
<tr>
<td>Self-care</td>
<td>5.3 (0.7)</td>
<td>3</td>
<td>5.2 (0.8)</td>
<td>5</td>
<td>5.1 (0.9)</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>Leisure</td>
<td>5.3 (0.5)</td>
<td>0</td>
<td>4.8 (0.9)</td>
<td>10</td>
<td>5.0 (1.1)</td>
<td>7</td>
<td>6.6*</td>
</tr>
<tr>
<td>Togetherness friends</td>
<td>5.1 (0.7)</td>
<td>3</td>
<td>5.0 (0.6)</td>
<td>3</td>
<td>4.9 (1.1)</td>
<td>7</td>
<td>1.7</td>
</tr>
<tr>
<td>Togetherness family</td>
<td>5.2 (0.6)</td>
<td>2</td>
<td>5.2 (0.6)</td>
<td>3</td>
<td>5.3 (0.8)</td>
<td>3</td>
<td>3.3</td>
</tr>
<tr>
<td>Marriage</td>
<td>5.1 (0.7)</td>
<td>2</td>
<td>5.1 (0.6)</td>
<td>3</td>
<td>5.2 (0.7)</td>
<td>0</td>
<td>0.9</td>
</tr>
<tr>
<td>Sexuality</td>
<td>4.9 (1.1)</td>
<td>9</td>
<td>4.6 (1.3)</td>
<td>16</td>
<td>4.5 (1.1)</td>
<td>12</td>
<td>6.5*</td>
</tr>
<tr>
<td>Total life satisfaction</td>
<td>36.0 (3.7)</td>
<td>34.9 (3.8)</td>
<td>35.3 (3.5)</td>
<td>5.8**</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Prediction of physical and emotional strain at T1 and T2

Cognitive and behavioural changes, physical disabilities, and mood did not differ between male and female patients or between right and left hemisphere stroke patients at T1 and T2. Table 3 shows that physical disabilities and cognitive and behavioural changes did not differ significantly from T1 to T2. On the other hand, the patient’s mood improved significantly from T1 to T2.

To examine the combined influence of the patient’s disabilities at T1 and T2 on partner strain at T1 and T2, GLM univariate analyses were performed. Besides patient disabilities, the partner’s gender was also included in the model.
Table 3. Paired-samples t-tests on physical disabilities, behavioural and cognitive changes and mood of the patient from T1 to T2 (n=67-69).
* p < .05; ** p < .01

<table>
<thead>
<tr>
<th></th>
<th>T1 M (SD)</th>
<th>T2 M (SD)</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical disabilities</td>
<td>4.7 (4.3)</td>
<td>4.5 (4.3)</td>
<td>0.7</td>
</tr>
<tr>
<td>Behavioural and cognitive changes</td>
<td>3.6 (3.1)</td>
<td>3.8 (3.8)</td>
<td>-0.3</td>
</tr>
<tr>
<td>Mood</td>
<td>5.9 (5.1)</td>
<td>4.3 (4.9)</td>
<td>2.7**</td>
</tr>
</tbody>
</table>

Table 4 demonstrates that, as expected, the physical disabilities of patients predicted the physical strain on partners at T1 and T2. As hypothesized, behavioural and cognitive changes also predicted physical strain at both times of measurement. Behavioural and cognitive changes proved most important in predicting emotional strain at T1 and T2. Physical disabilities also predicted emotional strain at T1, but did not have any predictive value concerning emotional strain at fifteen months post-stroke. The partner’s gender appeared to predict emotional strain at T2, with the female partners experiencing greater emotional strain than the male partners. Unexpectedly, the patient’s mood did not predict the strain on the partner at either time of measurement.

Table 4. Multiple prediction of physical and emotional strain in partners of stroke patients at T1 and T2 by gender of partner and disabilities and mood of the patient at T1 and T2 (n=64).

<table>
<thead>
<tr>
<th>Variables at T1/T2</th>
<th>Physical strain</th>
<th>Emotional strain</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 F p</td>
<td>T2 F p</td>
</tr>
<tr>
<td>Intercept</td>
<td>0.0 .87</td>
<td>0.7 .42</td>
</tr>
<tr>
<td>Gender partner</td>
<td>0.1 .74</td>
<td>0.1 .75</td>
</tr>
<tr>
<td>Physical disabilities</td>
<td>15.9 .00</td>
<td>23.6 .00</td>
</tr>
<tr>
<td>Behavioural and cognitive changes</td>
<td>8.3 .01</td>
<td>12.4 .00</td>
</tr>
<tr>
<td>Mood</td>
<td>0.0 .96</td>
<td>3.1 .08</td>
</tr>
<tr>
<td>Corrected model</td>
<td>13.2 .00</td>
<td>14.3 .00</td>
</tr>
<tr>
<td>R²=.48</td>
<td>R²=.50</td>
<td>R²=.50</td>
</tr>
</tbody>
</table>

Patient disabilities, strain, and life satisfaction of partners at T1 and T2

The hypothesis that strain mediates the relationship between patient disabilities and the life satisfaction of the partner was evaluated. Table 5 shows that physical disabilities
and changes in behaviour, emotion, and cognition had predictive value for the partner’s life satisfaction at T2.

Table 5. Multiple prediction of life satisfaction in partners of stroke patients at T1 and T2 by patient disabilities at T1 and T2 and by the combined prediction of patient disabilities and strain on partner at T1 and T2 (n=57).

<table>
<thead>
<tr>
<th>Patient variables at T1/T2</th>
<th>Life satisfaction</th>
<th>T1</th>
<th>p</th>
<th>T2</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>1298.1</td>
<td>.08</td>
<td>2930.7</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td>Physical disabilities</td>
<td>2.5</td>
<td>.12</td>
<td>6.4</td>
<td>.01</td>
<td></td>
</tr>
<tr>
<td>Behavioural and cognitive changes</td>
<td>1.7</td>
<td>.11</td>
<td>5.1</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td>Mood</td>
<td>1.1</td>
<td>.29</td>
<td>0.1</td>
<td>.72</td>
<td></td>
</tr>
<tr>
<td>Corrected model</td>
<td>2.4</td>
<td>.08</td>
<td>7.8</td>
<td>.00</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patient variables and partner strain T1/T2</th>
<th>Life satisfaction</th>
<th>T1</th>
<th>p</th>
<th>T2</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>1852.1</td>
<td>.00</td>
<td>3736.1</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td>Physical strain</td>
<td>5.8</td>
<td>.02</td>
<td>5.3</td>
<td>.03</td>
<td></td>
</tr>
<tr>
<td>Emotional strain</td>
<td>9.4</td>
<td>.00</td>
<td>6.3</td>
<td>.01</td>
<td></td>
</tr>
<tr>
<td>Physical disabilities</td>
<td>.03</td>
<td>.88</td>
<td>1.1</td>
<td>.29</td>
<td></td>
</tr>
<tr>
<td>Behavioural and cognitive changes</td>
<td>1.1</td>
<td>.30</td>
<td>0.3</td>
<td>.61</td>
<td></td>
</tr>
<tr>
<td>Corrected model</td>
<td>13.2</td>
<td>.00</td>
<td>11.7</td>
<td>.00</td>
<td></td>
</tr>
<tr>
<td></td>
<td>R²=.41</td>
<td></td>
<td>R²=.47</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

The patient’s mood was not a predictor for the life satisfaction of the partner. However, the patient’s disabilities did not independently predict the life satisfaction of partners when the strain on the partner was included in the model. Both physical and emotional strain appeared important in predicting the life satisfaction of partners at T1 and T2.

Female partners appeared to experience greater emotional strain at T2. Therefore, the impact of the partner’s gender on the prediction of life satisfaction by strain was further investigated. Interaction terms between gender and strain were included in the model to predict life satisfaction at both T1 and T2. As is presented in Table 6, gender appeared to influence the relationship between strain and life satisfaction. In male patients, at both T1 and T2, life satisfaction was only predicted by physical strain. In female patients, life satisfaction was predicted by physical strain at T1 and by emotional and physical strain at T2.
Table 6. Multiple prediction of life satisfaction at T1 and T2 by gender and strain on partner at T1 and T2 (n=57).

<table>
<thead>
<tr>
<th>Patient variables at T1/T2</th>
<th>T1 F</th>
<th>p</th>
<th>T2 F</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Intercept</td>
<td>1770.5</td>
<td>.00</td>
<td>4309.5</td>
<td>.00</td>
</tr>
<tr>
<td>Gender</td>
<td>2.4</td>
<td>.12</td>
<td>0.1</td>
<td>.76</td>
</tr>
<tr>
<td>Physical strain</td>
<td>8.8</td>
<td>.00</td>
<td>9.1</td>
<td>.00</td>
</tr>
<tr>
<td>Emotional strain</td>
<td>0.0</td>
<td>.93</td>
<td>.78</td>
<td>.38</td>
</tr>
<tr>
<td>Gender * Physical strain</td>
<td>4.1</td>
<td>.05</td>
<td>2.0</td>
<td>.17</td>
</tr>
<tr>
<td>Gender * Emotional strain</td>
<td>1.8</td>
<td>.19</td>
<td>4.3</td>
<td>.04</td>
</tr>
<tr>
<td>Corrected model</td>
<td>8.0</td>
<td>.00</td>
<td>10.5</td>
<td>.00</td>
</tr>
</tbody>
</table>

Discussion

**Level and course of strain and life satisfaction of partners of stroke patients**

At both T1 and T2, approximately 25% of the partners of stroke patients experienced considerable strain. This result is somewhat lower than that reported in a community based study of stroke caregivers 6 months post-stroke which found that 37% of caregivers experienced considerable strain, but similar to the 21% of caregivers scoring above CSI cut-off reported in a community based study of caregivers at least seven years post-stroke (Bugge, Alexander & Hagen, 1999; Wilkinson et al., 1997).

The life satisfaction of partners deteriorated from the time before stroke and remained at a lower level than pre-stroke levels of life satisfaction. The domains in which this change occurred, satisfaction with life in general and leisure and sexuality, were the same domains as those in which stroke patients themselves indicated a deterioration following stroke (Viitanen et al., 1988). A limitation of the present study is that pre-stroke levels of satisfaction were rated retrospectively which may have resulted in biased accounts including reports which were more positive than actuality warranted. Some researchers have commented that though life events may cause fluctuations in well-being, in general, people return to a baseline level of functioning (Headey & Wearing, 1992). Others have shown that there are some life events which can have such a negative impact on life satisfaction, that this baseline level is shifted downwards (Lucas et al., 2004; Lucas et al., 2003). When, in the present study, the actual level of satisfaction
in different domains is analysed, it shifted from ‘satisfied’ to ‘mostly satisfied’, indicating that the partners of stroke patients remained generally satisfied with life. Additionally, the number of partners dissatisfied with life domains did not change significantly from pre-stroke to post-stroke times of measurement. Although life satisfaction did not return to pre-stroke levels, the present results might be regarded as suggesting the presence of an adaptation process. The maintenance of a relatively high level of satisfaction might serve as a protection from psychological distress (Stiegelis et al., 2003; Hagedorn et al., 2002).

**SPF-theory**

*Components of strain and well-being*

The aim of this study was to examine the effects of stroke patients’ disabilities on the strain and well-being of their partners at three and fifteen months post-stroke. According to SPF-theory, the partners are thought to actively produce their own well-being by interacting with their environments. If changes occur within the environment that hinder their productive capacity, as would be the case if one’s spouse were to become ill, this could cause strain and could affect well-being. Strain, used as a measure of frustration in fulfilling individual goals, has many components. Within the present study, factor analysis revealed two components of strain, the first primarily concerned with physical strain as a result of the practical consequences of stroke, and the second consisting of items relating to emotional strain. These factors seem to support the theoretical division of well-being into physical and social components. A limitation of the present study is that the actual goals and resources such as the activities of partners and their network of social support have not been assessed in a more direct way. A finding revealed by factor analysis is that the item ‘feeling overwhelmed’ emphasizes physical strain, while intuitively it should be related to emotional strain. A close analysis of the Dutch translation of this item reveals some ambiguity of meaning. The item may be interpreted as both an emotional and a time-demanding consequence of care.

*The influence of patient disabilities on partner strain*

It was hypothesised that the physical disabilities of the patient would most strongly predict the physical strain experienced by the partner, while the behavioural and cognitive changes and the mood of the patient were expected to predict both emotional and physical strain of the partner. Our hypotheses were mostly confirmed, as at T1 and
T2, physical strain in the partner was predicted by the physical disabilities of the patient while behavioural and cognitive changes predicted both emotional and physical strain. Against expectations, however, physical disabilities also explained a proportion of the variance found in the emotional strain at T1, but it was not a predictive factor at T2. In the present study, only the behavioural and cognitive changes mentioned by both the patient and the partner were included. Therefore, the results might underestimate the size and impact of post-stroke changes in cognition and behaviour on the strain experienced by the partner. Previous analysis of the patient group showed that particularly right hemisphere stroke patients underestimated the presence of changes in emotion and cognition. Furthermore, the number of changes reported by partners, but not by patients was associated with greater distress in the partner (Visser-Keizer et al., 2002).

SPF-theory offers a valuable framework to explain that behavioural and cognitive changes in the patient, such as lack of initiative, irritability or disturbances in memory, could influence behavioural confirmation and affection in the relationship with the patient, influencing the possibilities for obtaining a satisfactory level of social well-being. On the other hand, physical disabilities and behavioural and cognitive changes in the patient might affect his or her independence, thus placing a greater demand on the partner. The goals of internal comfort level and activity level of the partner might be hindered, leading to a decreased possibility of obtaining physical well-being. Against expectations, the patient’s mood did not affect the partner’s physical or emotional strain. An explanation for this lack of relationship is the relatively mild character of mood disturbance experienced by the patient. Furthermore, running contrary to the physical disabilities and changes in behaviour and cognition, the patient’s mood showed improvement from the first to the second time of measurement.

**Strain as a mediator between patient disabilities and the partner’s life satisfaction**

SPF-theory states that psychological well-being, measured in this study with the life satisfaction scale, is dependent upon the realisation of physical and social well-being which is dependent upon the fulfilment of individual goals. It was therefore hypothesised that patient disabilities would only influence the partner’s life satisfaction by their influence on partner strain. As expected, when strain was included in the model predicting life satisfaction, specific patient disabilities did not independently predict the life satisfaction of the partner.
Gender differences in strain and life satisfaction

Physical, social, and psychological well-being are universal goals in SPF-theory, but individuals differ in the way they achieve well-being. Within this study emotional strain is thought to specifically impair the realisation of social well-being, while physical well-being is impaired by physical strain. The present results showed that at fifteen months post-stroke emotional strain was greater for women than for men. Life satisfaction in male and female caregivers was also differentially predicted by emotional and physical strain. Life satisfaction of male partners was only predicted by physical strain, while the life satisfaction of female partners was predicted by both physical and emotional strain. In the present study, male stroke patients did not show greater post-stroke disturbances, so this gender effect in partners could not be explained by patient characteristics.

Gender differences in strain have previously been described in stroke caregivers but also in caregivers of cancer patients and patients with dementia (Bugge, Alexander & Hagen, 1999; Blood et al., 1994; Collins & Jones, 1997, Almberg et al., 1998, van den Heuvel et al., 2001). These gender differences can be viewed in terms of the theory of social production function. One of the crucial differences between male and female caregivers may be their participation in their own activities. Male and female caregivers have traditionally been assigned different role expectations and different tasks when caring for patients. Women, for example, have been thought to be better suited to caring for patients, to feel more of a sense of obligation to the patient, and to carry out more tasks relating to patient care (Collins & Jones, 1997; Miller & Cafasso, 1992; Morris et al., 1991). Female caregivers, by performing more caregiver tasks, may be seriously impairing their own ability to find activity substitutes, but also in meeting others. Nieboer (1997) in a study on gender differences in caregiving, found that women engaged in more caregiving tasks than men, but also discovered that men received far more help from others than women when they were confronted with illness. In addition, Schure (1995) found that male stroke partners did not differ from male controls in their activity level and, in contrast to female stroke partners, they reported a significant increase in marital and leisure activities within one year post-stroke.

Practical implications

These results have practical clinical implications, as they draw attention to the impact of cognitive and behavioural changes in stroke patients on the strain and well-being of
their partners. Providing information on the behavioural consequences of stroke and ways to cope with these changes is crucial but is often lacking for stroke patients and partners living in the community. Attention also needs to be directed at the different factors of strain which influence the well-being of male and female partners. Female partners experience greater emotional strain which affects their life satisfaction. Professional support of female partners could be useful as it concerns coping with the impact of stroke on their relationship with the patient. They can be taught to find ways to substitute for affection, behavioural support and activation when this has diminished in their relationship with the patient. Engaging in their own activities should be encouraged, although this sometimes implies delegating caregiver tasks to professionals, friends, or other family members. Male partners do not mention greater strain compared to controls, and it is the physical strain they experience which predicts their life satisfaction. Perhaps, male partners would receive the most benefit from knowing how to deal with increasing demands in practical situations.
References


Abstract
Social Production Functions (SPF)-theory describes the engagement in activities as an important mean to obtain well-being. Aims of the present study were to describe the role of cognitive disabilities at three months post-stroke in the restoration of activities after stroke and to examine the predictive value of cognitive disabilities and activity level at three months post-stroke for life satisfaction at fifteen months after stroke. Life satisfaction of 101 community-dwelling, first-ever ischemic stroke patients was assessed at three and fifteen months post-stroke, while patients retrospectively rated life satisfaction before stroke. At the second assessment, life satisfaction of 70 elderly controls was also measured. The results showed that life satisfaction deteriorated from time before stroke to three months post-stroke and remained at this diminished level at fifteen months post-stroke. In comparison with control subjects, only male stroke patients reported a significantly lower level of life satisfaction. However, most patients remained relatively satisfied with life. While physical disabilities at three months after stroke predicted activity level at fifteen months post-stroke, higher reasoning abilities and faster mental speed at three months post-stroke were related to a greater restoration of activities from three to fifteen months post-stroke. Furthermore, activity level, memory functioning and reasoning capacities at three months post-stroke predicted life satisfaction at fifteen months post-stroke. The lower life satisfaction of male patients was explained by the relatively greater sensitivity of male activities to the effects of stroke. The present results draw attention to the impact of cognitive functioning on activities and life satisfaction of stroke patients living in the community. This patient group often does not gain access to patient education or cognitive rehabilitation.

Introduction

While early research on outcome after stroke used a dichotomous outcome score of life or death, in recent years more and more attention is paid to the quality of life and well-being of stroke survivors. In its origin, research on quality of life was directed at the evaluation of emotions such as happiness or satisfaction (Wyller et al., 1997). In recent studies, health-related measurements have often been used to assess quality of life after stroke. It has become apparent, though, that poor health does not necessarily mean a low sense of subjective well-being (Albrecht & deVlieger, 1999, Diener et al., 1999, Brief et al., 1993).

Subjective well-being represents the emotional and cognitive evaluation of one’s life, on a global level and on different domains in life (Diener, 1984). Subjective well-being includes the distinct concepts of life satisfaction, optimism, positive and negative affect (Lucas et al., 1996). Well-being is thought to be influenced by relatively stable resources as personality, culture or social class (Diener, Oishi & Lucas, 2003, Schimmack et al., 2002). Life events or daily hassles can cause fluctuations in well-being, but it has been proposed that, in general, people will return to a baseline level (Headey & Wear, 1992). In most people this baseline shows a tendency towards positive affect or optimism (Diener & Diener, 1996). Recent studies showed that, in the face of illness, a cognitive adaptation can take place by which patients shift to even higher levels of optimism. This cognitive adaptation seems to protect patients from psychological distress (Stieigelis et al., 2003; Hagedoorn et al., 2002; Taylor et al., 2000). Some life events, however, have such an impact on life satisfaction, that the level of satisfaction people return to is shifted downwards (Lucas et al., 2004; Lucas et al., 2003). Diener and colleagues (1999), in a review of studies on the impact of health on subjective well-being, concluded that when a disabling condition is severe or entails multiple and chronic problems, it may affect well-being. The impact of one’s health on well-being, however, depends on an individual’s perception of the illness (Diener et al., 1999).

Until now, the course of life satisfaction after stroke has hardly been studied. While life satisfaction after stroke has been found to be lower than life satisfaction of controls of similar age, almost all studies measured life satisfaction at only one moment after stroke (Carlsson et al., 2003; Clarke et al., 2002; Wyller et al., 1997). The aspects on which stroke patients were less satisfied concerned leisure, sexual, self-care and global satis-
faction (Carlsson et al., 2003; Viitanen et al., 1988). In accordance with the idea of a cognitive adaptation, most studies showed that life satisfaction of most stroke patients was fair to good several years after stroke (Viitanen, 1988; King, 1996; Löfgren et al., 1999). Astrom et al. (1992) found that life satisfaction improved from three to twelve months after stroke. However, those stroke patients with poor life satisfaction at one year after stroke, remained dissatisfied for at least two more years.

One of the key elements in the fulfilment of well-being is thought to be the engagement in activities (Csikszentmihalyi, 1997; Steverink et al., 1998). According to the Social Production Functions (SPF) theory, individuals actively try to maximise their psychological well-being by the realization of several lower-order goals (Steverink et al., 1998). Activities are regarded important in providing physical and mental stimulation and opportunities for social interaction. When confronted with sudden illness, such as a stroke, symptoms and functional limitations place constraints on the activities of the patient (Ormel et al., 1997). The patient has to adapt to this situation by finding new activities, perform activities in a different way or place greater value on other goals to obtain well-being. According to SPF-theory, cognitive processes are especially important in these processes of adaptation (Steverink et al., 1998). If someone cannot adapt to or substitute for losses, a more long-term negative effect on well-being is expected.

A great proportion of community-dwelling stroke patients has been found to experience a limitation of activities, and to perform less activities than controls of similar age (Mayo et al., 2002; Labi et al., 1980). The level of instrumental activities, leisure activities and social integration after stroke has been related to life satisfaction in different studies (Kim et al., 1999 Viitanen, 1988; Vestling et al., 2003; Sveen et al., 2004). With regard to the factors that influence the ability to perform activities of daily life, most researchers agree that physical disabilities after stroke have greatest impact (Bernspang et al., 1987; Mercier et al., 2001). In addition, the impact of cognitive disabilities on activities of daily life after stroke is more and more stressed (Gauggel et al., 2000; Filiatrault et al., 1991; Tatemiichi et al., 1994; Carter et al., 1988). Patients with impaired global cognitive functioning at three months post-stroke appeared to be less active up to 4 years after stroke than patients with intact global cognitive functioning (Patel et al., 2002). Less research has focused on the impact of distinctive cognitive domains on activities after stroke. So far, poorer attentional and executive functioning have been related to poorer daily functioning after stroke (McDowd et al., 2003; Pohjasvaara et al., 2002).
The first aim of the present study is to describe the course of life satisfaction from time before stroke to three and fifteen months post-stroke in a community based sample. The influence of demographical variables and side of lesion on the course of life satisfaction after stroke will be examined. In literature, no consistent effects have been described with regard to the impact of gender, age or lesion characteristics on life satisfaction after stroke. The final level of life satisfaction at fifteen months post-stroke will be compared to life satisfaction of age-matched controls. Second aim of this study is to analyse the role of post-stroke cognitive functioning in the restoration of activity level from three to fifteen months post-stroke. When patients return home after stroke, they have to adapt to a new situation. The success of this adaptation is expected to be related to the severity of physical disabilities of the patient, but also to the cognitive capability of the patient to compensate for losses. Three important cognitive domains, speed of information processing, learning capability and problem solving capability will be examined. It is hypothesized that the actual level of activities at three and fifteen months post-stroke will be mainly predicted by the level of physical disability of the patient, while cognitive performance at three months after stroke will be related to gain in activities from three to fifteen months post-stroke. Finally, the impact of cognitive functioning and activity level at three months post-stroke on life satisfaction at fifteen months post-stroke is analysed. SPF-theory describes activities as crucial in obtaining well-being, but the influence of cognitive functioning on well-being remains less clear. Cognitive disabilities can be regarded as constraints or loss of resources which influence the ability to perform or restore activities. In accordance with this idea it can be hypothesized that the influence of cognitive disabilities on life satisfaction will be mediated by the level of activities. On the other hand, because cognitive functions are important in the adaptation process itself, they might be independently related to life satisfaction after stroke.

Methods

Subjects

**Stroke patients**

First-ever, unilateral, ischemic stroke patients were recruited by 100 general practitioners (GPs) from the northern part of the Netherlands and by the Stroke Unit of the University Hospital Groningen. Stroke was defined as an acute disruption of blood
circulation in the brain with clinically visible symptoms lasting more than 24 hours. Patients with a history of neurological disturbances, psychiatric disturbances or substance abuse were excluded. A total of 235 patients were recruited of whom 122 met the inclusion criteria, were able and were willing to participate in the interview at T1. Within two weeks, 100 of these patients were assessed neuropsychologically. From the first (T1) to the second interview at fifteen months post-stroke (T2), 21 stroke patients dropped out of the study, so 101 were interviewed twice. Another 20 patients could not take part in the second neuropsychological assessment within the next two weeks. A total of 80 patients were neuropsychologically assessed at T2. See chapter 1 for a more detailed account of patients exclusion and drop-out. Patient drop-out appeared to be related to several variables of interest. Patients included at T1, but not at T2 were older, physically more disabled and less active than patients who stayed in the study. A similar number, but a greater proportion of female than male subjects dropped out. Furthermore, stroke patients who participated at T1, but no longer at T2, performed significantly worse than patients who stayed in the study on measures of reasoning and memory at T1. Drop-out of patients appeared not to be related to side of lesion or total life satisfaction.

All patients approved of the fact that their medical history and lesion characteristics were provided by GP and neurologist. Of the initial number of 122 patients, lateralisation of lesion could be classified for 119 patients on the basis of all neurological data: 54 had a right hemisphere infarction, 56 a left sided infarction, 4 bilateral lesions and 5 patients had lesions affecting brain stem or cerebellum. Only the patients with left and right hemisphere infarctions were included in the statistical analyses.

Control subjects
Control subjects were recruited among the population of four general practices from the northern part of the Netherlands. A stratified randomisation procedure was used to match the control subjects to patients on age and gender. Control subjects with a history of psychiatric disturbances, neurological conditions or substance abuse were excluded from the study (n=2). At T1 80 control subjects were interviewed, while 72 controls participated in the first neuropsychological assessment. At the interview at T2 the control group consisted of 70 subjects, 8 subjects had dropped out because they did not want to participate again (n=4), were too busy (n=2) or had moved (n=2). At the second neuropsychological assessment, 64 control subjects were assessed, 6 con-
trol subjects did not want to participate in the second neuropsychological assessment. Drop-out of control subjects was not related to any of the investigated variables.

**Procedure and measures**

The present study was approved of by the Medical Ethical Committee of the University Hospital Groningen. Stroke patients were assessed at three and fifteen months post-stroke at their own place of residence by trained interviewers. Control subjects were also interviewed twice at home with an interval of approximately one year. After signing an informed consent, several questionnaires concerning functional ability, mood and quality of life were administered. Within two weeks after the interview, the cognitive functions of the subjects were assessed using several neuropsychological tests. Only those instruments relevant for the current research questions will be described.

**Life satisfaction**

Global and domain specific satisfaction with life was measured using the Life Satisfaction Scale (Viitanen et al., 1988). Stroke patients and controls were asked to rate their satisfaction with life in general, leisure, togetherness with friends, togetherness with family, marriage, and sexuality on a numerical scale including "1" for very dissatisfied, "2" for dissatisfied, "3" for rather dissatisfied, "4" for rather satisfied, "5" for satisfied, and "6" for very satisfied. At T1 the satisfaction preceding the stroke (recorded as satisfaction at T0) and at three months after the stroke was rated. At T2, the satisfaction at fifteen months post-stroke was assessed. Controls rated their global and domain specific satisfaction with life at the second interview (T2). Ratings on life domains were summed to a total life satisfaction score (range 7-42). To document the number of satisfied or dissatisfied patients a dichotomy was used for each life domain. Satisfaction rated rather dissatisfied or lower, was scored as 'dissatisfied'. Reliability of the total satisfaction scale at the time of assessment (T1) (alpha=.81) and satisfaction rated retrospectively (T0) (alpha=.87) proved good in stroke patients.

**Activities**

The instrumental activities of daily life were assessed in stroke patients at T1 and T2 and in controls at T2 with ten items based on the Frenchay Activities Index (FAI) (Holbrook & Skillbeck, 1983). The 15 items of the original FAI can be divided into three subscales, ‘domestic activities,’ ‘outdoor activities’ and ‘leisure activities’ (Sveen et al., 1999; Cockburn
et al., 1990). In the present study, the subscales ‘outdoor activities and ‘leisure activities’ were used. To improve reliability of the scale, we omitted the item ‘gainful work’ (Schul- ing et al., 1993). Ratings of the frequency of the performance of separate activities were used in the statistical analyses, as well as a total activity score (range 0-28).

**Physical disabilities**
The SA-SIP, a 30-item stroke-adapted version of the original Sickness Impact Profile, was used to measure functional impairments of stroke patients (van Straten et al., 1997; Bergner et al., 1981). The scale was administered to patients at T1 and T2. Principal component analysis with Varimax rotation has shown that a physical disability scale could be formed by adding up the scales Body care and movement, Mobility, Household management and Ambulation (Eigen Value = 3.6; 44.6% Explained variance). Only the total score of the physical disabilities scale is used in the present study. Reliability proved to be good for the physical scale (alpha = .91) (van Straten et al., 1997).

**Cognitive functioning in stroke patients**

**Reasoning**
Three out of seven subtests of the SON-R 5½-17 were used to measure reasoning in stroke patients: Categories, Stories and Mosaics (Snijders et al., 1988; Lezak, 1995, Gerritsen, Berg, & Deelman, 2001). In Categories, a measure of abstract reasoning, subjects have to decide which two out of five line drawings belongs to three other drawings. The subtest Stories, a measure of concrete reasoning, requires subjects to arrange a set of pictures into a story with a logical time sequence. Patterns have to be copied using red/white squares in the visuo-spatial subtest Mosaics. Principal component analysis demonstrated that these three subtest measure one underlying factor in stroke patients (Eigenvalue = 2.1, variance explained = 71%).

In the selection of subtests, two adaptation were made to the original SON-R 5½-17. All stimulus material in the Categories and Stories was presented vertically instead of horizontally to rule out the effects of neglect as much as possible. Furthermore, time limits of the subtests were prolonged one and a half time. Before the test was administered, sample items were used to ensure that all patients met basic test requirements. Three subjects appeared to lack basic skills to complete the test. The sum of the three subtests was used for statistical analyses; higher scores indicate better performance.
Verbal memory

The Dutch version of the Rey Auditory Verbal Learning Test (RAVLT) was used as a measure of explicit memory. In this test, subjects have to learn 15 one-syllable words in five successive trials (Saan & Deelman, 1986). The immediate recall of words in each trial was summed to a total score of correct recalled words. Scores range from 0 to 75, with higher scores indicating better performance.

Mental speed

Reaction times were measured using a method developed by van Zomeren (1981). The reaction time was recorded by a computer and is divided into a decision component and a motor component. In this study only the decision times of the two conditions were used. The first is a simple mental speed condition in which subjects react to light stimuli, called visuomotor reaction time task. To measure more complex mental speed, a cognitive reaction time task was designed (Gerritsen et al., 2003). A computer screen was placed behind the reaction time apparatus on which words (Text task) or landscapes (Picture task) emerged. In the Text task, a category word (e.g. flowers) was presented on the upper half of the screen, while a stimulus word (e.g. rose) appeared in the lower half of the screen. Subjects were required to decide if a word fitted in the category. In the Picture task, a landscape was presented (e.g. beach) and a picture (e.g. kite) which did or did not fit into the landscape. Previous factor analysis on the reaction time components showed that visuomotor decision times and cognitive decision times formed two separate factors (Gerritsen et al., 2003).

Statistical analyses

First, the course of stroke patients’ total life satisfaction score from T0 to T2 was analysed using GLM Repeated Measures analysis, followed by post-hoc LSD analyses. Friedman’s test for several related variables was used to investigate the course of satisfaction with life domains from T0 to T2. Cochran’s Q was used to compare the number of patients dissatisfied with life domains from T0 to T2. To analyse the course of activity level from T1 to T2 in stroke patients, a paired-samples T-test was performed.

Secondly, total life satisfaction and activity level of stroke patients and controls were compared at T2 using independent-samples T-tests. Comparison of patients’ and controls’ satisfaction with life domains and the frequency of activity per item at T2 was performed.
by Mann-Whitney U-tests. Chi-square analyses were calculated to compare the number of patients and controls dissatisfied with life domains. Independent-samples t-tests were used to compare cognitive functioning and physical disabilities of stroke patients and controls at T1. Finally, two models concerning the factors influencing activity level and life satisfaction were analysed in the stroke group. The prediction of activity level at T1 and T2 and change in activity level from T1 to T2 by cognitive functioning and physical disabilities at T1 was investigated using General Linear Model (GLM) univariate analyses. GLM univariate analysis was also used to test the model predicting life satisfaction at T2 by activity level and cognitive functioning at T1. All analyses were performed in SPSS 10.0.

Results

Comparison of demographic variables
As Table 1 shows, stroke patients and controls did not differ significantly in age, gender, marital status or educational level. Stroke patients were less able to live independently and were less independent in self-care abilities than controls.

Table 1. Demographical variables and measures of independence in housing conditions and self-care for patients and controls at T1.

<table>
<thead>
<tr>
<th></th>
<th>Patient n=110</th>
<th>Control n=80</th>
<th>Statistics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, M (SD) range</td>
<td>66.5 (12.1)</td>
<td>66.3 (11.9)</td>
<td>t=-0.1</td>
</tr>
<tr>
<td>Gender, % male</td>
<td>60 %</td>
<td>55 %</td>
<td>X²=0.7</td>
</tr>
<tr>
<td>Education#, M (SD)</td>
<td>4.0 (1.5)</td>
<td>3.9 (1.4)</td>
<td>Z=-0.7</td>
</tr>
<tr>
<td>Marital status, % with partner</td>
<td>76 %</td>
<td>74 %</td>
<td>X²=0.2</td>
</tr>
<tr>
<td>Housing, % independent</td>
<td>82%</td>
<td>93%</td>
<td>tau=-2.5*</td>
</tr>
<tr>
<td>Housing, % semi-independent</td>
<td>4%</td>
<td>6%</td>
<td></td>
</tr>
<tr>
<td>Housing, % institution</td>
<td>14%</td>
<td>1%</td>
<td></td>
</tr>
<tr>
<td>Barthel Index, M (SD)</td>
<td>18.0 (3.7)</td>
<td>19.7 (0.8)</td>
<td>t=4.9***</td>
</tr>
</tbody>
</table>

# Classification Verhage, 1964

Male and female stroke patients did not differ in age, distribution of side of lesion, educational level or level of independence in basic ADL. Female patients were more often single than male patients (male 15% vs female 46%, X²=13.6, p=.000). Male and female controls did not differ significantly in age from stroke patients of the same gender.
Course of total life satisfaction of stroke patients

GLM Repeated Measures analysis showed a significant overall change in total life satisfaction from pre-stroke to post-stroke levels (F=8.1, p=.001). Post-hoc tests showed a significant decrease from T0 to T1 (T0: M=35.6, SD=3.7 T1: M=33.1, SD=4.6, F=16.3, p=.000), but no significant difference from T1 to T2 (T1: M=33.1, SD=4.6 T2: M=33.4, SD= 4.3, F=0.2, p=.65).

As illustrated in Figure 1, the course of life satisfaction did appear to be different for male and female stroke patients (F=3.0, p=.05). Male stroke patients showed a significant drop in total life satisfaction from T0 to T1, which was not found in female stroke patients (Gender*Life satisfaction, F=4.6, p=.04). At T2, female stroke patients reported a significantly higher level of total life satisfaction than male stroke patients (Male M=32.6, SD=4.8, Female M=35.1, SD=3.0, t=-2.5, p=.01). Age, marital status, level of education or side of lesion were neither significantly related to pre- or post-stroke levels of total life satisfaction nor to changes in total life satisfaction.

Figure 1. Total life satisfaction pre-stroke (T0) and at three (T1) and fifteen months (T2) post-stroke for male and female stroke patients.

Course of satisfaction with life domains of stroke patients

Table 2 presents the level of satisfaction with life domains before stroke and at three and fifteen months post-stroke. Stroke patients participating at T1, but no longer at T2
appeared to be less satisfied with self-care ($Z=-2.1$, $p=.03$) and sexuality ($Z=-1.9$, $p=.05$) at T1 than patients who stayed in the study. Of those patients interviewed twice, satisfaction with life in general ($X^2=18.2$, $p=.000$), self-care ($X^2=19.6$, $p=.000$) and leisure ($X^2=26.5$, $p=.000$) deteriorated significantly from time before stroke to three months post-stroke and remained at a diminished level at fifteen months post-stroke. Satisfaction with friends did not only deteriorate from time before stroke to three months post-stroke ($Z=-3.2$, $p=.001$) but showed further deterioration from three to fifteen months post-stroke ($Z=-2.0$, $p=.05$).

Separate analysis of the course of satisfaction with life domains for male and female patients showed that satisfaction only changed significantly for male patients. For male patients, satisfaction with life in general ($X^2=20.4$, $p=.000$), self-care ($X^2=17.9$, $p=.000$), leisure ($X^2=23.8$, $p=.000$) and togetherness with friends ($X^2=16.8$, $p=.000$) dropped significantly from time preceding stroke to fifteen months post-stroke. For female stroke patients, satisfaction with life domains did not change significantly.

Table 2. Level of satisfaction with life domains and percentages dissatisfied (DIS) before stroke (T0) at three (T1) and at fifteen months (T2) post-stroke and level of satisfaction and percentages dissatisfied of control subjects at T2.

<table>
<thead>
<tr>
<th>Satisfaction with</th>
<th>Stroke</th>
<th>Control</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T0</td>
<td>T1</td>
</tr>
<tr>
<td>Life in general</td>
<td>74</td>
<td>5.0 (0.8)</td>
</tr>
<tr>
<td>Self-care</td>
<td>74</td>
<td>5.1 (0.7)</td>
</tr>
<tr>
<td>Leisure</td>
<td>74</td>
<td>5.1 (0.7)</td>
</tr>
<tr>
<td>Togetherness friends</td>
<td>73</td>
<td>5.0 (0.7)</td>
</tr>
<tr>
<td>Togetherness family</td>
<td>66</td>
<td>5.3 (0.5)</td>
</tr>
<tr>
<td>Marriage</td>
<td>60</td>
<td>5.2 (0.5)</td>
</tr>
<tr>
<td>Sexuality</td>
<td>57</td>
<td>5.0 (0.8)</td>
</tr>
</tbody>
</table>

Table 2 also provides percentages of patients dissatisfied with life domains. Percentages of patients dissatisfied with the domains self-care (Cochran’s $Q=9.7$, $p=.008$), leisure (Cochran’s $Q=15.5$, $p=.000$) togetherness with friends (Cochran’s $Q=6.2$, $p=.04$) and sexuality (Cochran’s $Q=11.5$, $p=.003$) differed significantly from time before stroke to fifteen months post-stroke. Further analysis of the effect of gender showed that percentages dissatisfied with these life domains from T0 to T2 only increased significantly for
female stroke patients. At T1, the highest percentage of patients dissatisfied concerned the domains self-care and leisure (19%), at T2 the domains sexuality (19%) and leisure (16%). At T2, a significantly greater proportion of male stroke was dissatisfied with leisure than female patients (Male 19% vs Female 3%, $X^2=4.2$, $p=.04$).

**Course of activity level of stroke patients**

Total activity level of stroke patients showed a small and non-significant improvement from T1 to T2 (T1: $M=15.7$, $SD=6.7$, T2: $M=16.7$, $SD=6.2$, $F=3.7$, $p=0.06$). Age of stroke patients was neither significantly related to activity level at T1 and T2 nor to change in activities from T1 to T2. Higher educational level did show a significant correlation with higher activity level at both T1 ($rs=.26$, $p=.01$) and T2 ($rs=.32$, $p=.003$), but was not significantly related to change in activity from T1 to T2. Gender nor side of lesion affected total activity level at T1 or T2 or change in activities from T1 to T2.

**Comparison between stroke patients and controls**

**Life satisfaction at T2**

Stroke patients’ level of total life satisfaction at fifteen months post-stroke was significantly lower than life satisfaction of controls (Stroke $M=33.3$, $SD=4.5$, Control $M=36.7$, $SD=2.7$, $t=-5.0$, $p=.000$). While total life satisfaction of male stroke patients at T2 differed significantly from satisfaction of male control subjects ($t=4.8$, $p=.000$), female stroke patients’ level of total life satisfaction at T2 did not differ significantly from satisfaction of female control subjects ($t=1.5$, $p=.14$).

Table 2 presents the level of satisfaction with life domains for stroke patients and control subjects at T2. At T2, male stroke patients reported a significantly lower satisfaction than male controls on all domains expect for satisfaction with sexual life. While male patients differed from male controls on six domains, female stroke patients were only significantly less satisfied than female controls on the domains leisure and togetherness with family. At T2, a significantly greater percentage of patients than controls was dissatisfied with self-care ($X^2=10.2$, $p=.001$) and leisure ($X^2=5.5$, $p=.02$) than control subjects. A greater percentage of male stroke patients than male controls was dissatisfied with life in general ($X^2=5.8$, $p=.02$), self-care ($X^2=5.8$, $p=.02$), leisure ($X^2=6.9$, $p=.009$) and togetherness with friends ($X^2=8.6$, $p=.003$). Female patients only differed from female controls in the percentage dissatisfied with self-care ($X^2=4.3$, $p=.04$).
Total level of life satisfaction of stroke patients retrospectively estimated at time before stroke, did not differ significantly from the total level of life satisfaction of control subjects.

**Activities at T2**

At T2, total activity level of stroke patients was significantly lower than activity level of control subjects (Control: $M=20.4$, $SD=5.1$, Stroke: $M=16.8$, $SD=5.8$, $t=4.0$, $p=0.00$). In the control group, total activity scores were higher for male compared to female subjects ($t=2.4$, $p=.02$). While total activity score of male stroke patients was significantly lower than male control subjects ($t=4.6$, $p=.000$), female stroke patients did not differ in total activity score from female controls ($t=1.2$, $p=.22$).

Table 3. Percentages of stroke patients and controls in highest categories per item and comparison between categorical answers of patients (n=87) and controls (n=70) per item at T2.

<table>
<thead>
<tr>
<th>Activities</th>
<th>Stroke %</th>
<th>Control %</th>
<th>Z-score</th>
</tr>
</thead>
<tbody>
<tr>
<td>shopping for groceries, every week</td>
<td>70</td>
<td>87</td>
<td>-3.0**</td>
</tr>
<tr>
<td>social activities, every week</td>
<td>55</td>
<td>81</td>
<td>-3.5***</td>
</tr>
<tr>
<td>walking, every week</td>
<td>48</td>
<td>67</td>
<td>-2.1*</td>
</tr>
<tr>
<td>active leisure activities, every week</td>
<td>76</td>
<td>86</td>
<td>-1.6</td>
</tr>
<tr>
<td>driving a car, every week</td>
<td>51</td>
<td>57</td>
<td>-0.9</td>
</tr>
<tr>
<td>making trips, every week</td>
<td>13</td>
<td>19</td>
<td>-0.5</td>
</tr>
<tr>
<td>gardening, everything needed</td>
<td>32</td>
<td>38</td>
<td>-2.0*</td>
</tr>
<tr>
<td>fixing things, everything needed</td>
<td>24</td>
<td>51</td>
<td>-4.2***</td>
</tr>
<tr>
<td>reading books, 1 or &gt; in 2 weeks</td>
<td>20</td>
<td>29</td>
<td>-3.1**</td>
</tr>
<tr>
<td>watching television, hours each day</td>
<td>4.3</td>
<td>2.6</td>
<td>-1.5</td>
</tr>
</tbody>
</table>

As to specific activities, Table 3 shows that at T2, on group level, patients differed significantly from controls in the frequency of shopping for groceries, social activities, walking, reading books and performed less strenuous tasks in gardening and fixing things than controls.

**Cognitive performance and physical disabilities at T1**

Before cognitive and physical disabilities at three months post-stroke will be related to outcome measures at fifteen months after stroke, cognitive functioning and physical status of stroke patients and controls is compared at T1. Table 4 shows that, at three
months post-stroke, stroke patients performed worse on all four cognitive domains and were physically more disabled than controls. Within the stroke group, the effect of the demographical variables gender, age and educational level on cognitive performance is analysed at T1. Female stroke patients appeared to have better verbal memory performance than male stroke patients. Next, higher educational level was significantly related to higher performance on all cognitive tests. Higher age was related to lower performance on tests of reasoning, memory and complex mental speed and was associated with greater physical disabilities. With regard to the side of lesion, right hemisphere stroke patients were slower on the visuomotor decision task than left hemisphere stroke patients.

Table 4. Independent-samples t-tests on measures of reasoning, memory, mental speed and physical disabilities between stroke patients and controls at T1.

<table>
<thead>
<tr>
<th>Measures at T1</th>
<th>Stroke M (SD) n</th>
<th>Control M (SD) n</th>
<th>t-test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reasoning</td>
<td>29.7 (12.4) 86</td>
<td>39.0 (13.5) 68</td>
<td>4.4***</td>
</tr>
<tr>
<td>Memory</td>
<td>36.8 (10.8) 81</td>
<td>42.5 (10.4) 71</td>
<td>3.3**</td>
</tr>
<tr>
<td>Simple mental speed</td>
<td>0.429 (.124) 82</td>
<td>0.376 (.054) 71</td>
<td>-3.5**</td>
</tr>
<tr>
<td>Complex mental speed</td>
<td>1.031 (.320) 78</td>
<td>0.909 (.299) 71</td>
<td>-2.4*</td>
</tr>
<tr>
<td>Physical disabilities</td>
<td>5.2 (4.6) 110</td>
<td>1.8 (2.1) 79</td>
<td>-6.8***</td>
</tr>
</tbody>
</table>

**Prediction of activities**

The hypotheses concerning the prediction of activity level and activity gain of stroke patients by early cognitive status and physical disabilities were tested using multiple prediction. Table 5 shows that, as expected, physical disabilities at T1 most strongly predicted activity level at T1 and T2. Less physical disabilities at three months post-stroke were related to higher activity level at both three and fifteen months post-stroke. As hypothesized, better performance on reasoning tests and faster complex cognitive decision times at T1 predicted greater gain in activity from T1 to T2, but had no additional predictive value of activity levels at T1 or T2. This was also true for visuomotor mental speed, which was the most important variable in predicting gain in activity level from T1 to T2. In addition, visuomotor mental speed appeared to have predictive value of activity level at T1. Educational level of the patients, that was significantly correlated
with activity level in univariate analysis, was subsequently added to the models. It had neither predictive value, nor caused any significant change in the models.

Table 5. Prediction of activity level (FAI) of stroke patients at T1 (n=58), T2 (n=61) and change in activities from T1 to T2 (n=52) by physical disabilities and cognitive functioning at T1.
*p<.05; ** p<.01; *** p<.001 (2-tailed)

<table>
<thead>
<tr>
<th>Measures at T1</th>
<th>FAI T1</th>
<th></th>
<th>FAI T1-T2</th>
<th></th>
<th>FAI T2</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F</td>
<td>R²</td>
<td>F</td>
<td>R²</td>
<td>F</td>
<td>R²</td>
</tr>
<tr>
<td>Physical disabilities</td>
<td>23.7***</td>
<td>.46</td>
<td>0.5</td>
<td>20.1***</td>
<td>.40</td>
<td></td>
</tr>
<tr>
<td>Reasoning</td>
<td>3.1</td>
<td>6.7*</td>
<td>.07</td>
<td>0.3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Memory</td>
<td>0.0</td>
<td>2.8</td>
<td>0.5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Simple mental speed</td>
<td>7.6**</td>
<td>.12</td>
<td>9.4**</td>
<td>.09</td>
<td>0.1</td>
<td></td>
</tr>
<tr>
<td>Complex mental speed</td>
<td>0.0</td>
<td>5.0*</td>
<td>.05</td>
<td>1.0</td>
<td>.04</td>
<td></td>
</tr>
<tr>
<td>Corrected model</td>
<td>14.3***</td>
<td>.58</td>
<td>3.5*</td>
<td>.27</td>
<td>8.7***</td>
<td>.44</td>
</tr>
</tbody>
</table>

Prediction of life satisfaction

Next, the separate influences of activities and cognitive functioning on total life satisfaction were analysed. Table 6 presents the multivariate prediction of life satisfaction at T2 by activity level and cognitive functioning at T1. The results show that activity level and reasoning abilities at T1 predicted most variance in life satisfaction at T2. Memory functioning at T1 also predicted life satisfaction at T2, while visuomotor and cognitive mental speed at T1 did not appear to be predictive of life satisfaction at T2. At T2 female stroke patients reported higher levels of life satisfaction than male stroke patients. Gender, subsequently added to the GLM-model, neither explained an additional significant proportion of life satisfaction, nor changed the predictive value of activities and cognitive functioning for life satisfaction.

Table 6. Prediction of life satisfaction at T2 by activity level and cognitive functioning at T1 (n=54).

<table>
<thead>
<tr>
<th>Measures at T1</th>
<th>Life satisfaction</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>F</td>
</tr>
<tr>
<td>Activities</td>
<td>7.2*</td>
</tr>
<tr>
<td>Reasoning</td>
<td>7.4**</td>
</tr>
<tr>
<td>Memory</td>
<td>4.8*</td>
</tr>
<tr>
<td>Simple mental speed</td>
<td>0.1</td>
</tr>
<tr>
<td>Complex mental speed</td>
<td>0.1</td>
</tr>
<tr>
<td>Corrected model</td>
<td>3.2*</td>
</tr>
</tbody>
</table>
Discussion

Course and level of total life satisfaction after stroke
The present study in a community based sample of stroke patients showed that total life satisfaction deteriorated from time before stroke to three months post-stroke and, at fifteen months post-stroke, remained at a lower level than satisfaction before stroke. Although drop-out of patients from three to fifteen months was not related to total life satisfaction, patients who dropped out from T1 to T2 had significantly lower levels of satisfaction with self-care and sexuality than patients who stayed in the study. Drop-out appeared to be selective and concerned the more disabled patients. The results of the present study might therefore underestimate the impact of disabilities on life satisfaction after stroke. Another limitation of the present study is that satisfaction before stroke had to be rated retrospectively. An argument for a valid measurement, at least on group level, is the fact that pre-stroke levels of satisfaction did not significantly differ from satisfaction of control subjects.

The level and course of life satisfaction in stroke patients was not related to age of the patient, level of education, marital status or the side of stroke. At T2, however, female stroke patients appeared to report a higher level of satisfaction than male stroke patients. Further analysis of the course of life satisfaction showed that a drop in life satisfaction after stroke was only present in male patients. A previous Norwegian study also showed that subjective well-being, which included a measure of satisfaction, was higher in female stroke patients (Wyller, 1998). In contrast, other studies found higher subjective well-being after stroke in male compared to female patients (Wyller, 1997; Diener, 1984).

At fifteen months post-stroke, male stroke patients reported significantly lower life satisfaction than male control subjects while life satisfaction of female stroke patients did not differ significantly from female control subjects. Apparently, the stroke event had such an impact on the lives of male stroke patients that previous levels of satisfaction could not be regained within the first fifteen months post-stroke. This downward shift of the level of life satisfaction has previously been demonstrated in stroke patients, but was also found in subjects who experienced unemployment and marital transitions (Niemi et al., 1988; Lucas et al., 2004; Lucas et al., 2003). The impact of the loss of a spouse on life satisfaction has been found to be greater in men than women (Chipperfield & Havens, 2001).
Course and level of satisfaction with life domains after stroke

Satisfaction with life in general, self-care, leisure and togetherness with friends deteriorated from time before stroke to three months after stroke and remained at a lower level than pre-stroke satisfaction at fifteen months post-stroke. As was also found in a Scandinavian study, satisfaction with leisure showed greatest deterioration after stroke (Niemi et al., 1988). Further analysis showed that this downward shift in satisfaction with life domains was only present in male stroke patients. The largest gender difference in the present study was that, at fifteen months post-stroke, six times more male stroke patients were dissatisfied with leisure than female patients. An explanation for this difference might be that leisure activities of male stroke patients are more sensitive to the effects of stroke. Sjogren (1982) found that activities of male stroke patients followed traditional gender roles, indicating more outdoor and more straining leisure activities. In the present study, this gender difference in activities was also found in the control group. In the stroke group, male patients did not perform more leisure and outdoor activities than female patients. However, male control subjects performed more frequent and more strenuous activities than male stroke patients, while total activities of female patients did not differ from those of female controls. These findings suggest that male stroke patients might have experienced a greater drop in gender-related outdoor and leisure activities after stroke than female patients.

For both male and female stroke patients, satisfaction with family and marital life did not change after stroke, which is in line with findings from other western stroke studies (Astrom et al., 1992; King, 1996). A high level of satisfaction with family and marital life after stroke might reflect the importance of social interaction with those surrounding the patient. If interaction with others is limited by disabilities after stroke, affection and behavioural confirmation within one’s closest relationships might become the most important source to obtain social well-being.

At fifteen months post-stroke, patients’ level of satisfaction differed from controls on all domains, except for satisfaction with sexual life. Again, satisfaction of male stroke patients differed from male controls on a greater number of domains than satisfaction of female patients and controls. Fifteen months post-stroke, the highest percentage of stroke patients dissatisfied concerned the domain sexual life (19%), but this percentage appeared to be quite similar in control subjects (14%). In line with findings from Viitanen and colleagues (1988), a greater number of patients than controls were dissatisfied with self-care...
and leisure. On the other hand, most stroke patients reported a relatively high level of satisfaction with each life domain at fifteen months post-stroke. This finding corresponds to several other stroke studies and matches the idea that most people will try to maintain an optimistic view of life (Viitanen et al., 1988; King, 1996; Löfgren et al., 1999; Diener & Diener, 1996). Recent research showed that this ability may not only preserve mental health, but might also protect one’s physical health (Stieglis et al., 2003; Taylor et al., 2000).

**Role of cognitive status in gain of activities after stroke**

In line with other stroke studies, the level of activities of stroke patients remained lower than activity level of control subjects. It was hypothesized that physical disabilities restrict the activities that can ultimately be performed. In addition, cognitive functioning shortly after stroke was thought to be important in the adaptation process to regain outdoor and leisure activities in the first year after stroke. The results mostly confirmed our hypotheses. Physical disabilities at three months post-stroke not only predicted activity level at the same time of measurement, but also proved predictive of activity level at fifteen months post-stroke. Simple mental speed at three months post-stroke also predicted activity level at three months post-stroke. In a group of older adults, mental processing speed has been related to the time to complete everyday tasks (Owsley et al., 2002). Stroke patients with a basic slowness in mental speed can be seriously hindered in time-limited leisure and outdoor activities.

On group level, stroke patients showed a small and non-significant improvement in the frequency of activities from three to fifteen months post-stroke. In the present study no measures of the quality of the performance of the activities were included. Cognitive functioning at three months post-stroke appeared to make a small, but significant contribution to changes in activity level. Faster visuomotor and cognitive decision times at three months post-stroke were related to a greater recovery of activities within the first fifteen months after stroke. Although mental slowness is one of the most frequently mentioned cognitive changes after stroke, research on processing speed after stroke and its impact on the performance of activities of daily living has been scarce so far (Gerritsen et al., 2003; Visser-Keizer et al., 2002; Hochstenbach et al., 1998). Research on information processing speed in patients with traumatic brain injury indicated that impairments in mental speed should not be regarded in isolation. Information processing speed was related to several other cognitive functions such as attention and working memory (Rios et al., 2004; Chiaravalloti et al., 2003; Spikman et al., 1996).
Reasoning abilities at three months post-stroke also predicted change in activities from three to fifteen months post-stroke. Although physical disabilities restrain the activities one can perform, relatively intact problem solving abilities might help stroke patients to adapt to the circumstances after stroke. Patients with better reasoning capacities might, for example, chose to perform activities in a different way or might be able to shift to less demanding activities. Further inquiry into the way stroke patients perform activities or find alternative activities would be highly interesting for future research. A positive relationship between reasoning abilities and activities has been demonstrated in community dwelling elderly and deserves further attention in stroke research (Cockburn, Smith & Wade, 1990).

**Life satisfaction, activities and cognitive functioning after stroke**

The engagement in activities is regarded as an important mean to obtain well-being (Csikszentmihalyi, 1997; Steverink et al., 1998). After stroke, the performance of activities might be hindered, which poses a threat to the fulfilment of goals to obtain well-being. This assumption based on SPF-theory was confirmed for both male and female stroke patients as activity level at three months post-stroke independently predicted total life satisfaction at fifteen months post-stroke. Within SPF-theory, cognitive disabilities can be regarded as constraints or loss of resources, which can hinder one’s activities. It was therefore hypothesized that the relationship between cognitive abilities and life satisfaction would be mediated by level of activities. This hypothesis was partly confirmed for the more basic cognitive measurements of speed of information processing. However, the higher order cognitive functions of memory and reasoning abilities at three months post-stroke predicted life satisfaction at fifteen months post-stroke independently from activity level. These higher order cognitive functions cannot only be seen as restraints for performing activities, but might be regarded as important tools in the adaptation and evaluation process itself (Steverink et al., 1998). Furthermore, the impact of loss of complex cognitive abilities might go beyond the ability to perform activities. Poorer memory functioning and reasoning capabilities could also mean a loss of status or self-confidence, which might directly influence satisfaction with life.

The present results showed that activities and cognitive functioning predicted a quarter of variance in life satisfaction after stroke. This means that a great proportion of life satisfaction is explained by other variables, including personality, culture or social
class (Diener, Oishi & Lucas, 2003, Schimmack et al., 2002). For future research, it should be interesting to understand more about the complex interactions between personality characteristics, disabilities after stroke and the adaptation to the consequences of stroke in daily life.

**Implications for clinical practice**

The present study underlines the importance of activity level and cognition in the sub-acute phase after stroke in the prediction of life satisfaction in the chronic phase after stroke. Male stroke patients, who generally spend more time or effort in outdoor and active leisure activities than female stroke patients, might be at a relatively greater risk of dissatisfaction with several related life domains. Although physical disabilities restrict one’s activities, cognitive functioning in the early phase after stroke appears to contribute to the improvement of leisure and outdoor activities in the first year after stroke. This implies that stroke patients who are physically able to return home after stroke, will not always automatically be able to return to their activities. Cognitive disabilities, that are not always explicit enough to be noticed during hospitalisation, might become apparent at home. At home, hardly any attention is directed at the education of patients concerning cognitive disabilities and their impact on daily life. Furthermore, these patients generally do not receive professional support or training methods to compensate for cognitive losses. In the last decade, research on the effectiveness of cognitive rehabilitation is growing. The present state of knowledge indicates that cognitive rehabilitation of memory functioning and problem solving abilities directed at everyday situations can be valuable (Cicerone et al., 2000). Further research is needed to support the effectiveness of different programs of cognitive rehabilitation after stroke and to gain more insight into the best timing of cognitive rehabilitation. In adapting these programs to real life activities, gender differences should be taken into account.
References


Subjective well-being fifteen months after stroke


Chapter 9

General discussion and conclusions

Main findings

Main aim of the present study was to discuss the impact of changes in emotion and cognition on the lives of community dwelling stroke patients and partners in the acute and chronic phases after stroke. The present study demonstrated that changes in emotion and cognition were reported at three and fifteen months post-stroke by almost all of our stroke patients living in the community, irrespective of the side of lesion. At fifteen months post-stroke, only ten to fifteen percent of patients and an even lower percentage of partners did not report any changes. Although on both times of measurement partners tended to report a greater number and more severe changes than patients themselves, these differences were significant in the right hemisphere group only.

The number and severity of changes in emotion and cognition reported by patients slightly increased between three and fifteen months post-stroke. In contrast, anxious and depressive mood attributed to stroke and fatigue showed some improvement between three and fifteen months post-stroke. Nevertheless, at fifteen months post-stroke, stroke patients still reported more severe depressive mood and more frequent fatigue than control subjects. However, unexpectedly the level of anxiety did not differ between stroke patients and controls. Changes in emotion and cognition, psychosocial disabilities, mood and fatigue showed complex interrelations. While psychosocial disabilities best predicted post-stroke mood, mood and changes in emotion and cognition in turn predicted fatigue after stroke. The present study further illustrated that the psychosocial status of stroke patients must be considered within a broad health context. Not only stroke-related factors, but also diseases and life events other than the stroke influenced fatigue and mood respectively after the stroke event. A stroke generally does not develop ‘out of the blue’ and often coincides with comorbidity.
When investigating well-being of stroke patients and partners, it appeared on the one hand that life satisfaction deteriorated after the stroke event. As life satisfaction is generally considered to be stable across the life span, the decrease of satisfaction after stroke gives an impression of the impact of stroke. On the other hand, most patients and partners were able to maintain a positive view on life, although a quarter of partners reported increased strain.

It might not be coincidental that while male stroke patients reported poorer life satisfaction than male controls, their female spouses reported significantly greater emotional strain than male spouses. Emotional and cognitive changes in the patient appeared to influence both emotional and physical strain on the partner. These changes did not directly affect life satisfaction of the partner, but were mediated by the level of strain. In stroke patients, cognitive functioning at three months after stroke was related to the restoration of activities within the first fifteen months after stroke. Furthermore, both complex cognitive functions and activity level at three months post-stroke predicted life satisfaction at fifteen months post-stroke.

Throughout the study, right hemispheric stroke patients with attentional disorders stood out as a group with a distinct outcome after stroke. In this group, the severity of unilateral neglect was longitudinally related to less awareness of the changes in emotion and cognition compared to one’s partner. Furthermore, slower mental speed was related to a higher frequency of fatigue while the presence of neglect was related to a lower activity level at fifteen months post-stroke. In contrast, levels of distress in right hemispheric stroke patients with neglect showed greater improvement than in subjects without neglect. However, the opposite was found for partners, with greater unawareness of changes in emotion and cognition in the patient related to greater distress of their partner.

To sum up, changes in emotion and cognition were common in stroke patients living in the community and cannot be regarded as temporarily phenomena. Changes in emotion and cognition had several consequences for lives of patients and partners alike, influencing mood, fatigue, activities, strain and eventually life satisfaction of patient and partner.
Critical remarks

The present study has several limitations which influence the power of the study and the generalisability of the results to stroke patients living in the community. First of all, although the initial number of patients presented by GPs was sufficient, 15 percent of patients did not meet the criteria of a clinically first-ever, unilateral ischemic stroke. These criteria were formulated to compose a homogeneous group of stroke patients, but were quite strict as they excluded haemorrhages, patients with bilateral ischemic strokes and patients with a recurrent stroke. Another strict criterion that 5 percent of patients could not meet was that they should have been devoid of neurological or psychiatric disorders before the occurrence of the stroke. Subsequently, another 30 percent of patients could not be included at the first assessment because of severe disability, death or refusal. To facilitate participation in the study, the interview and the first neuropsychological assessment session were always held at the patient’s home. If necessary, neuropsychological data at the second session were also collected at the patient’s residence. Furthermore, the interview and the neuropsychological assessment were adapted in order to be able to include aphasic stroke patients. However, the presence of some communication skills was a prerequisite for the interview, therefore patients with severe aphasia or severe behavioural disturbances were excluded. The neuropsychological assessment required patients to be able to concentrate for at least half an hour, to have sufficient visual perception and to be able to manually respond to the stimuli, so patients with severe physical disabilities were also excluded.

Furthermore, during the study nearly 20 percent of these patients dropped-out before the second interview, while another 20 percent did not perform a second neuropsychological assessment. Stroke patients who dropped-out during the study were more severely disabled with regard to the physical, cognitive and emotional domains. It can be concluded that the sample of patients that performed all assessments in the present study was biased towards the less disabled stroke patients. To investigate whether patients included in the study were also biased towards those with a better health status, the prevalence of stroke-related comorbidity in the study sample was compared to comorbidity of patients from a regional database of general practices. Stroke-related comorbidity of patients in both groups appeared to be very similar, so patients referred to the present study by their GPs did not only involve patients with a lower vascular risk profile.
Although the number of patients included at both T1 and T2 was sufficient for overall data analyses, at times subgroups became too small to allow statistical comparisons. To increase the statistical power of the present study, stroke patients were also enrolled into this study at a hospital stroke unit. Analyses of stroke characteristics, however, indicated that the group recruited at the stroke unit differed slightly with regard to silent infarctions preceding the stroke, which might indicate a different vascular risk profile before stroke. Future researchers must consider the possibility of different stroke types and risk profiles of stroke patients admitted to a hospital stroke unit.

A successive stratified randomisation procedure was used to select patients from 4 general practices in the control group. An individual procedure in which each patient was matched to a control subject based on several characteristics such as age, gender and SES would have been more accurate. Quite unexpectedly, stroke patients and controls were comparable with regard to several risk factors for stroke. Because of the presence of vascular risk factors, it cannot be ruled out that some control subjects may have suffered asymptomatic damage to the brain. Because several risk factors, such as age, gender, region of residence and comorbidity were equally distributed among the stroke and control group, the distinct effects and impact of stroke on emotion and cognition could be studied. Moreover, the recruitment of both stroke patients and control subjects by GPs is to be preferred rather than the recruitment of relatively healthy elderly, for example by newspaper advertisements.

Although the research questions of the present study addressed behaviour, emotion and well-being of patients, the presence of neuro-imaging data concerning the extent and site of the lesion could have been of great benefit. This would allow to study the relationships between lesion characteristics and behaviour beyond the effects of lateralization of the lesion. Although CT-scans were available for almost all patients, these scans were made shortly after the onset of stroke resulting in a large proportion of negative findings. MRI-data were only available for a very small proportion of stroke patients. To obtain an indication of the stroke severity, the NIH stroke scale scores were rated retrospectively based on neurological reports. However, only those stroke patients admitted to a hospital were systematically screened on all symptoms. It appeared that in thirty percent of the patients the NIH stroke scale could not be completed because of missing data. This stroke severity score was therefore not included in the analyses. It should be determined which measure of acute stroke severity is useful in community-based studies.
As will also be addressed in the following paragraphs, during the initial phase of the study, selecting well-validated Dutch measurement instruments aimed at studying emotion and behaviour after stroke proved to be difficult. Therefore most of the instruments used in the present study were generic in nature and were not specifically designed to study impairments and disabilities after brain injury. The reliability of the measures included was assessed in the present patient group and appeared to be adequate. Nevertheless, emotion and behaviour after stroke could be measured more specifically with specific rather than generic scales that are developed and validated to address deficits after brain injury.

**Implications for future research**

First of all, in order to replicate and extend current findings, future studies into the emotional and cognitive consequences of stroke should include a larger number of community dwelling stroke patients. This may be difficult, however, and requires studies to be extended to larger demographic regions. In addition, several issues that have been investigated in the present study could be refined or examined in more detail.

To date, the relative contribution of brain lesions, pre-morbid personality and coping to the emotional outcome after stroke is largely unknown. Of all aspects of emotion and behaviour, only post-stroke depression has received considerable interest in recent years. Nevertheless, many questions have remained unanswered, partly because a dualistic approach, with either attention for the direct consequences of brain damage or the indirect emotional reactions, has long been favoured. Above all valid measurement instruments need to be developed for the assessment of the emotional consequences of stroke. In order to gain insight into the specificity of emotional reactions after stroke, changes in emotion and cognition could also be assessed in a group of patients suffering from a similar acute disease with a subsequent chronic course without the presence of brain injury such as amputees or patients with a myocardial infarction. Furthermore, by including neuro-imaging data at more than one point in time after stroke, the course of emotion and cognition can be related to possible recovery of brain functioning after stroke. A further investigation into the role of personality and coping on emotional outcome after stroke would contribute to the development of treatment programmes.
During the study, the question arose as to what extent premorbid functioning is already affected by comorbidity and vascular changes to the brain. Fatigue and depression, for example, have been described as risk factors to stroke and might already be present before stroke onset (Schuitemaker et al., 2004; Jonas & Mussolino, 2000). In addition, silent infarctions to the brain could have influenced overall cognitive functioning prior to the occurrence of a stroke event (Price et al., 1997). To gain insight into the course of mood, fatigue and cognition during the pre-stroke and post-stroke time periods, a prospective community-based study in patients with vascular comorbidity should be conducted.

Until recently, fatigue after stroke has been a neglected issue in research concerning the outcome after stroke. The present study showed that not only in severely physically disabled patients, but also in stroke patients with mild physical disability living in the community, levels of energy can be diminished long after stroke onset. Further investigation into the relationship between different cognitive functions and mental fatigue might provide direction to the development of the optimal treatment of fatigue after stroke. It would be valuable to be able to distinguish between different types of fatigue after stroke and their possible neurological and behavioural correlates. Fatigue scales that capture both physical and mental aspects of fatigue need to be validated in patients with brain injury.

In the present study, male patients and female partners appeared to have less favourable outcomes after stroke. It would be very interesting to investigate patterns of dyadic coping after stroke. Couples may react to each other’s way of coping with stressful situations, which in turn may influence their individual well-being. For example, spouses may employ coping strategies that will help the partner at their own expense of emotional well-being. Furthermore, attempts to regulate one’s reaction to a stressful event may limit emotional sources to support the other (Gottlieb & Wagner, 1991, Wood et al., 1990). The interaction between coping of patients and their partners has hardly been addressed in stroke research.

Finally, there is a need for research concerning the efficacy and timing of treatment methods for the emotional, behavioural and cognitive consequences of stroke. As will be discussed in the following paragraphs, evidence based on randomised controlled studies should expand the basis for administering cognitive rehabilitation and psychotherapy tailored to patients with brain injury.
Implications for clinical practice

In the following paragraphs implications for the assessment and treatment of emotional and behavioural consequences of stroke in clinical practice will be outlined. For a discussion concerning the clinical implications with regard to the cognitive sequelae of stroke, one is referred to the dissertation of Gerritsen (2004).

Assessment of changes in emotion and behaviour after stroke

In clinical practice, a thorough investigation of changes in emotion and behaviour after stroke should be conducted because, in nearly all patients, several aspects of emotional experience, emotional expression or behaviour can be subject to change. The present study showed that patients will not always be able to identify changes that have occurred after stroke. Observations of close relatives should complete the accounts of patients themselves.

Valid Dutch questionnaires measuring both pre-morbid and post-stroke emotion and behaviour are still lacking. The questionnaire used in the present study emphasised the most prevalent behavioural and emotional changes after stroke. In clinical practice, a more extensive range of changes should be addressed. The present scale might be adapted for this purpose and evaluated in a larger cohort of stroke patients.

Changes in emotion and behaviour after stroke can be regarded as the result of a complex interaction between pre-morbid personality, emotional reactions to the stroke event and changes caused by injury to the brain. It seems difficult to disentangle the emotional reactions or coping responses from changes induced by the brain injury. Recently, different studies have attempted to distinguish emotional denial from anosognosia based on information generated by a close examination of the behavioural reactions of the patient. The results showed that emotional reactions such as anger or avoidance coping appeared to be more closely linked to psychological denial than to impaired awareness of deficits (Kortte, Wegener & Chwalisz, 2003, Prigatano & Klonoff, 1997). Although in clinical practice the direct and indirect consequences of stroke cannot be distinguished easily, pre-morbid en current coping responses of the patients should always be assessed when studying post-stroke emotion and behaviour.
Assessment of depression and anxiety after stroke

Besides the more or less subtle changes in emotion and cognition, a smaller proportion of stroke patients may develop neuropsychiatric disturbances such as anxiety disorders, depression, pathological laughing or crying or mania (Gerritsen, Visser-Keizer & Deelman, 2002). The methods often used to assess emotional and behavioural disturbances are either semi-structured interviews based on DSM-criteria or questionnaires. When evaluating psychiatric disturbances in stroke patients by DSM-criteria some problems can arise. The diagnostic system of the DSM generally defines psychiatric problems irrespective of their aetiology. However, in order to diagnose some disorders, such as major depression or generalised anxiety disorder, the presence of a general medical condition must be ruled out. Another problem is that many symptom derived criteria of the DSM involve non-specific somatic complaints or cognitive deficits, such as fatigue or difficulties in attention or memory, which have also been found to occur without depression or anxiety in stroke patients.

One of the current problems in the assessment of emotion and behaviour after stroke using questionnaires, is that most available measures have been designed for psychiatric populations. Apart from determining whether these instruments can assess emotion and behaviour after brain injury in a valid and reliable way, the notion of change is hardly addressed. In our opinion, in measuring post-stroke depression or anxiety, an emphasis must be placed on the mood of the patient, such as diminished interest, pleasure or worries of the patient. Therefore, the Hospital Anxiety and Depression Scale (HADS) was chosen in the present study. The HADS is a screening instrument for depressive and anxious mood, but does not represent a clinical diagnostic tool. An advantage of this instrument is that it excludes vegetative symptoms, which tend to overestimate mood disturbances after stroke. Furthermore, as depression and anxiety often co-occur, the screening of both is preferred.

The HADS has been proven useful in assessing psychiatric patients, somatic patients including stroke patients, primary care patients and patients in the general population (Bjelland et al., 2002, Johnston et al., 2000). Based the suggestions of Johnson et al. (1995) for a community-based sample, in the present study cut-off scores of 5 for the depression scale and 6 for the anxiety scale were used. However, in clinical samples a stricter cut-off value of 8 or more for both anxiety and depression scale is recommended (Bjelland et al., 2002).
In the present study we have tried to capture the notion of change in mood, by asking patients if elevated levels of mood could be attributed to the stroke event. It appeared that patients were able to make this distinction. A pitfall for clinicians is to ascribe all seemingly abnormal behaviour to the effects of stroke. The present study, for example, showed that half of the disturbances in mood were attributed to causes other than stroke. To avoid this potential bias, information on pre-morbid behaviour, personality and life events before and after stroke should be obtained. Furthermore, the way patients coped with pre-stroke difficulties in life must be assessed. The present study also showed that depressive and anxious mood was classified differently on a self-rated scale and observation-based criteria. It is recommended that several sources of information are combined when measuring mood after stroke. Both subjective reports of the patient and of relatives and observations of behaviour should be included.

**Treatment of emotion and behaviour after stroke**

Although several necessary or highly recommended components of the psychological treatment of emotion and behaviour after brain injury have been addressed, to date no randomised controlled trials have been conducted on this subject. The ICAR model, for example describes four basic elements in managing psychiatric disturbances after brain injury, but this model has not been evaluated in controlled research (Prigatano et al., 2003). The components of the ICAR model (Information, Contingency, Awareness and Relationship) will be discussed below with regard to the treatment of stroke patients.

Before the start of the treatment of emotional and behavioural disturbances in stroke patients, conducting a neuropsychological assessment is highly recommended. One should of course be aware that mood disturbances and medication might influence test results. Nevertheless, having an indication of the current cognitive status of the patient at one's disposal will often be beneficial. The treatment methods described below should always be adapted to the cognitive abilities of the patient.

The first component in the ICAR model is providing information to patients and their family with regard to the emotional and behaviour sequelae of stroke. A systematic review has indicated that information provision to stroke patients and carers seemed more efficient when it is embedded in an educational context than the simple provision of a booklet or leaflet (Forster et al., 2001). The content and sources of information should be adapted to the patient’s cognitive abilities (Wachters-Kaufman et al., 2004).
Furthermore, information must be provided by skilled professionals in a clinically sensible and sensitive way (Prigatano et al., 2003). Providing information about the nature of emotional and behavioural problems after stroke might help to reduce anxiety and to prevent misunderstandings. In addition, the recognition of emotional and behavioural impairments can lead to specific interventions.

The second element in the management of behavioural problems after stroke is helping the patient regaining control over his or her emotional and behaviour responses by placing contingency on certain behaviour (Prigatano et al., 2003). Behavioural therapy can, for example, be effective in reinforcing appropriate behaviour or in the extinction of undesired behaviour (Ducharme, 2000). Stroke patients might lack the mental ability and flexibility to replace maladaptive behaviour by more effective behaviour on their own. If a patient is not at all capable of changing a behavioural pattern, attention must be directed to adapting the environment and education of their social system. The use of psychopharmacy might also be helpful in controlling behaviour. Antidepressants, for example, have been proven to be effective in reducing the frequency and severity of crying or laughing episodes after stroke (House et al., 2004).

The third factor in the ICAR model is to help patients to deal with disturbances in self-awareness. The present study showed that lack of awareness of deficits after stroke may not only impede rehabilitation, but can also be related to distress in those individuals surrounding the patient. Methods that have been described to increase awareness in the patient include giving feedback to the patient on their performance of activities or tests. Recent studies indicate that awareness may arise when these activities resemble or are identical to those performed in daily life before stroke (Dirette, 2002).

The final element in the management of behavioural and emotional problems might be by dealing with these disturbances in a therapeutic relationship. The use of psychotherapy in brain damaged individuals has long been considered inappropriate. However, the therapeutic opportunities provided by neuropsychotherapy, in which psychotherapeutic techniques are adapted to the deficits of brain injured patients, seem highly promising (Judd, 1999). As has been described previously, randomised controlled trials in which the efficacy of psychotherapy after stroke is assessed are rare. With regard to the treatment of depression after stroke, two systematic reviews have recently been published. These reviews identified a small but significant effect of psychotherapy on
improving mood after stroke, but no effect of either pharmacotherapy or psychotherapy on the treatment of depression after stroke (Anderson, Hackett & House, 2004, Hackett, Anderson & House, 2004). Recently, fatigue after stroke has also been classified among the emotional sequelae of stroke (Bogousslavsky, 2003). Neuropsychotherapy could be helpful in teaching patients to cope with fatigue after stroke. Current programmes that address fatigue after stroke should be evaluated in controlled trials.

It must be emphasised that the partner or other family members should be involved in the psychological treatment of stroke patients. They should not only be given information on the consequences of brain injury, but must also be taught ways to cope with these changes. The present study indicated that male and female partners may have different needs, which may demand different approaches.

**Implications for stroke care**

*Public awareness and recognition of changes in emotion and cognition after stroke*

In 1995, the Dutch Heart Foundation already published a report called ‘Care after Stroke’ in which several recommendations concerning patient care were described. One of the recommendations included was to pay attention to the observation that cognitive and emotional problems often become apparent during the recovery phase, which are often not understood by the patient and not recognised by health care providers. The neuropsychological disturbances require further investigation by either a neuropsychologist or a clinical linguist. However, these diagnostic specialists are not available everywhere or all the time. Even where this is not the case, they are often not consulted, either because the problem is not recognised or the attending physician finds no grounds for a referral (Meyboom-de Jong & Buis, 1995).

At the present time, the awareness of the mere existence of emotional and cognitive disturbances after stroke still is not widespread in the Netherlands. A recent population-based inquiry into the symptoms of stroke by the Dutch Heart Foundation showed that indeed most people are under the impression that a stroke only results in paralysis of the body. Only 8 percent of those interviewed reported neuropsychological consequences of stroke.
To increase the proportion of acute stroke patients that will be referred to a hospital within three hours after stroke, a public health campaign will be launched in the Netherlands directed at recognising the signs of stroke. In this campaign, the FAST (Face-Arm-Speech-Time) test will be promoted. This test describes impairments in motor functioning or speech as the most prominent signs of stroke. Hospital-based studies have reported that approximately 80 percent of patients present with a hemiparesis in acute stroke (Rathore et al., 2002, Melo & Bogousslavsky, 1998). It has not been documented properly how many stroke patients living in the community do not suffer from physical impairments in the acute phase after stroke. It can be estimated that at least 1 in every 5 stroke patients will not present with distinct visible physical impairments shortly after stroke onset. In the present study at three months post-stroke, 43 percent of patients did not demonstrate a paresis of the arm, 53 percent did not show paresis of the leg, while 37 percent had neither of these symptoms. Research has shown that the FAST-test can detect most total anterior circulation infarctions, but is less sensitive in detecting posterior circulation infarctions or lacunar infarctions (Nor et al., 2004, Harbison et al., 2003). Of the patients in the present study with OCSP-classifications, most suffered from lacunar infarctions (47%), with only a small proportion of total anterior circulation infarctions (11%). Although faster recognition of the physical symptoms of stroke is needed to improve acute stroke care, patients with mainly cognitive and emotional problems after stroke might go unnoticed by this test. Several case reports have shown that emotional or cognitive disturbances might be the only or the most prominent consequences of stroke. The cerebrovascular origin of the disturbances may not be recognised in these patients (Price, Whitlock & Hall, 1983). An unnecessary referral to mental health services, an inaccurate treatment or no treatment at all may be among the serious consequences.

The recognition of changes in cognition and emotion by clinicians will be influenced by the patient’s presentation of symptoms. Research has shown that, after stroke, gender differences can exist in the presentation of neuropsychological complaints. A large American study found that female stroke patients were far more likely than male stroke patients to report symptoms of changes in consciousness and disorientation after stroke at the emergency department. Male stroke patients were more likely to report traditional stroke symptoms such as hemiparesis (Labiche et al., 2002). The identification of stroke types representing with symptoms other than mainly physical symptoms is a major challenge to clinicians. Knowledge about the emotional, behavioural and
cognitive consequences of stroke is still lacking. Efforts should be directed to increasing awareness of these changes in the general population and in clinicians. It may be difficult to reach many of the people at risk, such as those with a low socio-economic status. Not only in the acute phase after stroke, but especially in the post-acute phase, clinicians should be aware of the long-term changes in emotion and cognition and their impact on daily life. (Neuro) psychologists can play an important role in the education of medical and psychology students, and in increasing the knowledge among health care colleagues about the cognitive and emotional sequelae of stroke.

Stroke care in the Netherlands

During the last years, quite an effort has been invested into the establishment of stroke services in the Netherlands. A recent publication of the Dutch Heart Foundation showed that in 2003 stroke services have extended to 69 services nation-wide (Verschoor, Stolk er & Franke, 2003). Most stroke services in the Netherlands incorporate a hospital with a specialised stroke unit, a nursing home, a rehabilitation centre and a home care organisation. In a quarter of stroke services, however, GPs do not participate, while half of the stroke services do not offer systematic care in the chronic phase after stroke. It is unknown in how many stroke services neuropsychologists participate. It is recommended that neuropsychologists always participate or are consulted in both the acute phase and the chronic phases after stroke. In the stroke services that follow-up patients into the chronic phase, home care visits by a nurse is one form of care provided. Nurses are taught to screen the presence of changes in emotion, behaviour and cognition by using a questionnaire. An advantageous component to this approach is that patients are visited at regular times after stroke. Because of the emotional or cognitive disturbances after stroke, patient will not always be able to implement visits to health care practitioners. It can be questioned, however, to what extent patients will be able to provide an adequate account of the changes in emotion and cognition after stroke. The present study shows that the accounts of patients should be supplemented by reports of close relatives. Furthermore, nurses must be able to observe and recognize cognitive deficits and emotional and behavioural disturbances after stroke during the home visits. In addition, regional availabilities of additional expertise in diagnosis or treatment of these problems should be known.

Another recent beneficial development is that several rehabilitation centres provide neuropsychological assessment, cognitive rehabilitation and neuropsychotherapy to
stroke patients in the chronic phase after stroke. Since the 1980’s and 1990’s rehabilitation centres in the Netherlands have increasingly directed attention to the neuropsychological consequences of stroke. Since the 90’s of the previous century, patients without apparent physical disabilities and their partners have access to cognitive rehabilitation programmes in the acute but also in the chronic phase after stroke. However, the availability of these outpatient treatment programmes is not widely known among patients and clinicians. Care in the chronic phase after stroke is fragmented, with different organisations providing care for different time periods. Future efforts should be directed at increasing awareness of the treatment options for the emotional and cognitive sequelae of stroke and at improving continuity of care in the chronic phase after stroke.

Role of GP in chronic care after stroke
In the concept National guidelines of the Dutch College of General Practitioners attention has been paid to the cognitive and emotional consequences of stroke. In particular in the rehabilitation phase, neuropsychological assessment (if necessary) is recommended. However, also in the chronic phase after stroke when patients reside at home again, attention must be directed at the cognitive and emotional changes. Either the GP or the nursing home practitioner should inquire on this matter, as these disturbances may affect activities of daily life including leisure activities, the ability to drive a car or the ability to return to work. As has been demonstrated by the present study, patients and partners may differ in their perception of cognitive deficits and emotional problems, partly because of the patient’s impaired awareness. In cases when either patients or their partners or the health care providers themselves - doctors, nurses, paramedics - have questions concerning possible cognitive or emotional disturbances after stroke, a neuropsychological assessment can help to gain insight into the neuropsychological functioning of the patient. Furthermore, the knowledge of deficits and reactions of the patient can give directions to the implementation of further interventions, including cognitive rehabilitation or neuropsychotherapy. To sum up, if GPs treat stroke patients according to the concept College Guidelines, many cognitive and emotional problems might be treated appropriately to the benefit of both patients and their partners. In the chronic phase after stroke providers should remain alert for possible so called ‘hidden consequences’ of stroke. These problems may cause great distress in the lives of patients and partners.
References


Summary

Aim of the present study was to investigate the impact of emotional and cognitive changes after stroke on the lives of patients and their partners. The emotional and cognitive consequences of stroke were measured at three and fifteen months post-stroke in a community based group of patients with a clinically first-ever, unilateral, ischemic stroke. Most stroke patients in the study sample were collected by GPs from the northern part of the Netherlands, while a small part was recruited at a hospital stroke unit. A control group, matched to patients on age and gender using a stratified randomisation procedure, was recruited through practices of 4 GPs. Only patients and controls without previous neurological or psychiatric disturbances and without a known history of substance abuse were included. Data collection at the two times of measurement included an interview at the patient’s residence, and subsequently a neuropsychological investigation divided into two sessions.

As described in chapter 1, a total of 100 stroke patients and 70 controls were interviewed twice. Stroke patients excluded from the study beforehand and patients who dropped out during the study concerned the older and more severely disabled patients. The question arose if patients referred to the study by the GPs concerned those with a better health status and a lower risk profile. To gain insight into this matter, stroke-related comorbidity of the study sample was compared to comorbidity in a large dataset of stroke patients collected through the Morbidity Registration Network Groningen (RNG). The results showed that stroke-related comorbidity in the study sample was very similar to comorbidity in the RNG sample. However, within the study sample, risk profiles and stroke characteristics differed between patients recruited by GPs and those collected at the hospital stroke unit. These findings stress the need for community based stroke studies, as samples derived from hospitals might be biased towards different stroke types and vascular risk profiles.
In chapter 2, an inventory was made of the presence and severity of changes in emotion and cognition as subjectively experienced at three months post-stroke. Changes reported by left and right hemispheric stroke patients and observed by their partners were compared. The results showed that, regardless of the side of stroke, several changes were reported by half of the stroke patients and their partners. It appeared that while left hemisphere stroke patients agreed with their partners on the number and severity of most changes, partners of right hemisphere stroke patients reported more frequent and more severe changes than the patients themselves. Several factors were investigated concerning their relationship with disagreement between patient and partner. The level of observability of the altered behaviour, distress of the partner and neglect of the right hemisphere stroke patient were related to greater disagreement between patient and partner. In left, but not right hemisphere stroke patients, greater disturbances in mood were related to greater disagreement between patient and partner.

In chapter 3, this same issue was addressed in a longitudinal design. Aim was to examine the time course of patients' awareness of changes in emotion and cognition after stroke and its longitudinal correlates. In addition, it was investigated if awareness of the patients was longitudinally related to their activity level. Awareness was defined as the number of changes acknowledged by the partner, but not by the patient. The results showed that patients reported changes in emotion and cognition slightly more often at fifteen months than at three months post-stroke. At fifteen months post-stroke, only 10 to 15 percent of patients and an even lower percentage of partners reported no changes at all. At the second time of measurement, partners of right hemisphere stroke patients still reported a greater number and severity of changes than patients themselves. The presence of silent brain infarctions and the level of neglect were related to greater unawareness in right hemisphere stroke patients. As was also found at three months post-stroke, distress of partners was longitudinally related to more changes perceived by partners than by patients, a relationship that strengthened in time for partners of right hemisphere stroke patients. Again, in left, but not right hemisphere stroke patients, greater distress appeared to be longitudinally related to a greater awareness of changes. Finally, not the level of awareness, but greater disturbances in mood and more severe neglect were longitudinally related to a lower activity level in left and right hemisphere stroke patients. The present results showed that less awareness of changes in emotion and cognition than one's partner is not a temporarily phenomenon after stroke and supported the neurological basis of impaired awareness in right hemisphere stroke patients.
Aims of \textit{chapter 4} were to describe the level and course of anxious and depressive mood between three and fifteen months post-stroke and to evaluate the effects of stroke characteristics, demographic variables, disabilities and life events on mood at fifteen months post-stroke. Mood was divided into late life and post-stroke mood by attribution of patients themselves. The results showed that late life anxious and depressive mood remained constant from three to fifteen months post-stroke, whereas post-stroke mood improved significantly. While disabilities not related to stroke were associated with late life mood, post-stroke disabilities were related to post-stroke mood. Psychosocial disabilities best predicted post-stroke anxious and depressive mood at fifteen months post-stroke. For post-stroke anxiety, the experience of life events and younger age were also predictive of higher anxiety at follow-up. As only half of the disturbances in mood were attributed to the stroke event, depressive and anxious mood of stroke patients should be considered in a broader health context.

In \textit{chapter 5}, the relationship between depressive mood and cognitive functioning was addressed. An observer-rated and a self-rated scale were used to assess depressive mood. Cognitive functioning was measured by several tests, while subjective cognitive changes were also assessed. The results showed that, although patients with depressive mood had more cognitive complaints than those without, the patients did not differ in cognitive test scores when mood was self-rated. Furthermore, changes in mood were not related to changes in cognitive performance. When the observer rated criteria of mood were applied, patients with depressive mood appeared to be mentally slower than those without. The frequently suggested relationship between post stroke depression and cognitive impairments was confirmed for the subjective, but not the objective cognitive data. Moreover, the data demonstrated the decisive role of the instruments that are used to assess depressive mood and cognitive performance after stroke.

In \textit{chapter 6}, the issue of fatigue after stroke was subject of investigation. Aim was to describe the course of fatigue between three and fifteen months post-stroke and to analyse the longitudinal determinants of fatigue. The results showed that although stroke patients improved in fatigue, they remained more often fatigued than controls at fifteen months post-stroke. In both groups fatigue could be predicted by the presence of heart disease and musculoskeletal diseases. In stroke patients, greater disturbances in mood, greater changes in emotion and cognition and more severe physical disabilities were longitudinally related to more frequent fatigue. In right hemisphere
stroke patients, slower complex mental speed was also related to a higher frequency of fatigue. At the end of the chapter, the implications of the findings for the treatment of fatigue after stroke are discussed.

In the final two chapters, the influence of the emotional and cognitive consequences of stroke on the subjective well-being of both patients and partners are analysed within the framework of the social production functions (SPF)-theory.

In chapter 7, the impact of impairments of the patient on strain and life satisfaction of the partner is examined. The results showed that one quarter of partners experienced considerable strain at both three and fifteen months post-stroke, whereas life satisfaction of the partners decreased from the time preceding stroke to three months after stroke. SPF-theory was supported as the disabilities of the patient did not directly affect the life satisfaction of the partner, but were mediated by strain on the partner. Physical disabilities and emotional and cognitive changes in the patients predicted the amount of physical strain experienced by the partner, while changes in emotion and cognition appeared most predictive of the emotional strain on partners. It appeared that at fifteen months post-stroke, female partners of stroke patients experienced greater emotional strain than male partners. In female partners, life satisfaction was predicted by both physical and emotional strain, whereas in male partners, only physical strain proved to be predictive. The impact of the patients’ disabilities on the strain and life satisfaction of the partner was explained by their restricting influence on comfort, activities, affection, and behavioural confirmation of the partner which are described in SPF-theory as instrumental goals to achieve well-being. Gender differences in strain were explained by the greater number of care tasks and the restriction of activity previously described in female carers. The chapter concludes with a call for more attention to changes in emotion and cognition in patients living in the community and more attention directed at gender differences in the well-being of stroke partners.

Finally, in chapter 8, the impact of cognitive disabilities on life satisfaction of the patient is examined. In SPF-theory activities are regarded important in obtaining well-being, therefore, the restricting influence of cognitive disabilities on leisure activities was investigated. Furthermore, the predictive value of cognitive disabilities and activity level at three months post-stroke for life satisfaction at fifteen months post-stroke was investigated. The results first showed that life satisfaction deteriorated from time be-
fore stroke to three months post-stroke and remained at this diminished level at fifteen months post-stroke. In comparison with control subjects, only male stroke patients reported a significantly lower level of life satisfaction. However, most patients remained relatively satisfied with life. While early physical disabilities predicted the final activity level at fifteen months post-stroke, higher reasoning abilities and faster mental speed at three months post-stroke were related to a greater restoration of activities from three to fifteen months post-stroke. Furthermore, activity level, memory functioning and reasoning capacities at three months post-stroke predicted life satisfaction at fifteen months post-stroke. The lower life satisfaction of male patients was explained by the relatively greater sensitivity of male activities to the effects of stroke. The results draw attention to the impact of cognitive functioning on the activities and life satisfaction of stroke patients living in the community. This patient group should more easily gain access to patient education or cognitive rehabilitation after stroke.

In chapter 9, the main findings are summarized, the limitations of the present study are discussed and the implications for research and clinical practice are outlined. It is emphasized that changes in emotion and cognition are common after stroke and influence the lives and well-being of patients and partners living in the community. Knowledge concerning the cognitive and emotional sequelae is scarce in the general population. Furthermore, clinicians often do not recognize these disturbances after stroke. Attention is directed at the lack of valid Dutch questionnaires measuring the emotional sequelae of stroke. In addition, controlled research concerning the efficacy of treatment methods for the emotional and behavioural consequences of stroke is scarce. Future efforts should be directed at developing valid diagnostic methods, at expanding evidence-based treatment for these consequences of stroke and at improving the continuity of care in the chronic phase after stroke.
Het doel van deze studie was het onderzoeken van de invloed van veranderingen in emotie en cognitie na een CVA op het leven van patiënten en hun partners. De emotionele en cognitieve gevolgen werden 3 en 15 maanden na het CVA gemeten in een groep patiënten met een klinisch eerste, unilateraal en ischemisch CVA. Het grootste deel van de patiënten in de onderzoeksgroep werd aangemeld door huisartsen uit Noord-Nederland. Daarnaast werd een klein deel van de patiënten verzameld via de Stroke Unit van het Academisch Ziekenhuis Groningen. Een controlegroep werd gevormd vanuit 4 huisartspraktijken, waarbij de controles qua leeftijds- en geslachtsverdeling werden gematched met de patiënten via gestratificeerde randomisatie. Alleen patiënten en controles zonder neurologische of psychiatrische ziektegeschiedenis en zonder verslavingsachtergrond werden geïncludeerd. Dataverzameling op de twee meetmomenten bestond uit een interview bij patiënten thuis, gevolgd door een neuropsychologisch onderzoek verdeeld over twee sessies.

Zoals beschreven in hoofdstuk 1 werden 100 patiënten en 70 controles tweemaal geïnterviewd. CVA-patiënten die werden geëxcludeerd voorafgaand aan het onderzoek en patiënten die uitvielen tijdens het onderzoek, bleken vooral de oudere en ernstiger beperkte patiënten te betreffen. De vraag ontstond of de patiënten die waren aangemeld door hun huisarts wellicht patiënten betrof met een relatief goede gezondheidstoe stand en een lager risicoprofiel. Om deze vraag te beantwoorden, werd de CVA-gere lateerde comorbiditeit in de onderzoeksgroep vergeleken met de comorbiditeit in een grote groep CVA-patiënten uit het Registratie Netwerk Groningen (RNG). De CVA-gere lateerde comorbiditeit in de onderzoeksgroep bleek vergelijkbaar met de comorbiditeit in de RNG groep. Echter, de patiënten die waren verzameld via huisartsen en patiënten verzameld via de Stroke Unit van het ziekenhuis bleken verschillend wat betreft risicoprofiel en CVA-kenmerken. Deze bevinding benadrukt de noodzakelijkheid van populatie gebaseerd CVA-onderzoek.
In hoofdstuk 2 werden de aanwezigheid en de ernst van veranderingen in emotie en cognitie zoals ervaren door patiënten en geobserveerd door hun partners 3 maanden na het CVA geïnventariseerd. Onafhankelijk van de zijde van het CVA, bleken diverse veranderingen door de helft van de patiënten en hun partners te worden genoemd. Patiënten met een linkerhemisferisch CVA waren het over het algemeen eens met hun partners. Partners van patiënten met een CVA in de rechterhemisfeer noemden echter een groter aantal en een ernstigere mate van veranderingen dan de patiënten zelf. De mate van observeerbaarheid van het veranderde gedrag, de stemming van de partner, en de mate van unilateraal neglect van de patiënt bleken samen te hangen met een grotere discrepantie tussen patiënten en hun partners. Daarnaast bleek ook de stemming van patiënten met een CVA in de linkerhemisfeer gerelateerd aan een grotere discrepantie tussen veranderingen genoemd door patiënten en hun partners.

In hoofdstuk 3 werd dit onderwerp geanalyseerd in een longitudinaal design. Het doel was om het tijdsverloop van het inzicht van de patiënt in de veranderingen in emotie en cognitie en de hieraan gerelateerde factoren te onderzoeken. Daarnaast werd onderzocht of het inzicht van de patiënt in de tijd was gerelateerd aan het activiteiten niveau. Het inzicht van de patiënt werd gedefinieerd als het aantal veranderingen dat geobserveerd werd door de partner, maar niet werd gerapporteerd door de patiënt. De resultaten lieten zien dat veranderingen in emotie en cognitie door patiënten 15 maanden na het CVA iets vaker werden genoemd dan 3 maanden na het CVA. Vijftien maanden na het CVA noemde slechts 10 tot 15 procent van de patiënten, en een nog lager percentage partners, geen enkele verandering in emotie of cognitie. Tijdens het tweede meetmoment noemden partners van patiënten met een CVA in de rechterhemisfeer nog steeds een groter aantal en een ernstigere mate van veranderingen dan de patiënten zelf. De aanwezigheid van stille infarcten voorafgaand aan het CVA en de mate van unilateraal neglect bleken gerelateerd aan een verminderd inzicht van patiënten met een rechterhemisferisch CVA. Zoals ook was gevonden 3 maanden na het CVA, bleek een slechtere stemming van partners in tijd gerelateerd aan meer veranderingen geobserveerd door partners dan door patiënten zelf. Bij partners van patiënten met een CVA in de rechterhemisfeer was deze relatie 15 maanden na het CVA sterker dan 3 maanden na het CVA. Opnieuw werd in patiënten met een CVA in de linkerhemisfeer gevonden dat de stemming van de patiënt samenhang met een grotere mate van inzicht in de veranderingen. Als laatste bleek dat niet de mate van inzicht van de patiënt, maar ernstigere stemmingstoornissen en een grotere mate van unilateraal ne-
gelekt longitudinaal gerelateerd waren aan het activiteitenniveau. De resultaten maakten duidelijk dat een verminderd inzicht in veranderingen in emotie en cognitie geen tijdelijk fenomeen is. Daarnaast ondersteunen de bevindingen een neurologische basis voor een verminderd inzicht in patiënten met een rechterhemisferisch CVA.

De doelen van hoofdstuk 4 waren het beschrijven van de ernst en het verloop van de angstige en sombere stemming van de patiënt van 3 naar 15 maanden na het CVA en het evalueren van de effecten van de kenmerken van het CVA, demografische variabelen, de beperkingen en het meemaken van life events op de stemming 15 maanden na het CVA. De resultaten lieten zien dat de stemming die niet toegeschreven werd aan het CVA stabiel bleef van 3 naar 15 maanden na het CVA, terwijl de stemming gerelateerd aan het CVA verbeterde. Beperkingen die niet veroorzaakt waren door het CVA waren geassocieerd met de stemming die niet toegeschreven werd aan het CVA, terwijl omgekeerd beperkingen na het CVA bleken samen te hangen met de stemming beïnvloed door het CVA. Psychosociale beperkingen na het CVA bleken de beste voorspeller voor de angstige en sombere stemming 15 maanden na het CVA. Het meemaken van life events en een jongere leeftijd voorspelden daarnaast een hogere mate van angst op 15 maanden na het CVA. Slechts de helft van de verstoorde stemming werd toegeschreven aan het CVA. Deze resultaten pleiten ervoor om sombere en angstige stemming na een CVA te evalueren in een brede gezondheidsgerelateerde context.

Het onderwerp van hoofdstuk 5 betrof de relatie tussen een sombere stemming en het cognitief functioneren na een CVA. Een tweetal meetinstrumenten, een observatieschaal en een vragenlijst werden gebruikt om een sombere stemming te meten. Het cognitief functioneren werd gemeten door diverse tests, terwijl ook de subjectief ervaren veranderingen in het cognitief functioneren werden geïnventariseerd. De resultaten lieten zien dat patiënten met een sombere stemming meer klachten over hun cognitief functioneren hadden dan patiënten zonder sombere stemming. Patiënten die op een vragenlijst een sombere stemming aangaven verschilden echter niet in cognitieve testscores van patiënten zonder sombere stemming. Patiënten die werden beoordeeld als somber op basis van de observatieschaal, bleken mentaal trager dan patiënten die niet als zodanig werden beoordeeld. De vaak geopperde relatie tussen depressieve stemming en cognitieve beperkingen werd bevestigd voor de subjectieve klachten, maar niet voor de objectieve data. Daarnaast lieten de
resultaten zien dat de instrumenten die gebruikt worden om de depressieve stemming en het cognitief functioneren te meten een doorslaggevende rol hebben.

In hoofdstuk 6 werd het onderwerp vermoeidheid na een CVA onderzocht. De doelen waren het beschrijven van het verloop van vermoeidheid van 3 naar 15 maanden na het CVA en het analyseren van de longitudinale voorspellers van vermoeidheid. De resultaten lieten zien dat, hoewel patiënten verbeterden in vermoeidheid, ze 15 maanden na het CVA nog vaker vermoeid waren dan de controleproefpersonen. In beide groepen voorspelden de aanwezigheid van hartzieken en spier- en gewrichtsaandoeningen de mate van vermoeidheid. In CVA-patiënten waren ernstigere stemmingsstoornissen, grotere veranderingen in emotie en cognitie en ernstigere fysieke beperkingen longitudinaal gerelateerd aan een frequenter optredende vermoeidheid. In patiënten met een CVA in de rechterhemisfeer was een trager mentaal tempo op een complexe taak ook gerelateerd aan een grotere frequentie van vermoeidheid. Aan het eind van dit hoofdstuk worden de implicaties van deze bevindingen voor de behandeling van vermoeidheid besproken.

In de laatste twee hoofdstukken werd de invloed van de emotionele en cognitieve gevolgen van het CVA op het subjectieve welbevinden van de patiënt en de partner geanalyseerd binnen het kader van de sociale produktiefuncties (SPF) theorie.

In hoofdstuk 7 werd de invloed van de beperkingen van de patiënt op de belasting van de partner en zijn/haar tevredenheid met het leven onderzocht. De resultaten lieten zien dat, zowel 3 maanden als 15 maanden na het CVA, een kwart van de partners een verhoogde belasting ervoer, terwijl hun tevredenheid met het leven daalde van de tijd voorafgaand aan het CVA tot 3 maanden na het CVA. Er werd een ondersteuning voor de SPF-theorie gevonden: de beperkingen van de patiënt hadden geen directe invloed op de tevredenheid van de partner, maar deze relatie werd beïnvloed door de mate van belasting van de partner. De fysieke beperkingen en de veranderingen in emotie en cognitie voorspelden de mate van fysieke belasting van de partner, terwijl de veranderingen in emotie en cognitie de beste voorspeller bleken voor de emotionele belasting van de partner. Vijftien maanden na het CVA bleken vrouwelijke partners een grotere emotionele belasting te ervaren dan mannelijke partners. De tevredenheid van vrouwelijke partners met het leven bleek zowel beïnvloed door de ervaren fysieke als de emotionele belasting, terwijl in mannelijke partners alleen de fysieke belasting voor-
spellend bleek voor de tevredenheid met het leven. De invloed van de veranderingen in emotie en cognitie in de patiënt op de belasting en tevredenheid van de partner werd vanuit de SPF-theorie verklaard door hun beperkende invloed op het comfort, de activiteiten, de affectie en de gedragsmatige bevestiging van de partner welke gezien worden als instrumentele doelen voor het bereiken van welbevinden. De sexeverschillen in belasting werden verklaard door het groter aantal taken die vrouwen in de verzorging kunnen uitvoeren en de in eerder onderzoek beschreven restrictie in activiteiten van vrouwelijke verzorgers. Het hoofdstuk eindigt met de vraag om meer aandacht voor de invloed van veranderingen in emotie en cognitie bij thuiswonende CVA-patiënten en meer aandacht voor de sexeverschillen in het welbevinden van hun partners.

Tenslotte werd in hoofdstuk 8 de invloed van cognitieve beperkingen op de tevredenheid met het leven in patiënten zelf onderzocht. Omdat in de SPF-theorie de deelname aan activiteiten als een belangrijk doel voor het verwerven van welbevinden wordt beschouwd, werd de beperkende invloed van cognitieve stoornissen op het uitvoeren van hobbymatige activiteiten en activiteiten buitenshuis geëvalueerd. Daarnaast werd gekeken naar de voorspellende waarde van het cognitief functioneren en het activiteitenniveau 3 maanden na het CVA voor de tevredenheid met het leven 15 maanden na het CVA. De resultaten lieten ten eerste zien dat de tevredenheid met het leven daalde van de tijd voorafgaand aan het CVA naar 3 maanden na het CVA en 15 maanden na het CVA op dit lagere niveau bleef. Vergeleken met controleproefpersonen rapporteerden alleen mannelijke patiënten een significant lager niveau van tevredenheid. De meeste patiënten bleven echter relatief tevreden met het leven. Terwijl de fysieke beperkingen 3 maanden na het CVA het uiteindelijke activiteitenniveau op 15 maanden na het CVA voorspelden, bleken een beter redeneervormen en een sneller mentaal tempo 3 maanden na het CVA gerelateerd aan een grotere verbetering in het activiteitenniveau van 3 naar 15 maanden na het CVA. Daarnaast voorspelden het activiteitenniveau, de geheugenfuncties en het redeneervormen 3 maanden na het CVA de tevredenheid met het leven 15 maanden na het CVA. Het lagere niveau van tevredenheid van mannelijke patiënten werd verklaard door de grotere kwetsbaarheid van de gemeten mannelijke activiteiten voor de effecten van het CVA. De resultaten richten de aandacht op de invloed van het cognitief functioneren op de activiteiten en de tevredenheid van thuiswonende CVA-patiënten. Deze patiëntengroep zou gemakkelijker toegang moeten kunnen krijgen tot een goede patiëntenvoorlichting of een programma voor neuropsychologische revalidatie na een CVA.
In hoofdstuk 9 worden de belangrijkste bevindingen samengevat, de beperkingen van het huidige onderzoek besproken en worden de implicaties voor toekomstig onderzoek en de klinische praktijk uiteengezet. Er wordt benadrukt dat veranderingen in emotie en cognitie frequent voorkomen na een CVA en het leven en welbevinden van patiënten en hun partners beïnvloeden. De kennis omtrent de cognitieve en emotionele gevolgen van een CVA is nog beperkt in de algehele bevolking. Daarnaast herkennen ook clinici deze gevolgen van het CVA niet altijd. Er wordt vervolgens aandacht besteed aan het ontbreken van gevalideerde Nederlandse vragenlijsten om de emotionele gevolgen van het CVA goed te meten. Tevens is gecontroleerd onderzoek naar de effectiviteit van behandelingsmethoden van de emotionele en gedragsmatige gevolgen van het CVA nog schaars. Toekomstige inspanningen zouden moeten zijn gericht op het ontwikkelen van gevalideerde onderzoeksmethodes, op het uitbreiden van evidence-based onderzoek naar de behandeling van deze gevolgen van het CVA en op het verbeteren van de continueitie van de zorg in de chronische fase na het CVA.
Nu het proefschrift klaar is, is het tijd om terug te kijken naar alle mensen die hebben bijgedragen aan het onderzoek en mij hebben ondersteund bij het schrijven van het proefschrift.

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