

# **The importance of psychological factors**

*The Restore4Stroke Patient Cohort study*

**Marloes van Mierlo**

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# **The importance of psychological factors**

*The Restore4Stroke Patient Cohort study*

## **Het belang van psychologische factoren**

*Het Restore4Stroke Patiënt Cohort onderzoek*

(met een samenvatting in het Nederlands)

### **Proefschrift**

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General introduction



**1**

The present thesis describes the results of the Restore4Stroke Patient Cohort study. This chapter serves as an introduction for this thesis and is structured as follows. First, an introduction into stroke and the possible consequences are described. Second, the concept of quality of life (QoL) and the influence of demographic factors, stroke-related factors and psychological factors are addressed. Third, the rationale for this thesis is discussed. And finally, the aims and outline of this thesis are presented.

## Stroke

Stroke is the second most common cause of death worldwide<sup>1,2</sup> and the third most common cause of disability.<sup>2</sup> A stroke can lead to physical, psychological, and psychosocial consequences.<sup>3</sup> Most of these problems are long lasting and can therefore be regarded as chronic. Due to the ageing population and major improvements in acute stroke care, such as the use of thrombolysis and the implementation of stroke units, the number of patients surviving a stroke is increasing although at the expense of a growing number of survivors who must cope with the chronic consequences of stroke.<sup>4,5</sup>

## The concept of quality of life

In recent decades, it has become clear that assessments of neurological impairment and disability alone are not sufficient to evaluate the entire impact of stroke on patients and their partners.<sup>6</sup> Together with the increasing number of chronic stroke patients this has led to a growing interest in QoL issues in stroke care and research.<sup>3,7</sup>

No generally accepted definition of QoL exists. In the literature, the following three approaches to the operationalization of QoL can be distinguished: QoL as synonymous with health, often referred to as health-related quality of life (HRQoL); QoL as synonymous with well-being; and QoL as a superordinate construct, covering both HRQoL and well-being.<sup>8</sup> In the present thesis we defined QoL as a multidimensional concept affected by the person's physical health, psychological state, level of independence, social relationships, personal beliefs and their relationship to salient features of their environment.<sup>9</sup> HRQoL in this perspective is a subset of QoL aspects related to health, comprising of domains of one's life such as physical, functional, psychological, emotional, and social health.<sup>10</sup> QoL can be considered both from a generic or disease-specific perspective. Specific domains of QoL can also be taken into account separately, such as participation, emotional functioning and subjective well-being.



## Quality of life in stroke patients

Research has shown that stroke patients perceive their HRQoL to be lower compared to the general population.<sup>11,12</sup> The course of HRQoL post stroke is, however, not yet clear. Several studies investigated HRQoL over time, but most with a short follow-up period up to 6 months post stroke, and only a few studies investigated HRQoL with longer follow-up periods of up to 12 months and 16 months post stroke.<sup>6,13</sup> In general, improvement of HRQoL is found between one and six months post stroke.<sup>14,15</sup> However, some studies found a decline after inpatient rehabilitation,<sup>16</sup> and for the long-term post stroke, the results are inconclusive.<sup>6,13</sup>

Taking a closer look at specific QoL domains, the course of emotional functioning, participation and subjective well-being post stroke is not clear also. Depressive symptoms are part of emotional functioning and some studies found a decrease in depressive symptoms in the first year post stroke,<sup>17,18</sup> with the peak in the first month.<sup>19</sup> On the other hand, increases in depressive symptoms in the second and third year post stroke have also been found.<sup>18</sup> Contradictory, a recently published study found stable depression levels during the first 18 months post stroke.<sup>20</sup> With respect to participation, it was found that in the first six months after discharge from hospital or rehabilitation institute the frequency of participation increases,<sup>21,22</sup> with most changes observed in the first three months. Furthermore, in the chronic phase post stroke a decline in participation was found between 6 months and 2 to 4 years.<sup>23</sup> Life satisfaction is part of subjective well-being and stroke patients experience their life satisfaction to be lower than the general population. One year post stroke 53–61% of the stroke patients is not satisfied with their life as a whole.<sup>24,25</sup> One study concluded that there is a further decline in the following years<sup>26</sup> but another study reported that only 32% of the stroke patients was dissatisfied with life three years post stroke. Furthermore, improvement in life satisfaction within the first year post stroke with stability in the following two years has also been found.<sup>27</sup>

## Determinants of quality of life

To date, the most commonly investigated determinants of QoL post stroke are demographic factors and stroke-related factors. Higher age, female gender, comorbidity, severity of stroke, daily functioning, physical impairment and cognitive decline are examples of predictors that have been found to be associated with QoL after stroke.<sup>3,12,28</sup> However, the associations found are mostly weak, and much of the variance in QoL is still unexplained.<sup>12,29</sup> Moreover,

demographic factors cannot be changed, and knowledge of stroke-related factors is utilized in the acute phase to optimize acute stroke care, but this means that there are still patients who need to cope with the consequences of their stroke on the long term.

## Psychological factors

For stroke patients it is of great importance to learn how to address, manage, cope and live with the long-term consequences post stroke to reintegrate successfully and to achieve optimal adaptation. Adaptation to living with a stroke is one of the main goals of stroke rehabilitation. Psychological factors may influence QoL in addition to demographic and stroke-related factors,<sup>3</sup> because these factors reflect the way people approach and react to stressful situations.<sup>30,31</sup> Using the ICF-model<sup>32</sup> we operationalized psychological factors as 'coping styles, overall behavior patterns and character style, individual psychological assets and other characteristics, which may play a role in disability at any level, but that are not part of a health condition or health states' (p. 17).<sup>32</sup> Examples of psychological factors are therefore personality traits such as neuroticism and coping styles such as passive coping but also illness cognitions such as feelings of helplessness.

The importance of psychological factors to QoL has already been demonstrated in other chronic conditions, such as spinal cord injury,<sup>33</sup> and in stroke patients, the influence of some psychological factors on QoL has been found.<sup>34-36</sup> However, at the start of our study the influence of psychological factors on QoL in stroke patients was not investigated very often and there were still several psychological factors that have not been evaluated for their possible influence on QoL, although their influence has been found for other chronic conditions.

In order to know how to optimize the adaptation process we need to identify the psychological factors that can predict at an early stage post stroke which patients are vulnerable and at risk of poor adaptation. It is a shortcoming in stroke rehabilitation that so little research has been performed on the influence of psychological factors on QoL because some psychological factors may be amendable to treatment. With this knowledge, we can develop adequate interventions to promote QoL in patients with unfavorable prospects. Therefore, we developed the Restore4Stroke Patient Cohort study.

## Restore4Stroke Research Program

The Restore4Stroke Patient Cohort study is part of the Restore4Stroke Research Program, which is funded by the VSBfonds, and co-ordinated by ZonMw (Dutch Organization for Health Research and Development). Restore4Stroke is a collaboration between three organizations with broad scientific expertise in the field of post-stroke rehabilitation care: Brain Center Rudolf Magnus and Center of Excellence for Rehabilitation Medicine, University Medical Center Utrecht and De Hoogstraat Rehabilitation in Utrecht; Maastricht University in Maastricht; and University Medical Center St. Radboud in Nijmegen.

The general aims of Restore4Stroke were to enhance successful social reintegration and to improve quality of life of stroke patients and their informal caregivers. In total four studies were executed:

1. The Restore4Stroke Cohort study is a multicenter longitudinal cohort study in which stroke patients and their partners were followed from stroke units up to two years post stroke, irrespective of their discharge destination. In total 5 assessments were executed: in the acute phase and at two months, six months, 12 months and 24 months post stroke. Description of the results of this study is divided into two parts: the first part focused on stroke patients (Restore4Stroke Patient Cohort study), which is described in the present thesis, and the second part focused on the partners of stroke patients (Restore4Stroke Partner Cohort study).
2. The Restore4Stroke post-stroke depression with or without anxiety (PSDA) trial is a randomized control trial in which an augmented cognitive behavioral therapy intervention, focused on PSDA, was investigated for its effectiveness.<sup>37</sup>
3. The Restore4Stroke Self-Management trial is a randomized controlled trial in which a stroke-specific self-management intervention based on proactive coping by stroke patients and their partners was investigated for its effectiveness.<sup>38</sup>
4. The €-Restore4Stroke study conducted an economic evaluation of stroke alongside the Restore4Stroke Cohort study. Furthermore, the cost-effectiveness of both the Restore4Stroke PSDA trial and the Restore4Stroke Self-Management trial were determined.<sup>39</sup>

## Aims of this thesis

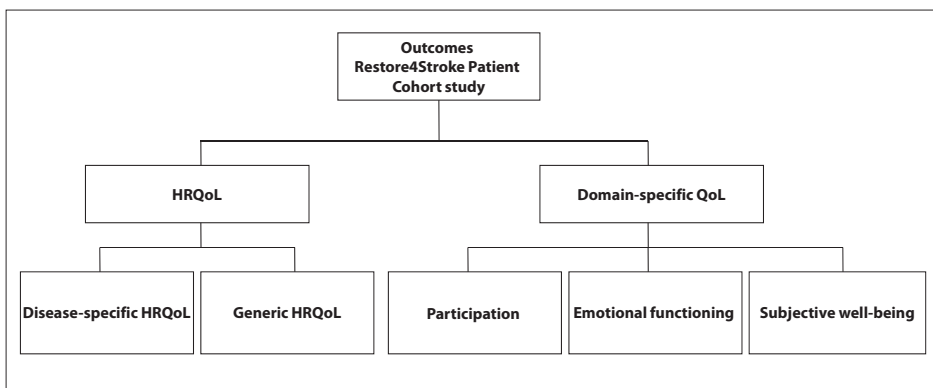
The aims of the Restore4Stroke Patient Cohort study were to investigate the course of QoL in stroke patients, and to determine factors predicting QoL, including demographic factors, stroke-related factors, and psychological factors, with special interest in the latter. The main outcome of the Restore4Stroke Patient Cohort study was QoL, which was investigated both from a HRQoL perspective and a domain-specific QoL perspective (see Figure 1.1). HRQoL was measured with a disease specific and a generic measure, and domain-specific QoL was examined by participation, emotional functioning and subjective well-being.

## Outline of this thesis

The aims of the Restore4Stroke Patient Cohort study are described in the two main parts of this thesis. **Chapter 2** of the introductory part first describes the protocol of the Restore4Stroke Cohort study. In this chapter inclusion- and exclusion criteria are presented, as well as the used measures and the times of administration during the study.

### Part I QoL after stroke

**Chapter 3** describes the course of the various aspects of QoL from two months to two years post stroke. For one of these aspects, the frequency of participation, retrospectively reported pre-stroke data were available. Therefore, **chapter 4** reports changes in the frequency of participation from pre-stroke to six months post stroke and reports if these changes are associated with subjective experiences of participation.



**Figure 1.1** Outcomes of the Restore4Stroke Patient Cohort study. HRQoL, health-related quality of life; QoL, quality of life.

## Part II Influence of psychological factors on QoL

**Chapter 5** reviews the literature regarding the psychological determinants of HRQoL post stroke and provides a systematic overview of this literature at the start of the Restore4Stroke Patient Cohort study. **Chapter 6** utilizes data from the test occasion two months post stroke to describe the independent associations between psychological factors and depressive symptoms two months post stroke. **Chapter 7** focuses on one particular type of psychological factor, illness cognitions, and describes the associations between illness cognitions and well-being two months as well as two years post stroke. **Chapter 8** describes the associations between psychological factors and distinct trajectories of physical and psychosocial HRQoL up to one year post stroke. These factors can help identify patients with unfavorable HRQoL trajectories.

### General discussion

To conclude, **chapter 9** offers a general discussion of this thesis, in which the main results as well as implications for clinical practice are discussed and ideas for future research are presented.

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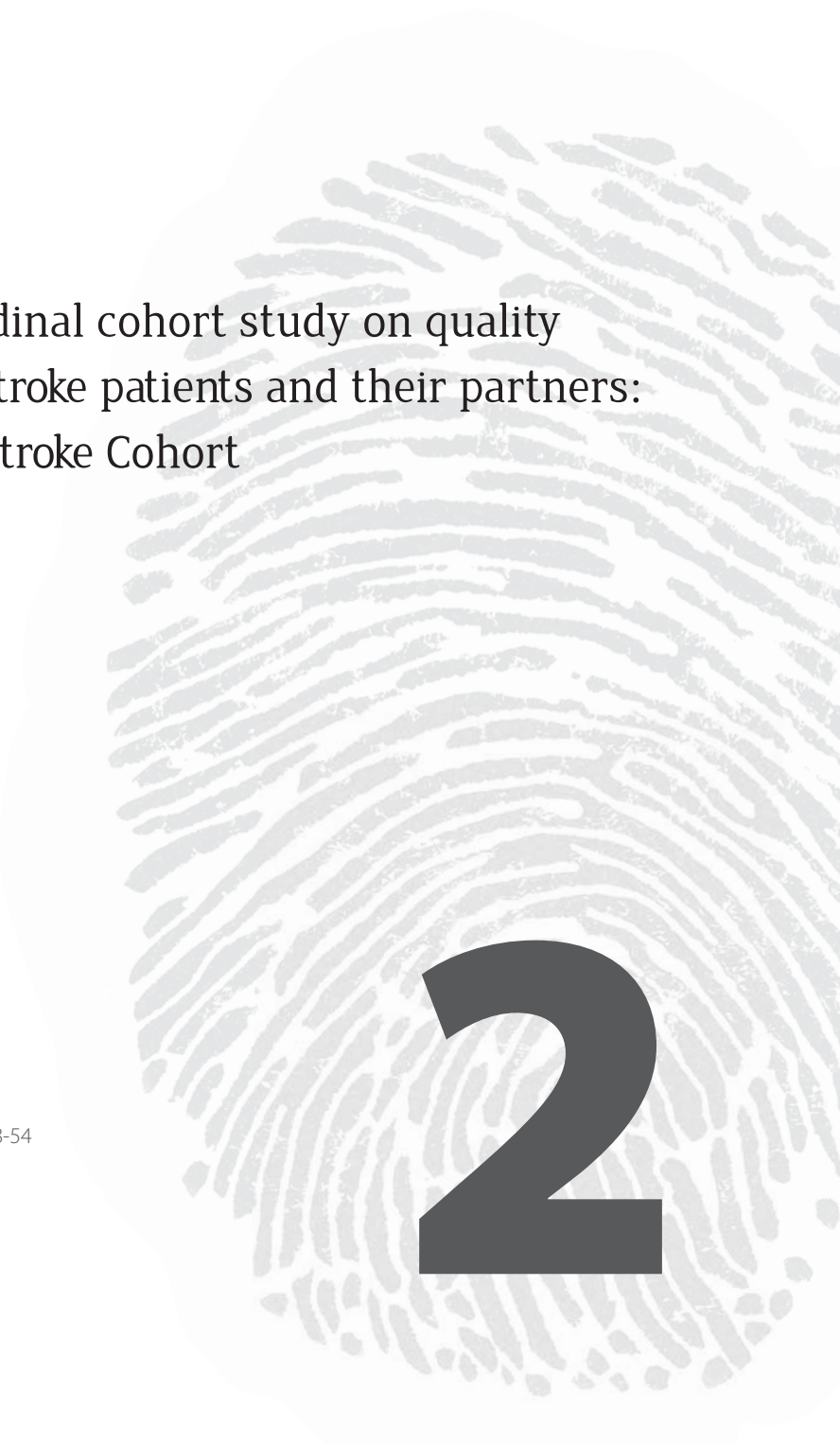
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# A longitudinal cohort study on quality of life in stroke patients and their partners: Restore4Stroke Cohort

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## Abstract

### Background

Stroke is a major cause of disability in the Western world. Its long-term consequences have a negative impact on the quality of life of both the patients and their partners.

### Aim

The aim of the Restore4Stroke Cohort study is to investigate the changes in quality of life of stroke patients and their partners over time, and to determine factors predicting quality of life in several domains, especially personal and environmental factors.

### Method

Multicentre prospective longitudinal cohort study. Inclusion and the first assessment take place during hospital stay in the first week post-stroke. Follow-up assessments take place at two months, six months, one year, and two years post-stroke. Recruitment of 500 patients from stroke units six participating hospitals is foreseen. If the patient has a partner, he or she is also asked to participate in the study.

### Outcomes

The main outcome is quality of life, considered from a health-related quality of life and domain-specific quality of life perspective. Factors predicting long-term quality of life will be determined by taking into account the health condition (pre-stroke health condition and stroke-related health condition), personal factors (e.g. coping and illness cognitions), and environmental factors (e.g. caregiver burden and social support).

### Discussion

This study is expected to provide information about the changes in quality of life of stroke patients and their partners over time. Furthermore, the identification of factors predicting quality of life can be used to improve rehabilitation care and develop new interventions for stroke patients and their partners.

## Introduction

In the Netherlands between 34000 and 41000 persons suffer a stroke each year,<sup>1</sup> making stroke one of the most common causes of disability in adults.<sup>2</sup> A stroke significantly influences the patient's physical, social, and psychological functioning.<sup>3</sup> Traditionally, much research and rehabilitation care has focused on the physical and functional impact of a stroke.<sup>3-5</sup> Recently, the impact of stroke on concepts like quality of life (QoL) have received more attention in the stroke literature.<sup>6</sup>

Post-stroke survival rates have been raised due to major improvements in acute stroke care, such as the implementation of stroke units and the use of thrombolysis. As a result, more people have to cope with the consequences of stroke,<sup>7,8</sup> experiencing long-term difficulties in terms of QoL,<sup>5,9</sup> social reintegration,<sup>7</sup> life satisfaction<sup>10</sup> and emotional functioning, including depression and anxiety.<sup>11</sup>

The patients themselves are not the only ones experiencing negative consequences after their stroke. After discharge from hospital, most stroke patients return to their own homes with or without rehabilitation treatment.<sup>12</sup> Home care is mostly provided by the partners. Taking care of a stroke patient can lead to high levels of caregiver burden in terms of feelings of responsibility, constant anxiety, decreased social activities, and feelings of loneliness.<sup>13-20</sup>

Results of earlier studies show that not only the consequences of the stroke (e.g. physical and cognitive) influence long-term QoL of stroke patients and their partners. Personal factors (e.g. passive coping)<sup>21,22</sup> and environmental factors (e.g. social support and family functioning),<sup>6,23</sup> defined according to the International Classification of Functioning (ICF),<sup>24</sup> also have a large impact on QoL.

Until now, not much attention has been paid in the stroke literature to the changes in QoL of stroke patients and their partners over time and the influence of personal and environmental factors on QoL. Additionally, sample sizes in previous studies have often been small.<sup>3,6,9</sup> With a new rehabilitation research programme, called Restore4Stroke, we want to overcome these shortcomings. Restore4Stroke aims to improve the quality of life of stroke patients and their partner. This will be accomplished through four projects; the present Restore4Stroke Cohort study, two randomized controlled trials (RCTs), and an economic evaluation study. The first RCT focuses on reducing depression and anxiety complaints in stroke patients (Restore4Stroke augmented Cognitive Behavioural Therapy), while the second RCT is aimed at enhancing self-management in stroke patients and their partners (Restore4Stroke Self-Management). In addition, an economic evaluation study

(€-Restore4Stroke) considers the economic aspects of stroke and the two intervention. The designs of these other three studies are submitted for publication elsewhere. In this paper, we present the study design of the Restore4Stroke Cohort study, which started in March 2011.

The aims of the Restore4Stroke Cohort study are (1) to investigate QoL over a two year period post-stroke in both stroke patients and their partners, and (2) to determine associations between health condition factors, personal factors, and environmental factors with QoL.

## Methods

### Design

The present study is a multicentre prospective longitudinal cohort study in which participants are followed using five assessments during the first two years from stroke onset.

### Patient population

A total of 500 patients are being recruited from stroke units in six participating hospitals in the Netherlands. If the patient has a partner, he or she is also asked to participate in the study.

It is expected that 40% of the stroke patients will drop out during the two year follow-up period due to various reasons (recurrent stroke, comorbidity, refusal, death). Inclusion of 500 stroke patients is therefore expected to lead to a total of 300 stroke patients being available to analyse determinants of long-term consequences. A total of 300 stroke patients will allow estimation of the prevalence of a certain consequence with satisfactory precision, for example a prevalence of 20% with a 95% confidence interval of +/- 4.6% ( $\alpha = .05$ ; power = .80). To analyse the associations with QoL over time, a total of 300 stroke patients will allow regression models with 15 determinants and 15 to 20 subjects per determinant.

We expect to include approximately 300 partners. This estimate is based on earlier research in which 68% of the stroke patients in a rehabilitation centre had a partner.<sup>25</sup> The inclusion period for each hospital is one year. As each of the six hospitals has a turnover of approximately 400 stroke patients a year, the inclusion of 500 stroke patients appears feasible.

## Inclusion and exclusion criteria

Stroke patients are eligible for this study if they have a clinically confirmed diagnosis of stroke (ischaemic or intracerebral haemorrhagic lesion) and have suffered their stroke within the last seven days. Partners of the participating stroke patients must be married to the stroke patients or be in a steady relationship with them. All participants must be at least 18 years old.

Participants (stroke patients and their partners) are excluded if they (1) have a serious other condition whereby an interference with the study outcomes is expected (e.g. neuromuscular disease); (2) were already dependent regarding activities of daily living before their stroke as defined by a Barthel Index score of  $\leq 17$ ;<sup>26</sup> or (3) have insufficient command of the Dutch language to understand and complete the questionnaires (based on clinical judgment). Furthermore, stroke patients are excluded if they were already suffering from cognitive decline as defined by a score of  $\geq 1$  on the Heteroanamnesis List Cognition, before their stroke.<sup>27</sup>

Post-stroke aphasia is not an exclusion criterion. If this problem renders patients incapable of filling in questionnaires during the follow-up assessments, only the observational measures are conducted. The ability to fill in questionnaires is evaluated by using the Stichting Afasie Nederland – Scale<sup>28</sup> at each assessment: if aphasia is considered on the basis of item 9 on the National Institutes of Health Stroke Scale (score  $\geq 1$ )<sup>29</sup> the Stichting Afasie Nederland – Scale is used to discriminate whether only observational measures are conducted (score 0 to 4) or observational measures and questionnaires are conducted (score 5 to 7).

## Procedure

All participants (stroke patients and partners) are informed of the nature of the study by a nurse practitioner or trial nurse. After informed consent is given, a nurse practitioner or trial nurse conducts the first assessment (T1) during hospital stay in the first week post-stroke.

The follow-up assessments take place at two months (T2), six months (T3), one year (T4) and two years (T5) post stroke. As the assessments of the stroke patients at T2 and T3 involve observational measures, a research assistant visits the stroke patient at home or at the institution where the patient is residing at that moment. In order to spread the burden for the participants, the outcome questionnaires are sent in advance, after the appointment for T2 and T3 is made. The observational measures and remaining questionnaires are completed during the visit.

At T3, T4 and T5, patients and their partners can decide if they want to complete the questionnaires on paper or online. Previous research has found no differences between electronically processed questionnaires and questionnaires administered on paper.<sup>30</sup>

## Measures

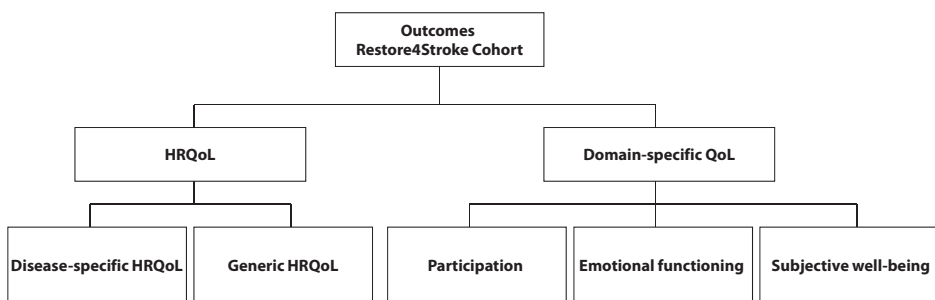
The main outcome is QoL, which is considered both from a general health-related QoL (HRQoL) and a domain-specific QoL perspective. The general HRQoL perspective is operationalized as disease-specific HRQoL and generic HRQoL. The domain-specific perspective consists of the domains of participation, emotional functioning and subjective well-being. An overview of this operationalization is shown in Figure 2.1.

An overview of all measurement instruments that are administered during the two year follow-up is shown in Table 2.1 (stroke patient) and Table 2.2 (partner).

## Outcome

Disease-specific HRQoL is measured with the short version of the Stroke-Specific Quality of Life Scale.<sup>31</sup> This instrument measures the impact of stroke on HRQoL and on two, physical and psychosocial, HRQoL domains. Each domain consists of six items. Psychometric properties of both the subscales and the total scale are sufficient.<sup>31</sup>

Generic HRQoL is measured with the Six-Dimensional EuroQoL,<sup>32</sup> which comprises six items: mobility, self-care, usual activities, pain/discomfort, anxiety/depression, and cognition. Each item is scored on a three-point scale, ranging from ‘no problems’ to ‘extreme problems’. The Six-Dimensional EuroQoL has shown good psychometric properties.<sup>32</sup>



**Figure 2.1** Outcomes of Restore4Stroke Cohort.  
HRQoL, health-related quality of life; QoL, quality of life.

Table 2.1 Overview of all measurement instruments for the stroke patients and the times of administration

Instrument		0 months	2 months	6 months	1 year	2 years
<b>Outcomes</b>						
<b>HRQoL</b>						
Disease-specific HRQoL	Stroke Specific Quality of Life Scale-12 <sup>31</sup>		X	X	X	X
Generic HRQoL	Six-Dimensional EuroQoL <sup>32</sup>		X	X	X	X
<b>QoL domains</b>						
Participation	Utrecht Scale for Evaluation of Rehabilitation – Participation <sup>33</sup>		X	X	X	X
Emotional functioning	Hospital Anxiety and Depression Scale <sup>34</sup>		X	X	X	X
Subjective well-being	Three life satisfaction questions <sup>35</sup>		X	X	X	X
<b>Determinants</b>						
<b>Pre-stroke health condition</b>						
Emotional functioning	Premorbid question of the Depression scale of the Hospital Anxiety and Depression Scale <sup>36</sup>	X				
Participation	Premorbid frequency scale of the Utrecht Scale for Evaluation Rehabilitation-Participation <sup>33</sup>	X				
Comorbidity	Cumulative Illness Rating Scale <sup>7</sup>		X			
<b>Stroke-related health condition</b>						
Stroke characteristics	Type: hemisphere; National Institutes of Health Stroke Scale <sup>29</sup>	X				
Motor impairment	Items 5ab and 6ab of the National Institutes of Health Stroke Scale <sup>29</sup>		X	X		
ADL	Barthel Index <sup>26</sup>		X	X		
	Modified Rankin Scale <sup>38</sup>			X		
Cognition	Montreal Cognitive Assessment <sup>39</sup>		X	X		
Impairment	Checklist for Cognitive and Emotional Consequences following stroke <sup>40</sup>		X	X		
Complaints			X	X		
Communication	Item 9 of the National Institutes of Health Stroke Scale <sup>29</sup>		X	X		

Table 2.1 continues on next page.

**Table 2.1 Continued**

	Instrument	0 months	2 months	6 months	1 year	2 years
<b>Personal factors</b>						
Demographic factors	Age, gender, education, marital status, ethnicity, work status	X				
Psychological factors						
Proactive coping	Utrecht Proactive Coping Competence Scale <sup>41</sup>		X			X
Passive coping	Passive coping scale of the Utrecht Coping List <sup>42</sup>		X			X
Self-efficacy	General Self-Efficacy Scale <sup>43</sup>		X			X
Neuroticism	Eysenck Personality Questionnaire – Neuroticism <sup>44</sup>		X			X
Extraversion	Eysenck Personality Questionnaire – Extraversion <sup>44</sup>		X			X
Optimism	Life Orientation Test – Revised <sup>45</sup>		X			X
Illness cognitions	Illness Cognition Questionnaire <sup>46</sup>		X			X
Care received	Cost Questionnaire		X	X	X	X

NOTE. The first assessment takes place in the first week post-stroke. The follow-up assessments take place at two months, six months, one year, and two years post stroke. HRQoL, health-related quality of life; QoL, quality of life.



Table 2.2 Overview of all measurement instruments for the partners and the times of administration

Instrument	0 months	2 months	6 months	1 year	2 years
<b>Outcomes</b>					
<b>HRQoL</b>					
Generic HRQoL		X	X	X	X
<b>QoL domains</b>					
Participation	X (only scale 1)	X	X	X	X
Emotional functioning		X	X	X	X
Subjective well-being		X	X	X	X
<b>Determinants</b>					
<b>Health condition</b>					
Burden		X	X	X	X
<b>Personal factors</b>					
Demographic factors	X				
Proactive coping		X			X
Self-efficacy		X			X
<b>Environmental factor</b>					
Social support	X	X	X	X	X

NOTE. The first assessment takes place in the first week post stroke. The follow-up assessments take place at two months, six months, one year and two years post stroke. HRQoL, health-related quality of life; QoL, quality of life.

Participation is assessed with the Utrecht Scale for Evaluation of Rehabilitation – Participation,<sup>33</sup> which consists of 32 items in three scales, representing the frequency of social activities (11 items), experienced participation restrictions (11 items), and satisfaction with participation (10 items). The Utrecht Scale for Evaluation of Rehabilitation - Participation was shown to be a valid and reliable measure to rate participation in patients with various physical disabilities, including stroke patients.<sup>49,50</sup>

Emotional functioning is measured with the Hospital Anxiety and Depression Scale,<sup>34</sup> consisting of 14 items measuring both anxiety and depression with seven items each. The Hospital Anxiety and Depression Scale has shown good psychometric properties,<sup>34</sup> and is a commonly used measure in stroke patients.<sup>51</sup>

Subjective well-being is measured with a brief life satisfaction measure consisting of three items. The first two items measure current and pre-stroke life satisfaction, respectively, and are scored on a six-point scale, ranging from 1 (very dissatisfied) to 6 (very satisfied). The third item asks the participants to compare their current life satisfaction with the pre-stroke situation, and is scored on a seven-point scale ranging from 1 (much worse) to 7 (much better). A two-item version of this measure proved a valid and sensitive measure to assess life satisfaction.<sup>35</sup> Furthermore, asking about pre-stroke life satisfaction at each measurement will allow us to detect a possible response shift in satisfaction with life.

## Determinants

According to the ICF model, the factors taken into account as potential determinants can be divided into three components. The first component is health condition, which in the present study covers both the pre-stroke health condition (e.g. comorbidity) and the stroke-related health condition (e.g. type of stroke). The second and third components consist of personal factors (e.g. coping), and environmental factors (e.g. social support), respectively. The measures that will be used to assess these factors are displayed in Table 2.1 (stroke patient) and Table 2.2 (partner). The partner factors will be analysed as potential environmental determinants of the outcome of the stroke patients, according to the ICF model, but also as outcome measures for the partners themselves.

Personal factors comprise a large proportion of the potential determinants investigated in this cohort study. We will investigate the influence of proactive coping using the Utrecht Proactive Coping Competence Scale;<sup>41</sup> passive coping using the Passive coping scale of the Utrecht Coping List;<sup>42</sup> self-efficacy using the General Self-Efficacy Scale;<sup>43</sup> neuroticism

and extraversion using the Eysenck Personality Questionnaire – Revised Short Scale;<sup>44</sup> optimism using the Life Orientation Test – Revised;<sup>45</sup> and appraisals of one's condition using the Illness Cognition Questionnaire.<sup>46</sup>

The influence of partner personal factors will be investigated using the Utrecht Proactive Coping Competence Scale<sup>41</sup> and the General Self-Efficacy Scale.<sup>43</sup>

In addition, a cost questionnaire on use of medical care, home care and support, and medication is administered during assessments T2 until T5. This questionnaire is part of the economic evaluation study, €-Restore4Stroke.

### **Statistical analyses**

We will first use descriptive statistics. Next, multilevel analyses will be performed to estimate differences between assessments (T2–T5). Multilevel analysis allows for correction for differences between study centres, and inclusion of persons with partly missing data in the analyses so that all available data can be used.

After that, latent class growth mixture modelling will be used to investigate if there are different trajectories of QoL between two months and two years after stroke and whether different trajectories can be distinguished.

Prediction of QoL problems on T4 and T5 will be analysed using multivariate regression models. It is hypothesized that lower QoL, at one and two years after stroke can reliably be predicted at T2 (two months after stroke), and that quality of life after stroke is associated with personal factors and caregiver variables, controlled for pre-stroke health situation and stroke-related health condition. All analyses will be done for the patients and partners separately. Effects with a p-value below .05 (two-tailed) will be regarded as significant.

### **Study organisation and funding**

Restore4Stroke is funded by the VSB foundation and Dutch Heart Foundation, and coordinated by ZonMw (Dutch Organization for Health Research and Development).

## Summary and conclusions

The Restore4stroke Cohort study investigates the changes in the QoL of stroke patients and their partners over time, and determines factors predicting QoL, especially the influence of personal and environmental factors.

There are several reasons why this cohort study is innovative. The first is its focus on the changes in QoL after stroke over time (in terms of disease-specific HRQoL, generic HRQoL, participation, emotional functioning and subjective well-being). Traditionally, much research and rehabilitation care has focused on the physical and functional impact of a stroke.<sup>3-5</sup> In addition, this study focuses on the long term, namely two years after stroke instead of the more common follow-up of one year after stroke.

Second, the present study extensively investigates the influence of personal factors on psychosocial functioning. Recent research has suggested the influence of coping on QoL.<sup>9</sup> However, there are still several personal factors that have not been evaluated for their possible influence on long-term QoL in stroke patients, although their influence has been proven in other conditions. Examples are perceived locus of control and hope in spinal cord injury.<sup>52</sup> That is why personal factors comprise a large proportion of the potential determinants investigated in this study. Moreover, possible changes in personal factors over time can be examined.

Third, the perspective of this study is family-centred. Not much research has been done into the reciprocal relationship between stroke patients and their families, especially their partners.<sup>53</sup> The present study therefore examines the influence of partners on the QoL of patients and vice versa.

Lastly, the factors that are investigated are a mixture of medical, paramedical, neuropsychological, and psychological factors, whereas theories and models are usually developed from a specific perspective, for example a medical perspective. However, as illustrated by the ICF model, it is necessary to better understand the relationships and interplay between all components of the model. This can be accomplished by means of trans-disciplinary theories and models that are able to link the various perspectives.<sup>54</sup> We hope that the results of Restore4Stroke will provide a starting point for this.

A limitation of this study is that, although we use limited exclusion criteria, the most serious affected patients are excluded, because these patients may not be able to give their consent in the first week post-stroke. This might jeopardize the generalizability of the results to all stroke patients. Furthermore, the outcome, QoL, is only measured with self-assessment

questionnaires. However, we do not consider this a problem, because QoL is a subjective concept as defined by the World Health Organization Quality of Life group as ‘individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations standards, and concerns’ (p.153).<sup>55</sup>

In conclusion, the information which will be gathered in the present study, especially about the influence of personal and environmental factors on QoL, will be used to establish better rehabilitation care and to develop new interventions for stroke patients and their partners. This should allow stroke patients and their partners to make optimal use of their capacity to recover from this common, serious and disabling condition.

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# **PART I**

QoL after stroke





# Quality of Life during the first two years post stroke: The Restore4Stroke Cohort Study

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**3**

## Abstract

### Background

Little information is available about the course of quality of life (QoL) post stroke and how dependency in activities of daily living (ADL) influences this course. The aim of this study was therefore to describe the course of QoL from two months up to two years post stroke and to study the influence of ADL dependency in the first week post stroke.

### Methods

This is a multicenter prospective longitudinal cohort study in which 368 stroke patients were included and data were collected at one week, two months, six months, 12 months and 24 months post stroke. QoL assessment included measures of health-related quality of life (HRQoL) (SS-QoL-12), emotional functioning (HADS), participation (USER-Participation), and life satisfaction (2LS). Dependency in ADL was defined as having a Barthel Index score  $\leq 17$  four days post stroke. Generalized Estimating Equations (GEE) analyses was performed to examine the course of the four domains of QoL. Furthermore, the possible confounding effect of age, gender, marital status, level of education and discharge destination was examined.

### Results

Results showed that HRQoL, participation and life satisfaction improved during the first year post stroke, with most changes occurring in the first six months. Furthermore, patients dependent in ADL scored consistently lower on all four QoL domains and test occasions compared to ADL independent patients. In both patient groups separately, no changes over time were found in emotional functioning. ADL independent patients improved in HRQoL ( $p = .002$ ), participation ( $p < .001$ ) and life satisfaction ( $p = .020$ ) between 2 and 6 months and in life satisfaction ( $p = .003$ ) between 6 and 12 months also. ADL dependent patients improved in HRQoL ( $p = .009$ ) between 2 and 6 months and in participation between 2 and 6 months ( $p = .001$ ) and between 6 and 12 months ( $p = .031$ ). Furthermore, they experienced no changes in life satisfaction. No confounding effect was found after adding age, gender, marital status, level of education and discharge destination.

### Conclusions

Most improvement in QoL occurred up to six months post stroke and showed different patterns for specific domains of QoL and for patients with and without dependency in ADL in the first week post stroke. It is therefore important to differentiate between these different domains of QoL when the long-term perspective is considered. Furthermore, patients dependent in ADL consistently scored lower on all QoL domains and did not reach the level of QoL of patients independent in QoL.

## Introduction

Stroke is a chronic condition that can lead to serious consequences in terms of physical,<sup>1</sup> cognitive<sup>2</sup> and emotional problems,<sup>3</sup> but may also affect social reintegration<sup>4</sup> and life satisfaction.<sup>5</sup> Assessment of impairment and disability alone provide insufficient information about the entire impact of stroke.<sup>6-8</sup> This has led to growing interest in psychosocial concepts such as quality of life (QoL).<sup>6,7</sup>

Changes in QoL post stroke have been investigated using health-related quality of life (HRQoL) measures or by assessing specific domains of QoL, such as emotional functioning, participation and life satisfaction. Most studies investigated the course of HRQoL only up to the first six months post stroke.<sup>9-11</sup> The few studies that used a longer follow-up period showed inconclusive and contradictory results.<sup>8,12,13</sup> The long-term course of HRQoL post stroke is therefore still unclear. Moreover, taking a closer look at specific QoL domains, the course of emotional functioning, participation and life satisfaction post stroke is not clear also.<sup>14-23</sup>

Investigating the long-term course of QoL after stroke will provide insight into the enduring consequences caused by stroke and will contribute to our knowledge about the expected outcome for patients. In addition, in the first week after stroke, decisions about discharge destination and rehabilitation treatment are made on the basis of the expected outcome, of which ADL is an important determinant.<sup>12</sup> Hence, the aim of this study was to describe the course of QoL from two months up to two years post stroke and to study the influence of ADL dependency in the first week post stroke.

## Methods

### Design and procedure

The current study is part of the multicenter prospective longitudinal Restore4Stroke Cohort study.<sup>24</sup> In this study, newly referred stroke patients were recruited in six general hospitals in the Netherlands between March 2011 and March 2013 and followed for two years. The medical ethics committees of all participating hospitals gave their approval, and informed consent was obtained from all included patients. The present study reports data at stroke onset and at two, six, twelve and twenty-four months post stroke.

After informed consent had been given, the first assessment concerned demographic and stroke-related factors. Information on stroke-related factors (e.g. type of stroke,

hemisphere, stroke severity) and ADL dependency, as assessed by the neurologist on day four, was extracted from the medical charts. Information on demographic factors was obtained from the patient or from family members. The second, third, fourth and fifth assessments took place two, six, twelve and twenty-four months post stroke. During these assessments, patients were asked to complete self-report scales on HRQoL, emotional functioning, participation restrictions and life satisfaction. Furthermore, during the second assessment, two months post stroke, a cognitive screening was conducted by a trained research assistant.

## Subjects

Stroke patients were eligible for this study if they had a clinically confirmed diagnosis of stroke (ischemic or intracerebral hemorrhagic lesion) and had suffered their stroke within the last seven days. All patients had to be at least 18 years old.

Patients were excluded from the study if they (1) had a serious other condition that was anticipated to interfere with the study outcomes; (2) were already dependent regarding ADL before their stroke as defined by a Barthel Index (BI) score of 17 or lower;<sup>25</sup> (3) had insufficient command of the Dutch language to understand and complete the questionnaires (based on clinical judgment); or (4) were already suffering from cognitive decline before their stroke as defined by a score of 1 or higher on the Heteroanamnesis List Cognition.<sup>26</sup>

## Measures

### *Dependent variables*

QoL was assessed with four measures: the short stroke-specific Quality of Life Scale (SS-QoL-12),<sup>27</sup> the Hospital Anxiety and Depression Scale (HADS),<sup>28,29</sup> the participation restrictions subscale of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation-R)<sup>30,31</sup> and the 2 Life Satisfaction questions (2LS).<sup>32</sup>

The short stroke-specific Quality of Life Scale (SS-QoL-12)<sup>27</sup> is a disease-specific HRQoL measure. The SS-QoL-12 consists of 12 items each scored on a 5 point scale. Items are averaged to obtain a mean score, and a higher score indicates a higher level of HRQoL. The SS-QoL-12 is a valid measure to assess HRQoL after stroke.<sup>27</sup>

The HADS was used to assess emotional functioning in terms of depressive and anxiety symptoms. This measure consists of 14 items, and the score ranges from 0 to 42. A higher



score indicates more emotional problems.<sup>28</sup> The HADS has shown good psychometric properties and is commonly used for stroke patients.<sup>28,29</sup>

The USER-Participation-R was used to assess experienced participation restrictions.<sup>30,31</sup> This scale consists of 11 items addressing difficulties experienced with vocational, leisure, and social activities caused by the stroke. Scores range from 0 to 100, and a higher score reflects better participation (fewer experienced restrictions). The USER-Participation has shown satisfactory reliability and validity and has been used for stroke patients previously.<sup>31</sup>

The 2LS was used to assess life satisfaction.<sup>32</sup> This measure consists of two items. The first item assesses current life satisfaction on a 6-point scale. The second item assesses current life satisfaction in comparison to life satisfaction before the stroke on a 7-point scale. The sum of these two questions ranges from 2 to 13, where a higher score indicates a higher level of life satisfaction. The 2LS has shown satisfactory validity and has been used in earlier publications.<sup>32,33</sup>

### ***Independent variables***

Information about gender, age, marital status, level of education, discharge destination, stroke severity, and ADL dependency was collected. For level of education, we used the Dutch classification system of Verhage (range 1–7).<sup>34</sup> Scores were dichotomized into low (up to completed secondary education) and high levels of education (completed university of professional education or higher). Discharge destination after hospitalization was categorized into home or inpatient rehabilitation. Stroke severity was assessed with the National Institutes of Health Stroke Scale (NIHSS).<sup>35</sup> Cognitive functioning was assessed using the Montreal Cognitive Assessment (MoCA) (range 0–30) two months post stroke.<sup>36</sup> The MoCA is a brief cognitive screening tool suitable for use in stroke patients.<sup>36</sup> ADL dependency was assessed using the BI, which is a validated measure often used in stroke.<sup>25</sup> The BI score was dichotomized into dependent (BI < 18) and independent (BI ≥ 18).

### **Statistical analyses**

Patients who completed one or more measurements were included in the analysis. Descriptive statistics were used to describe patients' characteristics and dependent variables using SPSS (version 22.0; IBM corp.; Armonk NY). To study the course of QoL, Generalized Estimating Equation (GEE) analyses with an exchangeable correlation structure was performed on the four dependent variables.<sup>37</sup> For each outcome measure, a GEE model was created with the measurement point as the main determinant, entered in the models as

a set of three dummy variables. To examine the course of the dependent variables in each time period, different dummy variables were used as a reference, meaning that the course was examined in three different time periods; from 2 to 6 months post stroke, from 6 to 12 months post stroke, and from 12 to 24 months post stroke. A major advantage of GEE is that patients with partly missing measurements do not have to be excluded from the analyses. To study whether there was a difference in course over time on the four dependent variables between patients who were independent in ADL and those who were dependent, first a model was analyzed that included the time dummies, the dichotomized BI score and interaction terms between the time dummies and the dichotomized BI score. If an interaction term was not significant, the analysis was repeated using a model including only the time dummies and the dichotomous BI score.

The possible confounding effect of age, gender, marital status, level of education and discharge destination on the course of QoL was examined by adding these variables together to the model. These characteristics were considered to be confounders if the coefficient of the time dummies or the dichotomous ADL score respectively changed more than 10% after adding the characteristics to the model. If not, they were left out of the analyses. P-values of  $< .05$  were considered to be statistically significant. GEE analyses were carried out using STATA, version 12.0.

## Results

A total of 395 stroke patients were included in the Restore4Stroke Cohort study. Three hundred and forty three patients participated in the assessments two months post stroke (86.8%), 344 at six months post stroke (87.1%), 326 at one year post stroke (82.5%), and 310 at two years post stroke (78.5%). A total of 368 patients completed at least one measurement with QoL data and were included in the analyses (93.2%).

Table 3.1 presents patients' characteristics for the total patient group and for patients who were dependent and independent in ADL 4 days post stroke, separately. Mean age at stroke onset was 66.8 (SD 12.3) years, and 64.4% of the patients were male. Four days post stroke, the mean BI score was 16.9 (SD 4.8) and 32.6% of the patients were dependent in ADL. Furthermore, 70.9% of the patients had been discharged directly home from the hospital. A comparison between patients who were dependent and independent in ADL showed that the patients dependent in ADL were older, had a partner less often, suffered a more severe stroke, and were more often discharged to inpatient rehabilitation.

**Table 3.1 Patients' characteristics (N = 368)**

	Total group (N = 368)	BI ≤ 17 (n = 120)	BI > 17 (n = 248)
<b>Demographic factors</b>			
Sex (male)	64.4	60.8	66.1
Age in years	66.8 ± 12.3	70.3 ± 12.6	65.1 ± 11.9*
Marital status, living together	69.3	60.8	73.4*
High education level <sup>a</sup>	27.2	23.3	29.0
<b>Stroke-related factors</b>			
Ischemic stroke	92.9	91.7	93.5
Left hemisphere	40.8 <sup>b</sup>	30.8	45.7
Severity of stroke four days post stroke	2.7 ± 3.2	4.7 ± 4.3	1.8 ± 1.9*
No stroke symptoms (NIHSS 0)	24.5	10.8	31.0
Minor stroke symptoms (NIHSS 1–4)	56.2	47.5	60.5
Moderate stroke symptoms (NIHSS 5–12)	17.1	35.0	8.5
Moderate to severe stroke symptoms (NIHSS ≥ 13)	2.2	6.7	0.0
ADL four days post stroke	16.9 ± 4.8	11.2 ± 4.6	19.6 ± 0.7*
Cognitive functioning two months post stroke	23.6 ± 4.0 <sup>c</sup>	23.0 ± 4.1 <sup>d</sup>	23.8 ± 3.9 <sup>e</sup>
Cognitively impaired (MoCA ≤ 25)	67.5	72.4	65.4
<b>Destination after discharge from hospital</b>			
Home	70.9	32.5	89.5*
Rehabilitation	29.1	67.5	10.5

NOTE. Values are percentages or mean ± SD.

<sup>a</sup> Completed University of Professional Education and higher.

<sup>b</sup> n = 363; <sup>c</sup> n = 345; <sup>d</sup> n = 105; <sup>e</sup> n = 240.

\* Significant difference between the patients dependent and independent in ADL 4 days post stroke.

Abbreviations: NIHSS, National Institutes of Health Stroke Scale; ADL, Activities of daily living; BI, Barthel Index; MoCA, Montreal Cognitive Assessment.

## Course of HRQoL

GEE analyses showed no statistically significant interaction effects between time and ADL dependency for all four QoL measures. In the subsequent analyses without the interaction terms significant differences between the two ADL groups were found ( $p \leq .001$ ). Thus, it was decided to analyze the two ADL groups independently in addition to analyses performed on the total population. The possible confounders were therefore analyzed separately in the patient groups dependent and independent in ADL.

Table 3.2 presents descriptive statistics of QoL at each measurement and Table 3.3 presents the course of QoL for the total patient group separately for patients who were independent in ADL and patients who were dependent in ADL. No confounding effect was found after

**Table 3.2** Descriptive statistics of quality life at each measurement separately for patients dependent (N = 120) and independent (N = 248) in ADL 4 days post stroke (mean  $\pm$  SD)

	2m post stroke	6m post stroke	1y post stroke	2y post stroke
ADL dependent (N = 120)	n = 105–106	n = 112	n = 109–111	n = 98–101
SS-QoL-12	3.6 $\pm$ .9	3.7 $\pm$ .8	3.7 $\pm$ .8	3.7 $\pm$ .9
HADS	10.4 $\pm$ 7.1	11.3 $\pm$ 7.1	11.3 $\pm$ 6.7	12.0 $\pm$ 7.8
USER-Participation-R	62.2 $\pm$ 23.1	68.1 $\pm$ 23.0	70.6 $\pm$ 21.3	70.0 $\pm$ 24.0
2LS	6.9 $\pm$ 2.2	6.8 $\pm$ 2.1	6.7 $\pm$ 2.1	6.9 $\pm$ 2.4
ADL independent (N = 248)	n = 234–238	n = 232–233	n = 216–220	n = 219–221
SS-QoL-12	4.1 $\pm$ .8	4.2 $\pm$ .7	4.2 $\pm$ .8	4.1 $\pm$ .8
HADS	8.9 $\pm$ 7.2	8.8 $\pm$ 7.0	8.6 $\pm$ 6.7	9.3 $\pm$ 7.3
USER-Participation-R	78.0 $\pm$ 20.1	82.0 $\pm$ 18.7	83.5 $\pm$ 19.0	83.7 $\pm$ 21.2
2LS	7.6 $\pm$ 2.0	7.8 $\pm$ 2.0	8.2 $\pm$ 1.9	7.9 $\pm$ 2.2

\* 2m: 2 months (T2); 6m: 6 months (T3); 1y: 1 year (T4); 2y: 2 years (T5).

\*\* higher scores on the SS-QoL-12, USER-Participation-R, and 2LS means better outcome. Higher scores on the HADS means worse outcome.

Abbreviations: ADL, activities of daily living; SS-QoL-12, short stroke-specific Quality of Life Scale; HADS, Hospital Anxiety and Depression Scale; USER-Participation-R, participation restrictions subscale of the Utrecht Scale for Evaluation of Rehabilitation-Participation; 2LS, 2 Life Satisfaction questions.

adding age, gender, marital status, level of education and discharge destination to the two separate models.

The score on the SS-QoL-12 increased between two and six months post stroke for both the total group ( $p < .001$ ) and for both groups separately (dependent  $p = .009$ ; independent  $p = .002$ ) (Figure 3.1). The score on the HADS did not change between two months and two years post stroke for both the total group and for both groups separately (Figure 3.2). The total patient group and the patient group independent in ADL showed an increase on the USER-Participation restrictions, meaning that they experienced fewer restrictions, between two and six months post stroke ( $p < .001$ ) (Figure 3.3). Furthermore, patients who were dependent in ADL four days post stroke showed an increase on the USER-Participation-R between two months and one year post stroke (two to six months post stroke,  $p = .001$ , and six to twelve months post stroke,  $p = .031$ ). The score on the 2LS showed an increase for the total patient group between six and twelve months post stroke ( $p = .018$ ) (Figure 3.4). The patient group independent in ADL showed an increase from two months up to twelve months post stroke (two to six months post stroke,  $p = .020$ , and six to twelve months post stroke,  $p = .003$ ). On the other hand, no increase on the 2LS was found for the patient group dependent in ADL.

**Table 3.3** GEE analyses for the course of quality of life from 2 months up to 2 years post stroke for the total group (N = 368) and separately for patients dependent (n = 120) and independent (n = 248) in ADL 4 days post stroke

Variables	Model for SS-QoL-12			Model for HADS			Model for USER-Participation-R			Model for 2LS		
	B	SE	p	B	SE	p	B	SE	p	B	SE	p
<b>Total group (N = 368)</b>												
Constant	3.56	.07		10.95	.58		62.4	1.88		6.6	.18	
Time (T3-T2)	<b>.14</b>	<b>.03</b>	<b>&lt; .001</b>	.14	.29	.622	<b>5.04</b>	<b>.99</b>	<b>&lt; .001</b>	.17	.11	.113
Time (T4-T3)	-.01	.03	.751	-.06	.26	.826	<b>2.29</b>	<b>.86</b>	<b>.008</b>	<b>.23</b>	<b>.10</b>	<b>.018</b>
Time (T5-T4)	-.03	.03	.402	.49	.29	.089	-.84	.90	.352	-.11	.10	.274
BI (dependent)	<b>.47</b>	<b>.08</b>	<b>&lt; .001</b>	<b>-2.18</b>	<b>.68</b>	<b>.001</b>	<b>14.6</b>	<b>2.06</b>	<b>&lt; .001</b>	<b>1.05</b>	<b>.20</b>	<b>&lt; .001</b>
<b>ADL dependent (n = 120)</b>												
Constant	3.53	.08		10.36	.66		60.80	2.23		6.85	.21	
Time (T3-T2)	<b>.19</b>	<b>.07</b>	<b>.009</b>	.97	.55	.077	<b>6.52</b>	<b>2.02</b>	<b>.001</b>	-.11	.20	.569
Time (T4-T3)	-.04	.06	.508	-.09	.46	.839	<b>3.86</b>	<b>1.79</b>	<b>.031</b>	-.01	.17	.953
Time (T5-T4)	.01	.07	.855	.46	.60	.445	-2.04	1.95	.295	.14	.19	.459
<b>ADL independent (n = 248)</b>												
Constant	4.05	.05		9.03	.46		77.64	1.308		7.51	.13	
Time (T3-T2)	<b>.11</b>	<b>.04</b>	<b>.002</b>	-.23	.34	.505	<b>4.40</b>	<b>1.10</b>	<b>&lt; .001</b>	<b>.30</b>	<b>.13</b>	<b>.020</b>
Time (T4-T3)	<.01	.04	.936	-.05	.32	.885	1.46	.92	.113	<b>.35</b>	<b>.12</b>	<b>.003</b>
Time (T5-T4)	-.05	.04	.230	.51	.31	.105	-.19	.96	.840	-.24	.13	.055

\* T2: 2 months post stroke; T3: 6 months post stroke; T4: 1 year post stroke; T5: 2 years post stroke.

Abbreviations: B, unstandardized coefficient; SE, standard error; ADL, activities of daily living; BI: Barthel Index; SS-QoL-12, short stroke-specific Quality of Life Scale; HADS, Hospital Anxiety and Depression Scale; USER-Participation-R, participation restrictions subscale of the Utrecht Scale for Evaluation of Rehabilitation-Participation; 2LS, 2 Life Satisfaction questions.

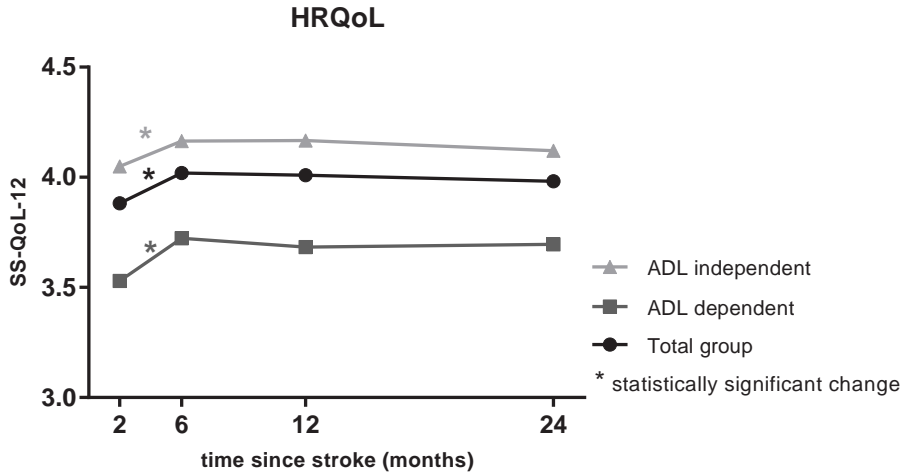


Figure 3.1 The course of HRQoL.

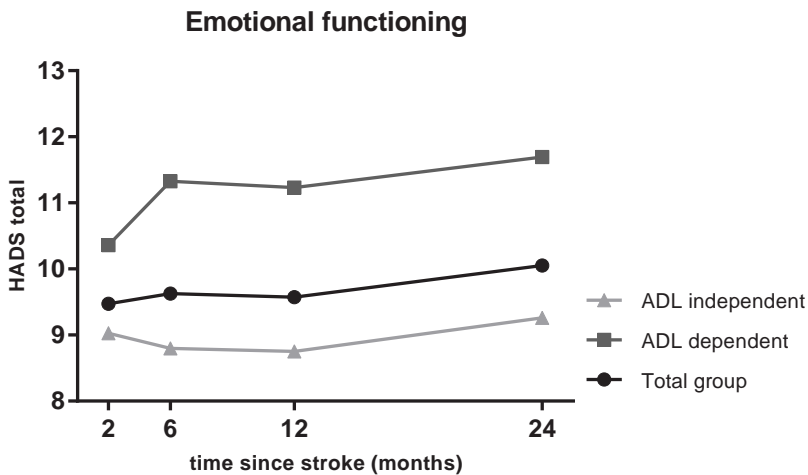


Figure 3.2 The course of emotional functioning.

## Discussion

The present study showed a general improvement of QoL from two months up to two years post stroke and patients independent in ADL consistently scored higher on all four QoL domains. Changes only occurred during the first year and mostly during the first six months post stroke. This is largely in agreement with the assumed time frame for functional recovery after stroke, which involves most of the functional recovery taking place in the first six months post stroke.<sup>38,39</sup>

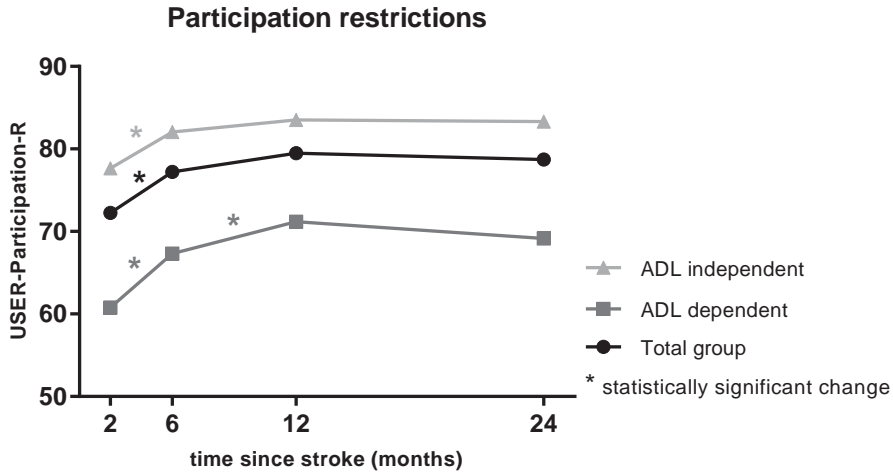


Figure 3.3 The course of participation restrictions.



Figure 3.4 The course of life satisfaction.

It is, however, remarkable that we found this same time frame for recovery in QoL. We assume that adaptation post stroke is a continuous process that stretches over a longer period that begins when the patient starts to realize that there will be no full recovery of functioning, despite rehabilitation efforts in the first 3–6 months.<sup>40</sup> A possible explanation is that in the present study even the ADL dependent patients were on average only moderately dependent in ADL four days post stroke and had already regained functioning in terms of ADL in the first few weeks post stroke. Additional analysis (not presented in the results) showed that two months post stroke, only 10% of the patients were dependent in ADL in

comparison to 33% of the patients four days post stroke. Furthermore, even though on average these patient groups showed no further signs of recovery one year after stroke, it is plausible that on an individual level, patients still show signs of recovery or decline. For example, a study on mobility found that between one and three years post stroke, a decline in mobility occurred in 21% of the patients, and approximately 7% of the patients had improved mobility.<sup>41</sup> Furthermore, another study found individual variation in the experience of depressive symptoms in the first years post stroke while the percentage of patients experiencing depressive symptoms during these years stayed relatively the same.<sup>42</sup>

Looking at the different domains, we do see differences in the course of QoL. HRQoL, participation restrictions and life satisfaction showed improvement over time, whereas emotional functioning did not. The stable levels of emotional functioning found in the present study, were in accordance with a recent study in which stability of depression was found during the first 18 months post stroke.<sup>16</sup> Emotional functioning is strongly related with psychological factors, such as neuroticism and passive coping,<sup>43,44</sup> and personality factors such as neuroticism are assumed to remain relatively stable throughout life.

In the patient group independent in ADL, life satisfaction increased up to one year post stroke and remained stable after that. In other research, it was also found that life satisfaction improved up to one year post stroke. Furthermore, this study found that once life satisfaction was restored, it remained stable, and poor life satisfaction at one year post stroke remained poor for the subsequent years.<sup>23</sup> Most studies investigating general HRQoL with a follow-up period up to six months post stroke found an improvement in HRQoL.<sup>9-11</sup> The results from these studies are largely in accordance with results from the present study. Improvement in participation, however, was seen for a longer period, especially in the group of ADL dependent patients. This may reflect the adaptation process, which needs more time from those patients who spend the most time and energy in improving daily activities in the first months post stroke; increasing levels of participation will follow later in those patients.

## **Strengths and limitations**

The present study has several strengths. First, a large group of patients (N = 368) was examined in a longitudinal design with repeated assessments up to two years post stroke. Second, results were analyzed with an advanced statistical technique; this allowed patients with at least one completed assessment to be included in the analyses, meaning that more patients were included in the analyses. Third, we investigated QoL from a broad perspective, measuring four domains of QoL.



The following limitations should be taken into account. The first assessment of QoL took place at two months post stroke; therefore we did not have information about changes in QoL in the first two months post stroke. Furthermore, most patients in the present study suffered a minor stroke, which limits the validity of our results for this population. Consequently, a lower number of patients in the present study were part of the patient group dependent in ADL in the acute phase post stroke, making it more difficult to find significant changes over time for this patient group.

## Conclusion

In general, most improvement in QoL takes place up to six months post stroke and shows different patterns for the specific QoL domains and for patients with and without dependency in ADL in the first week post stroke. It is therefore important to differentiate between the course of these different QoL domains when the long-term perspective is considered. Furthermore, patients dependent in ADL consistently scored lower on all QoL domains and did not reach the level of QoL of patients independent in ADL.

## Acknowledgement

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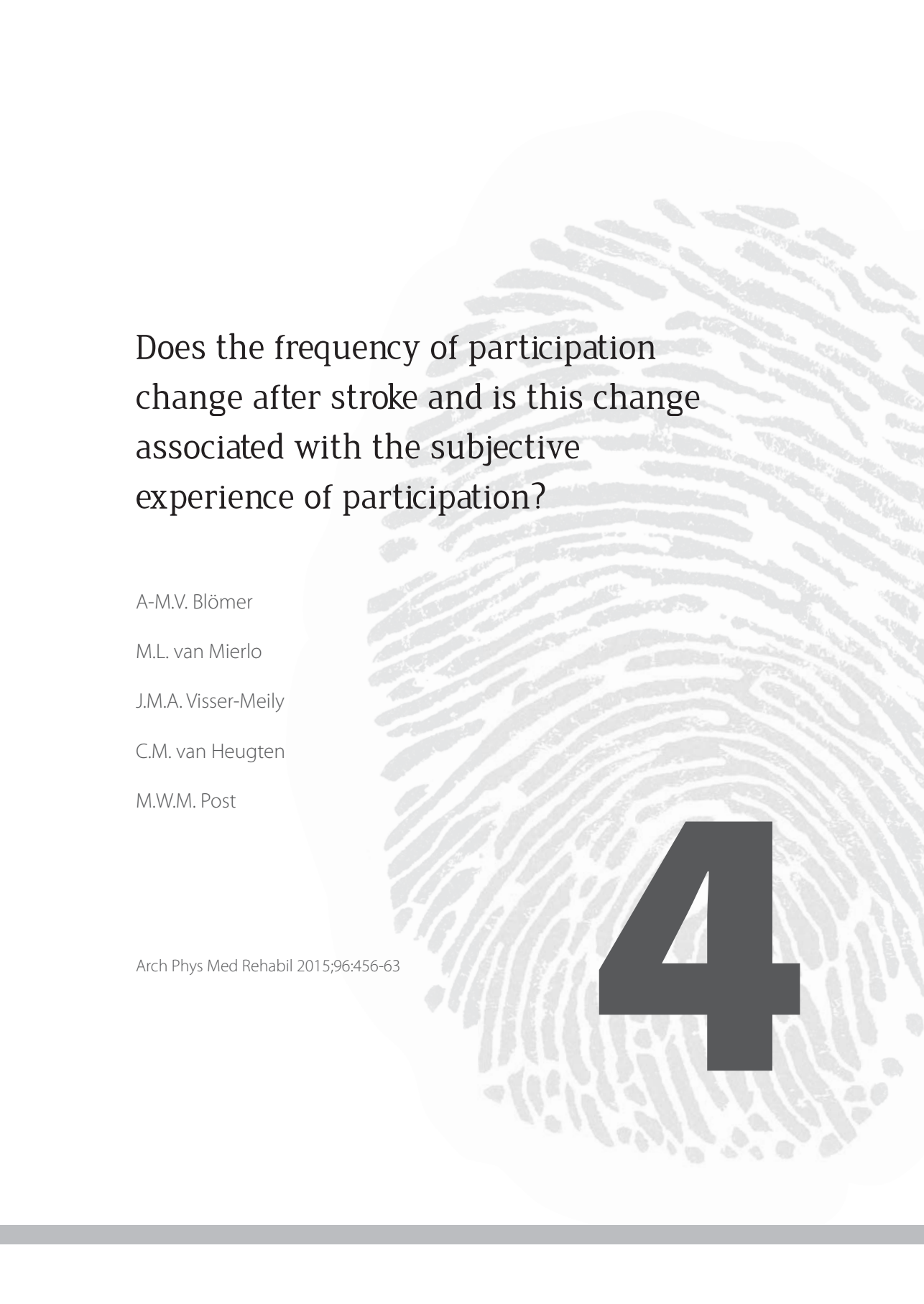
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# Does the frequency of participation change after stroke and is this change associated with the subjective experience of participation?

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**4**

## Abstract

### Objective

To investigate changes in the frequency of participation six months post stroke compared with prestroke; and to establish whether the change is associated with participation restrictions and satisfaction with participation six months post stroke.

### Design

Inception cohort study. Prestroke frequency of participation was measured retrospectively in the first week post stroke. Frequency, participation restrictions and satisfaction with participation were assessed six months post stroke.

### Setting

General hospitals and home residences.

### Participants

Patients with stroke (N = 325; 65.5% men; mean age  $66.9 \pm 12.2$  years) admitted to one of six participating general hospitals.

### Interventions

Not applicable.

### Main outcome measure

Utrecht Scale for Evaluation of Rehabilitation-Participation (0–100), which consists of three scales: frequency, restrictions and satisfaction. The frequency scale consists of two parts: vocational activities (work, volunteer work, education, household activities) and leisure and social activities.

### Results

Vocational activities showed a large decrease (effect size: .6) and leisure and social activities showed a small decrease (effect size: .13) post stroke. In multiple regression analyses, both the frequency of participation in vocational activities six months post stroke and the decrease in vocational activities compared with before the stroke were significantly associated with the participation restrictions experienced and satisfaction with participation after controlling for age, sex, level of education, dependency in activities of daily living, cognitive functioning, and presence of depressive symptoms. The presence of depressive symptoms showed the strongest association with the subjective experience of participation.

### Conclusions

The frequency of participation decreased after a stroke and this decrease was associated with participation restrictions experienced and satisfaction with participation. Resuming vocational activities and screening and, if applicable, treatment of depressive symptoms should be priorities in stroke rehabilitation.



## Introduction

Stroke is a major health problem worldwide.<sup>1</sup> The various physical, cognitive, behavioral and emotional problems associated with stroke can negatively affect participation in daily life.<sup>2-7</sup> Because participation is one of the main priorities in rehabilitation care, it is important to measure rehabilitation outcomes in terms of participation.

In the International Classification of Functioning, Disability and Health (ICF), participation in daily life is defined as involvement in a life situation.<sup>8</sup> Participation is a broad concept with an objective and a subjective dimension.<sup>9-12</sup> The objective dimension concerns observable actions and behaviors (e.g. amount or frequency of participation), whereas the subjective dimension reflects someone's experiences and feelings about participation (e.g. restrictions, satisfaction).<sup>9-12</sup> The objective and subjective dimensions are only weakly related; therefore it is important to measure both.<sup>11-13</sup>

Several studies have investigated poststroke participation by assessing only the objective dimension or both the objective and subjective dimension, using various measures.<sup>5,7,13-18</sup> Because one of the main goals of rehabilitation care is to minimize participation restrictions caused by stroke and to help patients return to their pre-injury level of participation, it is important to assess a person's prestroke functioning.<sup>17</sup> Of the studies that investigated participation, only a few focused on both pre- and poststroke participation. These studies found a decrease in the frequency of participation post stroke compared with before the stroke.<sup>5,7,14,15,19</sup>

It is likely that such a decrease is associated with participation restrictions that patients experienced and less satisfaction with participation post stroke. To our knowledge, however, this association has not been investigated previously. It is unknown whether subjective experiences of poststroke participation are more strongly associated with the frequency of participation post stroke or with the difference between the prestroke and poststroke frequency of participation.

The overall aims of this study were therefore to investigate whether a stroke contributes to changes in the frequency of participation and whether a change in the frequency of participation after stroke is associated with the restrictions experienced and satisfaction with participation. This association was corrected for age, sex, level of education, dependency in activities of daily living (ADL), cognitive functioning, presence of depressive symptoms, and poststroke frequency of participation because previous studies found associations between these variables and participation.<sup>5,7,13,14,16</sup> We hypothesized that

patients would participate less after a stroke and that both restrictions experienced and satisfaction with participation would be associated with the decrease in the frequency of participation.

## Methods

### Design and procedure

The present study is part of the longitudinal cohort study called Restore4Stroke.<sup>20</sup> The present study used data collected at stroke onset and six months post stroke. Patients at the stroke units of six general hospitals in the Netherlands were invited to participate.<sup>20</sup> The first assessment was conducted during the first week post stroke. Information on stroke-related factors was collected from medical files by the nurse practitioner of the hospital. Information on demographic factors and prestroke frequency of participation were obtained from the patient or family members.

At six months post stroke, a follow-up assessment was conducted by a trained research assistant at the patient's place of residence. The study was approved by the medical ethics committee of the St. Antonius hospital in Nieuwegein (The Netherlands) and by the medical ethics committees of the other participating hospitals. All patients gave informed consent.<sup>20</sup>

### Participants

Patients were enrolled in the Restore4Stroke Cohort study within the first seven days after stroke. Patients were included if they had suffered a stroke (ischemic or intracerebral hemorrhagic lesion) and were at least 18 years of age. Patients were excluded if they had another serious condition that could interfere with the study outcome; had been dependent in basic ADL before the stroke occurred, defined as a Barthel Index (BI)<sup>21</sup> score of  $\leq 17$ ; had insufficient command of the Dutch language, based on clinical judgment; or had suffered cognitive decline prior to the stroke, defined by a score of  $\geq 1$  on the Heteroanamnesis List Cognition.<sup>22</sup> Our analyses also excluded patients with incomplete participation data.

## Measures

### *Dependent variable: participation*

Utrecht Scale for Evaluation of Rehabilitation – Participation (USER-Participation) is a self-report questionnaire consisting of three scales: frequency of participation, participation restrictions experienced, and satisfaction with participation. The frequency scale measures the objective level of participation, whereas the restrictions and satisfaction scales provide information about the subjective rating of participation. It is a valid and reliable generic instrument to measure participation and has been used in patients with stroke in previous studies.<sup>11,13,23</sup>

The frequency scale consists of 11 items. Part A (vocational activities) measures the number of hours in a regular week spent on paid work, unpaid work, education and housekeeping, on a scale from 0 (none at all) to 5 ( $\geq 36$  hours). The 7 items in part B (leisure and social activities) measure the frequency of sports and physical exercise, going out, making day trips, leisure activities at home, visiting family or friends, receiving visits from family or friends, and contact by computer or telephone during the last four weeks. The item scores range from 0 (not at all) to 5 ( $\geq 19$  times).

The restrictions scale consists of 11 items on difficulties experienced with vocational, leisure, and social activities. This scale asks patients to rate the severity of the restrictions of participation caused by the stroke. Scores range from 0 (not possible to perform) to 3 (performed without difficulty). A score of not applicable is recorded if the patient does not perform the activity for reasons other than stroke.

The satisfaction scale consists of 10 items about satisfaction with vocational, leisure and social activities. Scores range from 0 (very dissatisfied) to 4 (very satisfied). Not applicable can be chosen in two items: if patients do not perform any vocational activities or if they do not have a partner.

All scales yield a sum score ranging from 0 to 100, with a higher score indicating a higher level of participation, meaning a higher frequency, less restrictions experienced, and more satisfaction.<sup>11,20</sup> The frequency scale of the USER-Participation was used within the first week after stroke onset to collect information about the patients' frequency of participation in the four weeks before the stroke. After six months, all three scales were administered.

***Independent variables: demographic and stroke-related factors***

Information about sex, age and level of education were collected. Level of education was classified according to criteria developed by Verhage,<sup>24</sup> and dichotomized into low (up to completed secondary education) or high (completed University of Professional Education or higher).<sup>25</sup> Information on the type of stroke and the hemisphere involved were obtained from medical charts. The severity of the stroke was assessed with the National Institutes of Health Stroke Scale (NIHSS),<sup>26</sup> administered four days post stroke.

ADL dependency was measured with the BI, which includes items such as personal care, dressing and undressing, and climbing stairs. This measure is valid and reliable for patients with stroke.<sup>21,27</sup> Scores range from 0 to 20 and patients with a score  $\leq 17$  were considered dependent. The BI was administered at four days and six months post stroke. The analyses used the BI score at six months.

Cognitive functioning was assessed with the Montreal Cognitive Assessment,<sup>28</sup> a brief cognitive screening tool suitable for use in patients with stroke. The measure is valid and reliable. Scores range from 0 to 30, and patients with a score  $\geq 26$  are considered to have no cognitive problems.<sup>28,29</sup>

The depression subscale of the Hospital Anxiety and Depression Scale was used to assess the presence of depressive symptoms.<sup>30</sup> Scores range from 0 to 21, and patients with a score  $\geq 8$  are considered to experience depressive symptoms.<sup>30,31</sup>

**Statistical analyses**

All analyses of data were conducted with IBM SPSS Statistics 20. A significance level of  $p < .05$  was established. Descriptive statistics were used to provide information about the study population and the outcome variables. Variables were checked for the assumption of normality, using scatterplots and quantile-quantile plots. One-way analyses of variance and chi-square tests were performed to evaluate differences in baseline characteristics between patients and drop-outs and patients with incomplete datasets. Paired t-tests were used to determine significant differences in the frequency of participation before and after stroke. Effect sizes were calculated to examine which part of the frequency scale (ie, vocational or leisure and social) contributed most to a change in the frequency of participation.<sup>32</sup> Wilcoxon signed-rank tests were used to analyze differences for each item on the frequency scale between the prestroke situation and six months post stroke.

Two backward multiple linear regression analyses were performed to investigate the relationship between the poststroke frequency of participation and the change in this frequency after stroke on the one hand, and restrictions experienced of and satisfaction about participation on the other hand, controlling for various covariates (ie, age, sex, level of education, ADL dependency, cognitive functioning, presence of depressive symptoms). The significance level to remove variables from the model was set at  $p > .10$ .

## Results

A total of 395 patients were enrolled in the Restore4Stroke study. As shown in Figure 4.1, datasets of 325 patients were complete and were used in the analyses. Of the 36 incomplete datasets, three were incomplete because of aphasia. Patient characteristics are displayed in Table 4.1. There were no significant differences in terms of baseline characteristics between patients and drop-outs and patients with incomplete datasets. However, drop-outs and patients with incomplete datasets were significantly more likely to have a higher score on the NIHSS and BI four days post stroke (Table 4.1).

Mean scores of the USER-Participation are displayed in Table 4.2. In general, the frequency score for vocational, and leisure and social activities on the USER-Participation scale had decreased significantly six months after the stroke compared with before the stroke (-4.8

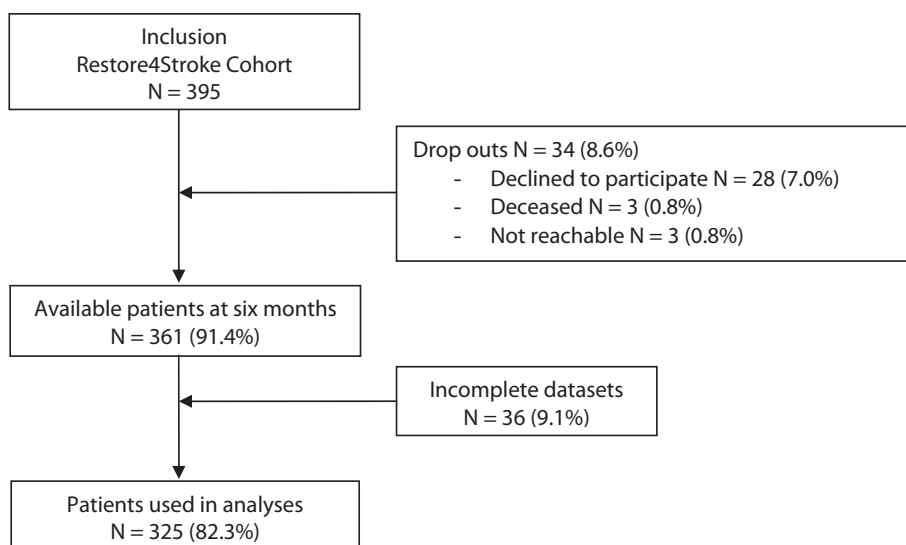


Figure 4.1 Flow chart of participating patients.

**Table 4.1 Patients' characteristics (N = 395)**

Characteristic	Patients (N = 325)	Drop-outs and patients with incomplete datasets (N = 70)
Sex (female)	34.5	38.6
Age in years	66.9 ± 12.2	65.4 ± 14.7
High education level <sup>a</sup>	27.7	20.3 <sup>b</sup>
Ischemic stroke	92.9	94.3
Stroke hemisphere (n = 321)		
Left	38.6	50.0 <sup>c</sup>
Right	44.6	35.3
Cerebellum or brainstem	16.8	14.7
Severity of stroke (NIHSS)*	2.5 ± 2.8	4.1 ± 4.5
No stroke symptoms (NIHSS 0)	24.9	18.6
Minor stroke symptoms (NIHSS 1–4)	57.9	47.1
Moderate stroke symptoms (NIHSS 5–12)	16.0	27.2
Moderate to severe stroke symptoms (NIHSS ≥ 13)	1.2	7.1
Destination after discharge from hospital		
Home	72.6	60.0
Rehabilitation center	13.2	22.9
Nursing home	14.2	17.1
Living situation 6m post stroke		
Home	95.1	-
Rehabilitation center	0.3	-
Nursing home	4.6	-
ADL (BI)		
4d post stroke*	17.1 ± 4.5	15.5 ± 6.0
6m post stroke	19.4 ± 1.5	-
Cognitive functioning six months post stroke (MoCA)	24.6 ± 3.5	-
Depression six months post stroke (HADS-D)	4.7 ± 4.0	-

NOTE. Values are percentages or mean ± SD.

Abbreviations: NIHSS, National Institutes of Health Stroke Scale; ADL, Activities of Daily Living; BI, Barthel Index; MoCA, Montreal Cognitive Assessment; HADS-D, Depression scale of the Hospital Anxiety and Depression Scale; d, days; m, months.

<sup>a</sup> Patients completed higher professional education or have an university degree; <sup>b</sup> n = 59; <sup>c</sup> n = 68.

\* p < .05.

± 10.8; p < .001). However, the change score ranged from -36.1 to 21.8, indicating that some patients scored higher on the frequency scale after their stroke than before it (32.9%). Furthermore, 0.9% of the patients showed no change and 66.2% of the patients showed a decrease in their frequency of participation. The frequency of vocational activities (part A) decreased more than the frequency of leisure and social activities (part B) (Table 4.2). The frequency of vocational activities decreased in 59.4% of the patients, remained unchanged

**Table 4.2 Mean scores on the three scales of USER-Participation (N = 325) and calculated effect sizes**

Scale	Before the stroke	Six months Post stroke	Difference	Effect size
Total score on Frequency scale	33.4 ± 10.7	28.6 ± 10.8	-4.8 ± 10.8**	.45
Part A: Vocational activities	21.0 ± 12.6	13.4 ± 9.9	-7.6 ± 11.4**	.60
Part B: Leisure and social activities	45.9 ± 16.2	43.8 ± 16.7	-2.1 ± 17.5*	.13
Restrictions scale	NA	78.0 ± 21.0	NA	NA
Satisfaction scale	NA	66.7 ± 17.2	NA	NA

NOTE. The scores on the frequency scale are shown both for the total score and for individual parts A and B. Values are mean ± SD or as otherwise indicated.

Abbreviation: NA, not applicable.

\*  $p < .05$ ; \*\*  $p < .001$ .

in 27.4% and increased in 13.2%. The frequency of leisure and social activities decreased in 49.5% of the patients, remained unchanged in 8% and increased in 42.5%.

Scores on the four individual items in part A of the frequency scale showed a significant reduction six months post stroke compared with the prestroke situation; the largest changes were found for performing paid work and household activities. One item of the leisure activities (part B) showed a significant increase post stroke (i.e. sports and physical exercise). Two of the social activity items (i.e. visiting family or friends and contact by telephone or computer) showed significant decreases post stroke (Table 4.3).

## Experienced restrictions and satisfaction

The mean scores for experienced restrictions and satisfaction at six months post stroke were  $78.0 \pm 21.0$  and  $66.7 \pm 17.2$ , respectively. More than 50% of the patients mentioned restrictions regarding paid work (67.2%), sports and physical exercise (56.5%), household tasks (54.9%), daytrips (51.8%), and going out (51.4%). More than 40% of the patients were not satisfied with their frequency of daytrips (50.8%), sports and physical exercise (49.8%), going out (49.8%), outdoor mobility (41.2%), and household tasks (40.1%).

## Relationship between objective and subjective participation

The changes in frequency for the individual parts of the frequency scale (Table 4.2) indicate that the decrease was greater and the effect size was larger for part A (vocational activities). Therefore, the linear regression analyses were performed with the two parts of the frequency scale as separate independent variables.

**Table 4.3** Frequency scale of USER-Participation: hours and number of times for each item before stroke and six months post stroke (N = 325)

<b>PART A: Vocational activities</b>			
Hours spent per week, per item	Patients before stroke (%)	Patients post stroke (%)	p-value*
<b>Paid work</b>			
None at all	61.7 <sup>a</sup>	76.0	< .001
1–24 hours	10.5 <sup>a</sup>	15.1	
≥ 25 hours	27.8 <sup>a</sup>	8.9	
<b>Unpaid work</b>			
None at all	67.1	77.8	< .001
1–24 hours	31.1	21.6	
≥ 25 hours	1.8	0.6	
<b>Education</b>			
None at all	94.1 <sup>b</sup>	97.5 <sup>a</sup>	.011
1–24 hours	5.3 <sup>b</sup>	2.5 <sup>a</sup>	
≥ 25 hours	0.6 <sup>b</sup>	0 <sup>a</sup>	
<b>Household activities</b>			
None at all	4.9	10.8	< .001
1–24 hours	79.4	82.4	
≥ 25 hours	15.7	6.8	
<b>PART B: Leisure and social activities</b>			
Number of times engaged in each item in the last four weeks	Patients before stroke (%)	Patients post stroke (%)	p-value*
<b>Sports and physical exercise</b>			
Not at all	21.4 <sup>c</sup>	16.6	.047
1–10 times	48.2 <sup>c</sup>	48.3	
≥ 11 times	30.4 <sup>c</sup>	35.1	
<b>Going out</b>			
Not at all	34.0 <sup>a</sup>	38 <sup>a</sup>	.612
1–10 times	64.5 <sup>a</sup>	60.8 <sup>a</sup>	
≥ 11 times	1.5 <sup>a</sup>	1.2 <sup>a</sup>	
<b>Daytrips</b>			
Not at all	21.6 <sup>a</sup>	25.4 <sup>c</sup>	.231
1–10 times	71.6 <sup>a</sup>	67.8 <sup>c</sup>	
≥ 11 times	6.8 <sup>a</sup>	6.8 <sup>c</sup>	
<b>Leisure activities at home</b>			
Not at all	11.1 <sup>a</sup>	12.0	.353
1–10 times	41 <sup>a</sup>	44.6	
≥ 11 times	47.9 <sup>a</sup>	43.4	
<b>Visiting family or friends</b>			
Not at all	5.9 <sup>c</sup>	10.3 <sup>d</sup>	.027
1–10 times	81.1 <sup>c</sup>	79.7 <sup>d</sup>	
≥ 11 times	13 <sup>c</sup>	10.0 <sup>d</sup>	

Table 4.3 continues on next page



Table 4.3 *Continued*

Number of times engaged in each item in the last four weeks	Patients before stroke (%)	Patients post stroke (%)	p-value*
Receiving visitors			
Not at all	3.1 <sup>c</sup>	5.8	.197
1–10 times	78.7 <sup>c</sup>	79.1	
≥ 11 times	18.2 <sup>c</sup>	15.1	
Contact by computer or telephone			
Not at all	4.6 <sup>c</sup>	8.6	< .001
1–10 times	44.3 <sup>c</sup>	52.3	
≥ 11 times	51.1 <sup>c</sup>	39.1	

NOTE. The answer categories of the USER-Participation frequency scale are combined into three categories in this table.

\* p-values based on Wilcoxon signed-rank test; all categories per item combined.

<sup>a</sup> n = 324;

<sup>b</sup> n = 322;

<sup>c</sup> n = 323;

<sup>d</sup> n = 321.

Experienced restrictions were associated with the frequency of poststroke vocational activities but also with the change in this frequency (Table 4.4). Being a woman, ADL dependency, presence of depressive symptoms, poststroke vocational activities, and change in vocational activities together explained 44% of the variance of participation restrictions experienced six months post stroke.

Satisfaction with participation was also associated with the poststroke frequency of vocational activities and with the change in the frequency of vocational activities (Table 4.5). Being a woman, presence of depressive symptoms, poststroke vocational activities, and change in vocational activities together explained 38.8% of the variance of satisfaction with participation six months post stroke.

An analysis of the total score on the frequency scale, rather than of parts A and B separately, yielded somewhat different results. The frequency of poststroke participation, but not the change in this frequency, was significantly associated with participation restrictions and satisfaction with participation (both  $p < .001$ ).

**Table 4.4 Linear regression analysis: variables explaining restrictions of participation experienced six months post stroke**

Variable	$\beta$	Std $\beta$	p-value
Constant	55.14		< .001
Demographic factors			
Age			-
High education level			-
Sex (female)	-4.27	-.10	.022
Stroke-related factors <sup>a</sup>			
Cognitive functioning (MoCA)			-
ADL dependency (BI)	-19.55	.27	< .001
Presence of depressive symptoms (HADS-D)	-15.68	-.32	< .001
Participation (USER-Participation)			
Change in vocational frequency	.23	.13	.005
Change in leisure and social frequency			-
Vocational frequency post stroke <sup>a</sup>	.57	.27	< .001
Leisure and social frequency post stroke <sup>a</sup>	.10	.08	NS

Abbreviations:  $\beta$ , unstandardized regression coefficient; std  $\beta$ , standardized regression coefficient; MoCA, Montreal Cognitive Assessment; BI, Barthel Index; HADS-D, Depression scale of the Hospital Anxiety and Depression Scale; USER-Participation, Utrecht Scale for Evaluation of Rehabilitation-Participation; NS, not significant; -, variables removed from the analysis using a backward procedure.

<sup>a</sup> Six months post stroke.

**Table 4.5 Linear regression analysis: variables explaining satisfaction about participation six months post stroke**

Variable	$\beta$	Std $\beta$	p-value
Constant	64.27		< .001
Demographic factors			
Age			-
High education level			-
Sex (female)	-3.35	-.09	.035
Stroke-related factors <sup>a</sup>			
Cognitive functioning (MoCA)			-
ADL dependency (BI)			-
Presence of depressive symptoms (HADS-D)	-18.62	-.46	< .001
Participation (USER-Participation)			
Change in vocational frequency	.16	.11	.019
Change in leisure and social frequency			-
Vocational frequency post stroke <sup>a</sup>	.38	.22	< .001
Leisure and social frequency post stroke <sup>a</sup>	.09	.09	NS

Abbreviations:  $\beta$ , unstandardized regression coefficient; std  $\beta$ , standardized regression coefficient; MoCA, Montreal Cognitive Assessment; BI, Barthel Index; HADS-D, Depression scale of the Hospital Anxiety and Depression Scale; USER-Participation, Utrecht Scale for Evaluation of Rehabilitation-Participation; NS, not significant; -, variables removed from the analysis using a backward procedure.

<sup>a</sup> Six months post stroke.

## Discussion

We hypothesized that patients would participate less after a stroke and that a decrease in the frequency of participation would be associated with experiencing more restrictions and less satisfaction. The first hypothesis was confirmed: on average, patients participated substantially less in vocational activities and slightly less in leisure and social activities six months post stroke. The second hypothesis was partially confirmed. Both the change in frequency of vocational activities and the poststroke frequency of vocational activities were significantly associated with subjective experiences. However, change in frequency and the poststroke frequency of leisure and social activities were not significantly associated with subjective experiences. This is one of the first studies to show not only that patients with stroke experience a decrease in participation after stroke, but also that this decrease is independently related to the subjective experience of participation.

Leisure and social activities contributed less to the decrease on the frequency scale than vocational activities. The former types of activity are probably easier to adjust to. For example, sports can be performed with the same frequency but with less intensity. Such adjustments are more difficult to make in paid or unpaid work because of social and other pressures.

Approximately one third of our study population showed a stable or even increased total frequency of participation post stroke. If a decrease regarding one part of the scale (e.g. working fewer hours) is compensated by an increase regarding other items (e.g. increasing social activities), this change leads to a stable or even increased total frequency of participation post stroke compared with the prestroke situation. Besides, for some patients, experiencing a mild stroke might be a wake-up call to change their lifestyle and become more active. Stimulating patients to be active is also a common goal of stroke rehabilitation. A study by Edwards et al. found that 26% of the patients with mild stroke did not show a lower activity level after a stroke compared with before stroke,<sup>14</sup> which is only slightly below the percentage found in our study.

We found that 67.2% of our study population experienced restrictions in performing paid work, whereas other studies reported fewer restrictions regarding this item, ranging from 12% to 45.2%.<sup>13,16,33</sup> This discrepancy might be explained by the timing of our follow-up measurement, (ie, six months post stroke) versus 12 months post stroke in the study by Eriksson et al<sup>16</sup> or by different cut-off points used to dichotomize this variable in these studies.<sup>13,16</sup> The finding that more restrictions were reported for vocational activities than for social activities is also in agreement with a previous study.<sup>33</sup>

In regard to satisfaction, not only was the total score on this scale similar to the findings of previous studies, but the items about which patients were dissatisfied were also the same.<sup>13</sup> Patients were the least dissatisfied about their social contacts, whereas more than one third of the patients were dissatisfied with vocational activities.<sup>5,13,16</sup>

The presence of depressive symptoms showed the strongest association with the experienced restrictions and degree of satisfaction in our study, based on a comparison of the standardized beta weights in Tables 4.4 and 4.5. Other studies also reported the importance of the presence of depressive symptoms in explaining experienced restrictions or satisfaction.<sup>5,13,14,16</sup> It remains unclear, however, whether it is the depressive symptoms which cause a more unfavorable subjective experience of participation or the other way around.

### **Study strengths**

One of the strengths of this study was the large study population, which was recruited at six different hospitals. The prestroke frequency of participation was assessed one week post stroke. Although this is a retrospective assessment, the short time after the stroke may make this assessment more reliable than the retrospective assessments of prestroke participation 6 to 12 months post stroke used in other studies.<sup>5,7,14,15,19</sup> Furthermore, the USER-Participation is a measure assessing multiple dimensions of participation with similar items. Previous studies that assessed both objective and subjective participation used different measures with partly diverging items, hampering the comparison between objective and subjective participation.

### **Study limitations**

A possible limitation of this study is the use of a self-report measure to assess objective participation. Results could have been different if actual participation had been measured in other ways (e.g. by observation or a Global Positioning System).<sup>34</sup> However, observation is not a feasible method, and leisure or social activities performed at home (e.g. receiving visitors) cannot be measured by a Global Positioning System. A second limitation is that the patient's family was allowed to fill out the frequency scale at the first assessment if necessary, which could have led to bias. However, given that this questionnaire measures the objective dimension of participation, this was not expected to produce different answers.

Finally, the proportion of patients in our study who suffered an ischemic stroke (92.9%) was higher than we expected based on population figures (85%).<sup>35,36</sup> One possible explanation for this is that hemorrhagic lesions are generally more severe,<sup>37</sup> which may result in greater

difficulty understanding the instructions for participating in the study and not being able to provide informed consent within one week after the event. Another possible explanation is that patients with hemorrhagic stroke are more often treated in university hospitals, whereas our study included patients from general hospitals.

### **Future research**

Our findings indicate a moderate association between the objective and subjective experience of participation post stroke. The next step would be to study the course of this association over time because a change in the association between objective and subjective participation might occur over time as patients with stroke adapt to their situation in the long term.

### **Clinical message**

The findings of the present study imply that even in a hospital-based sample in which most patients had no or minor stroke symptoms and function independently in ADL, having a stroke is associated with decreased participation and with participation problems. These findings underline the relevance of rehabilitation for this group. Participation is a complex topic comprising different elements regarding various activities. Administration of the USER-Participation instrument can be useful to identify participation problems and establish rehabilitation treatment goals regarding participation.

Depressive symptoms were associated with participation problems, pointing to the value of assessing depressive symptoms in rehabilitation. Poststroke rehabilitation care should focus on a combination of participation resumption post stroke, especially in regard to work and household activities and treatment of depressive symptoms, if applicable.

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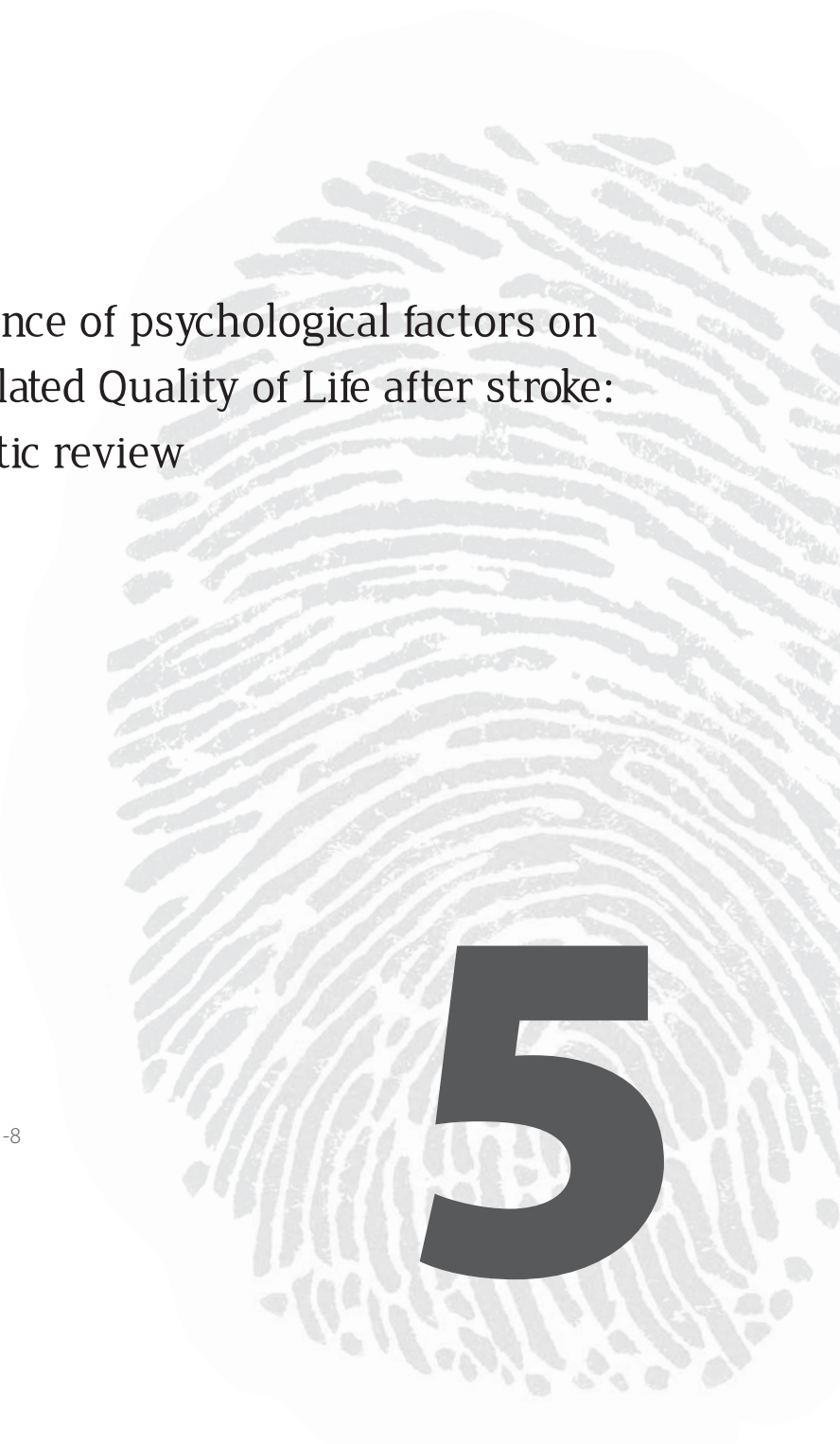




# **PART II**

Influence of psychological  
factors on QoL





# The influence of psychological factors on Health-Related Quality of Life after stroke: a systematic review

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## Abstract

### Background and purpose

Many stroke patients experience problems with health-related quality of life, but much of the variance of health-related quality of life after stroke remains unexplained. Health-related quality of life may be influenced by psychological factors, as these factors reflect the way people approach situations and react to stressful situations. The aim of this study was to systematically examine the relationship between psychological factors and health-related quality of life after stroke.

### Summary of review

A systematic literature search was conducted in online databases PubMed, Embase, PsycINFO, and CINAHL in November 2011. A total of nine studies were included. Personality (i.e. problems of temperament and personality functions, and neuroticism) was moderately negatively associated with health-related quality of life ( $r = .26-.49$ ). Coping (i.e. situational and personal adaptation), internal locus of control, self-worth (i.e. self-esteem and self-efficacy), and hope and optimism were moderately positively associated with health-related quality of life ( $r = .026-.81$ ). No evidence was found for an association between extraversion and health-related quality of life.

### Conclusions

There is still a paucity of studies on psychological determinants of post-stroke health-related quality of life. The reviewed studies supported the importance of psychological factors, but further research is needed to supplement the available evidence and to examine how psychological factors can be modified to improve health-related quality of life, and at what moment after the stroke these interventions should be given.

## Introduction

Stroke is a leading cause of mortality and disability in the Western world and is associated with physical, psychological, and social consequences.<sup>1-3</sup> Major improvements in acute stroke care have resulted in more people surviving after stroke, but many of them have to cope with the consequences<sup>4,5</sup> experiencing long-term difficulties in terms of social reintegration,<sup>4</sup> life satisfaction,<sup>6</sup> physical functioning,<sup>7</sup> and emotional functioning, including depression and anxiety.<sup>8</sup>

The growing number of chronic stroke patients has led to growing interest in the consequences of stroke for health-related quality of life (HRQoL).<sup>3,9-11</sup> HRQoL refers to 'how health impacts on an individual's ability to function and his or her perceived well-being in physical, mental and social domains of life'.<sup>12</sup> HRQoL can be seen as an overarching multidimensional construct, comprising different domains of one's life, such as physical, functional, psychological, and social health.<sup>9</sup>

The most commonly investigated determinants of post-stroke HRQoL are demographic factors, stroke-related factors, and physical impairments. However, they leave much of the variance of HRQoL unexplained.<sup>13,14</sup> Psychological factors may influence functioning and HRQoL,<sup>3</sup> because these factors reflect the way people approach situations and react to stressful situations.<sup>15,16</sup> Psychological factors are part of the contextual factors (personal and environmental factors) defined by the International Classification of Disability, Functioning and Health (ICF).<sup>17</sup>

The importance of psychological factors for HRQoL has already been demonstrated in other chronic conditions,<sup>18,19</sup> but an overview of the influence of psychological factors on the HRQoL of stroke patients is still lacking. The only available review<sup>3</sup> describing the determinants of the HRQoL of stroke patients was not systematic and did not focus on psychological factors alone. Consequently, it missed some of the relevant studies.<sup>20</sup> Hence, the objective of this study was to systematically examine the relationship between psychological factors and HRQoL post stroke.

## Methods

### Eligibility criteria

Studies that met the following criteria were included: (1) more than 50% of the study population had suffered a stroke (ischaemic or intracerebral haemorrhagic lesion); (2) all

patients had to be  $\geq 18$  years; (3) the outcome was HRQoL, assessed with a standardized measure; (4) the determinants studied were one or more psychological factors, assessed with a standardized measure. According to the ICF,<sup>17</sup> we operationalized psychological factors as ‘coping styles, overall behaviour patterns and character style, individual psychological assets and other characteristics, which may play a role in disability at any level, but that are not part of a health condition or health states’ (p.17).

The review was limited to articles written in English (5) that had been published as original reports (6), with quantitative data (7), in peer-reviewed journals (8); we excluded case reports.

### **Search strategy and methodological quality assessment**

Articles were identified by searching the databases PubMed, Embase, CINAHL and PsycINFO on November, 3, 2011. No constraint was placed on the year of publication. The search was conducted in triadic terms, combining a ‘stroke’ domain with a ‘psychological factor’ determinant and a ‘HRQoL’ outcome. Appendix 5.1 provides an overview of the search strategy used in PubMed, compiled together with an information specialist.

After duplicates had been removed, all articles were evaluated based on title and abstract. The remaining articles were then read in full and critically evaluated based on the inclusion and exclusion criteria. Both steps were conducted independently by two authors (MM, CS). In the case of disagreement between the two authors, a third author (JV) was consulted for a final judgement. With regard to the selection of articles based on title and abstract, Cohen’s Kappa was used to calculate concurrence between both authors (MM, CS). The reference lists of the selected articles were also examined to find relevant articles to complement the database search.

The methodological quality of all selected studies was assessed independently by MM and CS. The level of agreement between their ratings was calculated using the Intraclass Correlation Coefficient (ICC). Methodological quality was scored using an 8-point checklist, ranging from (1) lowest quality to (8) highest quality.<sup>18</sup>

### **Data extraction and analysis**

Correlation coefficients and standardized  $\beta$  coefficients were the most frequently reported statistics in the selected articles. We considered correlation coefficients to be weak if they

were below .3, moderate between .3 and .5, and strong above .5.<sup>21</sup> The unique proportion of the variance explained by psychological factors (change in  $R^2$ ) was reported if available.

Psychological factors were classified as consistent determinants if all, or nearly all, bivariate associations reported were statistically significant, and if the majority of these bivariate associations were moderate or strong. Factors were classified as inconsistent if only some of the bivariate associations were statistically significant, or if most of the significant bivariate associations were weak. Factors were considered unrelated to HRQoL if all, or nearly all, bivariate associations were non-significant. The results of multivariate regression analyses were used to examine the robustness of the bivariate associations.

## Results

### Search results and quality assessment

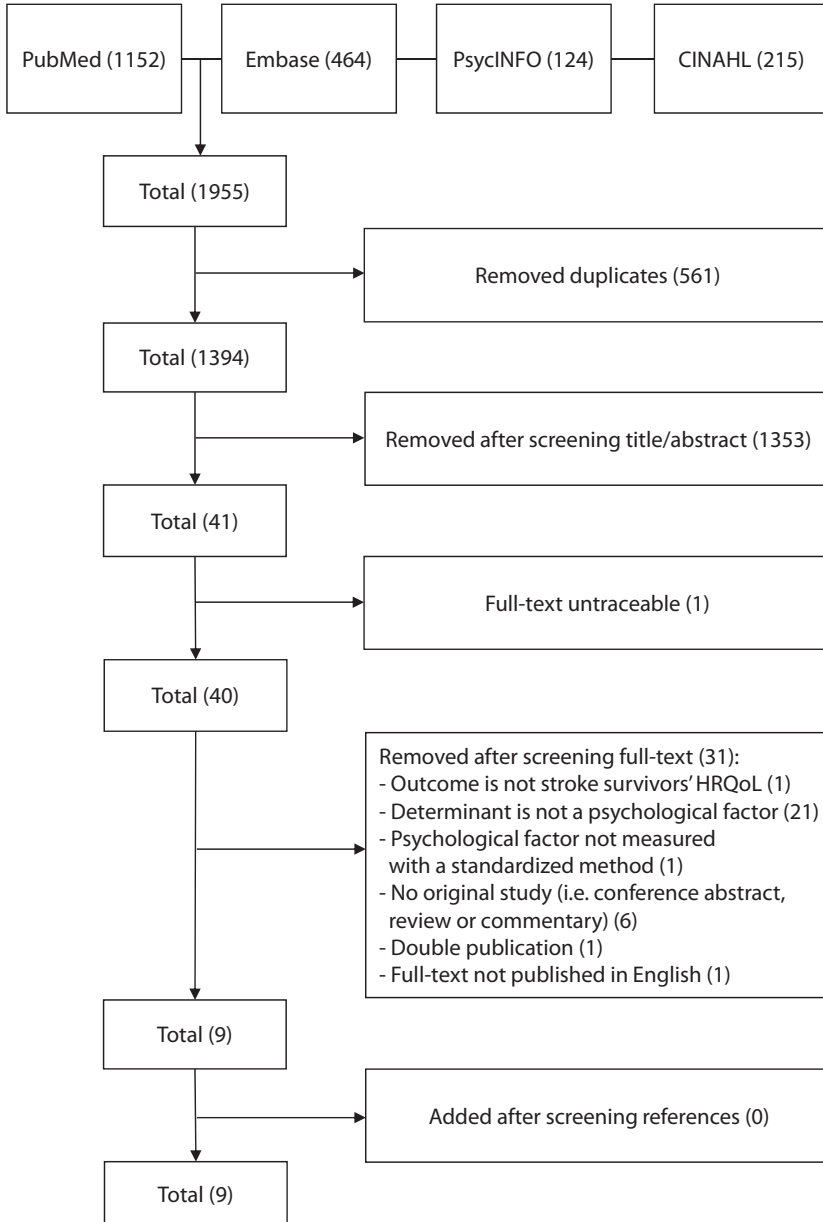
The search strategy yielded 1955 articles (Figure 5.1). After 561 duplicates had been removed, a further 1353 articles were removed after screening titles and abstracts. After the remaining 41 articles had been read in full, 32 more articles were removed. Agreement between the two authors about the selection of titles and abstracts was good (Cohen's kappa = .74). The screening of reference lists of included articles produced no additional articles, leaving a total of nine articles for inclusion in the review.

The characteristics of the nine articles are presented in Table 5.1. All nine articles had been written after 2000 and six of them since 2006. Only two studies had used longitudinal analyses, while six had longitudinal designs. Agreement between the two authors on methodological quality was sufficient (ICC = .66). On an 8-point scale the average methodological quality score was 5.3 (range 3–7). Most studies attained a methodological quality score of between 4 and 6 (Appendix 5.2).

### Psychological factors

A total of six psychological factors were measured: personality, coping, internal locus of control, self-worth, hope, and optimism. The different instruments used to measure these psychological factors are presented in Table 5.2 and the data extraction is presented in Table 5.3. Three articles subdivided HRQoL into mental HRQoL and physical HRQoL.

The relationships between psychological factors and these subdomains are presented in the text, but not in Table 5.3.



**Figure 5.1** Search and selection of eligible articles. HRQoL, health-related quality of life.



Table 5.1 Study characteristics

Author and country of research	Patient group	Participants		Time of assessment(s) Mean $\pm$ SD	HRQoL measure	Psychological measure
		N	Men (%) Mean age $\pm$ SD <sup>a</sup>			
<b>Cross-sectional<sup>P</sup></b>						
Algurén et al., Sweden <sup>11</sup>	Hospital	99	45 72 $\pm$ 13.1	During admission to the hospital, 6w, 3m, and 1yr post stroke	EuroQoL-5D Visual Analogue Scale (EQ-5D VAS)	Temperament and personality item (b126) of the extended version of the ICF Core Set for Stroke
Bluvol & Ford-Gilboe, Canada <sup>20</sup>	Rehabilitation	40	73 69.5 $\pm$ 9.45	2.5yr $\pm$ 1.66 post stroke	Reintegration to Normal Living Index (RNLI)	Herth Hope Index
Darlington et al., The Netherlands <sup>22</sup>	Hospital, rehabilitation centre, and nursing home	80	49 60.9 $\pm$ 16.9	At discharge (median 5.4w since admission), 2m, 5m, and 9–12m after discharge	<ul style="list-style-type: none"> <li>EuroQoL-5D (EQ-5D)</li> <li>Medical Outcomes Study 36-item short form health survey (SF-36)</li> </ul>	<ul style="list-style-type: none"> <li>Assimilative-Accommodative Coping Scale</li> <li>Eysenck Personality Questionnaire – Neuroticism subscale</li> </ul>
Johnstone et al., United States <sup>25</sup>	Hospital	32	47 NR	29m (range 4–180) post stroke	SF-36 subscales: <ul style="list-style-type: none"> <li>General Health perception</li> <li>General Mental health</li> </ul>	Brief multidimensional Measure of Religiousness/Spirituality, subscale religious and spiritual coping
LeBrasseur et al., United States <sup>26</sup>	Community dwelling	31	74 66.2 $\pm$ 1.5	17.5m $\pm$ 1.2 post stroke	Shortened Version of the Sickness Impact Profile (SIP68)	Ewart Self-Efficacy Scale
Robinson-Smith et al., United States <sup>27</sup>	Rehabilitation	63	55 71 (range 36–92)	1m and 6m post stroke	Quality of Life Index-Stroke Version (QLI)	Strategies Used by People to Promote Health

Table 5.1 continues on next page.

**Table 5.1** *Continued*

Author and country of research	Patient group	Participants		Mean age ± SD <sup>a</sup>	Time of assessment(s) Mean ± SD	HRQoL measure	Psychological measure
		N	Men (%)				
Teoh et al., Australia <sup>10</sup>	Community dwelling	135	68	67.5 ± 14.3	Inclusion 11.7m ± 4.9 post stroke Assessments: at inclusion, 10w and 6m after inclusion	<ul style="list-style-type: none"> <li>• Assessment of Quality of Life (AQoL)</li> <li>• Satisfaction with Life Scale (SWLS)</li> <li>• Stroke Impact Scale, physical domain (SIS)</li> </ul>	<ul style="list-style-type: none"> <li>• Life Orientation Test Revised</li> <li>• Rosenberg Self-Esteem Scale</li> <li>• Recovery Locus of Control Scale</li> </ul>
<b>Longitudinal</b> Darlington et al., The Netherlands <sup>24</sup>	Hospital, rehabilitation centre, and nursing home	80	49	60.9 ± 16.9	At discharge (median 5.4w since admission) and 9–12m after discharge	EQ-5D	Assimilative-Accommodative Coping Scale
Li et al., China <sup>23</sup>	Hospital	121	52	60.4 ± 8.1	1w before discharge from hospital (mean 37.9d post stroke) and 1yr after discharge	General Quality of Life Inventory (GQOLI), physical and mental health dimension	Eysenck Personality Questionnaire – Neuroticism and extraversion subscale

<sup>a</sup> Mean age combined with standard deviation (SD) was considered as preferable. If this is not reported, then the range is given.

<sup>b</sup> The studies of Alguren et al., Darlington et al., Robinson-Smith et al. and Teoh et al. have a longitudinal design; however, the statistics used in these articles cover only cross-sectional analyses.

Abbreviations: d, days; w, week; m, month; yr, year.

Table 5.2 Psychological factors and measures

Psychological factor	Subtypes	Psychological measure (ref.)	Number of items	Description variable	Scoring
Personality	Temperament & personality functions	Temperament & personality functions item (b126) of the Extended version of the ICF Core Set for Stroke <sup>11</sup>	1	The extend of a persons' problems in temperament & personality functions. <sup>11</sup>	5-point scale ranging from "no problem" (0) to "complete problem" (4). A higher score indicates more problems.
	Neuroticism	Eysenck Personality Questionnaire – subscale neuroticism <sup>23,28</sup>	12	Emotional instability. <sup>29</sup> <i>e.g. does your mood often go up and down?</i>	Items are scored as "yes" (1) or "no" (0). A higher sum score indicates a higher level of neuroticism.
	Extraversion	Eysenck Personality Questionnaire – subscale extraversion <sup>28</sup>	12	The tendency of having thoughts and activities satisfied by things outside the self. <sup>29</sup> <i>e.g. are you a talkative person?</i>	Items are scored as "yes" (1) or "no" (0). A higher sum score indicates a higher level of extraversion.
Coping	Situational adaptation	Assimilative – Accommodative Coping Scale (Tenacious Goal Pursuit, TGP) <sup>23,27</sup>	15	Refers to the coping strategy that is aimed at actively adjusting circumstances to personal preferences. <sup>27</sup> <i>e.g. when faced with difficulties I usually double my efforts.</i>	5 point scale ranging from "completely agree" (0) to "completely disagree" (4). Mean scores are calculated. Higher scores indicate better use of situational adaptation.
	Personal adaptation	Assimilative – Accommodative Coping Scale (Flexible Goal Adjustment) <sup>23,27</sup>	15	Refers to the coping strategy whereby the patient attempts to accept the consequences of the stroke by adjusting personal preferences and goals. <sup>27</sup> <i>e.g. I adapt quite easily to changes in plans or circumstances.</i>	5 point scale ranging from "completely agree" (0) to "completely disagree" (4). Mean scores are calculated. Higher scores indicate better use of personal adaptation.

Table 5.2 continues on next page.

Table 5.2 Continued

Psychological factor	Subtypes	Psychological measure (ref.)	Number of items	Description variable	Scoring
Internal locus of control	Religious/spiritual coping	Brief multidimensional measure of religiousness/spirituality subscale religious and spiritual coping <sup>24</sup>	7	The extend in which a Higher power is seen as benevolent and supportive or punishing and abandoning. <sup>24</sup> <i>e.g. I look to a higher power for strength, support, and guidance.</i>	6-point and 4-point scales ranging from "many times a day" (1) to "never or almost never" (6) and "strongly agree" (1) to "strongly disagree" (4). Lower scores are indicative of a higher degree of spiritual coping.
	Perceived control over the course of recovery	Recovery locus of control scale <sup>10</sup>	9	Measures internal and external control on a single dimension. Internal locus of control is the degree to which an individual believes the occurrence of reinforcements is contingent on his or her own behavior. <sup>30</sup> <i>e.g. my own contribution to my recovery doesn't account for much.</i>	5-point response with 5 items reflecting internal beliefs and 4 items reflecting external beliefs. A single sum score is obtained. A high score indicates a strong internal locus of control and a low score a strong external locus of control.
Self-worth	Physical self-efficacy	Ewart self-efficacy scale <sup>25</sup>		Self-perceived confidence to perform a number of physical tasks. <sup>25</sup> <i>e.g. climbing stairs.</i>	Scores range from 0 to 100. A higher score indicates higher levels of self-efficacy.
	Self-care self-efficacy	Strategies used by people to promote health <sup>26</sup>	36	Confidence in self-care behaviors. <sup>26</sup> <i>e.g. I have confidence in finding a way to help me through this time.</i>	5-point scale ranging from "very little confidence" (1) to "quite a lot confidence" (5). A higher sum score indicates higher levels of self-care self-efficacy.
	Self-esteem	Rosenberg self-esteem scale <sup>10</sup>	10	An overall evaluation of one's self-worth. <sup>10</sup> <i>e.g. on the whole I am satisfied with myself.</i>	4-point scale ranging from "strongly disagree" (0) to "strongly agree" (3). A higher sum score indicates higher levels of self-esteem.

Table 5.2 continues on next page.

Table 5.2 Continued

Psychological factor	Subtypes	Psychological measure (ref.)	Number of items	Description variable	Scoring
Hope		Herth Hope index <sup>20</sup>	12	A multidimensional life force, which is characterized by an expectation of achieving a future good that is realistic and significant to the person. <sup>31</sup> <i>e.g. I have a positive outlook toward life.</i>	4-point scale ranging from “strongly disagree” (1) to “strongly agree” (4). A higher sum score indicates a higher level of hope.
Optimism		Life orientation test-revised <sup>10</sup>	10 (including 4 filler items)	This scale measures dispositional optimism, which means that a person has the tendency to expect the occurrence of good outcomes in one’s life. <sup>32</sup> <i>e.g. in uncertain times, I usually expect the best.</i>	5-point scale ranging from “strongly disagree” (0) to “strongly agree” (5). A higher sum score represents higher levels of optimism.

**Table 5.3 Relationship between overall Health-Related Quality of Life (HRQoL) and psychological factors after stroke**

	Overall HRQoL				
	Time of assessment	HRQoL measure	r	b / $\beta$ / $\Delta R^2$	ref.
<b>Personality</b>					
Temperament & personality functions	6w post-stroke	EQ-5D VAS	-.323**	b = -17.2****a	11
	3m post-stroke		-.260*	ns	
Neuroticism	1yr post-stroke		-.485***	b = -18.6****a	
	At discharge from hospital, rehab centre or nursing home	EQ-5D	nr	$\beta$ = -.406**	23
	2m after discharge		nr	ns	
	5m after discharge		nr	$\beta$ = -.262*	
	9-12m after discharge		nr	ns	
<b>Coping</b>					
Situational adaptation (SA)	At discharge from hospital, rehab centre or nursing home	EQ-5D	.026	$\beta$ = .098	23
	2m after discharge	EQ-5D	.231	$\beta$ = .163	
		SF-36	nr	$\beta$ = .255*	
	5m after discharge	EQ-5D	.464***	$\beta$ = .399**	
		SF-36	nr	$\beta$ = .378**	
Personal adaptation (PA)	9-12m after discharge	EQ-5D	.435***	$\beta$ = .443***	
		SF-36	nr	$\beta$ = .453***	
	SA at discharge and HRQoL 9-12m after discharge (Longitudinal analysed)	EQ-5D	nr	$\beta$ = .068-.074	27
	At discharge from hospital, rehab centre or nursing home	EQ-5D	.100	$\beta$ = .077	23
	2m after discharge	EQ-5D	.271*	$\beta$ = .196	
	SF-36	nr	$\beta$ = .232		
Religious/spiritual coping	5m after discharge	EQ-5D	.279*	$\beta$ = .196	
		SF-36		$\beta$ = .250*	
	9-12m after discharge	EQ-5D	.362**	$\beta$ = .316**	
		SF-36	nr	$\beta$ = .382**	
	PA at discharge and HRQoL 9-12m after discharge (Longitudinal analysed)	EQ-5D	nr	$\beta$ = .116*-.126**	27
<b>Locus of control</b>	Mean 12m post-stroke	AQoL	.50***	$\beta$ = .29***	10
		SWLS	.40***	$\beta$ = .16*	

Table 5.3 continues on next page.

Table 5.3 Continued

		Overall HRQoL			
Time of assessment		HRQoL measure	r	b / $\beta$ / $\Delta R^2$	ref.
	Mean 14m post-stroke	AQoL	nr	$\beta = .18^*$	
		SWLS	nr	ns	
	Mean 18m post-stroke	AQoL	.30***	ns	
		SWLS	.29***	ns	
<b>Self-worth</b>					
Self-esteem	Mean 12m post-stroke	AQoL	.58***	ns	10
		SWLS	.59***	$\beta = .21^*$	
	Mean 14m post-stroke	AQoL	nr	$\beta = .20^*$	
		SWLS	nr	$\beta = .27^{**}$	
	Mean 18m post-stroke	AQoL	.60***	ns	
		SWLS	.68***	$\beta = .41^{***}$	
Physical self-efficacy	Mean 17m post-stroke	SIP68	nr	b = -60.70*** <sup>b</sup> / $\Delta R^2 = .21$	25
Self-care self-efficacy	1m post-stroke	QLI	.66***	ns	26
	6m post-stroke		.81***	ns	
Hope	Mean 2.5yr post-stroke	RNLI	.59***	$\beta = .351^*$	20
Optimism	Mean 12m post-stroke	AQoL	.39***	ns	10
		SWLS	.49***	ns	
	Mean 14m post-stroke	AQoL	nr	ns	
		SWLS	nr	ns	
	Mean 18m post-stroke	AQoL	.53***	$\beta = .21^{**}$	
		SWLS	.60***	ns	

\* $p < .05$ , \*\* $p < .01$ , \*\*\* $p < .001$ ;

<sup>a</sup> The given results of the regression analyses of temperament & personality functions were calculated with the Body functions component of the ICF only. The results of the regression analyses in which all three components of the ICF are represented are not significant for six weeks and three months post-stroke, but are significant at six months post-stroke, b = -16.7\*\*\*.

<sup>b</sup> Higher scores on the SIP68 indicate more health-related quality of life problems.

Abbreviation: w, week; m, month; yr, year; ns, not significant; nr, not reported; r, correlation; b, unstandardized regression coefficient;  $\beta$ , standardized regression coefficient;  $\Delta R$ , explained variance of the determinant; EQ-5D VAS, EuroQoL-5D Visual Analogue Scale; SF-36, Medical Outcomes Study 36-item short form health survey; AQoL, Assessment of Quality of Life; SWLS, Satisfaction with Life Scale; SIP68, Shortened Version of the Sickness Impact Profile; QLI, Quality of Life Index-Stroke Version; RNLI, Reintegration to Normal Living Index.

### Personality

Experiencing problems of temperament and personality functions, an ICF category that was not further specified, was moderately associated with lower HRQoL at six-weeks, three-months, and one-year post stroke. In the regression analysis, problems of temperament

and personality functions were most strongly associated with lower HRQoL at one-year post stroke.<sup>11</sup>

Neuroticism was moderately associated with lower HRQoL at discharge and five-months after discharge, but not at two-months and 9–12 months after discharge.<sup>22</sup> Furthermore, neuroticism one-week before discharge from the hospital was associated with lower mental HRQoL ( $\beta = -.27$ ), but not with physical HRQoL one-year after discharge.<sup>23</sup> In addition, extraversion was not associated with mental and physical HRQoL.<sup>23</sup>

### ***Coping***

Situational adaptation was not related to HRQoL at discharge and two-months after discharge, but was moderately to strongly related to higher HRQoL at five-months and 9–12 months after discharge.<sup>22</sup> In contrast to these cross-sectional data, three regression analyses found no relationship between situational adaptation at discharge and HRQoL 9–12 months after discharge.<sup>24</sup>

Personal adaptation was weakly to moderately related to higher HRQoL at all time points, except at discharge. Personal adaptation at discharge was related to higher HRQoL 9–12 months after discharge in all three regression analyses.

Religious and spiritual coping 2.5 years post stroke was not associated with overall HRQoL, but was moderately associated with higher mental HRQoL ( $r = .43$ ).<sup>25</sup>

### ***Internal locus of control***

Internal locus of control was moderately to strongly associated with higher HRQoL 12 and 18 months post stroke ( $r = .32$ ). Internal locus of control was also associated with higher physical HRQoL ( $r = .27$ ).<sup>10</sup> Multivariate regression analyses showed similar results for HRQoL (Table 5.3) and physical HRQoL ( $\beta = .16$  and  $\beta = .18$ ).<sup>10</sup>

### ***Self-worth***

Self-esteem was strongly associated with higher HRQoL (Table 5.3) and physical HRQoL 12 and 18 months post stroke ( $r = .45$  and  $r = .47$ , respectively).<sup>10</sup> The multivariate regression analyses revealed inconsistent results. For physical HRQoL, a significant relationship with self-esteem was found at 12 months ( $\beta = .23$ ), but not at 14 and 18 months post stroke.<sup>10</sup>

Physical self-efficacy was associated with higher HRQoL 17 months post stroke.<sup>26</sup> Self-care self-efficacy was strongly associated with higher HRQoL at one-month and six-months



post stroke. However, these associations were not significant in the multivariate regression analyses.<sup>27</sup>

### **Hope**

Hope was strongly associated with higher HRQoL at a mean of 2.5 years post stroke. This relationship was still significant in a multivariate regression analysis with control variables.<sup>20</sup>

### **Optimism**

Optimism was strongly associated with higher HRQoL and was moderately associated with higher physical HRQoL ( $r = .21$  and  $r = .39$ ).<sup>10</sup> However, only one of the three associations remained significant in the regression analyses, while none of the associations remained significant for physical HRQoL.<sup>10</sup>

## **Discussion**

The aim of the present review was to systematically examine the relationships between psychological factors and HRQoL post stroke. Negative personality characteristics (i.e. problems of temperament and personality functions, and neuroticism) were moderately associated with lower HRQoL. Coping (i.e. situational and personal adaptation, and religious and spiritual coping), internal locus of control, self-worth (i.e. self-esteem and self-efficacy), hope, and optimism were moderately associated with higher HRQoL.

### **Negative determinants**

The experience of problems with temperament and personality functions was already associated with lower HRQoL six-weeks post stroke. The negative associations between neuroticism and HRQoL are in accordance with those found in studies among patients with other chronic conditions, such as asthma and head and neck cancer.<sup>15,32</sup> Patients with high scores for neuroticism may experience lower HRQoL because they focus more on their symptoms and are likely to report more symptoms.<sup>33</sup>

### **Positive determinants**

Positive associations with HRQoL were found for situational and personal adaptation. There are several classification systems for coping. A frequently used classification

system divides coping into problem-focused (e.g. actively addressing the problem) and emotion-focused (e.g. accepting situations more easily) coping styles.<sup>34</sup> According to this classification situational and personal adaptation can be classified as problem-focused and emotion-focused coping styles, respectively. Darlington et al.<sup>22</sup> expected that in the first months after discharge higher HRQoL would be related to high levels of problem-focused coping styles, whereas higher HRQoL five-months after discharge would be related to high levels of emotion-focused coping styles. The results in the present study were not entirely in accordance with this expectation. Situational adaptation showed a relationship with HRQoL from five-months after discharge, and personal adaptation already from two-months after discharge. Furthermore, at five-months after discharge correlations between situational adaptation and HRQoL were somewhat higher than between personal adaptation and HRQoL. Recently, Brands et al.<sup>35</sup> suggested that a simultaneous and continuous interaction between both coping styles, that is, pursuing goals and adjusting to the changes where necessary, would be the best combination for the process of adjustment in patients with acquired brain injury. This assumption fits in better with the results reported by Darlington et al.,<sup>22</sup> so more research is needed to examine which combination of coping styles is the most beneficial, in terms of HRQoL post stroke. It is interesting that coping became more closely related to HRQoL as more time elapsed after the stroke: there was no association between personal adaptation until two-months after discharge and there was no association between situational adaptation and HRQoL until five-months after discharge. This effect was not studied for the other psychological factors. It might be that physical factors play a more prominent role in determining HRQoL in the acute post-stroke phase, whereas psychological factors are more important in the chronic phase.

It is important to know which psychological factors can be modified in order to optimize HRQoL post stroke. Personality is presumed to be a constant factor across a person's lifespan, in contrast to coping.<sup>22</sup> In recent years, positive psychology interventions aimed at strengthening psychological resources, for example self-esteem, have attracted increasing interest.<sup>36</sup> Our review found associations of self-worth, hope, optimism, and locus of control with HRQoL. Opportunities to modify these factors by means of therapy, and the effects of such interventions on HRQoL, should be further investigated.

### **Unrelated determinants**

No associations were found between extraversion and mental and physical HRQoL. However, this was not examined in bivariate correlational analyses, as was done for the

other psychological factors. A positive relationship between extraversion and HRQoL has been found in other patient groups, such as asthma patients.<sup>15</sup>

### **Limitations of the literature**

First, the number of included articles and the numbers of patients per article were small; three of the nine studies had fewer than 55 patients (necessary for a correlation of .33 or 10% explained variance to become significant). Second, the included articles were heterogeneous in terms of patient groups, time of assessment, and measures used to assess HRQoL. Third, only two of the nine studies had used longitudinal analyses. Finally, the small number of included articles meant that only a small number of psychological factors were measured, with only one or two articles per psychological factor.

### **Limitations of this review**

One limitation with respect to this systematic review is the lack of a generally accepted definition of psychologic factors. We operationalized psychological factors using the ICF, similar to the way the psychological-personal perspective of the ICF was captured in a study of spinal cord injury.<sup>37</sup>

The second limitation was that depression and anxiety were not captured in the operationalization of psychological factors. These concepts are part of the concept of (mental) HRQoL, so that studying depression and anxiety as determinants of HRQoL would result in strong conceptual overlap between determinants and outcomes.

### **Further research and clinical implications**

More research is needed into psychological characteristics of stroke patients and their impact on HRQoL. Longitudinal studies are particularly needed because they allow causal relationships and effects of time to be identified. It is also important to investigate which psychological factors can be modified by means of therapy, in order to optimize interventions for HRQoL after stroke.

It is important for clinicians to become aware of the relationship between psychological factors, such as personality and coping, and HRQoL post stroke, as this relationship identifies treatment targets other than the stroke itself or physical functioning, to improve HRQoL. Monitoring neuroticism and problems of temperament and personality in an

early stage post stroke may help identify patients at risk for poor long-term adjustment. Additionally, rehabilitation treatment should attempt to strengthen factors such as hope, optimism, self-worth, and personal and situational adaptation coping styles.

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## Appendix 5.2

### Methodological quality assessment

Name	Internal validity	Control of drop-out	External validity	Statistical validity	Proportion sample size: determinants	Multicollinearity	Confounding bias	Reporting	Total
Algurén (2012)	1	1	1	1	0	1	0	1	6
Bluvol (2004)	1	0	0	1	0	0	1	1	4
Darlington (2007)	1	0	1	1	1	0	1	1	6
Darlington (2009)	1	1	1	1	1	0	1	1	7
Johnstone (2008)	1	0	0	1	1	NA	0	0	3
LeBrasseur (2006)	1	0	1	1	0	0	1	1	5
Li (2001)	1	0	1	1	1	0	0	1	5
Robinson-Smith (2000)	1	0	0	1	1	0	1	1	5
Teoh (2009)	1	1	1	1	1	0	1	1	7



# Psychological factors determine depressive symptomatology after stroke

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6

## Abstract

### Objective

To identify psychological factors related to post-stroke depressive symptoms.

### Design

Cross-sectional study, with patients assessed at 2 months post stroke.

### Setting

Patients with stroke from 6 general hospitals.

### Participants

Stroke patients ( $N = 344$ ; mean age  $\pm$  SD,  $66.9 \pm 12.3y$ ).

### Interventions

Not applicable.

### Main outcome measures

The presence of clinical depressive symptoms was determined with the depression subscale of the Hospital Anxiety and Depression Scale 2 months post stroke. Psychological factors assessed were extraversion, neuroticism, optimism, pessimism, self-efficacy, helplessness, acceptance, perceiving benefits, proactive coping, and passive coping.

### Results

Bivariate correlations and multivariate backward logistic regression were used to analyze associations between psychological factors and post-stroke depressive symptoms, accounting for demographic and stroke-related factors. More neuroticism, pessimism, passive coping, and helplessness, and less extraversion, optimism, self-efficacy, acceptance, perceived benefits, and proactive coping were bivariately associated with the presence of depressive symptoms. Multivariate logistic regression analysis showed that more helplessness (odds ratio [OR] = 1.17) and passive coping (OR = 1.19) and less acceptance (OR = .89) and perceived benefits (OR = .89) were independently significantly associated with the presence of post-stroke depressive symptoms (Nagelkerke  $R^2 = .49$ ).

### Conclusions

We found a relationship between psychological variables and the presence of depressive symptoms two months post stroke. It is important to take these factors into account during post-stroke rehabilitation.

## Introduction

Depressive symptoms are common after stroke and have a profound influence on functioning and quality of life.<sup>1</sup> Reported prevalence rates of post-stroke depressive symptoms (PSDS) in the acute phase range from 5% to 54% and prevalence rates of major depression 2 years post stroke are still around 20%.<sup>1,2</sup>

The etiology of post-stroke depression is still unclear. Some researchers have proposed a biological mechanism in which depression is caused by brain damage disrupting neural circuits involved in mood regulation.<sup>3</sup> Others suggest that depression is caused by a psychological reaction to the social and psychological stressors associated with stroke.<sup>4</sup> There are several arguments for both theories, and post-stroke depression is most likely to be multifactorial in origin, a combination of both biological and psychological mechanisms.<sup>2</sup>

Until now, research into the determinants of PSDS has focused mainly on stroke-related factors (e.g. lesion location, severity of neurologic damage) and demographic factors (e.g. age, sex).<sup>5</sup> Prognostic studies found that stroke severity,<sup>6</sup> lesion location,<sup>7,8</sup> functional status,<sup>9</sup> younger age,<sup>10</sup> sex,<sup>11,12</sup> cognitive dysfunction,<sup>12</sup> and history of depression<sup>13</sup> explained only a small part of the variance of PSDS.

This implies that additional variables, such as psychological factors, should be considered. The influence of psychological factors on PSDS is of growing interest. It is assumed that the way patients think about and perceive their illness accounts for much of the individual differences in their physical and psychological health status.<sup>14</sup> The Common Sense Model (CSM) by Leventhal describes part of this adaptation process and assumes that when people are confronted with a chronic illness, they try to make sense of it by creating a cognition of it, which influences their coping styles and hence their illness adaptation.<sup>15</sup> In addition, a person's stable characteristics, such as personality traits, are assumed to influence the process of creating the illness cognitions.<sup>15,16</sup> Thus, the influence of personality traits on depressive symptoms is mediated through illness cognitions and coping styles.

Some research has been done on the influence of psychological factors on PSDS. Associations with personality traits such as neuroticism, extraversion, and conscientiousness have been evaluated in a number of studies, and only high levels of neuroticism were found to be related to higher levels of PSDS.<sup>5,17-19</sup> However, these studies used small samples and therefore lacked statistical power. Optimism has only once been investigated as a determinant of PSDS, and was not found to be a significant predictor of PSDS,<sup>19</sup> unlike what was found by studies in other diagnostic groups.<sup>20</sup> General self-efficacy has not

been associated with PSDS, but is a strong predictor of depression and quality of life in other diagnostic groups, such as cancer<sup>21</sup> and spinal cord Injury (SCI).<sup>22</sup> A specific form of self-efficacy, self-care self-efficacy, was associated with depression in stroke patients.<sup>23</sup> The influence of illness cognitions on PSDS has been investigated in 2 studies,<sup>24,25</sup> which found that several illness cognitions, such as acceptance of the illness, are associated with PSDS. However, other illness cognitions, such as helplessness and perceiving benefits, also need to be investigated for their influence on PSDS. Several coping styles, such as avoidance coping, have been found to be related to depressive symptoms in individuals with stroke.<sup>19,26,27</sup> Proactive coping was found to correlate with health-related quality of life.<sup>28</sup> Since, the evidence is, however, still limited, there is a need to further examine the associations between various psychological factors and PSDS.

Ultimately, taking the influence of psychological factors into account should result in more personalized rehabilitation treatment. The objective of this study was therefore to examine the influence of a broad spectrum of psychological factors on PSDS 2 months post stroke, namely personality traits (extraversion, neuroticism, optimism, pessimism, self-efficacy), illness cognitions (helplessness, acceptance, perceiving benefits), and coping styles (proactive coping, passive coping), while controlling for the influence of demographic and stroke-related factors.

## Methods

### Design and procedure

The current study is part of the longitudinal Restore4Stroke Cohort study, in which new stroke patients are followed up for 2 years.<sup>29</sup> Six general hospitals in the Netherlands participated, and stroke patients were recruited between March 2011 and March 2013. The medical ethics committees of all participating hospitals approved the Restore4Stroke Cohort study and informed consent was obtained from all included patients. The present study reports data from stroke onset and 2 months post stroke.

The first assessment (T1) regarded demographic and stroke-related factors. After informed consent had been given, the stroke-related factors, assessed by the neurologist on day 4, were extracted from the medical charts. Information on demographic factors was obtained from the patient or family members. In the second assessment, which took place 2 months post stroke (T2), patients were asked to complete the self-report scales for depression

and psychological factors, and cognitive screening was conducted by trained research assistants.

## Subjects

Stroke patients were eligible for this study if they were  $\geq 18$  years of age, had a clinically confirmed diagnosis of stroke (ischemic or intracerebral hemorrhagic lesion) and had suffered their stroke within the last 7 days.

Patients were excluded if they (1) had another serious health condition that could be expected to interfere with the study outcomes; (2) had already been dependent regarding activities of daily living (ADL) before their stroke, as defined by a Barthel Index (BI) of  $\leq 17$ <sup>30</sup>; (3) had insufficient command of the Dutch language to understand and complete the questionnaires, based on clinical judgment; or (4) had already been experiencing cognitive decline before their stroke, as defined by a score of  $\geq 1$  on the Heteroanamnesis List Cognition.<sup>31</sup>

## Measures

### *Dependent variable: presence of depressive symptoms*

The presence of depressive symptoms 2 months post stroke was assessed using the depression subscale of the Hospital Anxiety and Depression Scale (HADS-D).<sup>32,33</sup> The Hospital Anxiety and Depression Scale has shown good psychometric properties<sup>33</sup> and is commonly used for stroke patients.<sup>34</sup>

### *Independent variables: demographic and stroke-related factors*

We collected data on sex, age and level of education. For level of education we used the Dutch Verhage classification ranging from 1 (did not finish primary school) to 7 (university graduation).<sup>35</sup> The severity of the stroke was assessed with the National Institutes of Health Stroke Scale (NIHSS).<sup>36</sup> ADL was assessed using the BI, which is a validated measure often used in stroke.<sup>30</sup> Cognitive functioning was assessed using the Montreal Cognitive Assessment (MoCA).<sup>37</sup>

### *Independent variables: psychological factors*

Extraversion and neuroticism were assessed with 2 scales of the Eysenck Personality Questionnaire Revised Short Scale for Extraversion and Neuroticism (EPQ-RSS-E and N).<sup>38</sup> The extraversion (e.g. 'Are you a talkative person?') and neuroticism (e.g. Does your

mood often go up and down?') scales both consist of 12 items with dichotomous (yes/no) response options. A higher sum score indicates a higher level of extraversion or neuroticism, respectively. The internal consistencies of the neuroticism and extraversion scales are satisfactory (Cronbach's  $\alpha$  coefficient in the present study was .83 for both scales). Optimism and pessimism were assessed with the Life Orientation Test-Revised (LOT-R).<sup>39</sup> The LOT-R is a 6-item measure with 2 subscales which measure optimism (e.g. 'In uncertain times, I usually expect the best') and pessimism (e.g. 'If something can go wrong for me, it will'), respectively, with 3 items each. The LOT-R is scored on a 5-point response scale, ranging from 0 (strongly disagree) to 4 (strongly agree). Higher sum scores on the 2 subscales indicate a higher level of optimism or pessimism, respectively. The internal consistency for optimism in the present study was moderate (Cronbach's  $\alpha$  coefficient .62) while that for pessimism was sufficient (Cronbach's  $\alpha$  coefficient .72). Self-efficacy was assessed with the General Self-Efficacy Scale (GSES).<sup>40</sup> The GSES consists of 10 items scored on a 4-point scale, ranging from 'not at all true' to 'exactly true' (e.g. 'I am confident that I could deal efficiently with unexpected events'). A higher sum score indicates a higher level of self-efficacy. Psychometric properties of the GSES scale are satisfactory to good.<sup>40</sup> Internal consistency in the present study was high (Cronbach's  $\alpha$  coefficient .92).

Illness cognitions were measured with the Illness Cognition Questionnaire (ICQ).<sup>14</sup> This scale consists of 18 items that are scored on a 4-point scale ranging from 1 'not at all' to 4 'completely'. The items belong to 1 of 3 subscales: helplessness (e.g. 'my illness frequently makes me feel helpless'), acceptance (e.g. 'I can accept my illness well'), and perceived benefits (e.g. 'My illness has made life more precious to me'), each measured with 6 items and a scoring range of 6 to 24. The ICQ is a reliable instrument to assess illness cognitions in patients with several chronic diseases, such as rheumatoid arthritis and multiple sclerosis.<sup>14</sup> The internal consistencies in the present study were high: Cronbach's  $\alpha$  coefficients were .88 for the helplessness and acceptance subscales and .83 for the perceived benefits subscale.

Proactive coping competencies were assessed with the Utrecht Proactive Coping Competence List (UPCC).<sup>41</sup> The UPCC consists of 21 items scored on a 4-point scale, with scores of competence ranging from 'not at all' to 'very', resulting in a mean score ranging from 1 to 4, with a higher score indicating a higher level of proactive coping. An example question is 'To what extent do you have the capacity to recognize signals that something might go wrong'. The UPCC has shown good psychometric properties in stroke patients.<sup>28</sup> Internal consistency in the present study was high (Cronbach's  $\alpha$  coefficient .93). Passive coping was assessed with the passive reaction pattern subscale of the Utrecht Coping List



(UCL-P).<sup>42</sup> This subscale consists of 7 items that are scored on a 4-point scale ranging from 'seldom' to 'very often' (e.g. 'take refuge in fantasies'). A higher sum score indicates a higher level of passive coping. The internal consistency of this subscale in the present study was sufficient (Cronbach's  $\alpha$  coefficient .72) and the test-retest reliability is high (correlation coefficient .76).<sup>42</sup>

## Statistical analysis

Data were analysed with the SPSS statistical software package (version 21). Descriptive statistics were used to describe patients' characteristics.

Scores on the HADS-D were dichotomized into 'no depressive symptoms' (HADS-D < 8) and 'depressive symptoms' (HADS-D  $\geq$  8).<sup>33</sup> Bivariate logistic regression analyses were used to select bivariately significant determinants of PSDS ( $p < .05$ ). Sex, age and education were entered as demographic factors, and severity of stroke, ADL independence 2 months post stroke, and cognitive functioning 2 months post stroke were entered as stroke-related factors. The level of education was dichotomized into low (1–5) and high (6–7).<sup>43</sup> The BI score was dichotomized into 'dependent' (BI < 18) and 'independent' (BI  $\geq$  18). Scores on the psychological questionnaires were entered as continuous variables in the analyses.

Bivariately significant psychological factors were tested for multicollinearity (correlation coefficient  $> .7$ ), which did not reveal any problems. Demographic variables, stroke-related factors and the bivariately significant psychological factors were used in a multivariate hierarchical backward logistic regression analysis. Ensuring that the demographic and stroke-related factors could not be removed from the model, we used the Enter method in the first 2 blocks (demographic and stroke-related factors), and the stepwise backward method (likelihood ratio) in the last block ( $p$  in .05,  $p$  out .1). Goodness of fit of the multivariate model was tested with the Hosmer-Lemeshow test. In addition, odds ratios and their 95% confidence intervals were reported. The critical value of  $\alpha$  was set at .05.

## Results

### Participants

A total of 395 stroke patients were included in the Restore4Stroke Cohort study. The data of 344 participants (87%) were available for analysis. Three participants had died

and 18 refused further participation. Furthermore, 30 participants could not take part in the T2 assessment, 5 because of severe aphasia and 25 because of their general physical condition.

The mean age  $\pm$  SD at the onset of stroke was  $66.9 \pm 12.3$  years; 36% of the participants were female and 93% had suffered an ischemic stroke (Table 6.1). Four days post stroke, their mean ADL score was 17.2. Seventy-three percent of the participants were discharged home after acute care hospitalization. The descriptive statistics of the psychological measures are presented in Table 6.2.

**Table 6.1** Patients' characteristics (N = 344)

Factors	Values
<b>Demographic factors</b>	
Sex (female)	36
Age in years	$66.9 \pm 12.3$
Marital status, living together (n = 342)	68.7
High education level <sup>a</sup> (n = 342)	26.9
<b>Stroke-related factors</b>	
Ischemic stroke	93
Left hemisphere (n = 343)	39.9
Severity of stroke	$2.5 \pm 2.9$
No stroke symptoms (NIHSS 0)	25
Minor stroke symptoms (NIHSS 1–4)	57.9
Moderate stroke symptoms (NIHSS 5–12)	16.3
Moderate to severe stroke symptoms (NIHSS $\geq$ 13)	0.9
ADL 4d post stroke (n = 344)	$17.2 \pm 4.4$
ADL independent (BI 18–20)	68.9
ADL dependent (BI $\leq$ 17)	31.1
ADL 2mo post stroke (n = 343)	$19.3 \pm 2.03$
ADL independent (BI 18–20)	91.0
ADL dependent (BI $\leq$ 17)	9.0
Cognitive functioning 2mo post stroke (n = 339)	$23.5 \pm 4$
Normal cognition (MoCA 26–30)	32.2
Cognitively impaired (MoCA $\leq$ 25)	67.8
Destination after discharge from hospital	
Home	73.3
Rehabilitation centre	13.4
Nursing home	13.4

NOTE. Values are percentages or mean  $\pm$  SD.

Abbreviations: NIHSS, National Institutes of Health Stroke Scale; ADL, Activities of Daily Living; BI, Barthel Index; MoCA, Montreal Cognitive Assessment.

<sup>a</sup> Patients completed higher professional education or have a university degree.

**Table 6.2** Descriptive statistics of the psychological measures

Psychological factor	Measure	Actual range	N	Mean $\pm$ SD
Extraversion	EPQ-RSS-E	0–12	340	7.1 $\pm$ 3.2
Neuroticism	EPQ-RSS-N	0–12	341	3.6 $\pm$ 3.1
Optimism	LOT-R	2–12	341	8.2 $\pm$ 2.1
Pessimism	LOT-R	0–12	340	4.4 $\pm$ 2.8
Self-efficacy	GSES	10–40	340	31.6 $\pm$ 6.4
Helplessness	ICQ	6–24	341	11.9 $\pm$ 4.9
Acceptance	ICQ	6–24	340	16.4 $\pm$ 4.9
Perceived benefits	ICQ	6–24	339	15.0 $\pm$ 4.8
Proactive coping	UPCC	1–4	340	3.1 $\pm$ 0.6
Passive coping	UCL-P	7–23	341	10.5 $\pm$ 2.8

Abbreviations: EPQ-RSS-E, Eysenck Personality Questionnaire Revised Short Scale – Extraversion; EPQ-RSS-N, Eysenck Personality Questionnaire Revised Short Scale – Neuroticism; LOT-R, Life Orientation Test-Revised; GSES, General Self-Efficacy Scale; ICQ, Illness Cognition Questionnaire; UPCC, Utrecht Proactive Coping Competence List; UCL-P, Utrecht Coping List – passive reaction pattern subscale.

## Depressive symptoms

Two months post stroke, 21.5% of the participants experienced depressive symptoms. Of these patients, 71.6% had a score between 8 and 11 (mild), 17.7% had a score between 12 and 14 (moderate), and 10.7% had a score of  $\geq 15$  (severe) on the HADS-D.

## Bivariate analysis

Bivariate analysis showed that the presence of PSDS was associated with higher levels of neuroticism, pessimism, helplessness, and passive coping, and lower levels of extraversion, optimism, self-efficacy, acceptance, perceived benefits, and proactive coping (Table 6.3).

None of the demographic factors were significantly associated with PSDS, and of the stroke-related factors only poorer cognitive functioning was associated with the presence of PSDS.

## Multivariate analysis

The multivariate hierarchical backward logistic regression analysis showed that more helplessness and passive coping and less acceptance and perceived benefits were independently significantly associated with the presence of PSDS (Table 6.3). Nagelkerke  $R^2$  of the final model was .49. The multivariate model showed a good fit (Hosmer-Lemeshow test,  $p = .94$ ).

**Table 6.3** Bivariate and multivariate logistic regression analyses of PSDS

Factors	Measure	N	Bivariate analysis			Multivariate analysis (N = 334)								
			β	SE	p-value	Odds (95% CI)	β	SE	p-value	Odds (95% CI)				
<b>Demographic factors</b>														
Sex (female)		344	.39	.27	.147	1.47 (.87–2.49)								
Age		344	-.00	.01	.837	1.00 (.98–1.02)								
Education (low)		342	.65	.33	.051	1.92 (1.00–3.69)								
<b>Stroke-related factors</b>														
Severity of stroke	NIHSS	344	-.01	.05	.916	1.00 (.91–1.09)								
ADL (dependent)	BI	343	.48	.27	.080	1.62 (.95–2.76)								
Cognitive functioning	MoCA	339	-.09	.03	.006*	.92 (.86–.98)								
<b>Psychological factors</b>														
Extraversion	EPQ-RSS-E	340	-.10	.04	.021*	.91 (.84–.99)								
Neuroticism	EPQ-RSS-N	341	.30	.05	≤ .001*	1.35 (1.24–1.48)								
Optimism	LOT-R	341	-.43	.07	≤ .001*	.65 (.57–.75)								
Pessimism	LOT-R	340	.21	.05	≤ .001*	1.24 (1.13–1.36)								
Self-efficacy	GSES	340	-.08	.02	≤ .001*	.92 (.89–.96)								
Helplessness	ICQ	341	.20	.03	≤ .001*	1.22 (1.15–1.30)								
Acceptance	ICQ	340	-.24	.04	≤ .001*	.79 (.74–.85)								
Perceived benefits	ICQ	339	-.14	.03	≤ .001*	.87 (.82–.92)								
Proactive coping	UPCC	340	-.95	.22	≤ .001*	.39 (.25–.59)								
Passive coping	UCL-P	341	.38	.06	≤ .001*	1.46 (1.31–1.64)								
Constant														

Abbreviations: β, standardized regression coefficient; SE, Standard Error; CI, confidence interval; NIHSS, National Institutes of Health Scale; BI, Barthel Index; MoCA, Montreal Cognitive Assessment; EPQ-RSS-E, Eysenck Personality Questionnaire Revised Short Scale – Extraversion; EPQ-RSS-N, Eysenck Personality Questionnaire Revised Short Scale – Neuroticism; LOT-R, Life Orientation Test-Revised; GSES, General Self-Efficacy Scale; ICQ, Illness Cognition Questionnaire; UPCC, Utrecht Proactive Coping Competence List; UCL-P, Utrecht Coping List – passive reaction pattern subscale.

\* p-values are significant.

<sup>a</sup> Variables that were removed from the analysis using a backward procedure.

## Discussion

Two months after stroke, 21.5% of the participants had depressive symptoms in the clinical range, most of whom had mild symptoms. All psychological factors investigated were bivariately related to the presence of depressive symptoms 2 months post stroke. More helplessness and passive coping and less acceptance and perceiving benefits were identified as independent predictors of the presence of PSDS two months post stroke.

This is the first study to investigate the influence of a broad range of psychological factors on PSDS. Among the personality traits, all factors were found to be predictors of PSDS in the bivariate analyses. This is not entirely in agreement with earlier research in stroke patients, as some factors that were found to be predictive in the present study, such as extraversion and optimism, were not found to be predictors in earlier stroke studies. The influence of illness cognitions on PSDS has been found in 2 other studies,<sup>24,25</sup> and the relationship between illness cognitions and depressive symptoms has also been confirmed in patients with other diagnoses.<sup>44</sup> The influence of passive coping on PSDS that we found is also in agreement with the literature.<sup>18,25,26</sup> Whereas more active coping styles can reduce depressive mood, passive coping styles can increase feelings of depression.<sup>18</sup>

According to the CSM, patients create illness cognitions of their illness when they are confronted with it. These cognitions lead to the use of different coping styles in order to adapt to the illness. Furthermore, a person's stable characteristics, such as personality traits, are assumed to influence the process of creating the illness cognition.<sup>14,15</sup> In the present study we showed that personality traits, illness cognitions and coping styles are associated with PSDS. An interesting topic for future research would be to investigate if the relationships between these factors follow the path assumed in the CSM, that is, whether the influence of personality traits on depressive symptoms is mediated by illness cognitions and coping styles.

None of the demographic and stroke-related factors were significant determinants of PSDS in the bivariate analyses, except for cognitive functioning. This contrasts with the findings of other studies.<sup>5-11,13</sup> Our findings might be attributed to the high proportion (82%) of participants who had suffered a minor stroke, experiencing no or minor stroke symptoms and being independent in ADL 2 months post stroke. On the other hand, a relatively high proportion of participants were cognitively impaired (68%). It is interesting that even patients who have a mild stroke can be cognitively impaired after the stroke.

To optimize rehabilitation interventions for PSDS, we need to know which factors influence PSDS and which factors can be modified by means of therapy. Traditionally, it was

assumed that personality traits, like neuroticism, remain relatively stable throughout a person's lifespan.<sup>38,45</sup> This assumption has been partly confirmed by studies showing that personality traits were indeed relatively stable over time, as reflected in test-retest correlations of personality measures.<sup>46</sup> However, there is also increasing evidence that personality traits have the potential to change and develop during one's life.<sup>47</sup> A study assessing an individualized stroke self-management intervention found positive results in terms of changing self-efficacy after stroke.<sup>48</sup>

Studies in patients with other chronic diseases, such as inflammatory rheumatic diseases, have reported promising results concerning the possibility of modifying illness cognitions by means of multidisciplinary rehabilitation treatment and cognitive behavioral therapy.<sup>49,50</sup> Research has also shown that patients with traumatic brain injury can be taught to make use of more adaptive coping styles, such as active problem-focused styles.<sup>51</sup> A recent meta-analysis found moderate effectiveness of psychological treatment of depression in individuals with acquired brain injury, including stroke patients, suggesting the value of such interventions in rehabilitation practice.<sup>52</sup>

### **Study strengths**

This study has several strengths. First, it included a large group of patients who had had a stroke. Second, it investigated the influence of a combination of psychological factors on PSDS. Third, it examined a combination of demographic, stroke-related and psychological factors to identify their influence on PSDS. This has resulted in a more complete overview of the factors that together determine PSDS 2 months post stroke.

### **Study limitations**

Our results must be interpreted with the following limitations in mind. First, patients with an ischemic lesion were overrepresented in our cohort: 93% of the patients had an ischemic lesion, compared with 75% in the total stroke population in the Netherlands.<sup>53</sup> This is probably a result of recruiting patients from general hospitals and not from academic hospitals. Another reason could be that hemorrhagic lesions are generally more severe, which means that fewer patients are able to receive and understand information about the study and agree to participate within 1 week after the onset of stroke. However, we do not think that this overrepresentation of patients with ischemic stroke has led to problems regarding the generalizability of the results.

Second, this was a cross-sectional study in which both depressive symptoms and the psychological factors were assessed 2 months post stroke, so we were not able to determine causality. Future research should focus on longitudinal designs assessing the psychological factors in the subacute phase and the experience of depressive symptoms in the chronic phase post stroke. This will provide more insight into potential causal relationships between psychological factors and depressive symptoms.

Third, it is difficult to differentiate between psychological factors and depressed mood. For instance, depressed mood may lead to a high score for pessimism. In our opinion, however, these factors are conceptually different from depressed mood, and the questionnaires used to measure psychological factors and depressive symptoms use very different statements. Examples of questions used for depressive symptoms include ‘I feel tense or “wound up”’ and ‘I still enjoy the things I used to enjoy’, while questions for neuroticism include ‘Do you worry too long after an embarrassing experience?’ and those for acceptance include ‘I have learned to accept the limitations imposed by my illness.’ Furthermore, empirical research shows that the association between psychological factors and depressive symptoms is far from perfect, indicating that psychological factors and depression are at least partially distinct from each other. The literature shows that there are even psychological factors whose association with depressive symptoms in stroke has not yet been established. Earlier research did not find optimism to be associated with depressive symptoms,<sup>18</sup> but in the present study it was.

## Conclusion

This study shows the relevance of psychological factors for the presence of depressive symptoms 2 months post stroke. It is important to take these psychological factors into account during post-stroke rehabilitation.

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# Life satisfaction post stroke: the role of illness cognitions

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## Abstract

### Objective

To describe illness cognitions two months and two years post stroke and to investigate changes in illness cognitions over time. We also examined the associations between illness cognitions and life satisfaction at two months and two years post stroke and investigated if changes in illness cognitions predicted life satisfaction two years post stroke, taking demographic and stroke-related factors and emotional symptoms into account.

### Methods

Prospective cohort study in which 287 patients were assessed at two months and two years post stroke. The illness cognitions helplessness (maladaptive), acceptance (adaptive) and perceiving benefits (adaptive) were measured with the Illness Cognition Questionnaire. Life satisfaction was assessed with two life satisfaction questions. Correlational and regression analyses were performed.

### Results

Patients experienced both maladaptive and adaptive illness cognitions two months and two years post stroke. Only acceptance increased significantly from two months to two years post stroke ( $p \leq .01$ ). Helplessness, acceptance and perceiving benefits were significantly associated with life satisfaction at two months ( $R^2 = .42$ ) and two years ( $R^2 = .57$ ) post stroke. Furthermore, illness cognitions two months post stroke and changes in illness cognitions predicted life satisfaction two years post stroke ( $R^2 = .57$ ).

### Conclusion

Illness cognitions and changes in illness cognitions were independently associated with life satisfaction two years post stroke. It is therefore important during rehabilitation to focus on reducing maladaptive behavior and feelings to promote life satisfaction, and on promoting adaptive illness cognitions.

## Introduction

Stroke is one of the leading causes of disability in the Western world.<sup>1</sup> A stroke can lead to permanent physical, psychological, and psychosocial consequences, such as mobility problems,<sup>2</sup> emotional problems like anxiety and depression,<sup>3</sup> cognitive impairments,<sup>4</sup> and decreased life satisfaction.<sup>5,6</sup> Demographic factors, stroke characteristics and physical impairments are the most commonly investigated determinants of quality of life (QoL) post stroke.<sup>7</sup> These factors, however, do not completely explain why some patients with severe impairments adapt well, whereas other patients with minor impairments experience low levels of QoL.<sup>8</sup>

It is assumed that the way patients think about and perceive their illness accounts for much of the individual differences in their QoL.<sup>9</sup> According to Leventhal's Common Sense Model, patients create mental representations of their illness when faced with a chronic disease.<sup>10,11</sup> Through cognitive re-evaluation of uncontrollable illness experiences patients ascribe meaning to their illness and generate coping responses, which in turn affect outcome. These representations relate to thoughts about, for example, the causes of the illness, worries and fears, the ability to control the illness, and accepting the illness<sup>12</sup> and can be maladaptive as well as adaptive in terms of outcome<sup>9</sup> and some are typically more adaptive than others. These representations have been investigated using terms such as illness cognitions, illness perceptions, illness representations and appraisals. The role of illness cognitions has been recognized in the development, maintenance, and modification of psychological well-being in several chronic diseases, like rheumatoid arthritis and multiple sclerosis,<sup>9</sup> cancer,<sup>13,14</sup> chronic fatigue syndrome,<sup>15</sup> and spinal cord injury.<sup>16</sup>

Limited research has been performed into illness cognitions of stroke patients.<sup>17-20</sup> Acceptance of the illness and appraisals of threat and benefit were associated with depression post stroke.<sup>17,18</sup> Furthermore, female stroke patients associated their emotional state with the cause of pain,<sup>19</sup> and maladaptive illness cognitions were associated with more severe symptoms of posttraumatic stress disorder.<sup>20</sup> However, associations between illness cognitions and life satisfaction, and changes in illness cognitions over time have to our knowledge never been investigated in the stroke population.

Knowledge of associations between illness cognitions and life satisfaction in stroke patients and the susceptibility of illness cognitions to change over time is important. This knowledge may lead to the application of interventions to improve the life satisfaction of stroke patients by focusing on reducing illness cognitions which are negatively associated with life

satisfaction, but also on promoting illness cognitions which are positively association with life satisfaction. Hence, the first two aims of this study were to describe illness cognitions in stroke patients two months and two years post stroke and to investigate changes in illness cognitions over time. We expected feelings of helplessness to decrease over time and feelings of acceptance and benefits of the stroke to increase over time. The third aim was to examine the association between illness cognitions and life satisfaction at two months and two years post stroke. The fourth aim was to examine whether illness cognitions at two months are predictive of life satisfaction at two years and to examine associations between changes in illness cognitions with life satisfaction at two years post stroke.

## Methods

### Design

The current study is part of the longitudinal Restore4Stroke Cohort study in which stroke patients are followed for two years.<sup>21</sup> Six general hospitals in the Netherlands participated and stroke patients were recruited between March 2011 and March 2013. The medical ethics committees of all participating hospitals approved the Restore4Stroke Cohort study and informed consent was obtained from all included patients. The present study reports data from stroke onset, two months, and two years post stroke.

### Subjects

Stroke patients were eligible for this study if they had a clinically confirmed diagnosis of stroke (ischemic or intracerebral hemorrhagic lesion) and had suffered their stroke within the last seven days. All patients had to be at least 18 years old.

Patients were excluded if they (1) had a serious other condition which was expected to interfere with the study outcomes; (2) were already dependent in activities of daily living (ADL) before their stroke, as defined by a score of  $\leq 17$  on the Barthel Index (BI);<sup>22</sup> (3) had insufficient command of the Dutch language to understand and complete the questionnaires (based on clinical judgment); or (4) were already suffering from cognitive decline before their stroke, as defined by a score of  $\geq 1$  on the Heteroanamnesis List Cognition.<sup>23</sup>



## Procedure

Demographic and stroke-related factors were assessed at inclusion. After informed consent had been given, the stroke characteristics as determined by the neurologist of the concerning hospital at four days post stroke were extracted from the medical charts. Information on demographic factors was obtained from the patients. Two months post stroke, patients were assessed by a trained research assistant at home or at the institution where they were residing at that moment. This assessment included the illness cognitions, life satisfaction and emotional symptoms. In addition, ADL were assessed and a cognitive screening was conducted. Two years post stroke, the illness cognitions, life satisfaction and emotional symptoms were assessed by postal questionnaire.

## Measures

### *Independent variable: illness cognitions*

Illness cognitions were measured with the Illness Cognition Questionnaire (ICQ).<sup>9</sup> This scale consists of 18 items which are scored on a 4-point scale ranging from 1 'not at all' to 4 'completely'. The ICQ consists of three subscales, each representing an illness cognition: helplessness, acceptance, and perceived benefits. Each subscale has 6 items and a subscale scoring range of 6–24. Helplessness includes cognitions emphasizing the aversive meaning of the stroke (e.g. 'My illness frequently makes me feel helpless'); acceptance includes cognitions diminishing the aversive meaning of the stroke (e.g. 'I can accept my illness well'); and perceiving benefits includes cognitions giving a positive meaning to the stroke (e.g. 'My illness has made life more precious to me').<sup>9</sup> The ICQ is a reliable instrument to assess illness cognitions in patients with several chronic diseases, such as rheumatoid arthritis and multiple sclerosis.<sup>9</sup>

### *Control variables*

The demographic factors gender, age, and level of education were obtained from the patient. For level of education we used the Dutch classification system by Verhage<sup>24</sup> ranging from 1 (did not finish primary school) to 7 (university).

Stroke-related factors were stroke severity, ADL, and cognitive functioning. Stroke severity was assessed with the National Institutes of Health Stroke Scale (NIHSS) (range 0–42) and was administered 4 days post stroke.<sup>25</sup> The NIHSS includes items on level of consciousness, motor functioning, and communication and is a valid measure. ADL was

assessed using the BI (range 0–20) two months post stroke, which includes items such as personal care and mobility.<sup>22</sup> The BI is a validated measure and commonly used in stroke patients.<sup>22</sup> Cognitive functioning was assessed using the Montreal Cognitive Assessment (MoCA) (range 0–30) two months post stroke.<sup>26</sup> The MoCA is a brief cognitive screening tool suitable for use in stroke patients.<sup>26</sup>

Emotional symptoms, in terms of depressive and anxiety symptoms, was assessed using the total score of the Hospital Anxiety and Depression Scale (HADS) (range 0–42).<sup>27</sup> This measure is valid and commonly used in stroke patients.<sup>27,28</sup>

### ***Outcome variable***

Life satisfaction was operationalized as satisfaction with overall quality of life and was measured with two questions (2LS).<sup>29</sup> The first question ('What is your quality of life at the moment?') is scored on a 6-point scale, ranging from 1 (very unsatisfying) to 6 (very satisfying). The second question ('If you compare your life now with your life before the stroke, is your quality of life at the moment worse, equal, or better than before the stroke?') is scored on a 7-point scale, ranging from 1 (much worse) to 7 (much better). The sum of these two questions (range 2–13) is a valid and responsive measure of life satisfaction.<sup>29,30</sup>

## **Statistical analyses**

Descriptive statistics were used to describe patients' characteristics and item scores on the ICQ two months and two years post stroke.

Wilcoxon Signed Rank tests were used to determine changes in illness cognitions between two months and two years post stroke. Spearman correlation coefficients were calculated to assess cross-sectional associations between life satisfaction and illness cognitions. We considered correlation coefficients to be weak if below .3, moderate between .3 and .5, and strong above .5.<sup>31</sup>

Two hierarchical linear regression analyses were performed to investigate the cross-sectional relationships between illness cognitions and life satisfaction, controlling for demographic factors, stroke-related factors, and emotional symptoms. Step one consisted of entering the control variables. The three illness cognitions were added in the second step.

A third hierarchical linear regression analysis was performed to investigate longitudinal associations between illness cognitions and life satisfaction at two years post stroke. In step one the same control variables were entered. But this time also life satisfaction at two

months. The three illness cognitions at two months post stroke were added in the second step. Finally, in a third step the change scores of the illness cognitions from two months to two years post stroke were added to the regression model.

Level of education was dichotomized into low (up to completed secondary education) and high (completed University of Professional Education or higher). Dependency in ADL was dichotomized into 'dependent' ( $BI \leq 17$ ) and 'independent' ( $BI \geq 18$ ). Cognitive functioning was dichotomized into 'impaired cognitive functioning' ( $MoCA \leq 25$ ) and 'normal cognitive functioning' ( $MoCA \geq 26$ ). The critical value of  $\alpha$  was set at .05. All statistical analyses were performed using IBM SPSS version 22.0.

## Results

### Subjects

In total, 395 patients were enrolled in the Restore4Stroke Cohort study. Datasets of 287 patients were used in the analyses. Datasets of 108 patients could not be used: 71 did not complete the study and 37 had incomplete data. The 287 included patients had a lower age, less severe stroke, higher BI scores and were discharged home more often in comparison with the 108 patients not included in the analyses.

Patient characteristics are presented in Table 7.1. Mean age at the onset of stroke was 65.5 years, and 65.5% of the patients were male. Four days post stroke, the mean BI score was 17.3, and 74.6% of the patients had been discharged home from the hospital.

### Illness cognitions experienced

Table 7.2 presents the illness cognitions scores. There were no significant changes in the helplessness and perceived benefits scores between two months and two years post stroke. The acceptance score increased significantly between two months and two years post stroke ( $p \leq .01$ ). Correlations between illness cognitions scores two months and two years post stroke were moderate for acceptance and perceived benefits and strong for helplessness (Table 7.2).

Table 7.3 presents the percentages of patients scoring the two highest answer categories 'to a large extent' and 'completely' on each item of the ICQ. The largest changes were seen on the helplessness subscale (decreases) for the statements 'because of my illness, I miss

**Table 7.1 Patients' characteristics (N = 287)**

Factors	Values
<b>Demographic factors</b>	
Sex (male)	65.5
Age in years	65.5 ± 12.3
Marital status, living together	70.4
High education level <sup>a</sup>	26.5
<b>Stroke-related factors</b>	
Ischemic stroke	92.3
Left hemisphere (n = 284)	39.1
Severity of stroke 4d post stroke (NIHSS)	2.4 ± 2.9
No stroke symptoms (NIHSS 0)	25.4
Minor stroke symptoms (NIHSS 1–4)	58.9
Moderate stroke symptoms (NIHSS 5–12)	13.9
Moderate to severe stroke symptoms (NIHSS ≥ 13)	1.8
ADL 4d post stroke (BI)	17.3 ± 4.4
ADL 2m post stroke (BI)	19.4 ± 1.9
ADL 2m dependent (BI ≤ 17)	7.3
Cognitive functioning 2m post stroke (MoCA)	23.9 ± 3.7
Cognitively impaired (MoCA ≤ 25)	65.5
Emotional functioning 2m post stroke (HADS)	9.4 ± 7.2
Destination after discharge from hospital	
Home	74.6
Rehabilitation center	13.9
Nursing home	11.5

NOTE. Values are percentages or mean ± SD.

Abbreviations: NIHSS, National Institutes of Health Stroke Scale; ADL, Activities of Daily Living; BI, Barthel Index; MoCA, Montreal Cognitive Assessment; HADS, Hospital Anxiety and Depression Scale; d, days; m, months.

<sup>a</sup> Patients completed higher professional education or have a university degree.

**Table 7.2 Illness cognition scores at 2 months and 2 years post stroke mean ± SD and Spearman correlations for illness cognitions scores between 2 months and 2 years post stroke (N = 287)**

	2m post stroke	2yr post stroke	z-value	Correlation between 2m and 2yr post stroke
Helplessness	11.7 (4.8)	11.3 (5.0)	-1.24	.53*
Acceptance	16.4 (4.8)	17.4 (4.9)	-3.47*	.44*
Perceived benefits	15.1 (4.8)	15.1 (5.0)	-.05	.47*

\* p < .01.

z-value: difference between mean scores at 2 months and 2 years on the different subscales of the Illness Cognition Questionnaire.

Abbreviations: 2m: 2 months; 2yr: 2 years.

**Table 7.3 Percentages of patients scoring ‘to a large extent’ and ‘completely’ for each item of the Illness Cognition Questionnaire two months and two years post stroke (N = 287)**

	2m	2yr
<b>Helplessness</b>		
Because of my illness, I miss the things I like to do most	40.1	30.3
My illness controls my life	25.1	24.4
My illness makes me feel useless at times	22.0	20.9
My illness prevents me from doing what I would really like to do	40.5	32.6
My illness limits me in everything that is important to me	25.4	24.1
My illness frequently makes me feel helpless	13.6	17.2
<b>Acceptance</b>		
I can handle the problems related to my illness	70.7	69.6
I have learned to live with my illness	59.6	71.4
I have learned to accept the limitations imposed by my illness	47.7	58.9
I can accept my illness well	53.0	63.2
I think I can handle the problems related to my illness, even if the illness gets worse	45.6	48.2
I can cope effectively with my illness	64.1	67.9
<b>Perceived benefits</b>		
Dealing with my illness has made me a stronger person	41.3	44.6
I have learned a great deal from my illness	44.2	46.7
My illness has made life more precious to me	57.1	53.8
Looking back, I can see that my illness has also brought about some positive changes in my life	32.4	31.1
My illness has helped me realize what’s important in life	61.5	57.3
My illness has taught me to enjoy the moment more	64.8	63.8

Abbreviations: 2m: 2 months; 2yr: 2 years.

the things I like to do most’ and ‘my illness prevents me from doing what I would really like to do’, on the acceptance subscale (increases) for the statements ‘I have learned to live with my illness’ and ‘I have learned to accept the limitations imposed by my illness’, and on the perceiving benefits subscale for the statements ‘my illness has helped me realize what’s important in life’ (decrease) and ‘dealing with my illness has made me a stronger person’ (increase). Appendix 7.1 presents the percentages of patients scoring each of the four answering categories, for each item of the ICQ two months and two years post stroke.

## Life satisfaction

Two months post stroke, patients had a mean score of 7.3 (SD 2.1) on the 2LS. Two years post stroke, their mean score was 7.7 (SD 2.3), which was a significant change ( $p < .01$ ).

## Correlational analyses

Helplessness and acceptance showed strong correlations at both time points (Table 7.4). Helplessness and perceiving benefits were not correlation two months post stroke, but showed moderate correlations two years post stroke. Acceptance and perceiving benefits were moderately and strongly correlated at two months and two years post stroke, respectively.

More helplessness was strongly related to less life satisfaction and more acceptance to greater life satisfaction at both time points (Table 7.4). More perceiving benefits was weakly and moderately related to greater life satisfaction two months and two years post stroke, respectively.

## Regression analyses

The cross-sectional regression analysis at two months post stroke showed better emotional symptoms, less helplessness, and more acceptance to be independently associated with greater life satisfaction (Table 7.5). None of the demographic and stroke-related factors were associated with life satisfaction in the final model. The presence of emotional problems was the strongest predictor of life satisfaction at two months post stroke and acceptance after that. R-square of the final model was .42. The illness cognitions explained 7% of the variance of life satisfaction.

The second cross-sectional regression analysis showed that at two years post stroke, better emotional symptoms, less helplessness, more acceptance, and more perceived benefits were independently associated with greater life satisfaction. None of the demographic

**Table 7.4** Cross-sectional Spearman correlation matrix between life satisfaction and illness cognitions two months and two years post stroke

		Life satisfaction	Helplessness	Acceptance
Helplessness	2m	-.51*		
	2yr	-.69*		
Acceptance	2m	.55*	-.57*	
	2yr	.60*	-.63*	
Perceived benefits	2m	.22*	-.05	.40*
	2yr	.46*	-.33*	.58*

\*  $p < .01$ .

Abbreviations: 2m: 2 months; 2yr: 2 years.

Table 7.5 Hierarchical linear regression analyses of the effects of illness cognitions on life satisfaction (N = 287)

	Model 1: cross-sectional analysis 2m post stroke		Model 2: cross-sectional analysis 2yr post stroke		Model 3: longitudinal analysis		
	Step 1	Step 2	Step 1	Step 2	Step 1	Step 2	Step 3
<b>Demographic factors<sup>a</sup></b>							
Sex (female)	.03 <sup>e</sup>	.03	.07	.07	.04	.03	.06
Age	.05	.06	-.07	-.02	-.12*	-.10	-.01
Education (high)	-.07	-.05	-.06	-.01	-.01	.00	.02
<b>Stroke-related factors<sup>b</sup></b>							
Severity of stroke	-.14*	-.08	-.08	-.02	-.08	-.05	.01
ADL (independent)	.06	-.01	.07	.04	.10	.05	.05
Cognitive functioning (normal)	.09	.06	-.00	-.01	.03	.02	-.00
<b>Emotional functioning<sup>c</sup></b>	-.55**	-.34**	-.65**	-.25**	-.17*	-.09	.08
<b>Life satisfaction<sup>d</sup></b>							
Helplessness <sup>c</sup>		-.18*		-.35**		-.23*	-.37**
Acceptance <sup>c</sup>		.21*		.14*		-.03	.22*
Perceived benefits <sup>c</sup>		.05		.15*		.09	.16*
Helplessness 2yr-2m							-.39**
Acceptance 2yr-2m							.28**
Perceived benefits 2yr-2m							.19*
Explained variance	.35	.42	.46	.57	.21	.24	.57

\* p &lt; .05; \*\* p &lt; .001.

<sup>a</sup> Factors were measured at inclusion. <sup>b</sup> Severity of stroke was assessed at baseline, ADL and cognitive functioning 2 months post stroke. <sup>c</sup> emotional functioning and the illness cognitions in model 1 and 3 were assessed at two months post stroke. In model 2 emotional functioning and the illness cognitions were assessed at two years post stroke. <sup>d</sup> Life satisfaction was assessed at two months post stroke, only used in model 3. <sup>e</sup>  $\beta$ , standardized regression coefficient.

Abbreviations: 2m: 2 months; 2yr: 2 years.

and stroke-related factors were associated with life satisfaction at two years in the final model. Helplessness at two years was the strongest predictor of life satisfaction two years post stroke. R-square of the final model was .57. The illness cognitions explained 11% of the variance of life satisfaction.

The longitudinal regression analysis showed that greater life satisfaction at two years post stroke was predicted by greater life satisfaction, acceptance and perceiving benefits and less helplessness at two months post stroke. Furthermore a decrease in helplessness and increases in acceptance and perceiving benefits between two months and two years post stroke were associated with greater life satisfaction two years post stroke. R-square of the final model was .57. The change in illness cognitions explained 33% of the variance of life satisfaction two years post stroke.

## Discussion

Feelings of helplessness, acceptance and perceiving benefits of the stroke were present in our stroke patients at two months as well as at two years post stroke. However, the patients differed in the extent to which they had these cognitions. There was an increase in the acceptance of the stroke over time between two months and two years post stroke, but there were no changes in feelings of helplessness or perceiving benefits. All three illness cognitions were associated with life satisfaction and they explained 7–13% of the variance of life satisfaction two months and two years post stroke, respectively. Furthermore, feelings of helplessness, acceptance and perceiving benefits two months post stroke and a change in these illness cognitions between two months and two years post stroke predicted life satisfaction two years post stroke.

### Association between illness cognitions and life satisfaction

Evers et al.<sup>9</sup> reported that illness cognitions might play similar roles in determining long-term outcome in different diagnostic groups of patients with chronic diseases. Their study in patients with rheumatoid arthritis and multiple sclerosis showed similar relationships between maladaptive cognitions and negative outcome, such as worse psychological health status, and between adaptive cognitions and positive outcome, such as better psychological health status.<sup>9</sup> The uniformity of these relationships across different diagnostics groups supports the idea of the generic character of illness cognitions.<sup>9,13,14</sup>



The associations between illness cognitions and life satisfaction were stronger in the chronic phase than in the subacute phase post stroke. In the acute and subacute phases post stroke, most patients are very actively engaged in rehabilitation programs to regain physical functioning and reduce the consequences of the stroke. According to Leventhal's Common Sense Model, illness representations generate coping responses.<sup>10</sup> A frequently used classification system divides coping into problem-focused (e.g. actively addressing the problem) and emotion-focused (e.g. accepting situations more easily) coping styles.<sup>7</sup> Studies have found that problem-focused and emotion-focused coping also become more closely related to health-related quality of life (HRQoL) as more time elapses after a stroke, as the relationship with HRQoL was stronger at one year than at two months post stroke.<sup>32</sup> This is in accordance with what was found in the present study. Physical factors may play a more prominent role in life satisfaction in the acute and subacute phases post stroke, whereas psychological factors such as illness cognitions may become more important in the chronic phase.<sup>7</sup>

Helplessness, acceptance, and perceiving benefits are illness cognitions which are related to emotion-focused coping styles. Each type of coping is considered to be adaptive under different circumstances.<sup>33</sup> Problem-focused coping is more adaptive to psychological well-being when the stressor is seen as modifiable, and emotion-focused coping is more adaptive when the stressor is perceived as un-modifiable.<sup>34</sup> This could explain why the illness cognitions are more important in the chronic phase than in the subacute phase post stroke, as the consequences of the stroke can be considered largely un-modifiable two years post stroke.

### **Change in illness cognitions**

We found an increase in the acceptance of the stroke between two months and two years post stroke. Feelings of helplessness and perceiving benefits did not change between the subacute phase and the chronic phase, although it seems that there was a decrease in feelings of helplessness regarding some of the items (Table 7.3). This decrease seems most prevalent for items asking about feelings of helplessness regarding activities, rather than about feelings of helplessness in general, for example 'Because of my illness, I miss the things I like to do most' as opposed to 'My illness makes me feel useless at times'. There was no increase in the items of perceiving benefits, which we had hypothesized. The percentages of patients scoring the two highest answering categories even decreased for four out of six items on this scale. Items that increased related more to perceiving benefits

as a person, such as ‘dealing with my illness has made me a stronger person’, whereas items that decreased related more to perceiving benefits of the stroke in life, such as ‘my illness has helped me realize what’s important in life’.

This is the first study in stroke patients to investigate changes in illness cognitions over time. There has been some research into this among patients with other chronic diseases, but the results have been inconclusive. A study of patients with SCI found that feelings of helplessness, acceptance, and perceiving benefits were stable from the start of rehabilitation to six months after discharge from rehabilitation.<sup>35</sup> However, another study of patients with SCI found that they experienced less helplessness, more acceptance, and more benefits at discharge than at the start of inpatient rehabilitation.<sup>16</sup> A study among hemodialysis patients examined changes in illness cognitions over a six-year follow-up period and found changes in several illness cognitions.<sup>36</sup> At the end of follow-up, these patients experienced a less intense emotional response and considered that their illness had less serious consequences for their life. Unfortunately, the illness cognitions assessed in this study are not directly comparable with the illness cognitions measured in the present study.

Results of the longitudinal analysis suggest that changing illness cognitions in a more adaptive direction may increase life satisfaction post stroke. Modifying illness cognitions is a significant part of what a rehabilitation team (especially psychologist) tries to achieve during rehabilitation. However, no studies have investigated whether illness cognitions of stroke patients can be changed by means of therapy. In patients with inflammatory rheumatic diseases, some positive changes in maladaptive illness cognitions were observed after multidisciplinary rehabilitation treatment,<sup>37</sup> and in patients with rheumatoid arthritis after cognitive behavioral therapy,<sup>38</sup> although in both studies the interventions were not focused on changing illness cognitions. In conclusion, it seems possible to change illness cognitions through interventions in patients with other chronic diseases, although it remains to be investigated if this is also possible in stroke patients.

## **Strengths and limitations**

There are several strengths and limitations with regard to this study. One of the strengths is that it included a large group of stroke patients. Another is that this is the first study to investigate the association between illness cognitions and life satisfaction in stroke patients. Furthermore, we investigated various factors, i.e. demographic factors, stroke characteristics, emotional symptoms, and illness cognitions in a multivariate analysis to assess their association with life satisfaction, and estimated the amount of variance

explained by illness cognitions after taking these other factors into account. Finally, we investigated the influence of illness cognitions on life satisfaction in the subacute as well as the chronic phase post stroke.

However, our study results must be interpreted while taking account of the following limitations. First, patients with an ischemic stroke were overrepresented in our study population. Ninety-four percent of our patients had suffered an ischemic stroke, in comparison to 75% in the total stroke population in the Netherlands.<sup>39</sup> A possible explanation for this is that hemorrhagic strokes are generally more severe,<sup>40</sup> which may have resulted in patients having been excluded because of greater difficulty understanding the instructions for the study and not being able to provide informed consent within one week after the event. This overrepresentation of patients with an ischemic stroke may have led to fewer severe stroke patients in the study, which could have led to a bias regarding life satisfaction and the use of illness cognitions. Furthermore, the included patients in the present study were of lower age, had a less severe stroke, had a higher score on ADL and were discharged directly home from hospital more often than the patients that were not included in the analyses, which could have led to a bias regarding life satisfaction as well. Another limitation was that illness cognitions were assessed with the Illness Cognition Questionnaire, which has not yet been validated for stroke patients. However, mean scores in our study are similar to those in patients with other chronic diseases for which the questionnaire has been validated, and it is assumed that illness cognitions play a similar role in determining long-term in different diagnostic groups.<sup>9</sup> Finally, life satisfaction was assessed with the 2LS, a measure which assesses life satisfaction with two items only. However, the psychometric properties of the 2LS were satisfactory.<sup>29</sup>

## Conclusion

In the subacute phase as well as in the chronic phase post stroke, illness cognitions play a pivotal role in determining life satisfaction. It is therefore important during rehabilitation to focus not only on reducing maladaptive behavior and feelings in order to promote life satisfaction, but also on promoting illness cognitions which have a positive influence on life satisfaction.

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## Appendix 7.1

Percentage of patients scoring each of the answering categories, for each item of the Illness Cognition Questionnaire at two months and two years post stroke (N = 287)

		<i>Helplessness</i>			
		Not at all	Somewhat	To a large extent	Completely
		Because of my illness, I miss the things I like to do most			
2m		30.3	29.6	20.6	19.5
2yr		39.4	30.3	19.9	10.4
		My illness controls my life			
2m		42.2	32.7	17.1	8.0
2yr		44.5	31.1	16.3	8.1
		My illness makes me feel useless at times			
2m		59.2	18.8	14.7	7.3
2yr		55.4	23.7	11.1	9.8
		My illness prevents me from doing what I would really like to do			
2m		34.2	25.3	22.2	18.3
2yr		38.6	28.8	17.2	15.4
		My illness limits me in everything that is important to me			
2m		44.3	30.3	16.0	9.4
2yr		45.6	30.3	12.2	11.9
		My illness frequently makes me feel helpless			
2m		58.5	27.9	5.9	7.7
2yr		57.3	25.5	11.5	5.7
		<i>Acceptance</i>			
		Not at all	Somewhat	To a large extent	Completely
		I can handle the problems related to my illness			
2m		4.9	24.4	34.1	36.6
2yr		6.3	24.1	24.8	44.8
		I have learned to live with my illness			
2m		14.3	26.1	25.8	33.8
2yr		8.0	20.6	22.6	48.8
		I have learned to accept the limitations imposed by my illness			
2m		18.6	33.7	20.7	27.0
2yr		11.6	29.5	23.1	35.8
		I can accept my illness well			
2m		16.4	30.6	19.9	33.1
2yr		12.6	24.2	23.2	40.0

Appendix 7.1 continues on next page.

**Appendix 7.1 Continued**

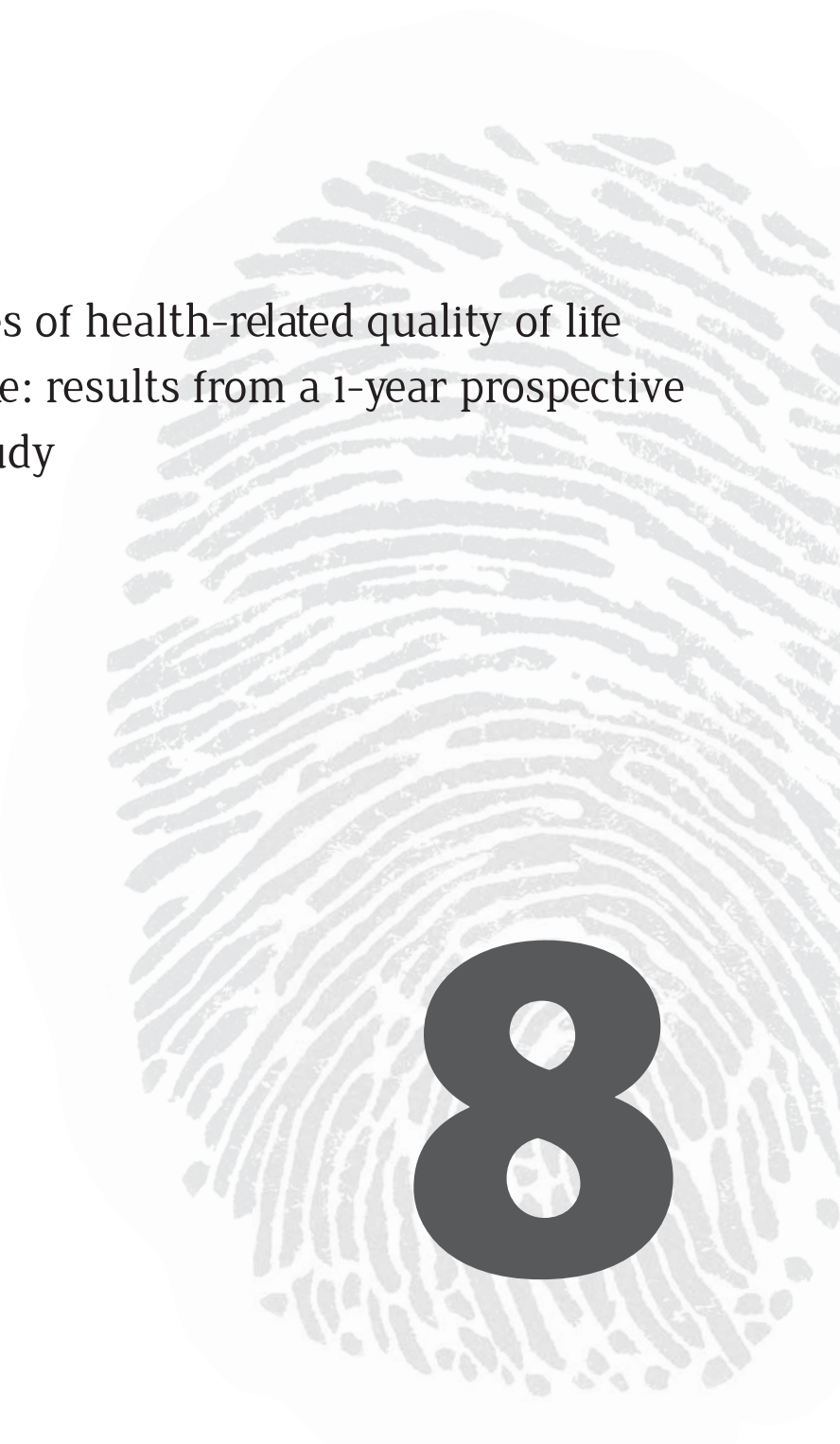
		<b>Acceptance</b>			
		Not at all	Somewhat	To a large extent	Completely
		I think I can handle the problems related to my illness, even if the illness gets worse			
2m		19.9	34.5	27.5	18.1
2yr		20.4	31.4	27.8	20.4
		I can cope effectively with my illness			
2m		8.0	27.9	29.6	34.5
2yr		8.7	23.4	26.1	41.8
		<b>Perceived benefits</b>			
		Not at all	Somewhat	To a large extent	Completely
		Dealing with my illness has made me a stronger person			
2m		30.4	28.3	21.0	20.3
2yr		28.9	26.5	19.2	25.4
		I have learned a great deal from my illness			
2m		20.7	35.1	25.3	18.9
2yr		17.8	35.5	29.6	17.1
		My illness has made life more precious to me			
2m		18.1	24.8	24.0	33.1
2yr		20.3	25.9	26.9	26.9
		Looking back, I can see that my illness has also brought about some positive changes in my life			
2m		35.9	31.7	17.4	15.0
2yr		41.3	27.6	14.3	16.8
		My illness has helped me realize what's important in life			
2m		18.2	20.3	32.5	29.0
2yr		16.1	26.6	28.0	29.3
		My illness has taught me to enjoy the moment more			
2m		16.4	18.8	31.0	33.8
2yr		12.9	23.3	27.2	36.6

Abbreviations: 2m: 2 months; 2yr: 2 years.









# Trajectories of health-related quality of life after stroke: results from a 1-year prospective cohort study

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## Abstract

### Purpose

The aims of this study were to identify trajectories of physical and psychosocial health-related quality of life (HRQoL) from two months to one year post stroke and to determine predictors of trajectory membership.

### Methods

Multicenter prospective cohort study in which 351 patients were followed up at two, six, and twelve months post stroke. Physical and psychosocial HRQoL were measured with the Short Stroke Specific Quality of Life Scale. Latent class growth mixture modelling was used to determine trajectories of physical and psychosocial HRQoL. Multinomial regression analyses were performed to predict trajectory membership. Potential predictors were demographic, stroke-related and psychological factors.

### Results

Four trajectories were identified for both physical and psychosocial HRQoL: high, low, recovery and decline of HRQoL. Comparing the low and recovery physical and psychosocial HRQoL trajectories, the patient groups with low HRQoL were more likely to have higher scores for neuroticism. Comparison of the decline and high trajectories yielded the following predictors of physical HRQoL: being discharged to a rehabilitation setting, less acceptance and more neuroticism, pessimism, helplessness and passive coping. Predictors of psychosocial HRQoL were: being discharged to a rehabilitation setting, less self-efficacy and proactive coping, and more helplessness and passive coping.

### Conclusions

The present study identified four distinct trajectories of physical and psychosocial HRQoL. The findings indicate that psychological factors are the most important factors in identifying patients at risk of unfavourable HRQoL trajectories. Using these predictors will help to identify vulnerable patients and guide rehabilitation in the early stages post stroke.

## Introduction

Stroke is a leading cause of death and disability in the Western world. Major improvements in acute stroke care have resulted in more people surviving a stroke, but many of them experience long-term difficulties in terms of social reintegration,<sup>1</sup> life satisfaction,<sup>2</sup> and physical,<sup>3</sup> cognitive<sup>4</sup> and emotional functioning.<sup>5</sup>

The increasing numbers of chronic stroke patients have led to growing interest in health-related quality of life (HRQoL).<sup>6-8</sup> HRQoL refers to 'how health impacts on an individual's ability to function and his or her perceived well-being in physical, mental and social domains of life.'<sup>9</sup> and can be seen as an overarching multidimensional construct, comprising different domains of one's life, such as physical, functional, psychological and social health.<sup>7</sup> HRQoL can also be divided into physical and psychosocial HRQoL.<sup>10</sup>

Research has shown that stroke patients perceive lower HRQoL than the general population.<sup>11</sup> The course of HRQoL over time has mostly been investigated with follow-up periods of up to 6 months post stroke. Some studies found improvement of HRQoL from one to six months post stroke,<sup>12,13</sup> whereas another study found that HRQoL increased during inpatient rehabilitation, but there was a decrease in the six months thereafter.<sup>14</sup> Only a few studies have investigated a longer follow-up period, up to 12 months and 16 months post stroke.<sup>15,16</sup> These studies also made a distinction between physical and psychosocial HRQoL, but their results were inconclusive and contradictory.<sup>15,16</sup>

Currently, most longitudinal studies use averaged group data to examine changes over time.<sup>17</sup> However, recovery after stroke is a dynamic process in which patients' outcome after stroke is heterogeneous and is characterized by individual recovery patterns.<sup>18</sup> Investigating averaged group data can therefore obscure distinctive subgroups of patients with specific trajectories of HRQoL. These trajectories provide information on both the level of HRQoL and the patterns of change over time.<sup>19</sup> According to Bonanno (2008)<sup>20</sup> there are four characteristic trajectories in response to potential trauma: resilience, with no or little dysfunction; recovery, with relatively mild and short-lived dysfunction; delayed dysfunction, in which dysfunction arises at a later stage after the event; and chronic dysfunction, in which dysfunction arises in the acute phase after the event.

Investigating the existence of different trajectories of HRQoL post stroke can help to identify those patients who adapt well after stroke and those who are at risk of unfavourable HRQoL trajectories. It is also important to identify factors that can predict in the early stages which trajectory patients will end up in. These predictors can be used during acute

and subacute rehabilitation to promote better physical and psychosocial HRQoL in the most vulnerable patients.

Research into the predictors of HRQoL has mainly focused on demographic and stroke-related factors, such as age, gender and physical state at hospital discharge. At different time points post stroke, the factors of age, daily functioning, depression, and physical impairment have been found to be independent predictors of HRQoL.<sup>21,22</sup> Psychological factors reflect the way people approach situations and adjust to chronic illness and therefore influence HRQoL.<sup>23,24</sup> A recent review identified factors such as coping, optimism and neuroticism as determinants of HRQoL after stroke.<sup>25</sup> However, the reviewed studies were often small and had a cross-sectional design, so that the evidence is still limited.<sup>25</sup>

Hence the first aim of the present study was to identify trajectories of physical and psychosocial HRQoL from two months to one year post stroke. The second aim was to determine factors that predict physical and psychosocial HRQoL trajectory membership. Potential predictors we examined included demographic factors, stroke-related factors, and psychological factors. It was hypothesized that the physical and psychosocial trajectories proposed by Bonanno would be present post stroke and that physical HRQoL trajectories would be predicted more by stroke-related factors, and psychosocial HRQoL trajectories more by psychological factors.

## Methods

### Design and procedure

The current study is part of the multicenter prospective longitudinal Restore4Stroke Cohort study, in which new stroke patients were followed for two years.<sup>26</sup> Six general hospitals in the Netherlands participated and stroke patients were recruited between March 2011 and March 2013. The medical ethics committees of all participating hospitals approved the Restore4Stroke Cohort study and informed consent was obtained from all included patients. The present study reports data at stroke onset and two, six and twelve months post stroke.

The first assessment concerned demographic and stroke-related factors. After informed consent had been given, information on stroke-related factors, as assessed by the neurologist on day four, was extracted from the medical charts. Information on demographic factors was obtained from the patient or family members. The second assessment took place two months post stroke. During this assessment, patients were asked to complete self-report

scales on HRQoL and all psychological factors. In addition, trained research assistants assessed activities of daily living (ADL) and comorbidity, and conducted a cognitive screening. The third and fourth assessments took place at six and twelve months post stroke, respectively and involved administering the self-report scale of HRQoL.

## Subjects

Stroke patients were eligible for this study if they had a clinically confirmed diagnosis of stroke (ischaemic or intracerebral haemorrhagic lesion) and had suffered their stroke within the last seven days. All patients had to be at least 18 years old.

Patients were excluded if they (1) had a serious other condition which could be expected to interfere with the study outcomes; (2) had already been dependent regarding ADL before their stroke as defined by a Barthel Index (BI) score of  $\leq 17$ ;<sup>27</sup> (3) had insufficient command of Dutch to understand and complete the questionnaires (based on clinical judgment); or (4) had already been suffering from cognitive decline before their stroke, as defined by a score of  $\geq 1$  on the Heteroanamnesis List Cognition.<sup>28</sup>

## Measures

### *Dependent variable: health-related quality of life*

HRQoL was assessed with the Short Stroke Specific Quality of Life Scale (SS-QoL-12),<sup>29</sup> a disease-specific HRQoL measure. The SS-QoL-12 consists of 12 items, each scored on a 5-point scale. Scores can be divided into a physical (e.g. 'Did you have trouble doing daily work around the house?') and a psychosocial (e.g. 'I felt I was a burden to my family') subscore, measured with 6 items each. Items are averaged to obtain subscores and a higher score indicates higher levels of HRQoL

### *Independent variables: demographic and stroke-related factors*

Information about gender, age and level of education was collected. For level of education we used the Dutch classification system proposed by Verhage (range 1–7).<sup>30</sup> The severity of the stroke was assessed with the National Institutes of Health Stroke Scale (NIHSS) (range 0–42).<sup>31</sup> ADL was assessed two months post stroke, using the BI (range 0–20), which includes items such as personal care and climbing stairs.<sup>27</sup> Comorbidity was assessed with the Cumulative Illness Rating scale (CIRS).<sup>32</sup> This scale measures physical impairment with 13 items based on 13 organ areas. Item 11 was deleted from the analyses, because this

item asks for neurological impairments and the stroke itself is incorporated in this item (range 0–48). Cognitive functioning was assessed with the Montreal Cognitive Assessment (MoCA) (range 0–30).<sup>33</sup>

### ***Independent variables: psychological factors***

Extraversion and neuroticism were assessed with two scales of the Eysenck Personality Questionnaire Revised Short Scale Neuroticism and Extraversion (EPQ-RSS-N and E).<sup>34</sup> The extraversion (e.g. ‘Are you a talkative person?’) and neuroticism (e.g. ‘Does your mood often go up and down?’) scales both consist of 12 items with dichotomous (yes/no) response options.

Optimism and pessimism were assessed with the Life Orientation Test-Revised (LOT-R).<sup>35</sup> The LOT-R is a six-item measure which assesses optimism (e.g. ‘In uncertain times, I usually expect the best’) and pessimism (e.g. ‘If something can go wrong for me, it will’) with 3 items each.

Self-efficacy was assessed with the General Self-Efficacy Scale (GSES).<sup>36</sup> The GSES consists of 10 items, an example question being ‘I am confident that I could deal efficiently with unexpected events’.

Illness cognitions were assessed with the Illness Cognition Questionnaire (ICQ).<sup>37</sup> The ICQ consists of three subscales: helplessness (e.g. ‘My illness frequently makes me feel helpless’), acceptance (e.g. ‘I can accept my illness well’), and perceived benefits (e.g. ‘My illness has made life more precious to me’), and each subscale consists of 6 items.

Proactive coping competencies were assessed with the Utrecht Proactive Coping Competence List (UPCC).<sup>38</sup> The UPCC consists of 21 items, an example question being ‘To what extent do you have the capacity to recognize signals that something might go wrong?’.

Passive coping was assessed with the passive reaction pattern subscale of the Utrecht Coping List (UCL-P) (e.g. ‘take refuge in fantasies’).<sup>39</sup> This subscale consists of 7 items.

## **Statistical analyses**

Patients who completed one or more measurements were included in the analysis. Descriptive statistics were used to describe patients’ characteristics using SPSS (version 22.0). Different trajectories of psychosocial and physical HRQoL were identified by fitting a latent class growth mixture model to the data<sup>40,41</sup> using the Mplus software program 7.11.<sup>42</sup> Latent



class growth mixture models are based on regression and structural equation modelling techniques. This technique assumes that there are subgroups in the patient sample that each have a unique trajectory with unique growth parameters (intercept and slope). The optimal model is one in which the individuals within a subgroup are most similar to each other and most different from the individuals in other subgroups. The optimal number of trajectories was determined using the Bayesian information criterion (BIC) and the bootstrap likelihood ratio test (BLRT). A difference in the BIC value of at least 10 points between two models indicates that the model with the lower BIC value has a better model fit.<sup>43</sup> A significant BLRT suggests that the model with  $k$  number of trajectories classes is significantly better than the previous model with  $k - 1$  number of classes.<sup>44</sup> Furthermore, patients were assigned to the trajectory to which they had the highest probability of belonging, using posterior probabilities. A high probability that approaches 1.0 suggests a good model fit, and a probability of 0.8 or higher is preferred.<sup>40</sup> The optimal model is chosen according to the best statistical fit.

After the patients had been assigned to the trajectories, multinomial bivariate regression analyses were performed to predict trajectory membership using the posterior class membership probabilities as the dependent variable, to account for possible bias in class membership uncertainty.<sup>45,46</sup> Demographic factors, stroke-related factors and psychological factors were entered as independent variables. Level of education was dichotomized into low (up to completed secondary education) and high (completed University of Professional Education or higher). Dependency in ADL was dichotomized into 'dependent' ( $BI \leq 17$ ) and 'independent' ( $BI \geq 18$ ). Cognitive functioning was dichotomized into 'impaired cognitive functioning' ( $MoCA < 26$ ) and 'normal cognitive functioning' ( $MoCA \geq 26$ ). The critical value of  $p$  was set at 0.05 for all analyses and was corrected for multiple testing.

## Results

### Participants

A total of 395 stroke patients were included in the Restore4Stroke Cohort study. Three hundred and forty-three patients participated at two months post stroke (86.8%), 344 at six months post stroke (87.1%), and 328 at one year post stroke (83.0%). A total of 351 patients completed at least one measurement with HRQoL data and were included in the analyses (88.9%).

Table 8.1 presents patients' characteristics. Mean age at stroke onset was 66.8 years, and 64.4% of the patients were male. Four days post stroke, the mean BI score was 17.0, and 71.8% of the patients had been discharged home from the hospital. Table 8.2 presents descriptive statistics of HRQoL and the psychological measures two months post stroke.

## Identifying HRQoL trajectories

Table 8.3 presents the results of the fit indices for models with 1 to 5 trajectories of physical and psychosocial HRQoL. According to the BIC, BLRT and average posterior probabilities, the 5-trajectory model for physical HRQoL was superior. The 5-trajectory model consisted

**Table 8.1** Patients' characteristics (N = 351)

Factors	Values
<b>Demographic factors</b>	
Sex (male)	64.4
Age in years	66.8 ± 12.5
Marital status, living together	69.5
High education level <sup>a</sup>	27.4
<b>Stroke-related factors</b>	
Ischaemic stroke (n = 350)	93.1
Left hemisphere (n = 347)	39.5
Severity of stroke four days post stroke	2.6 ± 3.1
No stroke symptoms (NIHSS 0)	24.8
Minor stroke symptoms (NIHSS 1–4)	57.0
Moderate stroke symptoms (NIHSS 5–12)	16.5
Moderate to severe stroke symptoms (NIHSS ≥ 13)	1.7
ADL four days post stroke (n = 344)	17.0 ± 4.7
ADL-dependent (BI ≤ 17)	32.5
ADL two months post stroke (n = 338)	19.3 ± 2.0
ADL-dependent (BI ≤ 17)	9.5
Cognitive functioning two months post stroke (n = 333)	23.6 ± 3.9
Cognitively impaired (MoCA ≤ 25)	67.0
Comorbidity (n = 338)	6.0 ± 2.8
Destination after discharge from hospital	
Home	71.8
Rehabilitation centre	14.0
Nursing home	14.2

NOTE. Values are percentages or mean ± SD.

Abbreviations: NIHSS, National Institutes of Health Stroke Scale; ADL, Activities of daily living; BI, Barthel Index; MoCA, Montreal Cognitive Assessment.

<sup>a</sup> Patients completed higher professional education or have a university degree.

**Table 8.2** Descriptive statistics of the health-related quality of life and psychological measures at two months post stroke

Factor	Measure	Range	Actual range	N	Cronbach's alpha	Mean ± SD
HRQoL – Physical	SS-QoL-12	1–5	1.2–5	332	.77	4.1 ± 0.8
HRQoL – Psychosocial	SS-QoL-12	1–5	1–5	332	.86	3.7 ± 1.1
Extraversion	EPQ-RSS-E	0–12	0–12	335	.83	7.1 ± 3.2
Neuroticism	EPQ-RSS-N	0–12	0–12	335	.83	3.6 ± 3.1
Optimism	LOT-R	0–12	2–12	335	.61	8.2 ± 2.1
Pessimism	LOT-R	0–12	0–12	334	.72	4.4 ± 2.8
Self-efficacy	GSES	10–40	10–40	334	.92	31.6 ± 6.3
Helplessness	ICQ	6–24	6–24	335	.88	11.9 ± 4.9
Acceptance	ICQ	6–24	6–24	335	.88	16.4 ± 4.8
Perceived benefits	ICQ	6–24	6–24	335	.83	15.1 ± 4.8
Proactive coping	UPCC	1–4	1.5–4	334	.93	3.1 ± 0.6
Passive coping	UCL-P	7–28	7–23	335	.72	10.5 ± 2.8

Abbreviations: HRQoL, Health-Related quality of life; SS-QoL-12, Stroke Specific Quality of Life Scale; EPQ-RSS-E, Eysenck Personality Questionnaire Revised Short Scale Extraversion; EPQ-RSS-N, Eysenck Personality Questionnaire Revised Short Scale Neuroticism; LOT-R, Life Orientation Test-Revised; GSES, General Self-Efficacy Scale; ICQ, Illness Cognition Questionnaire; UPCC, Utrecht Proactive Coping Competence List; UCL-P, Utrecht Coping List passive reaction pattern subscale.

of a stable high and a stable low physical HRQoL trajectory, while the other 3 trajectories were intermediate trajectories which were intertwined with each other. One of the trajectories concerned only a small group of patients ( $n = 3$ ), which made a meaningful interpretation difficult, so the 4-trajectory model was selected for physical HRQoL. This 4-trajectory model for physical HRQoL consisted of a stable high, a stable low and two intermediate trajectories, with one of the latter increasing between two months and six months (i.e. recovery) and one slightly decreasing in the same period (i.e. decline). These intermediate trajectories crossed in this period (Figure 8.1).

According to the BIC, BLRT and average posterior probabilities, the 4-trajectory model for psychosocial HRQoL was superior, and this was therefore selected. The 4-trajectory model consisted of a stable high and a stable low psychosocial HRQoL trajectory and two intermediate trajectories, with one of the latter increasing between two months and six months (i.e. recovery) and one slightly decreasing in the same period (i.e. decline). These intermediate trajectories crossed in this period (Figure 8.2).

**Table 8.3 Fit indices for models with 1 to 5 trajectories of physical and psychosocial HRQoL**

<i>Physical HRQoL</i>								
Number of trajectories	BIC	BLRT	Average posterior probability	Number of patients in each trajectory class				
				1	2	3	4	5
1	1731.967	NA	1.0	351				
2	1707.318	p < .001	.895	273	78			
3	1689.257	p < .001	.874	254	74	23		
4	1667.653	p < .001	.868	227	46	20	58	
5	1652.770	p < .001	.906	3	59	54	218	17
<i>Psychosocial HRQoL</i>								
Number of trajectories	BIC	BLRT	Average posterior probability	Number of patients in each trajectory class				
				1	2	3	4	5
1	2573.452	NA	1.0	351				
2	2546.187	p < .001	.907	244	107			
3	2522.731	p < .001	.851	211	96	44		
4	2512.672	p < .001	.835	158	54	64	75	
5	2506.350	p < .001	.809	157	72	8	59	55

Abbreviations: BIC, Bayesian Information Criterion; BLRT, Bootstrap Likelihood Ratio Tests; NA, Not applicable.

## Predictors of physical and psychosocial HRQoL

Demographic factors, stroke-related factors and psychological factors for each physical and psychosocial HRQoL trajectory are displayed in Table 8.4. Multinomial bivariate regression analyses were performed to determine the predictors which could discriminate between the physical and psychosocial HRQoL trajectories. Results are presented in Table 8.5. Comparisons between the low and high trajectories are presented because we expected that the largest differences would be found between these trajectories. In addition, comparisons are presented for the low vs. recovery trajectory and the decline vs. high trajectory, as these comparisons are clinically most relevant. The other three comparisons for the physical and psychosocial HRQoL trajectories (recovery vs. high, decline vs. recovery and low vs. decline) are presented in Appendix 8.1.

Compared with the high physical HRQoL patient group (N = 227), the patients with low physical HRQoL (N = 46) were more likely to have a more severe stroke, to be discharged to a rehabilitation setting, to be dependent in ADL two months post stroke, to have higher

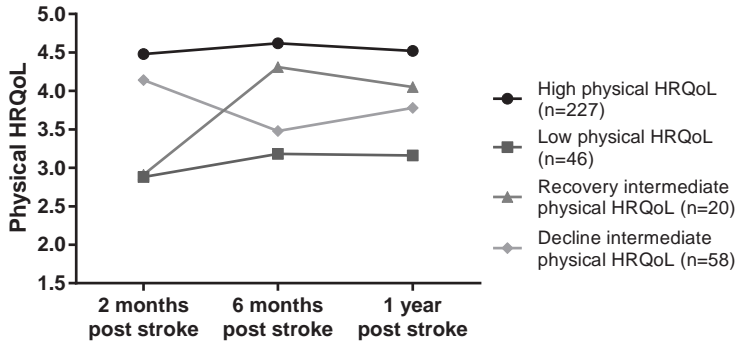


Figure 8.1 Four-trajectory model of physical HRQoL.

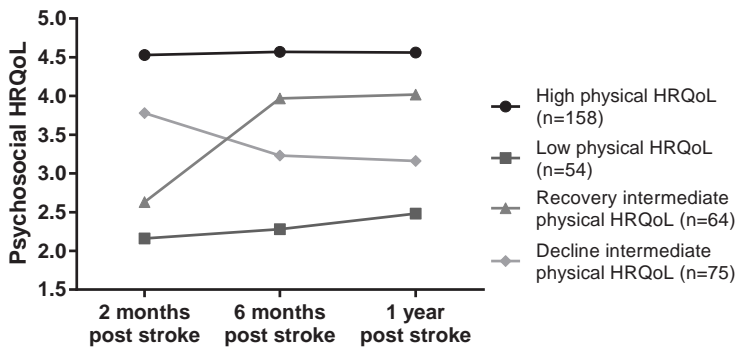


Figure 8.2 Four-trajectory model of psychosocial HRQoL.

scores for neuroticism, pessimism, feelings of helplessness and passive coping, and to have lower scores for acceptance of the stroke and proactive coping. Comparing the low ( $N = 46$ ) and recovery ( $N = 20$ ) trajectories shows that the patient group with low physical HRQoL was more likely to have higher scores for neuroticism. Compared with the high physical HRQoL patient group ( $N = 227$ ), the patients with a decline in HRQoL ( $N = 58$ ) were more likely to be discharged to a rehabilitation setting, to have higher scores for neuroticism, pessimism, feelings of helplessness and passive coping, and to have lower scores for acceptance of the stroke.

Compared with the high psychosocial HRQoL patient group ( $N = 158$ ), the patients with low psychosocial HRQoL were more likely to be dependent in ADL two months post stroke, to have higher scores for comorbidity, neuroticism, pessimism, helplessness and passive coping, and to have lower scores for optimism, self-efficacy, acceptance, perceived benefits, and proactive coping. Comparing the low ( $N = 54$ ) with the recovery ( $N = 64$ )

**Table 8.4** Demographic, stroke-related and psychological factors for different trajectories of physical and psychosocial HRQoL

	Physical HRQoL				Psychosocial HRQoL			
	Class 1, high (n = 227)	Class 2, low (n = 46)	Class 3, recovery (n = 20)	Class 4, decline (n = 58)	Class 1, high (n = 158)	Class 2, low (n = 54)	Class 3, recovery (n = 64)	Class 4, decline (n = 75)
<b>Demographic factors</b>								
Sex (male)	66.5	65.2	65.0	55.2	67.1	64.8	60.9	61.3
Age in years	64.7 ± 11.6	72.3 ± 12.0	67.2 ± 13.9	70.2 ± 13.8	66.2 ± 12.0	65.3 ± 13.1	68.1 ± 14.4	67.9 ± 11.3
Marital status, living together	71.4	69.6	60	65.5	69.0	74.1	68.8	68
High education level <sup>a</sup>	30.8	19.6	10.0	25.9	29.1	22.2	20.3	33.3
<b>Stroke-related factors</b>								
Severity of stroke	2.2 ± 2.5	3.9 ± 4.4	3.8 ± 4.8	3.0 ± 2.8	2.2 ± 2.7	2.9 ± 3.8	2.9 ± 3.7	2.9 ± 2.7
Discharge home from hospital	81.1	52.2	55.0	56.9	81	63.0	70.3	60.0
ADL-dependent (BI ≤ 17)	2.3	38.6	20.0	11.1	3.2	17.0	15.9	11.9
Cognitively impaired (MoCA ≤ 25)	61.6	82.5	65.0	77.8	58.1	72.5	73.8	77.3
Comorbidity, mean (SD)	3.7 ± 2.5	4.8 ± 2.6	3.8 ± 2.7	4.8 ± 3.2	3.6 ± 2.5	4.6 ± 2.3	3.6 ± 2.7	4.8 ± 3.2
<b>Psychological factors</b>								
Extraversion	7.3 ± 3.1	6.4 ± 3.3	6.5 ± 4.0	7.0 ± 3.3	7.7 ± 3.1	6.5 ± 3.4	6.5 ± 3.3	6.8 ± 3.1
Neuroticism	3.2 ± 3.0	5.1 ± 3.3	3.1 ± 2.4	4.5 ± 3.1	2.5 ± 2.6	6.1 ± 3.7	4.1 ± 2.5	3.8 ± 3.0
Optimism	8.4 ± 2.1	7.4 ± 2.2	8.3 ± 2.0	7.8 ± 2.3	8.7 ± 2.0	6.8 ± 2.0	7.8 ± 2.2	8.3 ± 2.0
Pessimism	4.0 ± 2.8	5.3 ± 2.5	3.7 ± 2.3	5.3 ± 2.7	3.7 ± 2.9	5.2 ± 2.7	5.0 ± 2.4	4.6 ± 2.5
Self-efficacy	32.2 ± 6.2	29.3 ± 7.8	30.1 ± 4.4	31.3 ± 5.8	33.7 ± 5.7	28.6 ± 7.4	30.2 ± 5.5	30.2 ± 6.0
Helplessness	10.3 ± 4.1	16.6 ± 4.7	15.0 ± 4.1	13.3 ± 5.0	9.4 ± 3.9	15.9 ± 4.5	14.2 ± 4.8	12.4 ± 4.1
Acceptance	17.6 ± 4.6	13.5 ± 4.8	14.0 ± 3.8	14.9 ± 4.6	18.4 ± 4.5	12.9 ± 4.0	14.5 ± 4.3	16.3 ± 4.4
Perceived benefits	15.3 ± 4.7	13.9 ± 5.5	15.2 ± 4.2	14.8 ± 5.1	15.9 ± 4.9	12.9 ± 4.3	15.0 ± 4.4	14.9 ± 4.8
Proactive coping	3.2 ± 0.5	2.8 ± 0.7	2.9 ± 0.4	3.0 ± 0.6	3.3 ± 0.5	2.7 ± 0.7	2.9 ± 0.5	3.0 ± 0.5
Passive coping	9.9 ± 2.4	12.4 ± 3.7	11.2 ± 2.7	11.4 ± 3.0	9.4 ± 2.2	12.7 ± 3.7	11.1 ± 2.4	11.0 ± 2.5

NOTE: values are percentages or mean ± SD.

There were some missing values on cognition, comorbidity and all psychological variables. The number of patients on these measures varied for physical HRQoL: high 218–220; low: 40–44; decline: 53–54. The number of patients on these measures varied for psychosocial HRQoL: high: 154–155; low: 51–53; recovery: 61–63; decline: 65–67. <sup>a</sup> Patients completed higher professional education or have a university degree.

Table 8.5 Multinomial bivariate regression analyses to distinguish between the physical and psychosocial HRQoL trajectories (n = 351)

	Physical HRQoL				Psychosocial HRQoL			
	Low (reference) vs. high	Low (reference) vs. recovery	Decline (reference) vs. high		Low (reference) vs. high	Low (reference) vs. recovery	Decline (reference) vs. high	
	Odds ratio	Odds ratio	Odds ratio	95% CI	Odds ratio	Odds ratio	Odds ratio	95% CI
<b>Demographic factors</b>								
Sex (female)	NS	NS	NS	NS	NS	NS	NS	NS
Age	NS	NS	NS	NS	NS	NS	NS	NS
Relationship (yes)	NS	NS	NS	NS	NS	NS	NS	NS
Education (high)	NS	NS	NS	NS	NS	NS	NS	NS
<b>Stroke-related factors</b>								
Severity of stroke	0.81	0.70–0.94	NS	NS	NS	NS	NS	NS
Discharge (home)	5.17	2.16–12.39	NS	NS	4.02	1.83–8.83	NS	NS
ADL (independent)	109.40	5.60–2135.29	NS	NS	NS	NS	8.94	1.82–43.88
Cognition (normal)	NS	NS	NS	NS	NS	NS	NS	NS
Comorbidity	NS	NS	NS	NS	NS	NS	0.84	0.74–0.96
<b>Psychological factors</b>								
Extraversion	NS	NS	NS	NS	NS	NS	NS	NS
Neuroticism	0.79	0.69–0.89	0.78	0.66–0.93	0.85	0.75–0.95	0.64	0.54–0.75
Optimism	NS	NS	NS	NS	NS	NS	1.65	1.36–2.00
Pessimism	0.82	0.72–0.93	NS	NS	0.82	0.71–0.94	0.79	0.69–0.91
Self-efficacy	NS	NS	NS	NS	NS	NS	1.20	1.09–1.31
Helplessness	0.69	0.62–0.78	NS	NS	0.84	0.77–0.92	0.64	0.55–0.75
Acceptance	1.30	1.12–1.52	NS	NS	1.16	1.06–1.27	1.37	1.23–1.53
Perceiving benefits	NS	NS	NS	NS	NS	NS	1.16	1.07–1.26
Proactive coping	5.65	1.95–16.42	NS	NS	NS	NS	14.15	5.24–38.23
Passive coping	0.70	0.60–0.82	NS	NS	0.79	0.68–0.91	0.55	0.45–0.68
								0.76
								1.19
								0.65–0.89
								NS
								NS
								4.52
								0.53–0.82

Abbreviations: CI, confidence interval; NS, non significant.

trajectory showed that the patient group with low psychosocial HRQoL was more likely to have higher scores for neuroticism. Compared with the high physical HRQoL patient group (N = 158), the patients with a decline in HRQoL (N = 75) were more likely to be discharged to a rehabilitation setting, to have higher scores for helplessness and passive coping, and to have lower scores for self-efficacy and proactive coping.

## Discussion

The present study identified four distinct trajectories for both physical and psychosocial HRQoL in stroke patients during a one-year follow-up period post stroke. Trajectories identified for both physical and psychosocial HRQoL were: high, low, recovery and decline of HRQoL. Psychological factors proved to be the most important factors determining trajectory membership.

To our knowledge, this is the first study to examine the presence of different trajectories in the course of physical and psychosocial HRQoL post stroke and to determine predictors of these different trajectories. In the present study, a large group experienced a high stable physical (65%) and psychosocial (45%) HRQoL trajectory. According to Bonanno et al. (2008),<sup>20</sup> resilience with little or no dysfunction is the most common outcome in response to potential trauma, which is in agreement with what we found in the present study. The other three trajectories Bonanno proposed, recovery with a relatively mild and short-lived dysfunction, delayed dysfunction and chronic dysfunction, were partially found in the results of the present study. This confirms our hypothesis regarding the number and course of the trajectories. The low HRQoL trajectory corresponds to the chronic dysfunction trajectory, while the recovery and decline HRQoL trajectories correspond to the recovery and delayed dysfunction trajectories proposed by Bonanno, respectively. However, the recovery of HRQoL in the recovery trajectory did not reach the level of HRQoL found in the high trajectory. In the decline trajectory, the decrease in HRQoL was minor and it ended up at a moderate level. Furthermore, it is not clear what the starting point of HRQoL was and when the decline started. It may have already started in the acute phase post stroke, rather than at two months post stroke, as that was the moment when HRQoL was assessed in the present study.

Recovery of both physical and psychosocial HRQoL seems to take place in the early months post stroke, and to stabilize thereafter. It is difficult to compare our findings with those of earlier studies, because earlier findings were inconclusive: one study found a decline



in psychosocial HRQoL between 6 and 12 months<sup>15</sup> while in another study psychosocial HRQoL increased and physical HRQoL decreased between 4 and 16 months post stroke.<sup>16</sup> The findings of the present study indicate that where there is recovery of HRQoL, most of it takes place in the first months post stroke. This is in agreement with the assumed time-frame for functional recovery after stroke, which involves most of the functional recovery taking place in the first six months post stroke,<sup>18</sup> and, recovery reaching a plateau at an average of three to six months after stroke onset.<sup>47</sup> It is surprising that we found the same time-frame for the recovery of HRQoL post-stroke, as we assume that adaptation post stroke, especially psychosocial adaptation, is a continuous process which stretches over a long period that begins when the patient starts to realize that there will be no full recovery of functioning, despite rehabilitation efforts in the first 3–6 months.<sup>48</sup> In any case, the present results indicate that it is important to be aware of this comparable time-frame for the recovery of HRQoL post stroke, and to identify and start caring for patients at risk of unfavourable HRQoL trajectories as early as two months post stroke, and preferable already in the acute phase.

The second aim of this study was to determine factors that can predict physical and psychosocial trajectory membership, in order to identify those patients at risk of poor adaptation post stroke. These are the patients in the low and decline HRQoL trajectories, and they made up about 30–37% of our total patient group, which is somewhat higher than Bonanno proposed for the chronic dysfunction and delayed dysfunction trajectories (10–20%).<sup>20</sup> Two months post stroke, the low and recovery trajectories both had a relatively low physical and psychosocial HRQoL score, while the decline and high trajectories both had a relatively high physical and psychosocial HRQoL score two months post stroke (Figures 8.1 and 8.2). Thus, it is possible and relevant to discriminate the low from the recovery trajectory and the decline from the high trajectory as early as two months post stroke.

Compared with the recovery HRQoL patient groups, the groups with low physical and psychosocial HRQoL were only more likely to have higher scores for neuroticism. Fortunately, more factors were found to distinguish between the decline and high trajectories. For the decline versus high trajectory, the following predictors were found for physical HRQoL: being discharged to a rehabilitation setting, less acceptance, and more neuroticism, pessimism, helplessness and passive coping. Predictors for psychosocial HRQoL were largely the same: being discharged to a rehabilitation setting, less self-efficacy and proactive coping, and more helplessness and passive coping. We had hypothesized that physical

trajectories would be predicted more by stroke-related factors and psychosocial trajectories more by psychological factors. Our results show that psychosocial trajectory membership is indeed predicted more by psychological factors, but these psychological factors are also more important than stroke-related factors in predicting physical trajectory membership. This is surprising, as stroke-related factors such as physical disability and daily functioning have consistently been found to be independent predictors of HRQoL.<sup>21,22</sup> This means that psychological factors are more important in determining HRQoL trajectory membership than demographic and stroke-related factors. This is promising, because stroke-related factors are difficult to modify after the acute phase, while some of the psychological factors may be amendable to treatment.

The psychological predictors that we found may be used to modify the vulnerable trajectories into more favourable trajectories. Neuroticism and pessimism are personality traits which are assumed to remain relatively stable throughout life.<sup>49</sup> Fortunately, however, it has been shown that coping styles are modifiable; traumatic brain injury patients can be taught to make use of more adaptive coping styles, such as active problem-focused styles.<sup>50</sup> A study assessing an individualized stroke self-management intervention found positive results in terms of changing self-efficacy after stroke<sup>51</sup> Furthermore, studies of patients with other chronic diseases, such as inflammatory rheumatic diseases, have reported promising results concerning the possibility of modifying illness cognitions by means of multidisciplinary rehabilitation treatment and cognitive behavioural therapy.<sup>52,37</sup> More research is necessary to find out if there are more factors which determine favourable or unfavourable HRQoL trajectories post stroke and how these factors can be changed.

### **Strengths and limitations**

The study had several strengths and limitations. One of the strengths is that it included a large group of stroke patients (N = 351) examined in a longitudinal design, with several follow-up assessments up to one year post stroke. Another is that this is the first study to investigate the course of psychosocial and physical HRQoL on the basis of several trajectories. Finally, we investigated predictors that can discriminate between these trajectories, taking into account a broad range of potential predictors, i.e. demographic factors, stroke-related factors and psychological factors.

However, interpretation of our results must take account of the following limitations. First, most patients included in the present study seemed to have suffered a minor stroke, and experienced minor physical problems. A possible explanation for this is that patients

who had suffered a severe stroke may have had difficulty understanding the instructions for the study and not may have been able to provide informed consent within one week after the event. Nevertheless, we think we have captured the 'average' stroke patient. In our view the majority of stroke patients suffers a mild stroke and experiences minor physical problems. Even patients who suffer a mild stroke can have problems which interfere with their daily lives.<sup>7</sup>

Another limitation is that the follow-up period was one year post stroke. Although most of the changes in the course of HRQoL in the present study occurred in the first six months post stroke, it is possible that HRQoL still changes after one year post-stroke. For example, a study on life satisfaction in patients with spinal cord injury found no changes between discharge from inpatient rehabilitation and two years later, but increases were found in life satisfaction from two to five years post discharge.<sup>53</sup>

## Conclusion

Patients who suffer a stroke can show psychosocial and physical HRQoL trajectories that can be characterized as stable high or low, recovery, or decline. The findings indicate that psychological factors are the most important factors that can be used to identify patients at risk of unfavourable physical and psychosocial HRQoL trajectories. Determining these predictors as early as two months post stroke will help to identify those patients at risk of poor adaptation post stroke, and to guide rehabilitation in the early stages post stroke.

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## Appendix 8.1

Multinomial bivariate regression analyses to distinguish between the physical and psychosocial HRQoL trajectories (n = 351)

	Physical HRQoL				Psychosocial HRQoL			
	Recovery (reference) vs. high	Decline (reference) vs. recovery	Low (reference) vs. decline		Recovery (reference) vs. high	Decline (reference) vs. recovery	Low (reference) vs. decline	
	Odds ratio	Odds ratio	Odds ratio	95% CI	Odds ratio	Odds ratio	Odds ratio	95% CI
<b>Demographic factors</b>								
Sex (female)	NS	NS	NS	NS	NS	NS	NS	NS
Age	NS	NS	NS	NS	NS	NS	NS	NS
Relationship (yes)	NS	NS	NS	NS	NS	NS	NS	NS
Education (high)	NS	NS	NS	NS	NS	NS	NS	NS
<b>Stroke-related factors</b>								
Severity of stroke	NS	NS	NS	NS	NS	NS	NS	NS
Discharge (home)	4.15	1.45–11.85	NS	NS	NS	NS	NS	NS
ADL (independent)	NS	NS	NS	NS	NS	NS	NS	NS
Cognition (normal)	NS	NS	NS	NS	NS	NS	NS	NS
Comorbidity	NS	NS	NS	NS	NS	NS	NS	NS

Appendix 8.1 continues on next page.



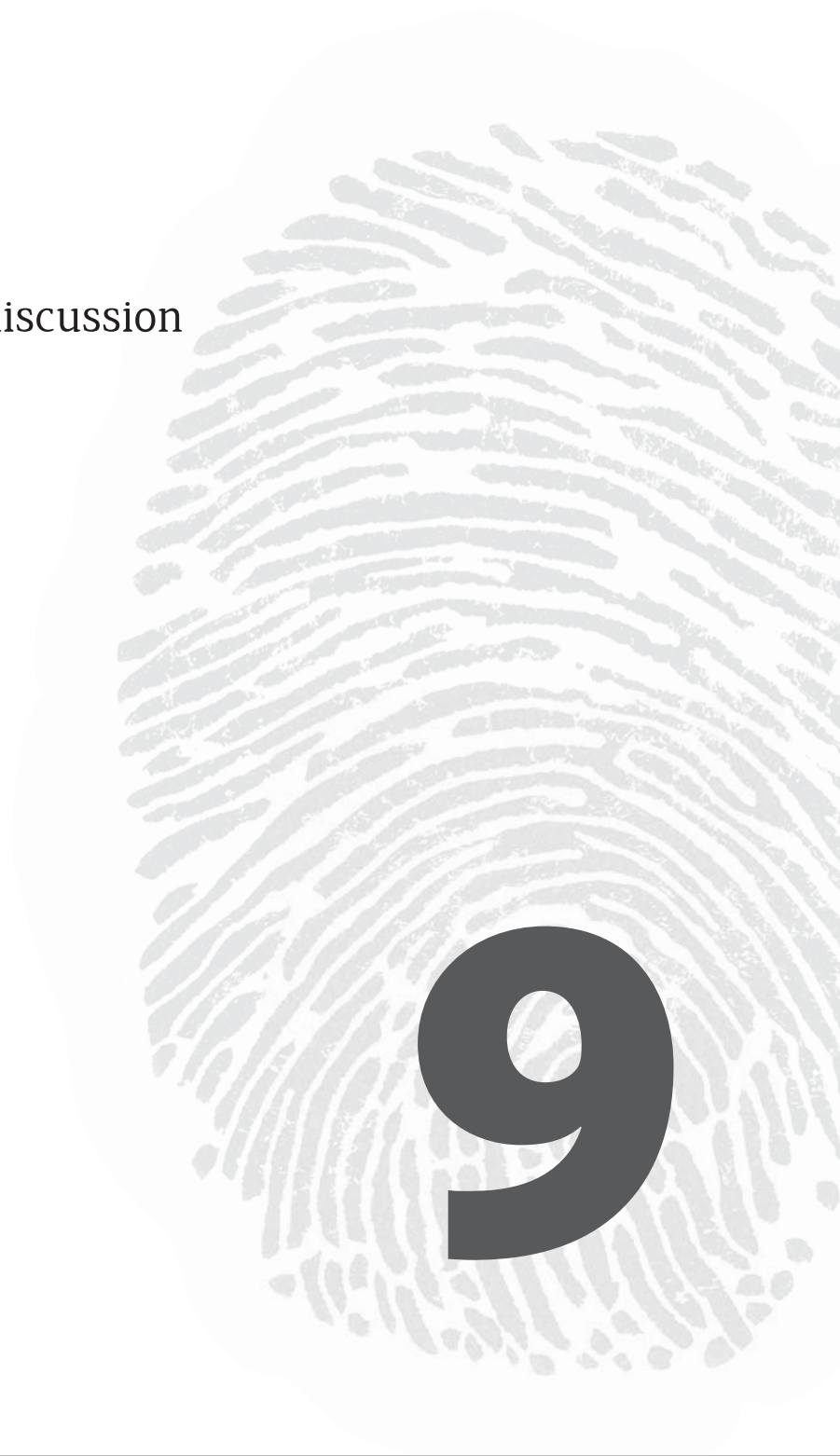
Appendix 8.1 Continued

	Physical HRQoL			Psychosocial HRQoL		
	Recovery (reference) vs. high	Decline (reference) vs. recovery	Low (reference) vs. decline	Recovery (reference) vs. high	Decline (reference) vs. recovery	Low (reference) vs. decline
	Odds ratio	Odds ratio	Odds ratio	Odds ratio	Odds ratio	Odds ratio
	95% CI	95% CI	95% CI	95% CI	95% CI	95% CI
<b>Psychological factors</b>						
Extraversion	NS	NS	NS	NS	NS	NS
Neuroticism	NS	NS	NS	0.79	0.69–0.90	0.78
Optimism	NS	NS	NS	NS	NS	1.51
Pessimism	NS	NS	NS	0.80	0.70–0.92	NS
Self-efficacy	NS	NS	NS	1.16	1.06–1.27	NS
Helplessness	0.77	0.70–0.85	NS	0.68	0.58–0.81	0.85
Acceptance	1.21	1.10–1.34	NS	1.27	1.15–1.40	1.21
Perceiving benefits	NS	NS	NS	NS	NS	NS
Proactive coping	2.92	1.60–5.36	NS	7.39	3.46–15.78	NS
Passive coping	NS	NS	NS	0.66	0.55–0.81	NS

Abbreviations: CI, confidence interval; NS, non significant.



General discussion



The aims of the Restore4Stroke Patient Cohort study were to investigate the course of quality of life (QoL) in stroke patients and to determine factors predicting QoL, including demographic factors and stroke-related factors and with special interest in psychological factors. The results of this study were presented in the previous chapters. This final chapter starts with an overview of the main findings and conclusions. Subsequently, theoretical considerations and implications for clinical practice are discussed. Finally, methodological considerations and ideas for future research are presented.

## Main findings

### Part I QoL after stroke

In the studies described in **chapters 3 and 4** the focus was on the consequences of stroke for QoL of the patients involved. **Chapter 3** described the course of QoL in four domains: stroke-specific health-related quality of life (HRQoL), emotional functioning, participation restrictions and life satisfaction. In general, the results showed that most recovery of QoL takes place in the first six months post stroke. In the second year post stroke no significant changes in any QoL domain were found. Furthermore, this study showed that the course of QoL from two months up to two years post stroke is different for patients dependent in activities of daily living (ADL) compared to patients independent in ADL in the first week post stroke. Patients dependent in ADL showed longer periods of improvement on participation than patients independent in ADL. On the other hand, patients independent in ADL showed longer periods of improvement on life satisfaction than patients dependent in ADL. Moreover, patients independent in ADL had consistently higher levels of QoL. **Chapter 4** focused on one QoL domain, participation. The results showed that the frequency of participation declines after a stroke in comparison with the pre-stroke situation. This decrease in frequency of participation was most apparent in vocational activities and less in leisure and social activities.

### Part II Influence of psychological factors on QoL

**Chapter 5** described the results of a systematic review of the literature on psychological factors that are associated with HRQoL post stroke. All psychological factors considered, except extraversion, were significantly associated with HRQoL. The results revealed that psychological factors can be divided into factors that are positively or negatively related

to HRQoL post stroke. Personality characteristics, such as problems with temperament and personality functions as well as neuroticism, were moderately associated with lower levels of HRQoL. Optimism, hope, internal locus of control, self-worth, and coping (i.e. situational and personal adaptation, and religious and spiritual coping) were moderately associated with higher levels of HRQoL.

In **chapters 6, 7 and 8**, the associations between psychological factors and QoL were investigated taking demographic and stroke-related factors into account. The results revealed that psychological factors play an important role in determining QoL post stroke. In **chapter 6**, the relationship between psychological factors and post-stroke depressive symptoms two months post stroke was examined. More helplessness and passive coping and less acceptance and perceived benefits of the stroke were independently related with the presence of depressive symptoms. **Chapter 7** focused on one particular psychological factor, namely illness cognitions. The following illness cognitions were measured: feelings of helplessness, acceptance of the stroke and perceiving benefits of the stroke. The results showed that all illness cognitions two months post stroke and changes in illness cognitions between two months and two years post stroke predicted life satisfaction two years post stroke. **Chapter 8** revealed that not all patients experience recovery of HRQoL. Four trajectories for both physical and psychosocial HRQoL post stroke were revealed: high, low, recovery and decline of HRQoL. In the high, low and decline trajectories no recovery of HRQoL took place. Furthermore, in general, patients in the more unfavorable trajectories, decline and low HRQoL, had higher levels of psychological factors such as passive coping and neuroticism, which had a negative influence on HRQoL, and lower levels of positive psychological factors such as self-efficacy and feelings of acceptance of the stroke. Just as in **chapter 6 and 7**, psychological factors were the most important factors, while demographic and stroke-related factors played a minor role in determining trajectory membership of HRQoL post stroke.

## Theoretical considerations

### The Restore4Stroke Patient Cohort study embedded in stroke research in the Netherlands

Looking back, how can we link the results of the Restore4Stroke Patient Cohort study to earlier studies performed in the Netherlands? Over the last 15 years, the concept of QoL

has become increasingly popular in healthcare and research. Functional recovery was no longer solely the focus of rehabilitation and research. Longitudinal studies were executed that place importance on the psychosocial functioning of the patient, and QoL and HRQoL measures were developed and investigated in stroke patients.<sup>1,2</sup> From these studies, it became clear that after a stroke, patients experience problems in daily activities and psychosocial functioning and that stroke-related and demographic factors do not tell the whole story of a patient's functioning. These factors do not explain why some patients with severe impairments adapt well, whereas other patients with minor impairments experience low levels of QoL.<sup>3</sup> This has led to growing interest in the influence of psychological factors on QoL post stroke because it has been considered that these factors reflect the way people approach and react to stressful situations.<sup>4</sup> Furthermore, these two earlier studies included only patients discharged to inpatient rehabilitation.<sup>1,2</sup> However, the largest group of stroke patients is discharged directly home after hospitalization.<sup>5</sup> Results of our systematic review (**chapter 5**) revealed that at the start of the Restore4Stroke Cohort study only nine studies examined the association between psychological factors and QoL. Two of these studies were executed in the Netherlands<sup>6,7</sup> but QoL was investigated only up to one year post stroke and as psychological factor only coping was taken into account. The results of the present thesis add to these earlier studies and expand our knowledge about the course of QoL in the entire group of stroke patients (discharged to rehabilitation center and directly to home) and the influence of psychological factors alongside demographic and stroke related factors.

The first part of the theoretical considerations focuses on the knowledge about the concept and the course of QoL, and the second part addresses the influence of psychological factors on QoL.

### **QoL as a concept**

In the Restore4Stroke Patient Cohort study we used an extensive set of measures to assess the influence of stroke on QoL. Using the International Classification of Functioning, Disability and Health (ICF) model helps to place all of these measures in perspective and in relation to each other. The ICF-model was developed by the World Health Organization to provide a standard language and framework for the description of health and health-related states<sup>8</sup> and describes human functioning at three levels: at the level of body or body part, at the level of the whole person, and at the level of the whole person in a social context. This information is organized in three domains, respectively: body functions & structures,

activities and participation. Disability involves dysfunction at one or more of these domains: impairments, activity limitations and participation restrictions. Furthermore, contextual factors are also part of this model. These are divided into environmental factors and personal factors and can influence each of the three domains of the ICF-model.

The factors assessed in the Restore4Stroke Patient Cohort study cover all of the domains of the ICF-model. For example, cognition and emotional functioning are part of the body functions & structures domain; activities of daily living are part of the activities domain; and participation is part of the participation domain. Furthermore, demographic factors and psychological factors, such as personality and coping styles, are part of the personal factors, and factors related to the partner are part of the environmental factors.

In chapter 1 we explained that no generally accepted definition of QoL exists. Furthermore, in the literature, these concepts are used interchangeably, which makes it hard to compare results across different studies. The ICF-model does not specify QoL. We considered QoL to be a superordinate construct comprising HRQoL and well-being. From this perspective, QoL stands above the three domains of the ICF, body functions & structures, activities and participation. Post et al. (2005)<sup>9</sup> proposed a useful conceptual model that integrates QoL as superordinate construct in the ICF-model. The proposed model adds one domain to the ICF-model, namely overall well-being. Together, the consequences of the stroke (body functions & structures, activities, and participation) and overall well-being cover the most relevant domains of QoL according to the superordinate approach<sup>9</sup> (see Figure 9.1). Personal and environmental factors can influence the consequences of the stroke and overall well-being, but they are not part of QoL.

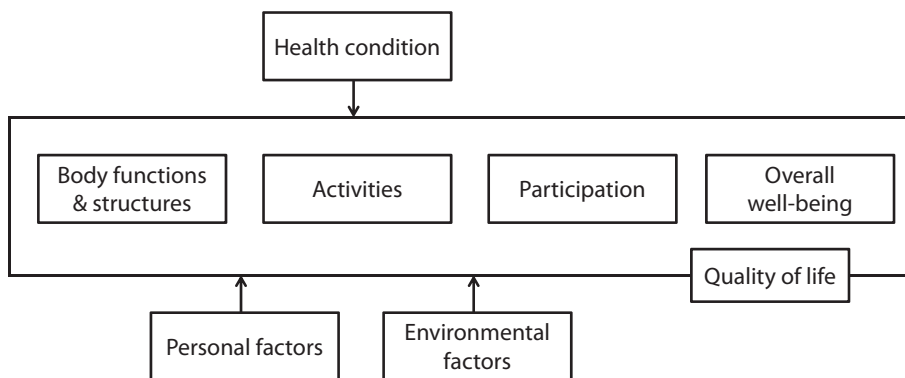


Figure 9.1 Conceptual model of quality of life.

In the present thesis we assessed QoL by means of several measures. The measures that assessed specific domains of QoL cover the body functions & structures domain (emotional functioning), the participation domain (participation restrictions), and the well-being domain (life satisfaction). HRQoL is a subset of QoL aspects related to health and is related to the body functions & structures, activities and participation domains. The proposed conceptual model provides a framework that can be used to specify the domain of QoL that has been measured in research and stroke care and shows that QoL can be measured from different perspectives. Therefore, we recommend using a model in future studies which defines QoL, as studies become better comparable when the domain of QoL that is measured, is specified.

### Quality of life after stroke

The course of QoL, presented in **chapter 3**, was assessed by several measures covering all the domains of QoL as proposed in Post's model, presented above. In general, these QoL measures showed similar patterns, namely that most recovery of QoL took place in the first six months post stroke, which was also found in **chapter 8**, and that no changes in QoL occurred between 1 and 2 years post stroke. This is surprising, because we assume that adaptation post stroke is an ongoing process in which patients, on the one hand, try to achieve their maximal restoration of functioning but, on the other hand, need to adjust to the alterations in life and other consequences of their stroke.<sup>10</sup> This process is considered to take more time than six months. For example, increases in HRQoL have been found up to 16 months post stroke.<sup>11</sup> That all measures showed relatively the same course of recovery of QoL post stroke strengthens our conclusion regarding the time frame of recovery and adaptation and shows that all these measures are related to each other and to the concept of QoL. However, it must be noted that some QoL domains such as participation showed longer periods of improvement up to one year post stroke. Furthermore, these results reflect average scores on the QoL measures. The trajectory analyses described in **chapter 8** revealed that only a minority of the patients showed recovery of HRQoL and other subgroups showed stable high or low HRQoL scores over the follow-up period. Even these subgroup trajectories reflect however group data. It is plausible that individual patients may still show signs of recovery or decline one year post stroke. For example, a study on mobility found that between one and three years post stroke 72% had maintained their mobility, 21% experienced a decline in mobility and 7% had improved mobility.<sup>12</sup>

Regarding the patients who were dependent in ADL four days post stroke, the only domain in which recovery continued during the first year post stroke was their experienced



participation restrictions. In patients independent in ADL, we found recovery in participation restrictions up to six months post stroke. The first priority of patients after a stroke is to regain functioning in terms of activities. Before recovery of participation could take place, recovery at the activity level is required. For example, someone must be able to walk before he can do his shopping by foot. This process takes time, which might explain the longer time-frame of recovery in participation restrictions in patients who suffered a more severe stroke in comparison to patients with minor strokes. These patients experience more problems after their stroke and have more to 'gain'.

For future research we therefore recommend measuring QoL in stroke care, particularly at the activities and participation level because activities and participation are closely linked to the goals that patients set after a stroke and are, in our opinion, less influenced by personal and environmental factors than much broader concepts such as HRQoL and life satisfaction. Furthermore, these broad concepts could be harder to change through the achievement of one, individual, goal. Finally, we believe that it is also important to consider QoL from different perspectives, as this will lead to a more complete picture of QoL. Post's model,<sup>9</sup> as described above, can be used for the selection of domains of QoL.

## Psychological factors

### *Theoretical models addressing psychological factors*

In the Restore4Stroke Cohort study we have measured several psychological factors. The influence of factors such as neuroticism, self-efficacy, optimism, and coping on QoL post stroke was already demonstrated in earlier studies.<sup>6,7,13-19</sup> However, the number of patients and psychological factors per study were small and most studies had a cross-sectional design.

Several models exist addressing the influence of psychological factors on adaptation. The most important of these theories are the Common Sense Model (CSM) by Leventhal<sup>20</sup> and the Transactional Model of Stress and Coping of Lazarus.<sup>21</sup> The CSM assumes that when people are confronted with a chronic disease, they try to make sense of it by creating a cognition of it, which influences their coping strategies and hence their illness adaptation.<sup>22</sup> In addition, a person's stable characteristics, such as personality traits, are assumed to influence the process of creating the illness cognitions.<sup>22,23</sup> Thus, the influence of personality traits on QoL is mediated through illness cognitions and coping styles. The Transactional Model of Stress and Coping offers a framework for evaluating the processes of coping with stressful events. Stressful experiences are construed as person-environment transactions.

These transactions depend on the impact of the external stressor (here, the consequences of stroke). When a stressor is experienced, the person evaluates the potential threat, which is called the primary appraisal. Primary appraisal is a person's judgement about the significance of an event as being stressful. When the stressor is evaluated as being stressful, secondary appraisal follows. Secondary appraisal addresses what can or cannot be done about the stressful event and is an assessment of personal coping options. The process of secondary appraisal results in coping.<sup>21,24,25</sup>

In general, these two models are comparable; they both define distinctive psychological factors, such as illness cognitions and coping styles, and propose a mechanism through which these factors influence each other and outcomes in terms of QoL. Furthermore, the illness cognitions in the CSM are comparable to what are called appraisals in the Transactional Model of Stress and Coping. In order to modify psychological factors post stroke to promote adaptation in terms of QoL, the essential first step is to investigate if psychological factors are indeed associated with QoL post stroke, which was one of the aims of the present thesis. We wanted to investigate the influence of a broad spectrum of psychological factors on QoL and used the CSM to select the psychological factors assessed in the Restore4Stroke Cohort study. We have chosen to use the CSM to emphasize the role of illness cognitions because not much was known about illness cognitions in stroke patients, and these factors may be amendable to treatment.

To our best knowledge we executed the first research in stroke patients that used one of these theoretical models to select psychological factors. Using the CSM model ensured not only a conscious selection of psychological factors but also allowed us to investigate the mechanisms between the psychological factors and QoL because we now know that several of these psychological factors are associated with QoL post stroke.

### ***Psychological factors associated with QoL***

In our cohort study we found that all psychological factors taken into account were related to a QoL domain (**chapters 6, 7, and 8**). Some factors were consistently associated across QoL domains: neuroticism (negative), passive coping (negative), and the illness cognitions helplessness (negative), acceptance (positive) and perceiving benefits (positive).

The association between neuroticism and HRQoL in stroke patients was already found in our systematic review (**chapter 5**) and in a more recent study.<sup>26</sup> In this recent study it was also found that neuroticism was associated with several domains of QoL. Passive coping was not examined as a psychological factor in one of the included articles in the

systematic review, but in patients with acquired brain injury and aneurysmal subarachnoid hemorrhage, passive coping was consistently found as a factor of QoL.<sup>27,28</sup> The role of illness cognitions has been recognized in the development, maintenance, and modification of psychological well-being in several chronic diseases.<sup>29-32</sup> However, in the stroke literature, the associations between illness cognitions and QoL are new. Until now, it was only found that low levels of acceptance in the subacute phase post stroke predicted depression nine months post stroke.<sup>33</sup> However, our finding that a change in maladaptive (helplessness) as well as adaptive (acceptance and perceiving benefits) illness cognitions is associated with life satisfaction two years post stroke (**chapter 7**) is important, as it can be used to develop interventions to try to change illness cognitions.

### *Changeable psychological factors*

The goal of stroke care is to prevent complications, to minimize impairments and to maximize functioning so that patients can participate in society at the most independent level possible. From the results of the present thesis we now know that a broad spectrum of psychological factors are associated with QoL post stroke. To use these factors in interventions to optimize adaptation post stroke in terms of QoL, the next step in research would be to investigate if these psychological factors are subjective to change. What do we already know about the changeability of psychological factors in patient groups?

Illness cognitions were consistently related to QoL and seem modifiable. Questioning the maladaptive cognitions patients have about their stroke and trying to change the way patients encounter problems and consequences of the stroke should therefore be a target during rehabilitation. In the stroke literature not much is written about changing illness cognitions factors by means of therapy. On the other hand, challenging and questioning illness cognitions is a significant part of what psychologists already do.<sup>34</sup> Furthermore, research in patients with other chronic diseases found positive changes in maladaptive illness cognitions after multidisciplinary rehabilitation treatment or cognitive behavioral therapy,<sup>35,36</sup> and it was found that patients with traumatic brain injury can be taught to make use of more adaptive coping styles.<sup>37</sup>

Promising results have also been found in strengthening task-specific self-efficacy beliefs, such as memory self-efficacy in stroke patients<sup>38</sup> and self-efficacy in coping in brain injury patients.<sup>39</sup> Furthermore, optimizing general feelings of self-efficacy in stroke patients has also been found to be beneficial.<sup>40</sup> In the present thesis we assessed general self-efficacy, the patient's general confidence that they can be successful in tasks and situations, irrespective

of the task or situation, but unfortunately this form of self-efficacy was not consistently found as a predictor in the present thesis.

Other personality characteristics, such as neuroticism and extraversion, are assumed to remain relatively stable over the life span.<sup>41</sup> However, there is also increasing evidence that personality characteristics have the potential to change and develop during one's life. This could be caused by psychological maturation, the changing of social roles in adulthood, or significant life events<sup>42</sup> but also by severe brain injury.<sup>43</sup> Nonetheless, it is unclear if personality characteristics can be changed by means of therapy.

Summarizing, positive results have been found for changing illness cognitions, passive coping and task-specific self-efficacy. The present knowledge about the changeability of these psychological factors provides a starting point for developing interventions aimed at changing these psychological factors post stroke.

## Clinical implications

How can we use the current knowledge about the influence of psychological factors on QoL in stroke care? First, professionals should become more aware of the role of psychological factors during rehabilitation and of the fact that patients differ from each other in terms of personality, illness cognitions and coping styles. They should understand how these factors could hamper an optimal rehabilitation trajectory, which is illustrated in Figure 9.2.

Furthermore, it is essential to know if and how patients with different psychological factors should be treated to optimize rehabilitation and to allow patients to receive the maximum benefit from their rehabilitation, even without the intention of changing these psychological factors. For example, for patients with high levels of neuroticism, it might be effective to offer them structure during rehabilitation and to let them 'experience' what happens in certain circumstances, for example, by using a heart rate monitor for external feedback. For patients with low levels of self-efficacy, it is important to offer the exercises during rehabilitation in small steps to create 'success' experiences. It would be an improvement if collection and documentation of psychological factors for multidisciplinary use took place. Research has shown that these factors are most of the time not part of a neuropsychological investigation.<sup>44</sup>

We should shift towards personalized healthcare in which we tailor the management and treatment of each patient to his or her individual characteristics, instead of just

**Self-efficacy (low)****Psychological factors of the patient observed by the therapist**

The patient asks for help but then often states that she cannot achieve her goals. She often doubts her own abilities. Furthermore, she takes her mother with her to therapy and asks almost immediately for assistance from her.

**Experiences of the therapists during stroke care**

The patient is hard to motivate to try something new and often responds 'I cannot do that' or 'My mother always does this'.

**Passive coping (high)****Psychological factors of the patient observed by the therapist**

The patient leads a withdrawn existence. He finds it difficult to label changes and problems caused by the stroke. The patient avoids situations in which problems could be experienced, spends most time indoors, and undertakes fewer activities than before the stroke. Most of the time, he is watching at his aquarium. Furthermore, the patient worries a lot, especially about his work, and experiences depressive symptoms.

**Experiences of the therapists during stroke care**

It is difficult to explicate what the patient wants to achieve. The strategies the patient has learned during inpatient rehabilitation are not being executed at home. The patient prefers to avoid problems rather than to try problem-solving strategies.

Figure 9.2 Two cases of patients.

following protocols.<sup>45</sup> Recently, we started an implementation project in which results of the Restore4Stroke Cohort Study are implemented in stroke care. We are developing a course in which professionals will gain insight into the role of psychological factors on adaptation in terms of QoL and in how these factors could be taken into account during general stroke care without changing them. We believe that this knowledge should become part of the education for paramedics, such as physiotherapists and occupational therapists.

Third, even though we observed that most changes in QoL occurred in the first six months post stroke, we think that there could be an indication for rehabilitation treatment after these six months. At six months post stroke, which is considered to be the chronic phase, most patients no longer have contact with healthcare professionals.<sup>46</sup> However, a substantial number of patients experiences problems with psychosocial functioning and over half of all patients living at home report that their life is lacking in some aspect of social, recreational, or purposeful activity.<sup>47</sup> Furthermore, patients could still have goals, which could either be ongoing or newly assigned. Moreover, they could still need help with their adaptation process. Therefore, the focus in the chronic phase should be on improvement of functional ability, social reintegration and on enhancing autonomy.<sup>46</sup> Moreover, we should better identify those patients in need of care and monitor them also in the chronic phase post stroke. In the present thesis we found that the largest group of stroke patients experiences high levels of QoL. However, approximately 30% of the patients are at risk of experiencing low levels of QoL: patients who show a decline in QoL and patients who

experience stable levels of low QoL. Not stroke characteristics, such as the severity of the stroke, but psychological factors, such as passive coping and illness cognitions, are the most important factors in determining if patients are at risk of lower levels of QoL. Thus in the early stages post stroke, patients at risk of lower levels of QoL should be identified using these psychological factors, and we should be aware that these might also be patients who suffered a minor stroke.

## Methodological considerations

### Strengths

The Restore4Stroke Patient Cohort study and the empirical data presented in the present thesis have several strengths. In the Restore4Stroke Patient Cohort study a large group of stroke patients was included and followed with a longitudinal design and repeated assessments up to two years post stroke. Most other longitudinal studies focused on QoL had cross-sectional designs or had follow-up periods no longer than six to twelve months post stroke.<sup>6,7,13-19</sup> Furthermore, we included a large cohort of stroke patients during hospitalization in the acute phase. Other longitudinal stroke studies in the Netherlands included patients from rehabilitation centers, were focused on cognitive functioning instead of QoL or had follow-up periods up to 6 months post stroke.<sup>1,2,48,49</sup> This means that in the Restore4Stroke Patient Cohort study, a more representative group of stroke patients is included than in earlier research.

The influence of psychological factors on HRQoL is not studied very often. In the systematic review of chapter 5, only nine studies were identified, and most of them investigated only one psychological factor through a cross-sectional design with small sample sizes. The present study contained a broad spectrum of potential demographic, stroke-related and psychological factors. We had a special interest in psychological factors, and we controlled for the potential influences of the demographic and stroke-related factors in chapters 6,7 and 8.

The present thesis described QoL from different perspectives, with different measures, and with several advanced statistical analyses. In general these measures showed relatively the same results: recovery of QoL up to six months post stroke and psychological factors are important in determining QoL. However, as seen from the relatively low score on the NIHSS and the relatively high percentage of patients being independent in ADL four days post stroke, most patients included suffered a minor stroke.

## Limitations

Although the studies in the present thesis had several strengths, there is one main limitation that may affect the generalizability of the findings. At the start of the Restore4Stroke Patient Cohort study we expected that most of the stroke patients admitted to the hospitals could be included. We considered our inclusion criteria to be broad. However, patients were included in the first week post stroke, and those who suffered a severe stroke could not receive and understand information regarding the study and therefore could not agree to participate within one week after the onset of the stroke. This underrepresentation of patients who suffered a severe stroke is reflected in the percentage of patients discharged to inpatient rehabilitation. There are no recent publications about discharge destination of stroke patients in the Netherlands, but recent numbers of hospitals itself (collected by Kennisnetwerk CVA) show that approximately 60–65% of the stroke patients are discharged home after hospitalization, while 35% are referred to inpatient rehabilitation.<sup>50</sup> In the Restore4Stroke Patient Cohort study, 70% of the patients were discharged home after hospitalization. This means that we ‘missed’ approximately 5% of the patients discharged to inpatient rehabilitation, which are the patients who were admitted to long stay facilities such as a nursing home after inpatient geriatric rehabilitation. Nevertheless, we believe that the results of the present thesis can be generalized to the patient group discharged home, and this is the largest segment of all stroke patients. Furthermore, the present thesis shows that even if patients are discharged home and experience minor physical problems, they can have severe problems, such as depressive symptoms, that interfere with their daily life.

Finally, in research, choices must be made regarding which factors are taken into account. In the Restore4Stroke Cohort study we assessed a broad spectrum of psychological factors, which were selected using the CSM. Nonetheless, we acknowledge that other psychological factors were not taken into account that have been found to be important determinants of QoL in other diagnostic patient groups such as locus of control,<sup>51</sup> sense of coherence,<sup>51</sup> and resilience.<sup>52</sup>

## Directions for future research

Future research should focus on several aspects. First, investigating QoL at more time points and with follow-up periods up to 3 or 4 years post stroke is important. We observed that most recovery in QoL takes place between two and six months post stroke. However, we do not know exactly when this recovery takes place because we assessed QoL only at two

months and six months post stroke. If we really want to know when recovery in QoL occurs after stroke, we need to assess it more often in the subacute phase post stroke. Furthermore, a follow-up of 3 or 4 years post stroke would provide more insight and certainty about the stability of QoL over the long term. It is possible that QoL still changes after two years post-stroke. For example, a study on life satisfaction in patients with spinal cord injury found no changes between discharge from inpatient rehabilitation and two years later, but increases were found from two to five years post discharge.<sup>53</sup>

Second, more research is needed on subgroups of patients for other domains of QoL. Recovery after stroke is a dynamic process in which patient outcomes are heterogeneous and characterized by individual recovery patterns.<sup>54</sup> Using averaged data might obscure distinct subgroups of patients because when the largest group of patients experiences stable levels of high QoL, the patients in the more unfavorable trajectories will not be identified.

Third, the present thesis provides a starting point for unravelling the associations between psychological factors and QoL. More research should be conducted to understand the causal mechanisms between psychological factors and QoL. How are personality characteristics, illness cognitions and coping styles related to each other and to QoL?

Finally, more knowledge is needed about the changeability of psychological factors in stroke care. Are psychological factors, such as illness cognitions and coping styles, subjective to change in stroke patients and does this optimize QoL? We need interventions to be investigated through randomized controlled trials before we can apply this knowledge to stroke care.

## Conclusions

The findings in the present thesis contribute to our understanding about the long-term course of QoL post stroke and the significant influence of psychological factors. Changes in the course of QoL appear to take place in the first months post stroke, which pleads for a systematic approach in identifying patients at risk of low levels of QoL in the acute and subacute phase post stroke. Demographic and stroke-related factors are not as important as psychological factors in this identification process and in determining QoL. Psychological factors should therefore be used for the identification of stroke patients at risk and they should be taken into account during stroke care.



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## Summary



Stroke is a leading cause of mortality and disability in the Western world and can lead to physical, psychological, and psychosocial consequences. Research has shown that stroke patients perceive their quality of life (QoL) to be lower compared to the general population. The most commonly investigated determinants of QoL post stroke are demographic factors and stroke-related factors. However, these factors do not completely explain why there are patients with severe impairments who adapt well, whereas other patients with minor impairments have severe problems with adaptation. Furthermore, demographic factors cannot be changed, and stroke-related factors are the target of interventions in the acute phase to optimize acute stroke care. However, this means that in the subacute and chronic phase post stroke, many patients must learn to live with the consequences of their stroke. To know how we can help these stroke patients to adapt, we need to know the course of QoL post stroke and identify which factors can be used to predict which patients are vulnerable and at risk of poor adaptation. It is hypothesized that psychological factors, such as personality and coping styles, play an important role in determining QoL, and these factors may be amendable to treatment. Therefore, the Restore4Stroke Patient Cohort study, as part of the Restore4Stroke Cohort study, was developed.

The aims of the Restore4Stroke Patient Cohort study were to investigate the course of QoL in stroke patients and to determine factors predicting QoL, including demographic factors, stroke-related factors, and psychological factors, with a special interest in the latter. Results from the present thesis are derived from this multicenter longitudinal cohort study, of which the protocol is presented in **chapter 2**. In total, 395 stroke patients were followed for a period of two years and 5 assessments were executed: in the acute phase, and at 2 months, 6 months, 12 months and 24 months post stroke. The main outcome was QoL, and this was investigated both from a HRQoL and a domain-specific perspective (participation, emotional functioning and subjective well-being). Furthermore, this chapter described which measures were assessed at each measurement.

The first part of this thesis described QoL in stroke patients from two months up to two years post stroke. **Chapter 3** described the course of QoL in the first two years post stroke in terms of HRQoL and QoL domains emotional functioning, participation, and life satisfaction. The results showed that changes in QoL only seem to occur up to one year post stroke, with most changes occurring in the first six months. Furthermore, this study assessed whether the course of QoL from two months up to two years post stroke was different for patients who were dependent in ADL than for patients independent in ADL four days post stroke. It was found that patients dependent in ADL consistently scored lower on all four



QoL domains. Furthermore, in both patient groups emotional functioning did not change during the first two years post stroke and HRQoL increased between two months and six months post stroke. Patients dependent in ADL had improved participation between two months and one year post stroke, while patients independent in ADL experienced improvement in participation only up to six months post stroke. Life satisfaction increased up to one year post stroke in patients independent in ADL and in patients dependent in ADL no changes in life satisfaction occurred. In conclusion, most improvement in QoL occurred up to six months post stroke and patients dependent in ADL consistently scored lower than patients independent in ADL. Furthermore, differences in the course of QoL have been found in the different domains of QoL. It is therefore important to differentiate between these domains when QoL is taken into account.

**Chapter 4** focused on one QoL domain, namely participation. The research question in this chapter was ‘Does the frequency of participation change after a stroke and is this change associated with experienced participation restrictions and satisfaction with participation?’ Results showed that the frequency of participation declines after a stroke. This decrease was most apparent in vocational activities and less in leisure and social activities. The restrictions caused by the stroke experienced by patients six months post stroke were associated with the frequency of vocational activities at that moment but also with the change in vocational activities from pre-stroke to six months post stroke. Satisfaction with participation six months post stroke was also associated with the frequency of participation at that moment but also with a change in vocational activities from pre-stroke to six months post stroke. These results show that the rather ‘objective’ measure of frequency of vocational participation is associated with the rather ‘subjective’ measure of experienced restrictions and satisfaction in participation. Furthermore, a change in the frequency of vocational participation is related to experienced restrictions and satisfaction in participation. This means that it is important to maintain or restore the level of vocational participation as soon as possible after a stroke to decrease the restrictions in participation that patients experience and to increase their level of satisfaction with participation.

The second part of this thesis focused on how psychological factors and QoL are related. **Chapter 5** provided a systematic review of the psychological factors that were associated with HRQoL after a stroke. A total of 9 studies were included which assessed the following psychological factors: personality, optimism, hope, self-worth, internal locus of control, and coping. The results from the review show that the psychological factors can be divided into factors that are positively and negatively related to HRQoL post stroke. Furthermore,



there is also one factor, extraversion, which was not found to be associated with HRQoL. Negative personality characteristics, such as problems with temperament and personality functions but also neuroticism, were moderately associated with lower levels of HRQoL. Optimism, hope, internal locus of control, self-worth, and coping were moderately associated with higher levels of HRQoL. An important methodological limitation of the included articles in this review was that only two of the nine articles had a longitudinal design, making it difficult to investigate causal relationships. In conclusion, the reviewed studies supported the importance of psychological factors, but further research is needed to supplement the literature.

In **chapter 6** the relationship between psychological factors and post-stroke depressive symptoms two months post stroke was examined. Both psychological factors and depressive symptoms were measured two months post stroke. All psychological factors measured were bivariately related with depressive symptoms. More neuroticism, pessimism, passive coping, and feelings of helplessness, and less extraversion, optimism, self-efficacy, acceptance of the stroke, perceived benefits of the stroke, and proactive coping were associated with the presence of depressive symptoms two months post stroke. Of the demographic and stroke-related factors cognitive functioning was the only factor bivariately related with depressive symptoms. Multivariate analysis showed that more helplessness and passive coping, and less acceptance and perceived benefits of the stroke were independently related with the presence of depressive symptoms. Further research should investigate if and how these factors can be changed in stroke patients to optimize interventions aimed at reducing depressive symptoms.

**Chapter 7** focused on one particular type of psychological factor measured in the Restore4-Stroke Patient Cohort Study, namely illness cognitions. The research questions answered in this chapter were as follows: Which illness cognitions are experienced by stroke patients two months and two years post stroke, and is there a change over time? Furthermore, are illness cognitions associated with life satisfaction two months and two years post stroke, and can a change in these illness cognitions predict life satisfaction two years post stroke? Illness cognitions can have a maladaptive or an adaptive influence on QoL. The illness cognitions that we measured were feelings of helplessness, acceptance of the stroke and perceiving benefits of the stroke. Helplessness can be considered to be a maladaptive illness cognition and acceptance and perceiving benefits to be more adaptive illness cognitions. Only the acceptance of the stroke increased significantly from the subacute to the chronic phase post stroke. Furthermore, all three illness cognitions were significantly associated

with life satisfaction two months and two years post stroke. Demographic and stroke-related factors played a minor role in the association with life satisfaction. Finally, the illness cognitions experienced at two months post stroke and a change in the illness cognitions from two months to two years post stroke predict life satisfaction two years post stroke. Promoting adaptive illness cognitions should be just as important as trying to challenge the maladaptive illness cognitions.

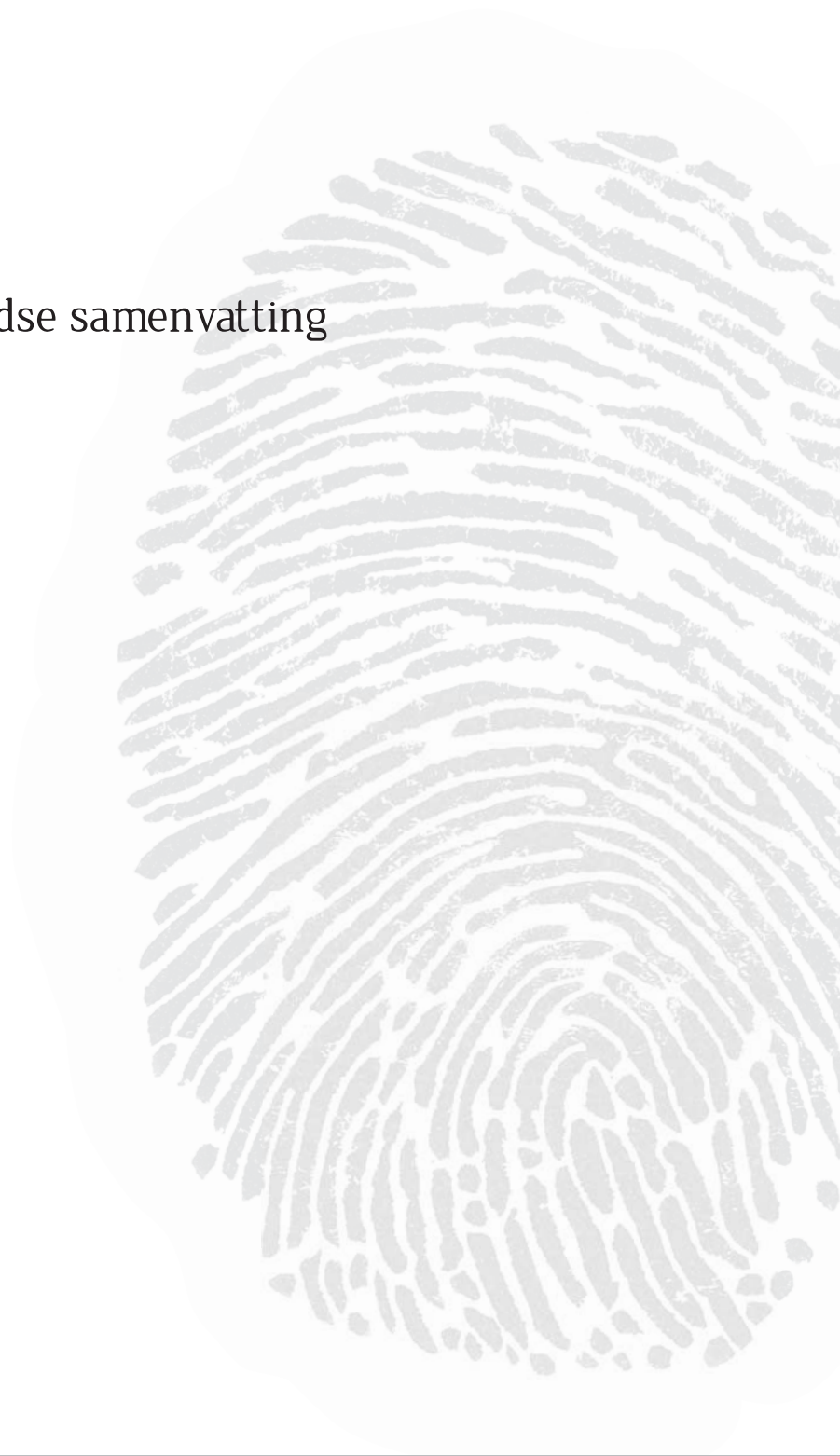
**Chapter 8** investigated if different trajectories of HRQoL could be identified from two months up to one year post stroke, and if predictors could be identified that determined trajectory membership. In this chapter, HRQoL was divided into physical and psychosocial HRQoL. It was hypothesized that membership in the physical trajectories would be determined more by demographic and stroke-related factors and that membership in the psychosocial trajectories would be determined more by psychological factors. The results revealed four trajectories for both physical and psychosocial HRQoL: high, low, recovery and decline of HRQoL. Changes in HRQoL in the recovery and decline trajectories appear to take place in the first six months post stroke and stabilizes thereafter. In general, patients on the more unfavorable trajectories, decline and low HRQoL, had higher levels of negative psychological factors, such as passive coping and neuroticism, and lower levels of positive psychological factors, such as self-efficacy and acceptance of the stroke. The factors that determined trajectory membership partially confirmed our hypothesis; results showed that psychosocial trajectory membership is predicted more by psychological factors, but the psychological factors are also more important than stroke-related factors in predicting physical trajectory membership. These results indicate that it is important to make use of psychological factors to identify patients at risk of poor adaptation post stroke.

Finally, **chapter 9**, the general discussion, summarizes the main findings of this thesis, discusses theoretical considerations and provides clinical messages and ideas for future research. In the present thesis we found that most changes in the course of QoL take place in the first six months post stroke and that psychological factors are the most important factors in determining QoL. These factors should therefore be taken into consideration during stroke care.





## Nederlandse samenvatting



Een beroerte is een belangrijke oorzaak van sterfte en invaliditeit in de Westerse wereld en kan leiden tot lichamelijke, psychische en psychosociale problemen. Onderzoek heeft aangetoond dat patiënten met een beroerte een lagere kwaliteit van leven (KvL) ervaren dan de algemene bevolking. De factoren die het meest zijn onderzocht in relatie tot KvL na een beroerte zijn demografische kenmerken, zoals leeftijd en geslacht, en factoren gerelateerd aan de beroerte, zoals de ernst van de beroerte en de cognitieve problemen die uit een beroerte voortkomen. Echter, deze factoren kunnen niet goed verklaren waarom er patiënten zijn met ernstige beperkingen ten gevolge van de beroerte, maar die een goede KvL ervaren, en waarom er patiënten zijn die lichte beperkingen hebben, maar die moeite hebben zich aan de gevolgen van de beroerte aan te passen en een lage KvL ervaren. Bovendien kunnen demografische kenmerken niet veranderd worden en zijn de beroertegerelateerde factoren, zoals een verlamming, het doelwit van interventies in de acute en revalidatiefase in het ziekenhuis. Teneinde te weten te komen hoe we deze patiënten het beste kunnen helpen zich zo succesvol mogelijk aan de gevolgen van de beroerte aan te passen, is het noodzakelijk om niet alleen het beloop van KvL na een beroerte in kaart te brengen. Daarnaast is het belangrijk om factoren te identificeren die kunnen voorspellen welke patiënten moeite zullen hebben met het aanpassen aan de gevolgen van de beroerte. We verwachten dat psychologische factoren, zoals persoonlijkheid en copingstijl, een belangrijke rol spelen bij KvL. Daarnaast zijn psychologische factoren mogelijk te veranderen door middel van therapie en interventies. Daarom is de Restore4Stroke Patiënt Cohort studie ontwikkeld.

De doelstellingen van de Restore4Stroke Patiënt Cohort studie waren het in kaart brengen van het beloop van KvL tot twee jaar na de beroerte en het signaleren van factoren die KvL kunnen belemmeren of bevorderen. Factoren die hierbij zijn meegenomen zijn demografische factoren, factoren gerelateerd aan de beroerte en psychologische factoren. Wij hadden daarbij bijzondere interesse in psychologische factoren. De resultaten van dit proefschrift zijn gebaseerd op deze multicenter longitudinale cohort studie, waarvan het protocol in **hoofdstuk 2** is gepresenteerd. In totaal werden 395 patiënten met een beroerte gevolgd vanaf de ziekenhuisopname tot twee jaar daarna. In deze twee jaar zijn vijf metingen uitgevoerd: tijdens de ziekenhuisopname in de acute fase, 2 maanden, 6 maanden, 12 maanden en 24 maanden na de beroerte. De hoofduitkomst was KvL, en dit werd onderzocht zowel vanuit een gezondheidsgerelateerd (KvL-G) als een domein-specifiek (participatie, emotioneel functioneren, subjectief welbevinden) KvL perspectief. Daarnaast is in **hoofdstuk 2** beschreven welke meetinstrumenten op welke meetmomenten zijn afgenomen.

Het eerste deel van dit proefschrift beschrijft KvL bij patiënten met een beroerte van twee maanden tot twee jaar na de beroerte. In **hoofdstuk 3** werd het beloop van KvL in de eerste twee jaar na een beroerte onderzocht in termen van KvL-G en de specifieke KvL-domeinen emotioneel functioneren, participatie en tevredenheid met leven. De resultaten laten zien dat veranderingen in KvL alleen plaats lijken te vinden tot één jaar na de beroerte, waarbij de meeste veranderingen plaatsvinden in de eerste zes maanden. Verder is in deze studie onderzocht of het beloop van KvL verschillend is voor patiënten die vier dagen na de beroerte afhankelijk waren in hun Activiteiten van Dagelijks Leven (ADL) in vergelijking met patiënten die onafhankelijk waren in hun ADL. We vonden dat patiënten afhankelijk in ADL consistent lager scoorden op alle vier de uitkomstmaten. Daarnaast werd gevonden dat, in beide patiëntgroepen, emotioneel functioneren niet veranderde over de tijd. KvL-G nam toe in beide patiëntgroepen van twee tot zes maanden na de beroerte. Patiënten afhankelijk in ADL hadden een toename in participatie tussen twee maanden en één jaar na de beroerte, terwijl patiënten onafhankelijk in ADL alleen een toename in participatie hadden tot zes maanden na de beroerte. Tevredenheid met leven nam toe bij patiënten onafhankelijk in ADL tot één jaar na de beroerte en bij patiënten afhankelijk in ADL vonden er geen veranderingen in tevredenheid met leven plaats in de eerste twee jaar na de beroerte. Concluderend kunnen we zeggen dat de meeste verbetering in KvL plaatsvindt in de eerste zes maanden na de beroerte en dat patiënten afhankelijk in ADL consistent een lagere KvL hebben dan patiënten onafhankelijk in ADL. Daarnaast vonden we verschillen in het beloop tussen de verschillende domeinen van KvL. Het is daarom belangrijk om onderscheid te maken tussen deze domeinen van KvL.

**Hoofdstuk 4** onderzocht één KvL domein, namelijk participatie. De onderzoeksvraag was: 'Verandert de frequentie van participatie-activiteiten na een beroerte en hangt deze verandering samen met de ervaren beperkingen in en de tevredenheid met participatie?' De resultaten in dit hoofdstuk laten zien dat de frequentie van activiteiten (binnen het participatiedomein) afneemt na een beroerte. Deze afname vindt met name plaats in werk- en huishoudelijke activiteiten en minder in vrijetijd- en sociale activiteiten. Zes maanden na de beroerte hangen de ervaren beperkingen in participatie en de tevredenheid met participatie samen met de frequentie van werk- en huishoudelijke activiteiten op dat moment, maar ook met de verandering in de frequentie van werk- en huishoudelijke activiteiten van voor de beroerte tot zes maanden daarna. Deze resultaten laten zien dat de meer 'objectieve' maat van frequentie van werk- en huishoudelijke activiteiten samenhangt met de meer 'subjectieve' maten van ervaren beperkingen en tevredenheid met de participatie. Dit betekent dat het belangrijk is om na de beroerte de frequentie van werk- en huishoudelijke



activiteiten consistent te houden of zo snel mogelijk te verhogen om zodoende de ervaren beperkingen te verminderen en de tevredenheid met participatie te verhogen.

Het tweede deel van dit proefschrift beschrijft hoe psychologische factoren en KvL zijn gerelateerd.

In **hoofdstuk 5** wordt een systematisch literatuuronderzoek beschreven naar de samenhang tussen psychologische factoren en KvL-G na een beroerte. In totaal zijn er negen artikelen samengevat die de volgende psychologische factoren hebben onderzocht: persoonlijkheid, optimisme, hoop, eigenwaarde, interne locus of control en coping. De resultaten van deze review laten zien dat de psychologische factoren verdeeld kunnen worden in factoren die positief of negatief samenhangen met KvL-G. Daarnaast is er een factor gevonden die helemaal niet samenhangt met KvL-G, namelijk extraversie. Negatieve persoonlijkheidskarakteristieken, zoals het ervaren van problemen in temperament en persoonlijkheid, maar ook neuroticisme, hangen samen met lagere niveaus van KvL-G. Optimisme, hoop, interne locus of control, eigenwaarde en coping (probleemgerichte coping en emotiegerichte coping) hangen samen met hogere niveaus van KvL-G. Een belangrijke methodologische beperking van de opgenomen artikelen in deze review was dat slechts twee van de negen artikelen een longitudinaal design hadden, waardoor het moeilijk is om causale verbanden te onderzoeken. Concluderend kunnen we stellen dat de geïncludeerde artikelen in deze review het belang van psychologische factoren in KvL-G na een beroerte onderstrepen, maar dat er meer onderzoek nodig is om te weten te komen welke psychologische factoren nog meer samenhangen met KvL-G.

In **hoofdstuk 6** worden de resultaten van de relatie tussen psychologische factoren en depressieve symptomen twee maanden na de beroerte beschreven. Alle psychologische factoren hingen bivariaat samen met depressieve symptomen. Meer neuroticisme, pessimisme, passieve coping en gevoelens van hulpeloosheid, en minder extraversie, optimisme, zelfeffectiviteit, acceptatie van de beroerte, het ervaren van voordelen van de beroerte en proactieve coping hingen samen met de aanwezigheid van depressieve symptomen. Van de demografische en beroerte-gerelateerde factoren hing alleen cognitief functioneren bivariaat samen met depressieve symptomen. Multivariate analyses lieten zien dat meer hulpeloosheid en passieve coping en minder acceptatie van de beroerte en het ervaren van voordelen van de beroerte onafhankelijk waren geassocieerd met de aanwezigheid van depressieve symptomen. Onderzoek is nodig of en hoe deze psychologische factoren veranderd kunnen worden bij patiënten met een beroerte. Deze kennis zou dan ingezet kunnen worden om interventies gericht op het verminderen van depressieve symptomen te verbeteren.



**Hoofdstuk 7** heeft één psychologische factor van de Restore4Stroke Patiënt Cohort studie onderzocht, namelijk ziektecognities. In dit hoofdstuk is onderzocht welke ziektecognities patiënten twee maanden en twee jaar na de beroerte ervaren en of er een verandering over de tijd plaatsvond. Daarnaast is onderzocht of ziektecognities geassocieerd zijn met tevredenheid met leven twee maanden en twee jaar na de beroerte en of een verandering in ziektecognities tussen twee maanden en twee jaar, tevredenheid met leven twee jaar na de beroerte kan voorspellen. De ziektecognities die meegenomen zijn waren: gevoelens van hulpeloosheid, acceptatie van de beroerte en het ervaren van voordelen van de beroerte. Hulpeloosheid kan beschouwd worden als een maladaptieve ziektecognitie en acceptatie en het ervaren van voordelen als meer adaptieve ziektecognities. Alleen de acceptatie van de beroerte nam toe tussen de subacute en de chronische fase van de beroerte. Gevoelens van hulpeloosheid en het ervaren van voordelen bleven gelijk tussen de subacute en chronische fase van de beroerte. Daarnaast hingen alle drie de ziektecognities significant samen met tevredenheid met leven, zowel twee maanden als twee jaar na de beroerte. Demografische en beroerte-gerelateerde factoren speelden een kleine rol in de associatie met tevredenheid met leven. Ten slotte, alle drie de ervaren ziektecognities op twee maanden na de beroerte én een verandering in de ziektecognities tussen twee maanden en twee jaar voorspelden tevredenheid met leven twee jaar na de beroerte. Het promoten van adaptieve ziektecognities moet daarom net zo belangrijk worden in de zorg voor patiënten met een beroerte als het uitdagen van maladaptieve ziektecognities.

In **hoofdstuk 8** is onderzocht of verschillende trajecten van KvL-G tussen twee maanden en één jaar na de beroerte geïdentificeerd kunnen worden. Daarnaast is gekeken of er factoren zijn die voorspellen in welk traject iemand terecht komt. In dit hoofdstuk is KvL-G opgedeeld in fysieke en psychosociale KvL-G. We verwachtten dat demografische en beroerte-gerelateerde factoren meer zouden voorspellen in welk fysieke KvL-G traject iemand terecht zou komen en dat psychologische factoren meer zouden voorspellen in welk psychosociale KvL-G traject iemand terecht zou komen. In totaal werden er vier verschillende trajecten geïdentificeerd, zowel voor fysieke KvL-G als psychosociale KvL-G: hoog, laag, herstel en daling van KvL-G. Veranderingen in KvL-G in de herstellende en de dalende trajecten lijken plaats te vinden in de eerste zes maanden na de beroerte. In het algemeen kan gesteld worden dat patiënten in de meer ongunstige trajecten, de dalende en de lage KvL-G trajecten, hogere niveaus van negatieve psychologische factoren hebben, zoals passieve coping en neuroticisme, en lagere niveaus van positieve psychologische factoren hebben, zoals zelfeffectiviteit en acceptatie van de beroerte. De factoren die voorspellen in welk traject iemand terecht komt bevestigden onze hypothese gedeeltelijk. De resultaten



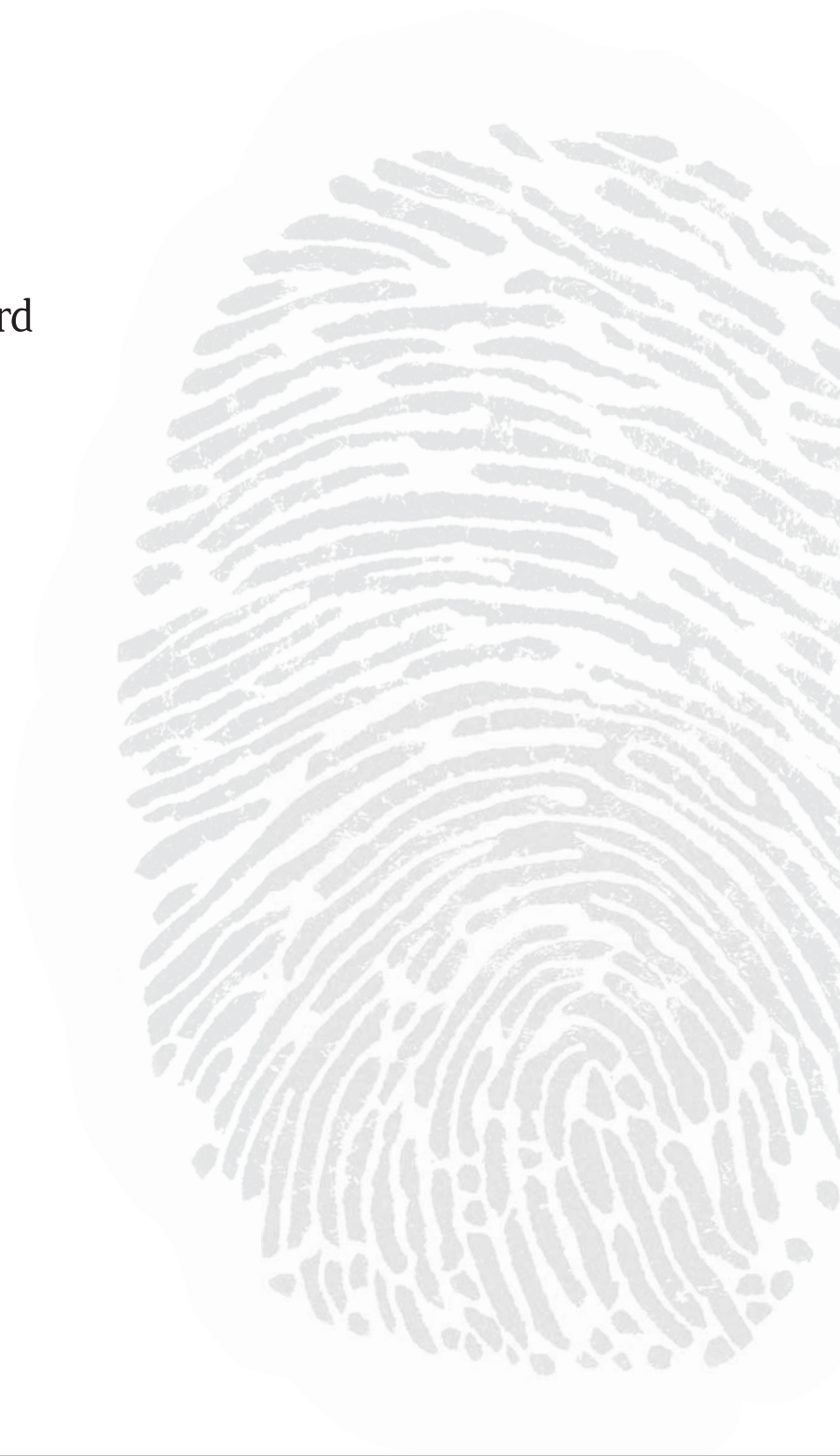
laten zien dat het 'lidmaatschap' van de psychosociale KvL-G trajecten meer voorspeld wordt door psychologische factoren, maar dat de psychologische factoren ook belangrijker zijn dan de demografische en de beroerte-gerelateerde factoren in het voorspellen van het 'lidmaatschap' van de fysieke KvL-G trajecten. Deze resultaten geven aan dat het belangrijk is psychologische factoren te meten voor het identificeren van patiënten die het risico lopen in een van de ongunstige KvL-G trajecten terecht te komen.

Tot slot wordt in **hoofdstuk 9**, de algemene discussie, een samenvatting van de belangrijkste bevindingen van dit proefschrift weergegeven. Verder worden theoretische overwegingen met betrekking tot de twee doelstellingen van de Restore4Stroke Patient Cohort studie bediscussieerd en komen klinische implicaties, zorginnovaties en ideeën voor vervolgonderzoek aan bod. In dit proefschrift hebben we gevonden dat de meeste verandering in KvL plaatsvindt in de eerste zes maanden na de beroerte en dat psychologische factoren de belangrijkste factoren zijn bij het bepalen van KvL. Er moet daarom rekening worden gehouden met deze factoren tijdens de zorg voor patiënten die een beroerte hebben gehad.





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De Restore4Stroke Patiënt Cohort studie maakte onderdeel uit van een groter onderzoeksconsortium waarbij in totaal vier studies werden uitgevoerd. Wat fijn om al onze krachten te bundelen en van al jullie expertise gebruik te kunnen maken. Samen staan we sterker!

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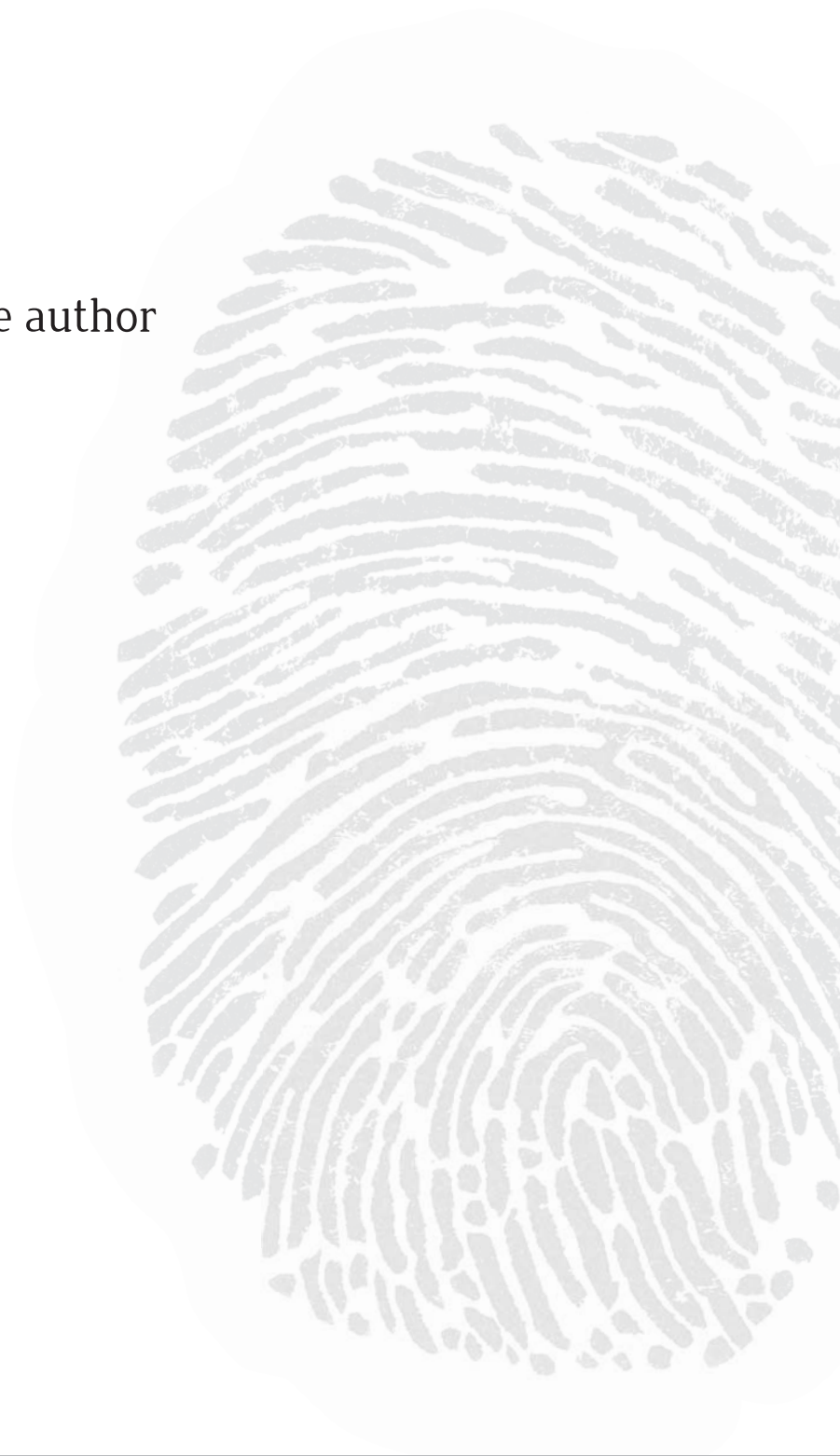
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About the author



## Curriculum Vitae

Marloes van Mierlo werd op 29 oktober 1987 geboren te Kampen. In 2005 behaalde ze haar VWO-diploma aan het Ichthus College te Kampen, waarna ze startte met de studie Psychologie aan de Radboud Universiteit te Nijmegen. In het derde studie jaar koos zij voor de afstudeerrichting Neuro- en Revalidatiepsychologie. Haar klinische stage volgde zij bij Maria Mackenzie, een centrum voor ouderenpsychiatrie. Voor haar onderzoeksstage werkte Marloes mee aan een onderzoek naar chronische vermoeidheid na CVA (COGRAT-studie). In oktober 2009 behaalde ze cum laude haar masterdiploma. Na haar afstuderen bleef ze betrokken bij de COGRAT-studie, maar nu als onderzoeksassistente. In augustus 2010 werd Marloes aangesteld bij het Kenniscentrum Revalidatiecentrum Utrecht van de Hoogstraat Revalidatie en het Universitair Medisch Centrum Utrecht om haar promotieonderzoek, zoals beschreven in dit proefschrift, te starten. Tijdens haar promotie volgde ze haar onderzoeksopleiding aan de Graduate School of Life Sciences ten behoeve van het Clinical and Experimental Neuroscience programma.

Vanaf januari 2015 heeft Marloes haar promotietraject gecombineerd met de functie van projectleider voor de implementatie van de Restore4Stroke resultaten. Tijdens dit project worden de resultaten uit de vier Restore4Stroke onderzoeken geïmplementeerd in de zorg. Zo worden er onder andere twee cursussen voor professionals die in de CVA-zorg werken ontwikkeld. Een van deze cursussen gaat over de invloed van psychologische factoren tijdens de revalidatie na CVA waarbij het doel is: bewustwording van het belang van psychologische factoren en de rol die deze spelen bij de dagelijkse revalidatie, ze leren herkennen en ermee leren omgaan in de dagelijkse revalidatiepraktijk, zonder deze factoren te willen veranderen.

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