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

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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 in six participation 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.

Key words: longitudinal cohort, personal factors, quality of life, stroke

Introduction

In the Netherlands between 34 000 and 41 000 persons suffer a stroke each year (1), making stroke one of the most common causes of disability in adults (2). A stroke significantly influences the patient's physical, social, and psychological functioning (3). Traditionally, much research and rehabilitation care has focused on the physical and functional impact of a stroke (3–5). Recently, the impact of stroke on concepts like quality of life (QoL) has received more attention in the stroke literature (6).

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 (7,8), experiencing long-term difficulties in terms of QoL (5,9), social reintegration (7), life satisfaction (10), and emotional functioning, including depression and anxiety (11).

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 (12). 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 (13–20).

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) (21,22) and environmental factors (e.g. social support and family functioning) (6,23), defined according to the International Classification of Functioning (ICF) (24), 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 (3,6,9). With a new rehabilitation research programme, called Restore4Stroke, we want

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to overcome these shortcomings. Restore4Stroke aims to improve the QoL 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 interventions. 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 $\pm 4\text{--}6\%$ ($\alpha = 0.05$; $\text{power} = 0.80$). 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 (25). 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 17 or lower (26); 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 1 or higher on the Heteroanamnesis List Cognition, before their stroke (27).

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 (28) at each assessment: if aphasia is considered on the basis of item 9 on the National Institutes of Health Stroke Scale (NIHSS) (score >0) (29), 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 (30).

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 Fig. 1.

An overview of all measurement instruments that are administered during the two year follow-up is shown in Table 1 (stroke patient) and Table 2 (partner).

Outcome

Disease-specific HRQoL is measured with the short version of the Stroke-Specific Quality of Life Scale (31). 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 (31).

Generic HRQoL is measured with the Six-Dimensional EuroQoL (32), 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 (32).

Participation is assessed with the Utrecht Scale for Evaluation of Clinical Rehabilitation – Participation (33), 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 Clinical Rehabilitation – Participation was shown to be a valid and reliable measure to rate participation in patients with various physical disabilities, including stroke patients (49,50).

Emotional functioning is measured with the Hospital Anxiety and Depression Scale (34), consisting of 14 items measuring both anxiety and depression with seven items

each. The Hospital Anxiety and Depression Scale has shown good psychometric properties (34), and is a commonly used measure in stroke patients (51).

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, 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 (35). 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 1 (stroke patient) and Table 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 (41); passive coping using the Passive coping scale of the Utrecht Coping List (42); self-efficacy using the General Self-Efficacy Scale (43); neuroticism and extraversion using the Eysenck Personality Questionnaire – Revised Short Scale (44); optimism using the Life Orientation Test (45); and appraisals of one’s condition using the Illness Cognition Questionnaire (46).

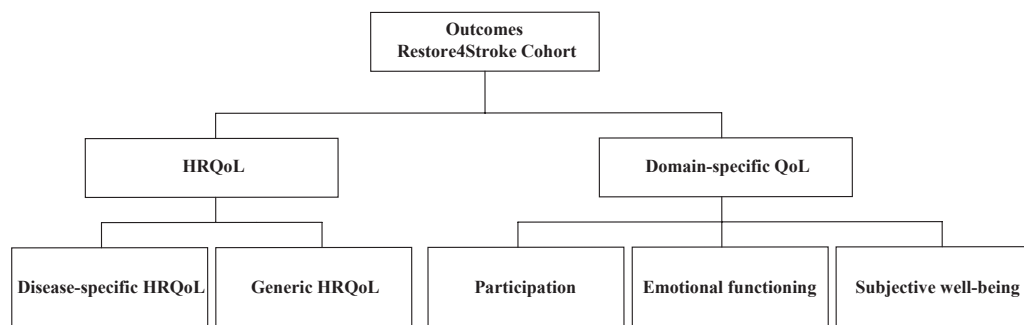


Fig. 1 Outcomes of Restore4Stroke Cohort. HRQoL, health-related quality of life; QoL, quality of life.

Table 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
Outcomes						
HRQoL						
Disease-specific HRQoL	Stroke Specific Quality of Life Scale-12 (31)		X	X	X	X
Generic HRQoL	Six-Dimensional EuroQoL (32)		X	X	X	X
QoL domains						
Participation	Utrecht Scale for Evaluation of Rehabilitation – Participation (33)		X	X	X	X
Emotional functioning	Hospital Anxiety and Depression Scale (34)		X	X	X	X
Subjective well-being	Three life satisfaction questions (35)		X	X	X	X
Determinants						
Pre-stroke health condition						
Emotional functioning	Premorbid question of the Depression scale of the Hospital Anxiety and Depression Scale (36)	X				
Participation	Premorbid frequency scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation (33)	X				
Comorbidity	Cumulative Illness Rating Scale (37)		X			
Stroke-related health condition						
Stroke characteristics	Type; hemisphere; National Institutes of Health Stroke Scale (29)	X				
Motor impairment	Items 5ab and 6ab of the National Institutes of Health Stroke Scale (29)		X	X		
ADL	Barthel Index (26)	X	X	X		
	Modified Rankin Scale (38)			X		
Cognition						
Impairment	Montreal Cognitive Assessment (39)		X	X		
Complaints	Checklist for Cognitive and Emotional Consequences following stroke (40)		X	X		
Communication	Item 9 of the National Institutes of Health Stroke Scale (29)		X	X		
Personal factors						
Demographic factors	Age, gender, education, marital status, ethnicity, work status	X				
Psychological factors						
Proactive coping	Utrecht Proactive Coping Competence Scale (41)		X			X
Passive coping	Passive coping scale of the Utrecht Coping List (42)		X			X
Self-efficacy	General Self-Efficacy Scale (43)		X			X
Neuroticism	Eysenck Personality Questionnaire – Neuroticism (44)		X			X
Extraversion	Eysenck Personality Questionnaire – Extraversion (44)		X			X
Optimism	Life Orientation Test (45)		X			X
Illness cognitions	Illness Cognition Questionnaire (46)		X			X
Care received	Cost Questionnaire		X	X	X	X

The first assessment takes place in the first week post-stroke. The follow-up assessments take place at two months, six months, 1 year, and 2 years post-stroke. HRQoL, health-related quality of life; QoL, quality of life.

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

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 QoL after stroke is associated with personal factors and caregiver variables, controlled for pre-stroke health condition and stroke-related health condition. All analyses will be done for the patients and partners separately. Effects with a *P* value below 0.05 (two-tailed) will be regarded as significant.

Table 2 Overview of all measurement instruments for the partners and times of administration

Instrument	0 months	2 months	6 months	1 year	2 years
Outcomes					
HRQoL					
Generic HRQoL	Six-Dimensional EuroQoL (32)	X	X	X	X
QoL domains					
Participation	Utrecht Scale for Evaluation of Rehabilitation – Participation (33)	X (only scale 1)	X	X	X
Emotional functioning	Hospital Anxiety and Depression Scale (34)	X	X	X	X
Subjective well-being	Three life satisfaction questions (35)	X	X	X	X
Determinants					
Health condition					
Burden	Caregiver Strain Index Expanded (47)	X	X	X	X
Personal factors					
Demographic factors	Age, gender, education, ethnicity, work status	X			
Proactive coping	Utrecht Proactive Coping Competence Scale (41)		X		X
Self-efficacy	General Self-Efficacy Scale (43)		X		X
Environmental factor					
Social support	Social Support List (48)	X	X	X	X

The first assessment takes place in the first week post-stroke. The follow-up assessments take place at two months, six months, 1 year and 2 years post-stroke. HRQoL, health-related quality of life; QoL, quality of life.

Study organization 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 (3–5). 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 (9). 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 (52). 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 (53). 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 (54). 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) (55).

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.

Authors' contributions

J.V., C.H., and M.P. developed the idea and procured funding for the study. All authors contributed to the design and the protocol of the study. All authors reviewed the manuscript and approved the final version.

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