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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 ( $p \le 0.01$ ). Helplessness, acceptance and perceiving benefits were significantly associated with life satisfaction at two months ( $R^2 = 0.42$ ) and two years ( $R^2 = 0.57$ ) post stroke. Furthermore, illness cognitions two months post stroke and changes in illness cognitions predicted life satisfaction two years post stroke ( $R^2 = 0.57$ ).

*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.

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#### Introduction

Stroke is one of the leading causes of disability in the Western world [1]. A stroke can lead to permanent physical, psychological, and psychosocial consequences, such as mobility problems [2], emotional problems like anxiety and depression [3], cognitive impairments [4], and decreased life satisfaction [5, 6]. Demographic factors, stroke characteristics and physical impairments are the most commonly investigated determinants of quality of life (QoL) post stroke [7]. 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 [8].

It is assumed that the way patients think about and perceive their illness accounts for much of the individual differences in their QoL [9]. According to Leventhal's Common Sense Model, patients create mental representations of their illness when faced with a chronic disease [10, 11].

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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 [12] and can be maladaptive as well as adaptive in terms of outcome [9] and some are typically more adaptive than others. These representations have been investigated using terms such as illness cognitions, 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 [9], cancer [13, 14], chronic fatigue syndrome [15], and spinal cord injury [16, submitted].

Limited research has been performed into illness cognitions of stroke patients [17–20]. Acceptance of the illness and appraisals of threat and benefit were associated with depression post stroke [17, 18]. Furthermore, female stroke patients associated their emotional state with the cause of pain [19], and maladaptive illness cognitions were associated with more severe symptoms of posttraumatic stress disorder [20]. 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 [21]. 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 17 or lower on the Barthel Index (BI) [22]; (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 [23].

#### 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) [9]. 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) [9]. The ICQ is a reliable instrument to assess illness cognitions in patients with several chronic diseases, such as rheumatoid arthritis and multiple sclerosis [9].

#### 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 [24] 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 [25] 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 [22] The BI is a validated measure and commonly used in stroke patients [22]. Cognitive functioning was assessed using the Montreal Cognitive Assessment (MoCA) (range 0–30) two months post stroke [26]. The MoCA is a brief cognitive screening tool suitable for use in stroke patients [26].

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) [27]. This measure is valid and commonly used in stroke patients [27, 28].

#### Outcome variable

Life satisfaction was operationalized as satisfaction with overall quality of life and was measured with two questions (2LS) [29]. 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. [29, 30].

#### 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 0.3, moderate between 0.3 and 0.5, and strong above 0.5 [31].

Two hierarchical linear regression analyses were performed to investigate the cross-sectional relationships between illness cognitions and life satisfaction, controlling for demographic factors, strokerelated 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 Download English Version:

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