



WHAT ABOUT SELF-MANAGEMENT POST-STROKE?

Challenges for stroke survivors, spouses and professionals

Ton Satink

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The work described in this thesis was carried out at the Radboud university medical centre, Radboud Institute for Health Sciences, Scientific Institute for Quality of Healthcare (IQ Healthcare), Nijmegen and the HAN University of Applied Sciences, Research Group Neurorehabilitation.

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For reasons of consistency within this thesis, some terms have been standardized throughout the text. As a consequence the text may differ in this respect from the articles that have been published.

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Voor jullie, papa en mama

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The first weeks at home were tough and very challenging, because then you literally bump into all kinds of boundaries. In the beginning your wife still makes a sandwich for you, but at some point, if you want to make a sandwich yourself, then you find out that everything is difficult. I mean, with pleasure she puts a sandwich ready but then it is lying on the bottom shelf for instance, where I cannot reach it you know? Or the cheese in the cheese tin, I do not get it open well, that kind of very simple things. Literally everything has to be organized when you're going to cook. And then the oil appears to be on the left so that you cannot reach it. Then you have to sit in your wheelchair to roll 50 cm aside. All that kind of stuff, everything is confronting. [...] Look, in the past you had a nice day when you had nicely worked in the garden or, uh, when the garden looked beautiful or if the basement was painted or whatever, but that's all gone now.

Stroke survivor, 3 months post-discharge,
Participant 6, Longitudinal Qualitative study, Chapter 6



Chapter 1

General Introduction

Consequences and impact of stroke

In the Netherlands, approximately 45.000 people suffer their first stroke each year¹, and stroke is the leading cause of disability.² A stroke is an acute disturbance of the blood supply to the brain and often results in neurological symptoms. Strokes can be divided into either ischemic strokes (85% of cases) or hemorrhagic (15% of cases), respectively. In general practice, the incidence of stroke is 2 per 1000 persons per year; among the elderly (aged 65 or older), the incidence is 14 per 1000 per year. Furthermore, due to the aging population an increase of the incidence of stroke is expected.^{3,4}

Stroke consequences vary drastically: Patients may suffer relatively few complications, recover gradually or suffer permanent limitations.³ Clinical symptoms often depend on the location of the stroke. For example, sensory-motor and speech or swallowing difficulties can occur or stroke survivors' cognitive functioning and social and emotional dynamics are affected.⁵⁻⁷ Furthermore, stroke also affects the spouse or other family members of the stroke survivor.^{8,9} Spouses often get an additional role of caregiver beside their role as life partner, and the new situation often causes emotional and physical burden.^{8,9} To support stroke survivors and their spouses to better care for themselves and to live a meaningful life post-stroke, self-management is recognized as an important concept in stroke rehabilitation.^{10,11}

Changing society and changing perspectives on health

The development of stroke self-management programs is not a separate movement. Several societal developments have influenced the values and organization of health care services as well as the services for stroke survivors. Three of such developments include (1) the shift away from a paternalistic view of health care towards an active involvement of patients to take responsibility of their own health^{12, 13}; (2) the increased prevalence of community health-care services that result in stroke survivors' earlier return to the home environment¹⁴ and (3) a proposal by an international group of health experts to change the WHO definition of health and to include an emphasis on the patients' ability to adapt and self-manage in the face of social, physical and emotional challenges to their health.¹⁵

Self-management

Self-management is not new. It is something everybody is doing. Self-management' describes an individual's ability to make autonomous decisions, such as deciding whether to nap, having extra fruit with lunch or asking for help in appropriate situations.¹⁶ Self-management has become a 'hot topic' especially when we talk about patients with chronic conditions.

In some contexts, self-management and self-care are used interchangeably.¹⁷ The concept of self-management comprises different possible interpretations,^{18, 19} including a patient's ability to deal with a chronic condition, interventions to support patients in the development of self-management or—as policymakers frequently see it—a paradigm that requires patients to participate in the management of their chronic condition.

In this thesis, we focus mainly on self-management as ability to deal with a chronic condition. Past definitions of self-management vary widely. Though no 'golden standard definition' exists¹², we use Wilkinson & Whitehead's²⁰ definition for the purpose of this thesis: an *'individual's ability, in conjunction with family, community, and the appropriate health-care professionals, to manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a chronic disease'*.^{20(p. 1145)}

Self-management consists of three central domains: medical management, role or behavioral management, and emotional management.²¹ Alternatively, in a qualitative meta-synthesis Schulman-Green et al.²² identified three categories of self-management processes: focusing on illness needs, activating resources, and living with a chronic illness. Further, Lorig and Holman²³ identified five core self-management skills: problem solving; decision making; appropriate resource utilization; forming a partnership with a healthcare provider; and taking necessary actions.

Self-management post-stroke

With regard to self-management of chronic conditions, stroke survivors have a similar desire to take charge of living with their condition when compared with persons with for example chronic pain and arthritis.²⁴ On the other side, from a functional perspective and the possibilities to develop self-management skills, prospects for post-stroke patients differ from those with chronic pain or arthritis. People with a slowly progressing long term condition like chronic pain may be able to learn to self-manage step by step; in contrast, stroke survivors confront a 'sudden situation and stroke consequences' which they must manage.⁶ This difference might affect stroke survivors' readiness to self-manage and should be seriously considered.^{10, 11} Furthermore, the functional recovery of stroke survivors often results in increased participation in activities and roles, which may not be the case with diseases such as chronic pain or arthritis. Moreover, a stroke may also negatively affect cognitive abilities, impacting an individual's ability to self-manage and navigate day to day decisions and actions.^{10, 11} Furthermore, the informal caregiver—often a spouse or family member—has an enhanced role in the support of stroke survivors—especially immediately post-stroke. This differs for people with, for example, arthritis.^{8, 25}

Stroke self-management programs

Self-management programs aim to support participants to make informed choices and then plan and carry out those decisions.²³ Despite deliberation about the application of self-management principles to stroke victims,^{10,26} several programs have utilized self-management principles in stroke interventions.²⁷⁻³² Most programs were delivered in the first period post-stroke, sometimes delivered as a clinical program, and other times post-discharge, like Tielemans et al.³⁰ who delivered a program to stroke survivors living at home. Most programs included mainly goal setting, problem solving, action planning, structured information and professional support. Reviews indicated that self-management interventions can significantly increase patient participation.^{26,33} However, measures of a program's content, delivery and outcome still show clinical heterogeneity.^{33,34} Critics commonly cite the risks associated with a 'one-size-fits-all' approach.¹¹

When designing self-management programs, professionals should consider several factors that influence the abilities of stroke survivors. Examples of these factors include the effects of strokes on decision making, action planning and problem solving; the readiness of stroke survivors to self-manage; and the role of informal caregivers. Modern stroke self-management programs should be designed to respond to the dynamic conditions of a stroke survivor who progress from an acute stroke to long term survivorship, and who learn to deal with a new disability after discharge. This could lead to develop stroke self-management models that integrates secondary and primary care and adopts a system perspective instead of an individual perspective.²⁶ In this regard, survivors' and spouses' perspectives can inform health professionals regarding developing and customizing stroke self-management interventions to individual needs. Patient's involvement plays a valuable role in these processes; their perspectives offer unique insight derived from lived experience with their personal situation, illness, recovery and treatment.^{35, 36} However, the viewpoints and experiences of the stroke survivors and their spouses on the process of self-management post-stroke are hardly described. Moreover, evaluations of professionals in stroke rehabilitation should be performed in order to determine if they can interact with patients in supporting and stimulating self-management.¹¹

Aims and questions of this thesis

With the aim to develop a stroke self-management intervention in the future that follows the process of intervention mapping,³⁷ we first wanted to conduct an in depth needs assessment regarding self-management post-stroke. Therefore the general objective of this thesis was to improve the understanding of self-management of stroke survivors from the perspectives of relevant stake holders, namely the stroke survivors, their spouses, and health professionals. Furthermore, the objective was to explore how stroke survivors and spouses self-manage post-discharge.

As a result, this thesis addresses the following research questions:

- *What is the impact of stroke on stroke survivors' roles and self?*
- *How do stroke survivors, spouses and professionals experience and reflect on self-management post-stroke?*
- *How does self-management post-stroke evolve over time in everyday life?*
- *How do stroke survivors and spouses manage themselves post-discharge?*

Outline of this thesis

This thesis comprises a series of studies that were originally written as a separate article. **Chapter 2** describes the first study, a thematic synthesis of qualitative studies that aimed to capture stroke survivors' perspectives on the impact of stroke on their post-stroke roles and self.

Chapter 3, 4, and 5 include the articles of three focus group studies that we conducted with stroke survivors, spouses of stroke survivors and allied health professionals. We have interviewed them about their view on the concept of self-management post-stroke and self-management support that was received or given. The focus group study described in **Chapter 3** consisted of two different groups with stroke survivors that we interviewed twice. The first interview sought stroke survivors' views on self-management. In the other interview, we asked stroke survivors about self-management support they may have received. **Chapter 4** describes a focus group study with spouses of stroke survivors. In this study four different groups of spouses were interviewed. As in the previous chapter, we focused on the spouses' opinions of self-management and the self-management support provided to them. **Chapter 5** describes the focus group study with allied health professionals. We asked four different groups to reflect on the concept of self-management, the state of self-management intervention delivery and how self-management could be better delivered in the future.

Beside the thematic synthesis and the three focus group studies, we also explored how stroke survivors managed their lives post-discharge in the context of everyday activities at home, how the self-management evolved over time and how they gave meaning to this. This study resulted into two papers that we present in chapter 6 and 7. **Chapter 6**, which describes a longitudinal qualitative study, presents the findings of participant observations and interviews with ten stroke survivors at their homes at 3, 6, 9, 15 and 21 months post-discharge; we chose a constant comparative method to analyze the data. The chapter further describes how the process of self-management post-stroke develops and how everyday activities play an important role in this process. Following a picture of the process of self-management post-stroke, **Chapter 7** presents a case study about two stroke survivors and their spouses. For this case study we used the data of the participant observations of two participants of the longitudinal qualitative study. In the case study, we describe the self-management and interaction of two stroke survivors and

their spouses in more detail. We followed a narrative approach and focused in the analysis on the narratives-in-action. Then, in **Chapter 8**, we present and discuss the main findings of the separate studies and put forward suggestions for future implementation and future research.

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Chapter 2

Patients' Views on the Impact of Stroke on Their Roles and Self: A Thematic Synthesis of Qualitative Studies

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Archives of Physical Medicine and Rehabilitation 2013, 94(6):1171-1183.

Abstract

Objective: To synthesize patients' views on the impact of stroke on their roles and self.

Data sources: PubMed, CINAHL, Embase, PsycINFO and Cochrane searched from inception to September 2010, using a combination of relevant MeSH and free text terms. This search was supplemented by reference tracking.

Study selection: Qualitative studies reporting the views of people post-stroke. The search yielded 494 records. Opinion papers, quantitative studies or those reporting somatic functioning were excluded. Thirty three studies were included.

Data extraction: Data extraction involved identifying all text presented as 'results' or 'findings' in the included studies, and importing this into software for the analysis of qualitative data.

Data synthesis: The abstracted text was coded and then subject to a thematic analysis and synthesis, which was discussed and agreed by the research team. Three over-arching themes were identified: (1) managing discontinuity is a struggle; (2) regaining roles: to continue or adapt?; and (3) context influences management of roles and self. Regaining valued roles and self was an on-going struggle, and discontinuity and uncertainty were central to the adjustment process after stroke.

Conclusions: The thematic synthesis provides new insights into the post-stroke experience. Regaining or developing a new self and roles was problematic. Interventions targeted at self-management should be focused on the recognition of this problem, and included in rehabilitation, to facilitate adjustment and continuity as far as possible in life post-stroke.

Introduction

Stroke is a major cause of disability worldwide.¹ A stroke may affect physical, cognitive, social and emotional functioning. Although some empirical studies recommend that rehabilitation programs pay attention to the psychological impact of stroke,^{2,3} this does not always happen.⁴ Persons with stroke report feeling not ready to manage their daily life when discharged⁴ and lacking support to regain former and new roles.⁵ Roles are sets of connected behaviours, rights and obligations related to social status, identity and self.⁶ Self can be described as a cognitive representation a person makes of his/her identity.⁷ Identity is the fact of being who or what a person is, and a social identity refers to a collection of roles a person has in the society.^{6,8}

Self-management interventions may enable people to manage their lives, roles and self after stroke.⁹ Wilkinson and Whitehead¹⁰ define self-management as *"an individual's ability, in conjunction with family, community and health care professionals, to successfully manage the symptoms, treatment, physical, psychosocial, cultural and spiritual consequences and inherent lifestyle changes required for living with a long-term chronic disease"* (p.1145). Three types of self-management for people with chronic diseases have been identified.^{11,12} These are 1) medical (behavioral) management, which is about dealing with the illness; 2) emotional management, which refers to coping with the emotions associated with the illness and experienced changes; and 3) role-management, which is about the way people continue their normal life and regain and maintain roles.¹³

Before designing a self-management program, and tailor it to the needs of people after stroke, the authors first wanted to understand the patients' perspectives about the impact of stroke on their roles and self and how they regained their roles and self after stroke.

Although there are some primary studies about how persons with stroke experience the process of regaining their self and roles after stroke, these have not been systematically reviewed. Syntheses of qualitative research are a well-established form of systematic literature review that draws together findings of qualitative studies to contribute new understandings of patients perspectives.¹⁴⁻¹⁷ Noblit and Hare¹⁶ published one of the first books about synthesizing qualitative studies in 1988. In a synthesis, findings of single studies with a variety of designs, methods, populations and timeframe are analysed, synthesised and integrated with the aim to *"attain a level of conceptual and theoretical development beyond that achieved in any individual empirical study"*.¹⁵

A thematic synthesis was performed to gain a better understanding of post-stroke experiences of stroke patients.¹⁸ Campbell et al.¹⁵ suggest that syntheses of qualitative research gives a stronger voice to patients' perspectives than single studies do. Our synthesis addressed the question "How do persons with stroke view the impact of stroke on their roles and self?"

Methods

The method was a four stage, thematic synthesis of qualitative studies.¹⁸ The first stage was searching the literature and selecting relevant primary studies. Next, the included studies were subjected to a quality appraisal. The third stage was data extraction. Finally, descriptive and analytical themes were identified that reflected the perceptions of persons with stroke concerning the impact of stroke on roles and self.

Search strategy and selection criteria

Five, relevant electronic databases were searched from inception to September 2010. The databases were PubMed, CINAHL, Embase, PsycINFO, Cochrane. A librarian was consulted to refine the search terms and strategies. The search question was divided into four concepts: stroke, role or self, management (of role or self), and the process of adaptation after stroke. The individual concepts have been searched with thesaurus terms (e.g. MeSH) or free text terms. The index terms for each database were used. Search terms were exploded and combined. The search in Pubmed was: (stroke[MeSH] OR stroke OR cerebrovascular accident OR cerebrovascular disease) AND (role[MeSH] OR ego[MeSH] OR self OR role) AND (self care[MeSH] OR self management OR role management OR self management OR self care) AND (adaptation, psychological[MeSH] OR social adjustment[MeSH] OR emotions[MeSH] OR adaptation OR adjustment OR transition OR transformation OR coping). Cited-reference searching was also done. The search term "qualitative" or related terms were not used because each database uses different index terms which makes it problematic to locate qualitative studies.¹⁹ Selection of qualitative studies was done in the abstract selection by the first two authors (TS, EC).

Qualitative studies were included if they contained original data describing the perceptions of persons with stroke on their role, self and/or the management of these factors. Reviews, opinion papers, quantitative studies or studies with findings only at the level of body function were excluded. Studies where the perceptions of the persons with stroke could not be separated from other patient groups were also excluded. When multiple reports of the same study were found, the articles were compared and only selected if each paper presented distinct findings, based on different study aims and questions about the same material.

Quality appraisal

The Critical Appraisal Skills Program tool (CASP)²⁰ for reviewing qualitative studies was used to appraise the methodological quality of the studies. The items, which are for example referring to the study aim, study design, data collection and data analysis, were scored with Yes or No, depending on whether the topic was described sufficiently or not. An additional score of 'Unclear' was added to differentiate between sufficiently and insufficiently. This resulted in three options: 1 – ½ – 0. The higher the total score, the better

the methodological quality, with a maximum score of 10. The studies were independently appraised by the first two authors. Any difference in item and total scoring was resolved through discussion. The purpose of the quality appraisal was to ascertain the methodological quality of the studies included in the synthesis.

Data extraction, analysis and synthesis

The data extraction stage involved identifying text labelled as 'results' or 'findings' in the selected studies, and importing this data into Atlas.ti qualitative analysis software. Theoretical perspectives or discussion of findings by primary authors were not extracted. If different client groups were interviewed in the same study, only the findings related to persons post-stroke were extracted.

The data analysis and synthesis consisted of three steps.¹⁸ Firstly the extracted text was read as a whole, and meaningful segments in the text were labelled with a free code. Meaningful segments were parts of the text like quotations or metaphors from participants, and phrases from authors of the primary data, and often consisted of more than one line or sentence. Free codes were described by the first author (TS) and paralleled the meaning and content of the segments of the primary data. At the next step, the coded meaningful segments were organised into related areas to develop descriptive themes. A descriptive theme was a theme which stayed close to the original meaning of the primary data. Finally the descriptive themes were discussed, and more abstract and analytical themes were developed. This involved developing interpretations that go beyond the primary studies. Concept mapping supported the discussion and the process of generating the descriptive and analytical themes. The first author (TS) performed all steps. The second author (EC) served as peer reviewer during the process of coding, and the development of descriptive and analytical themes. The process and content of the steps were regularly discussed with the whole research team.

Results

The systematic search of five electronic data bases yielded 494 studies. The titles and abstracts of the 494 studies were screened, and 129 full text articles were examined. Finally 33 primary studies were included for appraisal and synthesis. Figure 1 summarises the process of identifying 33 articles for the thematic synthesis. The team agreed to include two papers from single studies by Bendz^{21,22}, Ellis-Hill^{4,23} and Pound^{24,25} because they had different aims and presented distinct findings. However, only one of four papers by Proot²⁶ was included. This was because it presented the whole longitudinal study²⁶ and the other papers did not report anything new.²⁷⁻²⁹

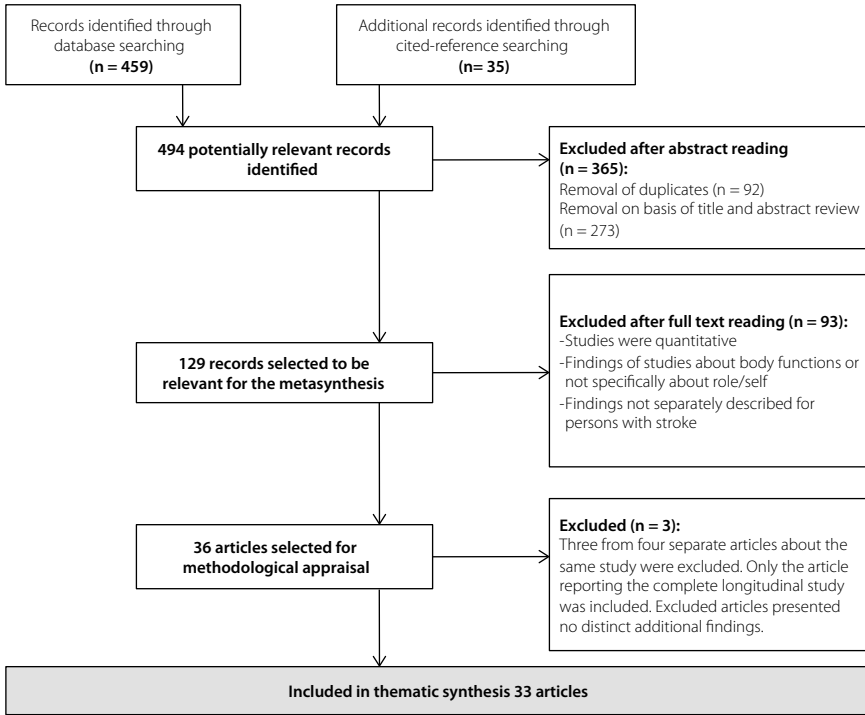


Figure 1 Flow diagram showing identified and selected studies included in the thematic synthesis

Characteristics of included studies

Most studies were set in the United Kingdom (12/33), North America (9/33) or Scandinavia (8/33). The publication dates ranged from 1995 to 2009. The majority (25/33) were published in the 2000s. The characteristics of the 33 studies are shown in Table 1.^{2-5, 21-26, 30-52}

The studies offered the perspective of at least 465 stroke survivors. The number of participants in each study ranged from 13³ to 51⁴⁷. Most qualitative studies (22/33) had less than twenty participants. One focus group study did not mention the number of stroke patients.³ Although not all studies described the gender of the participants, there were at least 246 men and 156 women. The age ranged from 19 to 93 years. Acute care, rehabilitation, discharge from the hospital, rehabilitation centre or nursing home, as well as the chronic phase after stroke were covered by the studies.

Methods and quality

All studies explored the post-stroke experience. The study aims were heterogeneous, including patients experiences of rehabilitation, discharge and the adaptation process after stroke; adaptation and adjustment after a stroke; the implications, meaning and impact of stroke; and quality of life, return to work and spousal relationships. One third of the primary studies (11/33) had more than one interview; nine of these studies were longitudinal studies. From the longitudinal studies, most offered the perceptions of stroke patients 12 months after a stroke about the impact of stroke on roles and self. In two studies, there was a longer time perspective: one reported the experiences at 5 and 10 years⁵⁰ and one self-report³³ described the reflections over an 8 year period.

Most data was collected using individual and focus group interviews. Some studies used additional data collection methods such as a diary³⁰, observations^{47, 50}, medical records^{21, 22, 50}, questionnaires³⁹, e-mail interviews⁵ or field notes.³⁹

Quality ratings, using the adapted version of the qualitative studies CASP tool, ranged from 4 to 10 with a mean of 7.8. Studies with lower scores tended to provide insufficient information about ethical issues and the reflexivity of the researcher, which refers to how researchers critically examined their own role, potential bias and influence during data collection or sampling. Studies with lower scores were included because of the value of the content. The primary studies applied a variety of methodologies and data collection methods. Fourteen studies^{4, 24, 25, 30, 34-36, 42, 45-49, 52} did not mention a specific methodology, only that a qualitative design was used. For the other studies, seven employed a phenomenological/hermeneutic methodology^{2, 5, 37, 40, 43, 44, 51}, three used a case study methodology^{31, 38, 50}, two described a phenomenographic methodology^{22, 32}, two were grounded theory studies^{26, 39}, and there were single examples of life-narrative methodology²³, self-report³³, and discourse analysis.²¹ Two reported a qualitative design with focus group interviews.^{3, 41}

Synthesis

Free coding of the primary data produced 648 coded meaningful segments. These meaningful segments were discussed and organised into seven descriptive themes about recurring concepts, namely discontinuity, uncertainty, and regaining continuity. Further analysis produced the three overarching analytical themes of 'managing discontinuity is a struggle,' 'regaining roles: to continue or adapt?' and 'context influences management of roles and self.' Table 2 lists the codes, descriptive and analytical themes developed in the thematic synthesis. Table 3 shows the occurrence of the descriptive and analytical themes in each of the 33 studies. The reviewers' interpretation and synthesis of the primary data in three analytical themes is described next. Most revealing quotations of participants (persons with stroke) of the primary studies are used to support the content of the themes.

Table 1 Characteristics of included studies

Study	Country	Aim
Alaszewski 2007 ³⁰	UK	Examine respondents' relationship with work following a stroke and explore their experiences including the perceived barriers to and facilitators of a return to employment.
Arnaert 2006 ³¹	Canada	Explore perceptions of hope from patients during the acute care phase of stroke.
Backe 1996 ³²	Sweden	Find out how stroke patients conceived their life situation within the first week of the acute care phase as seen from the nurses' viewpoint.
Bendz 2000 ²¹	Sweden	Explore how stroke survivors under 65 understand and deal with the activities of the rehabilitation process and explore how the same patients and their rehab processes were described in medical records and ultimately to compare the two results.
Bendz 2003 ²²	Sweden	Highlight divergent ways in which a group of people hit by a stroke and their health care professionals understand the implications of having a stroke.
Burton 2000 ²	UK	Identify the lived experience of recovery from stroke from the patient's perspective; specifically the issues and themes identified by patients to describe their own recovery over time.
Busscherhof 1998 ³³	US	Not explicitly described.
Clarke 2005 ³⁴	Canada	Investigate the complexity of factors of that influence quality of life after stroke in community dwelling older adults.
Dixon 2007 ³⁵	UK	Explore constructs relevant for self-efficacy in neurological rehabilitation.
Dowswell 2000 ³⁶	UK	Identify what mattered to patients and caregivers in the recovery process and how patients and caregivers measured progress in the year following stroke.
Ellis-Hill 2000 ²³	UK	Explore the life narratives of people following a single stroke to understand how they constructed the meaning of the stroke within their life story and to identify the main issues that they were facing.
Ellis-Hill 2009 ⁴	UK	Develop understanding of what constitutes a 'good' or 'poor' experience in relation to the transition from hospital to home following a stroke.
Hilton 2002 ³⁷	US	Discover meanings of stroke in elderly, non-institutionalized women survivors.

Characteristics of participants	Methodology (as reported by authors)	Data collection and time frame	Quality rating
43 first time stroke patients - 30-59 years old	Qualitative study	4 interviews Diary (over period of 18 months)	7
8 first time stroke patients - 19-90 years old	Qualitative case study	1 interview (during acute care)	8
6 first time stroke patients - 50-66 years old	Phenomenographic study	1 interview (3 weeks after stroke)	9.5
10 first time stroke patients - 58-65 years old	Qualitative study with discourse analysis	One interview Medical records (in first 3 months)	8
15 stroke patients - all below 65 years	Phenomenographic study	3 interviews Medical records (3 months, 6 months and 12 months after admission)	8
6 first time stroke patients - 52-81 years old	Phenomenological study	Monthly interviews (for at least 1 year, starting after admission in hospital)	8
1 stroke patient - 49 years old	Qualitative self-report	8-year period	4
8 stroke patients - 60-81 years old - time since stroke 2-9 years.	Qualitative study	1 focus interview	7
24 neurological patients - 8 stroke patients, 6 TBI, 10 neurological impairment - 17-59 years old	Qualitative study	1 interview	8
30 stroke patients - 60-94 years old	Qualitative study	1 interview	7
8 stroke patients - 56-82 years old	Narrative study	3 narrative interviews (in hospital, 6 months and 1 year after discharge)	8.5
20 stroke patients - 53-85 years old	Qualitative study	1 interview (at discharge)	6.5
5 stroke patients - 66-80 years old	Phenomenological study	2 interviews (Time frame not stated)	9.5

Table 1 Continued

Study	Country	Aim
Kirkevold 2002 ³⁸	Norway	Developing a theoretical account of essential characteristics of the evolving adjustment process following a stroke as described by patients undergoing the process.
Koch 2005 ³⁹	US	Explore experiences of right hemisphere stroke survivors in their attempt to return to work after the onset of stroke.
Kvigne 2004 ⁴⁰	Norway	Explore how female stroke survivors experienced their life following stroke and how they managed their altered situation.
Lock 2005 ⁴¹	UK	Explore stroke survivors' own perspectives about what helps and hinders paid or voluntary work after stroke.
McPherson 2004 ⁴²	New Zealand	Explore the applicability of a previously derived model of 'what matters most' in people with stroke and chronic pain in addition to arthritis.
Medin 2006 ⁴³	Sweden	Describe the experience of return to work after stroke from the patient's perspective.
Murray 2004 ⁵	UK	Investigate the meaning and experience of being a stroke survivor.
Nilsson 1997 ⁴⁴	Sweden	Elucidate the experience of stroke victims during the course of disease and the few months after discharge.
O'Connell 2001 ³	Australia	Determine the impact of stroke on survivors and to identify their physical and psychosocial needs in rural and regional settings.
Olofsson 2005 ⁴⁵	Sweden	Find out about the experiences of stroke patients concerning their falling ill, their stay in hospital discharge and homecoming.
Pilkington 1999 ⁴⁶	Canada	Enhance understanding about quality of life after stroke from the patient's own perspective.
Pound 1998 ²⁴	UK	Explore subjective accounts of the consequences of stroke.

Characteristics of participants	Methodology (as reported by authors)	Data collection and time frame	Quality rating
9 first time stroke patients - 40-83 years old	Qualitative prospective case study design	Average 7 interviews (in first 2 months (1,2,4,6,8 weeks) and after 3,6,9,12 months)	8
12 stroke patients with right hemisphere stroke - mean age 61 years	Grounded theory study	1 interview Demographic questionnaires Field notes	8
20 stroke patients - 37-78 years old	Longitudinal phenomenological study	3 interviews (6 weeks after onset stroke and 6 and 12 months after returning home)	9.5
37 stroke patients - 20 till over 65 years old	Qualitative methodology	5 focus group interview	8
30 participants (10 stroke, 10 chronic pain, and 10 arthritis) - 42-62 years old - mean time since stroke onset 1 year	Qualitative study	1 interview	8
6 first time stroke patients - 30-65 years old	Phenomenological study	1 interview	9
10 first time stroke patients - 38-81 years old - mean time since stroke 9 years	Interpretative Phenomenological Approach	1 face-to-face or 1 e-mail interview	8
10 first time stroke patients - 53-81 years old	Phenomenological hermeneutic study	2 interviews (1 and 2 months after discharge)	5.5
40 participants (stroke patients carers, key informants) - stroke patient 20-89 years old - mean time since stroke 4.5 years	Not stated	1 focus group interview (3 groups with stroke survivor, 1 with carers, 1 with key informants)	5.5
9 stroke patients - 64-83 years old)	Qualitative study	1 interview (4 months after stroke at home)	8.5
13 stroke patients - 40-91 years old)	Longitudinal qualitative study	3 interviews (acute phase, 1 and 3 months post stroke)	9.5
40 stroke patients - 40-87 years old	Qualitative study	1 interview (10 months post stroke)	6

Table 1 Continued

Study	Country	Aim
Pound 1999 ²⁵	UK	Find out whether people with stroke and their families take positive actions in response to the condition; to explore the nature of these actions.
Proot 2007 ²⁶	Netherlands	Explore stroke patients' experiences of health professionals approach towards autonomy in a longitudinal way.
Rittman 2004 ⁴⁷	US	Describe the dimensions of the experience of time during the transition from hospital to home following stroke.
Robinson 1995 ⁴⁸	US	Describe the effects of a CVA in one partner on married elderly couples.
Robison 2009 ⁴⁹	UK	Explore the activities stroke survivors have identified as important to them pre-stroke, the extent to which they were able to resume these activities and the factors that helped them to do so.
Roman 2006 ⁵⁰	US	Describe how one recovers after stroke, what the process is and how a sense of normality is restored and one's sense of self is involved.
Secrest 1999 ⁵¹	US	Investigate the quality of life as experienced by stroke survivors following rehabilitation.
Thompson 2009 ⁵²	UK	Explore the impact of stroke consequences on spousal relationships from the perspective of the person with stroke.

Abbreviations: CVA, cerebrovascular accident; TBI, traumatic brain injury; UK, United Kingdom; US, United States

Managing discontinuity is a struggle

The first analytical theme comprised three sub-themes about discontinuity in body, self and roles and uncertainty after discharge.

I am 'half a person'

In 12 studies, participants expressed how they struggled with the discontinuity of their body, self and roles as three elements. This challenged how they managed these elements (see figure 2). They felt as *"I am only half a person"*^{23(p.728)} and they experienced a split or discontinuity in the connection between their body and their self. Several parts of their body felt alien. Participants in four studies experienced their body as unreliable,^{23, 24, 31, 32} and in five studies^{2, 24, 33, 34, 44} participants expressed that they experienced this as a threat to their self and identity. This change was frustrating and confusing, as one participant said: *"Who [...] are you... it looks me but it isn't!"*^{5(p.811)} In three studies, participants feared they would never be a *"whole person"* again following the change and loss of roles.^{47, 48, 51}

Characteristics of participants	Methodology (as reported by authors)	Data collection and time frame	Quality rating
40 stroke patients - 40-87 years old	Qualitative study	1 interview (10 months post stroke)	7
20 stroke patients - 50-85 years old	Grounded Theory - longitudinal design	3 interviews (after admission, during rehab and after discharge)	8.5
51 stroke patients - 46-84 years old	Qualitative study	1 semi-structured interview Field observations (1 month post discharge)	6
7 stroke patients - 60-79 years old	Qualitative study	1 interview (between 6 and 12 months post stroke)	7.5
19 stroke patients - 53-85 years old	Qualitative study	2 interviews (after discharge and 12 months post stroke)	8
2 stroke patients - 50 and 80 years old - 5 and 9 years after stroke	Case study research	Interview Observations Records	5
14 stroke patients - 40-93 years old - mean time since stroke 2 years	Phenomenological study	1 interview	9.5
16 stroke patients - 33-78 years old	Qualitative study	1 (short) interview (after discharge)	8.5

Struggle with discontinuity in roles

Experiences of discontinuity in body, identity and self, resulted in a discontinuity in roles, a theme that featured in 17 studies. For example, some people talked about a pre- and post-stroke self,⁵² comparing themselves with their former capacity, their pre-stroke self, life and roles.⁴⁴ In six studies, this comparison was experienced as a struggle.^{2, 21, 36, 38, 40, 42} When they talked about their roles in life, they implicitly also talked about their self and identity and the complexity of who they are: *“Who I am is continuous with who I was before the stroke but, paradoxically, is discontinuous with who I was.”*^{51(p.242)} Previous roles were associated with a sense of self and social identity. Changes in status and roles as a partner, at home, within the family, as a worker and roles in the society were noted as difficult to deal with in four studies.^{2, 39, 47, 49} This change was expressed as *“It’s a big thing going from being a home owner and the head of the family to... being totally reliant and having to be subservient to everybody.”*^{42(p.997)}

Table 2 Development and content of descriptive and analytical themes

Step 1 Coding of Meaningful Segments	Step 2 Development of Descriptive Themes	Step 3 Development of Analytical Themes
Data from included studies resulted in 648 coded meaningful segments	<i>I am 'half a person'</i>	
	<i>Struggle with discontinuity in roles</i>	<i>Managing discontinuity is a struggle</i>
	<i>Uncertainty after discharge</i>	
	<i>The desire to regain continuity in roles</i>	<i>Regaining roles: to continue or adapt?</i>
	<i>Hope to continue or adapt</i>	
	<i>From passive to active in context</i>	<i>Context influences management of roles and self</i>
	<i>Gap between persons with stroke and health care professionals</i>	

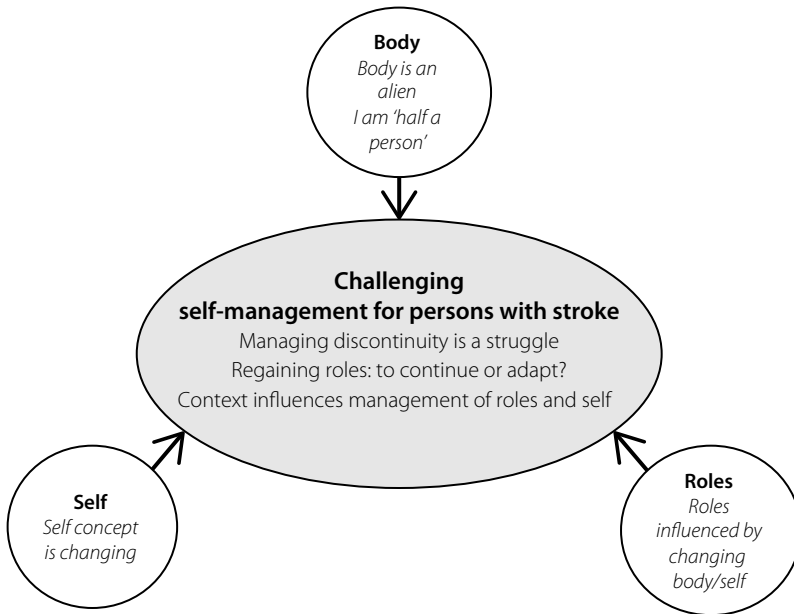


Figure 2 Personal elements challenging self-management after stroke

Table 3 Analytical themes and descriptive themes identified in each study

Analytical Themes and Descriptive themes	References																																		
	30	31	32	21	22	2	33	34	35	36	23	4	37	38	39	40	41	42	43	5	44	3	45	46	24	25	26	47	48	49	50	51	52		
Managing discontinuity is a struggle																																			
<i>I am 'half a person'</i>	X	X				X	X	X	X		X									X	X				X			X	X					X	
<i>Struggle with discontinuity in roles</i>		X	X	X		X				X	X	X	X	X	X	X			X	X	X	X			X			X	X	X	X			X	X
<i>Uncertainty after discharge</i>	X	X	X			X	X	X	X		X	X	X	X	X	X			X	X	X	X													X
Regaining roles: to continue or adapt?																																			
<i>The desire to regain continuity in roles</i>	X	X	X	X	X	X	X	X	X		X	X	X	X	X	X			X	X	X	X			X			X	X	X				X	X
<i>Hope to continue or adapt</i>	X	X	X	X	X	X				X	X	X	X	X	X	X			X	X	X	X			X			X	X	X				X	X
Context influences management of roles and self																																			
<i>From passive to active in context</i>	X	X	X			X				X									X	X	X	X			X			X	X	X				X	X
<i>Gap between persons with stroke and health care professionals</i>						X				X	X	X							X	X	X														

The discontinuity from being the strong caregiver to becoming a care-receiver was experienced as difficult by several participants in four studies.^{5, 33, 36, 48} For example, *"It's hard struggling with the loss of me, especially the strong, capable and always caregiver me."*^{5(p.811)} Discontinuity and change in the role of partner was reported in three studies,^{3, 24, 52} where intimacy between spouses became friendship.

Uncertainty after discharge

In 14 studies, participants portrayed discharge as provoking feelings of discontinuity, uncertainty and ambiguity. Although going home was a rehabilitation goal, giving hope of return to a normal life, discharge was also perceived as a loss of a supportive environment in three studies.^{3, 4, 35} In one study, several participants felt 'dumped' in the community and became isolated.³ To manage an 'uncertain self' was not easy and persons with stroke felt unable to plan, felt unsure about the future and did not really know where to start.^{4, 22} A discontinuity in the safe and comfortable relationship between their body and different environments was depicted in four studies.^{2, 4, 23, 49} Coming home was initially experienced as a shock because they had to leave the safe rehab setting and had to pick up life by themselves.^{4, 47} Their house became a comfortable place where persons with stroke felt they could be themselves and where they started to trust their body again. However, outside their homes, persons with stroke described feeling uncomfortable and becoming more 'silent'. In new environments they felt less able to control their body and were concerned about attracting unwanted social attention.^{2, 4, 23, 49}

In six studies^{2, 4, 21, 36, 40, 44}, persons with stroke gave more negative than positive comments when questioned about how well they managed after discharge. Although ambiguous about discharge, participants realized that the real work started at home and that life should go on.^{21, 35} Going home was considered to be essential to appreciate the consequences of stroke and to be able to manage on their own without professional support. In three studies^{21, 39, 45}, participants reported using information from other people which reinforced their self-efficacy beliefs concerning rehabilitation and recovery.

Regaining roles: to continue or adapt?

The second analytical theme contains two descriptive sub-themes, namely the regaining continuity in roles, and hope to continue or adapt in their roles.

The desire to regain continuity in roles

The desire to regain continuity in roles was mentioned in 20 studies. Many participants expressed a desire to regain some continuity in their life roles and former social and work positions.^{21, 22, 30, 34-36, 38, 39, 42, 46, 47, 50} Participants stated they wanted to recapture and continue pre-stroke roles and valued activities: *"Getting back to normal"*⁴⁶ In order to regain (new) roles, persons with stroke learned to think about themselves in different ways and

re-establish priorities.²⁵ Participants in eight studies spoke about a constant re-appraisal and adaptation to salient roles in order to maintain aspects of their 'self'.^{2, 34, 37, 38, 40, 47, 48, 51}

Four studies depicted the different phases of the process of regaining roles.^{31, 33, 37, 38} In all these studies, the process started with loss and discontinuity on the level of body, self and roles. Next there was re-appraisal, re- adjustment and regaining of roles and finally, there was going on with life.

Hope to continue or to adapt

This subtheme featured in 20 studies. Post-stroke, many people reported hoping to continue or adapt their roles. Hope seemed to be an important strategy and a major element of emotional recovery. People after stroke expressed their hope to return to a normal pre stroke life, optimism, connectedness with one's self, spiritual connectedness and social connectedness with family, friends and others. However, hope was reported to disappear after discharge, as people experienced that rehabilitation services had stopped or changed, and that the expected return to normal life did not happen. Hope was often related to a future goal, for example *"If only I manage to get home, I'll get better."*^{45(p.437)} Hope and keeping negative or disabling feelings at bay, was said to be a way of managing daily life.^{31, 37, 40, 45}

In eight studies, participants spoke about the adaptations they made during their rehabilitation together with their therapists, partner, family and/or employer.^{5, 24, 35, 40, 41, 48, 50, 52} The changes included the male and female aspects of their roles in a relationship. A spouse was experienced as a best friend or protégé and couples tried to establish a new routine with each other. Some reported letting friends and acquaintances know in advance about the difficulties they faced (e.g. memory, fatigue, communication-phone calls). Fatigue stopped participants doing daily activities or making appointments in five studies.^{21, 25, 31, 38, 47}

To continue work, persons with stroke altered the way they viewed and acted as employees.^{39, 41, 43} For example, participants described avoiding stress at work, by working fewer hours, resting in between tasks, scaling down the scope of activities and tolerating a lesser job performance. Participants reported trying to find employment consistent with their abilities and interests. In three studies, an active and disciplined attitude was said to be a way to be proactive and make 'things' happen during the day.^{30, 39, 43}

Participants in three studies avoided or modified the demands of former social positions. For example, *"I want to do different things now. I want to live and I want to spend more time with my grandchildren."*^{22(p.220)} Others developed a new pattern of interdependence, which meant greater dependence on others for family visits, outings and support to leave the home.^{25, 33}

Context influences management of roles and self

The final analytical theme has two sub-themes that highlight the influence of the context.

From passive to active in context

This sub-theme was evident in 15 studies. Immediately post-stroke, participants were said to be passive. They trusted and valued the input of health care providers and family members, having a 'wait and see' attitude.^{2, 21, 26, 35, 45, 50} The process of becoming active and taking charge in managing roles⁴², and in regaining valued activities and roles, seemed to be dependent on the context. In two studies^{47, 52}, paternalism of health care providers and family members, and over-protectionism of family were recognized as a barrier to regaining autonomy and becoming active. A decrease in support from health care providers, as well as a changing attitude of the family was reported to be helpful in promoting a more active attitude in seven studies.^{25, 26, 39, 42, 43, 46, 52} This helped people to become more involved in their daily life and manage themselves. One stroke survivor said about a supportive husband: *"My husband is good because he gradually made me do things on my own."*^{42(p.994)} In one self-report study, the participant commented that being encouraged to talk about their losses was helpful.³³ In three studies^{5, 26, 35}, the contribution of other patients and family members was acknowledged. Family was a motivator for discharge. They gave emotional support and organized outings when they returned home.

Gap between persons with stroke and health care professionals

The final sub-theme was noted in five studies where participants perceived a gap between their own goals and the goals of health care providers.^{4, 22, 36, 41, 43} Participants described their recovery in relation to social and emotional functioning, whereas health care providers viewed recovery from a biomedical perspective. During acute care and the rehabilitation phase, the major focus of the health care providers was on bodily improvements. Persons with stroke considered that the health care interventions did not always fit their needs. Participants wanted more attention to be paid to their psychosocial needs, to regaining roles and the practicalities of managing at home, to preparing for return to work, to adapting to life situations, and discussing the transition to independence.

Discussion

This thematic synthesis of 33 qualitative studies with 465 participants from eight countries offers fresh insights into the adjustment process post-stroke, particularly the impact of stroke on the management of roles and sense of self over time, which was experienced as a struggle. They offer new understanding about the challenges of managing discontinuity and the influence of the context on moving from passivity, through coping with the uncertainty of discharge, to resuming valued activities and roles. Such an in-depth, insider

perspective should inform both rehabilitation programs and self-management interventions for persons with stroke.

The concepts of discontinuity and uncertainty were central to the adjustment process. Many studies described the constant appraisal of roles and self after stroke, leading to uncertainty. Participants were in a state of flux, between their former self and their present or future self. This confirms the finding of a review about the experiences of living with a stroke.⁵³ The thematic synthesis reveals the depth of discontinuity experienced post-stroke. There was discontinuity of care after discharge, a discontinuity in feelings of comfort in different contexts, and a discontinuity in the sense of self, identity and valued life roles of people after stroke. The problem was that health professionals did not fully recognise nor address this in their interventions. Similar lack of continuities have been described by people with chronic diseases, including chronic pain, chronic obstructive pulmonary disease, cancer and spinal cord injury.⁵⁴⁻⁵⁷ These findings support Hammell's⁵⁸ proposal that continuity should be explored in rehabilitation programs. If (dis)continuity is used by health care providers in supporting persons after stroke, then discontinuity in roles post-stroke could be discussed, as well as ways of regaining continuity and coherence between life before and after a stroke.⁵⁸ Acknowledging the feelings associated with the 'discontinuity of care after discharge' may alleviate some of the uncertainty.

Role-management is about restoring and adapting familiar roles, and developing new ones that accommodate the consequences of the disease.¹³ Lorig¹³ suggests that people with chronic diseases should resume their customary activities and roles and become a 'self-manager'. However the findings of this synthesis show that this is a challenging expectation for people post-stroke. Some roles, such as worker and spouse, may not be regained; and modifying these roles or developing new ones by persons after stroke is difficult. The person's readiness to confront these discontinuities is important. Health care professionals need to be sensitive to the right moment to talk with people about becoming a self-manager and to address the question "Who would you like to be and can you be after the stroke?". Lorig¹³ states that "*It is impossible to have a chronic condition without being a self-manager*" (p17). A good self-manager has to develop "*an interrelated set of behaviours with the aim to manage the medical, functional, economic, and social implications of a disability*" and it needs to become a significant part of the person's identity.^{12, 13, 58} Nevertheless the role of self-manager is new and requires further development.^{13, 59, 60} Raising the issue of being a self-manager, and incorporating self-management interventions in rehabilitation programs may help counter the fears about being unable to manage when discharged.^{3, 36, 61}

Strengths and limitations of the thematic synthesis

The thematic synthesis adhered as much as possible to relevant Preferred Reporting Items for Systematic Meta-Analysis (PRISMA)⁶² standards for reporting systematic reviews. The 33 studies covered the acute, rehabilitation, discharge and chronic phases post-stroke.

Most studies were published in the 2000s and presented ‘the voice of stroke survivors’ about the impact of stroke on roles and self in eight different countries. These aspects enhance both the trustworthiness and transferability of the findings.¹⁷

Another strength is that well established applied methods for reviewing, appraisal and synthesis of qualitative studies were used for this study.^{14, 17, 18} All the procedures, including the four stage data analysis and synthesis process, were conducted by the first two authors and then discussed by the full research team to optimise the validity of the synthesis.¹⁷ Although discontinuity and uncertainty about the adjustment process were consistent findings in the included studies, this may reflect a publication bias as papers that find trouble-less transition to post-stroke life might not get published because of bias by authors, peer reviewers or editors. However, findings of a synthesis in qualitative studies are *“reviewers constructions, of researchers constructions, of the data researchers of primary studies generated in the interaction with the participants”*.^{17(p.236)}

The findings are less applicable to stroke patients with severe cognitive impairments and communication disorders as these groups were excluded from most of the primary studies.

The search strategy, using five databases and a combination of MeSH and free text terms produced a heterogeneous set of studies. Searches of other databases, such as Web of Science and Sociological Abstracts, may have produced relevant studies. The decision not to use ‘qualitative’ as search term increased the yield and therefore the likelihood of finding relevant studies. Search terms like ‘qualitative’ or related terms differ with each database making it problematic to locate qualitative studies.¹⁹

Quality rating

There is an ongoing debate about the value of quality ratings in reviews of qualitative studies.^{17, 18, 63} We used the adapted CASP tool to review the methodological quality of each study, rather than as an exclusion criteria. Four studies^{3, 33, 44, 50}, were rated as 5.5 or less on the 10 point scale. This was because they contained insufficient information about ethical issues and reflexivity of the researcher. Although rated low, we decided to retain these studies. For example, the experiences presented by Buscherhof³³, a researcher affected by a stroke, deepened and strengthened the findings. Sandelowski and Barosso¹⁷ observe that qualitative studies tend not to provide enough methodological details, but when the aim is to use patients’ stories she considers that, if the quality of the study is sufficient, it would be a mistake to exclude these rich, authentic descriptions.

Implication for practice

The views of people post-stroke should inform the design of self-management programs to ensure that the programs address the patients' struggle in regaining a sense of self and valued roles. This synthesis suggests that attending to "(dis)continuity" and "uncertainty" would add value to stroke rehabilitation.

Self-management encompasses medical, role and emotional management.^{11, 13} Patients' narratives indicate that the process and moment in the timeline of becoming a self-manager on itself, as well as managing the impact of stroke on roles and self is difficult. Self-management programs after discharge can have a stronger focus on role management to support people in the process of regaining, adapting or pursuing their valued roles. One of the overarching themes was the influence of context on self-management. Persons with stroke are 'self-managers in context' interacting with their partners and family. This means that self-management interventions need to focus on people in their social context. If interventions are developed with stroke survivors, then they are more likely to be sensitive to struggles to regain former and/or new roles and self. Such programs would reflect the goal of stroke rehabilitation which is to enable patients and their families to live their lives to the fullest.⁶⁴

Future research

Further research is needed to enhance understanding of the way patients manage discontinuities post-stroke and how this can be ameliorated. Longitudinal narrative studies could give greater insight into the changing perceptions of self, identity and roles; and the shifting priorities during the process of role management. Such studies would tell us more about becoming a self-manager after stroke. This knowledge could be incorporated into self-management programs, which would then require evaluation to establish their efficacy and cost effectiveness.

Conclusion

This thematic synthesis of 33 qualitative studies with 465 participants from eight countries adds new knowledge about the impact of stroke on self and roles. The analysis and synthesis of the primary studies showed that many persons after stroke experienced discontinuity and uncertainty as they struggled to adapt and regain their lives. Developing a (new) self and roles was difficult, especially when they did not feel ready to manage themselves after discharge. These findings are pertinent to rehabilitation programs because they highlight the need to address role management and emotional management, and to assist people post-stroke to regain a sense of self and continuity.

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Appendix 1 Search string for PubMed

Search	Query	Items found
#31	Search ((stroke[Mesh] OR stroke OR cerebrovascular accident OR cerebrovascular disease) AND (role[Mesh] OR ego[Mesh] OR self OR role) AND (self care[Mesh] OR self management OR role management OR self management OR self care) AND (adaptation, psychological[Mesh] OR social adjustment[Mesh] OR emotions[Mesh] OR adaptation OR adjustment OR transition OR transformation OR coping)) Filters: Publication date from 1990/01/01 to 2010/08/30	265
#30	Search (((#5) AND #10) AND #16) AND #28 Filters: Publication date from 1990/01/01 to 2010/08/30	265
#29	Search (((#5) AND #10) AND #16) AND #28	349
#28	Search ((((((#17) OR #19) OR #21) OR #23) OR #24) OR #25) OR #26) OR #27	818527
#27	Search coping	111155
#26	Search transformation	177089
#25	Search transition	175823
#24	Search emotions [Mesh]	149454
#23	Search social adjustment [Mesh]	20132
#22	Search adjustment [Mesh]	109731
#21	Search adjustment	196967
#20	Search psychological adaptation [Mesh]	93561
#19	Search psychological adaptation	97195
#18	Search adaptation [Mesh]	9853
#17	Search adaptation	213361
#16	Search (((#11) OR #12) OR #14) OR #15	254327
#15	Search role management	146483
#14	Search self management	115161
#12	Search self care [Mesh]	35795
#11	Search self care	100272
#10	Search (((#6) OR #7) OR #8) OR #9	2048658
#9	Search role [Mesh]	84110
#8	Search role	1642788
#7	Search self [Mesh]	6784
#6	Search self	456330
#5	Search (((#1) OR #2) OR #3) OR #4	352380
#4	Search CVA	188128
#3	Search cerebrovascular accident	189166
#2	Search cerebrovascular disease	267149
#1	Search stroke	186984

Search string for PubMed with filter in publication date. Checked November 22, 2012



Chapter 3

How Is Self-Management Perceived by Community Living People after a Stroke? A Focus Group Study

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Abstract

Purpose: Self-management has become an important concept in stroke rehabilitation; however, the way that people post-stroke reflect on the concept of self-management has not yet been studied. This qualitative study explored the reflections of persons post-stroke on self-management, readiness and needs in self-management support.

Method: Focus group interviews were conducted with 16 community living stroke survivors (53–84 years of age). Both verbal questions and photo elicitations were used to collect data. A constant comparative framework was used for the analysis.

Result: Participants described their self-management as a complex, long-term, personal learning process. Post-discharge, participants were not ready to self-manage. Aside from individual self-management, participants also mentioned co-management with relatives. Relatives could provide support, but they also limited the development of participants' self-management skills. Participants missed having professional support post-discharge and would have appreciated additional psychological and emotional support in their process of self-management.

Conclusion: Self-management post-stroke is complex. Stroke self-management programs may be optimised when integrating role and emotional management in addition to medical management. Although readiness to self-manage differs amongst individuals, support should start as soon as possible and continue post-discharge in people's personal environments. Self-management programs should not only focus on self-management of stroke survivors but also on co-management with relatives.

Introduction

Stroke is a common cause of long-term disability in the developed world.¹ The World Health Organisation (WHO) reported in 2004 that 15 million people worldwide suffer from strokes each year.² In the Netherlands, approximately 47,000 Dutch individuals are affected by stroke,³ and the incidence of stroke is predicted to increase by 17% from 2010 to 2020.^{4, 5} A stroke may affect physical, cognitive, social and emotional functioning. After strokes, people face problems during the acute phase, after discharge and in the long term.⁶⁻⁹ Long-term needs of people after strokes differ according to the individual, depending on the severity of the stroke and personal and environmental factors.⁹ Furthermore, strokes affect not only the persons with the stroke but also their partners and families.¹⁰⁻¹²

In recent years, interest in the development of self-management programs post-stroke has increased.^{1, 13-15} Self-management is defined as an 'individual's ability, in conjunction with family, community, and the appropriate health-care professionals to manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a chronic disease.'^{16(p. 1145)} Huber et al.¹⁷ even proposed that the term *self-management* should be integrated into a new definition of health. Indeed, Huber et al. suggest a reformulation of the WHO definition of health, to include 'the ability to adapt and to self-manage in the face of social, physical and emotional challenges.'¹⁷ Limitations to the current definition are that it is too medical and focused on recovery and that it does not pay sufficient attention to individuals' capacities to cope autonomously with challenges in life and to function with fulfilment and a feeling of well-being when facing a chronic disease or disability.¹⁷

Self-management is a multifaceted process, and the work of Corbin and Strauss highlights three key domains: (a) medical management, (b) emotional management, and (c) role management.¹⁸ Medical management pertains to dealing with the consequences of a stroke; emotional management refers to coping with the emotions and lifestyle changes associated with a stroke; and role management refers to the way people continue their lives and regain and maintain roles.^{18, 19} Moreover, self-management is a dynamic, interactive and daily process.²⁰⁻²² Alternatively, Schulman-Green et al.²² have identified three processes of self-management in chronic illness: focusing on illness needs, activating resources and living with chronic illness. Each process has its own challenges, and persons need to fulfil and develop different tasks and skills depending on the process—for example, taking ownership of health needs, performing health promotion activities, action planning, prioritizing and pacing, problem solving, communicating effectively for self-advocacy, identifying and benefiting from resources, processing and sharing emotions, adjusting to illness and 'new' self, seeking normalcy in life, and carrying out tasks and responsibilities as much as possible.^{19, 22} When considering the processes identified by Schulman-Green et al.,²² it is not clear whether stroke survivors have the capacity to efficiently self-manage illness needs, such as utilize resources and live with

chronic illness, considering the impact of the residual deficits of stroke. Indeed, the Dutch Care Standard CVA/TIA²³ even states that self-management of people post-stroke might be limited due to their resulting cognitive disabilities and language problems.

Self-management is, nevertheless, increasingly perceived as an important concept in rehabilitation programs, as these programs support patients post-stroke to conduct their lives to the fullest¹⁵; interventions encompass not only dealing with the illness (medical management) but also focusing on emotional and role management.^{15, 18, 19} Although several stroke self-management programs are developing, the format for delivery of those interventions still needs improvement in content and structure.^{1, 24} Several papers^{6, 8, 21, 25-27} described stroke survivors' perspectives on their transformation and adaptation process post-stroke, including their feelings of uncertainty; loss of self and roles; and their physical, nonphysical, and informational needs. However, these clients' perspectives are not fully integrated in the self-management programs. Moreover, little is known about how patients perceive the concept of self-management themselves and what they need to become 'self-managers' after a stroke.

This study had two aims: (1) to deepen understanding about the reflections of persons with stroke about the concept and readiness for self-management, and (2) to describe the needs of persons with stroke regarding their self-management support.

Methods

Study design

This qualitative study was conducted during the spring of 2011, and it used focus group methods to explore stroke survivors' reflections about the concept of self-management, their perceived readiness for self-management and their needs in regard to self-management support. A naturalistic study design,²⁸ based upon a constructionist epistemology,²⁹ was utilized for the study's exploratory aims. A constructionist epistemology assumes that reality is socially constructed and that research should be conducted through interaction between researchers and participants. We expected that discussions among the group members would have additive value in exploring the perceptions of the participants, leading to more in-depth insights than individual interviews.^{30, 31} This study involved two focus groups conducted in two stages. In the first meeting of the focus groups, the concept of self-management and participants' own self-management post-stroke experiences were explored. In the second meeting, the participants' perceptions concerning self-management support and needs post-discharge to home were explored.

Participants and context

Recruitment took place in the east of the Netherlands. After receiving approval from the Regional Committee on Research Involving Human Subjects (ref no. 2011/006), potential participants were selected from a list of clients who had been discharged to home after

rehabilitation in nursing homes and via a stroke support group. In the Netherlands, stroke survivors who cannot go home after their hospital stay can receive rehabilitation in rehabilitation centers or nursing homes. Depending on the availability of inpatient rehabilitation places (which differs per region) and the prognosis to recover, patients are referred to nursing homes or rehabilitation centers.

Thirty-six potential participants, who had been living at home for at least three months post-stroke, received a letter about the study on behalf of the researcher and were contacted by phone after a week by research assistants who provided additional information and asked potential participants if they were willing to take part in the study. It was explained to potential participants that sufficient communication skills for a focus group interview were needed to be included in the study. We used purposive sampling to achieve a diverse range of participants. From the 36 potential participants who were approached for the study, 18 declined for several reasons (e.g., having no time, having no interest in the study, wanting to forget everything after the stroke, experiencing language problems, or feeling too tired). Two other potential participants judged themselves as not having sufficient communication skills for a focus group interview. Finally, 16 participants provided informed consent and participated in the study. Participants were permitted to choose whether they wanted to participate in a focus group in the northeast or southeast in the Netherlands. Focus groups were organized in convenient meeting places: the location of the stroke support group or a nursing home in the northeast of the Netherlands. There were two focus groups composed of eight participants.

Participants varied in age, gender, number of years post-stroke, marital status and use of services (see Table 1). All participants were native Dutch speakers with no observable communication problems, aside from one participant who demonstrated mild aphasia, which did not hinder his communication.

Data collection procedures

Data collection was conducted in two stages, as each focus group involved two meetings. For each meeting, a semi-structured interview guide with nondirective, open-ended questions^{30, 31} was developed. All participants organized their own transportation. They were welcomed with coffee and tea after they had been comfortably and randomly seated at a round table. The focus groups were held over a two-hour period with a break halfway for coffee and tea. During the first focus group meeting, the aim of the study was explained, and subsequently, an open question was posed about what the word *self-management* meant to the participants. No framework or definition was introduced because the aim was to receive the participants' open reactions and insight into the perceptions of the participants regarding the word *self-management*. After collecting reflections from the participants, the conversation continued about their own self-management after their stroke. Participants were asked to reflect on photographs and a visualized narrative (see Figure 1) about their own self-management post-discharge. They were invited to talk

Table 1 Participant demographic characteristics (N = 16)

Focus Group	Participant	Gender (M/F)	Stroke	Age	Marital status	Consequences	Health care and/or support
1	1	M	2004	83	Widowed	Walking stick	Domestic help
	2	M	2003	65	Married	Communication problems - Walking stick Hypertonic right arm	-
	3	F	2005	53	Married	Hemiplegic left side Electric wheelchair	Community-based care
	4	F	2006	64	Divorced	Light attention problems	-
	5	F	1990, 2001	62	Married	Hypotonic left arm Fatigue	Community-based care
	6	F	1995, 2005, 2010	60	Married	Fatigue Light attention problems	Domestic help Community-based care
	7	M	1959	74	Married	Left leg hemiplegic Walking stick	-
	8	F	2008	82	Widowed	Light mobility problems Fatigue	Domestic help
2	9	M	2010	65	Married	Less strength left arm Fatigue	Community-based care
	10	F	2010	84	Married	Light communication problems Light attention problems	Community-based care
	11	M	2010	76	Divorced	Light communication problems	-
	12	F	2009	69	Married	Light attention problems	Community-based care
	13	M	2010	70	Married	Less strength right leg	Community-based care
	14	M	2009	68	Single	Light coordination problem left arm Fatigue	-
	15	F	2009	76	Married	Walking stick Light hypotonic left arm	-
	16	F	2010	82	Widowed	Walking stick	Community-based care

about critical incidents or events regarding the process of self-management after a stroke and about contextual factors contributing to their own self-management. The second focus group was held two weeks after the first; it started with a summary of the first focus group, followed by participants' reflections on the summary. During the second focus group, questions were more focused on the support and needs of the participants in relation to their self-management after discharge to home.

To facilitate data generation and to adapt and attune to people with possible communication or cognitive disorders, different strategies were used during the focus group interviews.^{31,32} A round-robin approach was implemented to equalise participation of all participants in the meetings^{30, 31}, and group members were asked to write down their ideas about their questions and pertaining issues if they felt that that would support them in the conversation. Besides verbal interview questions, we used photographs to evoke responses and emotional feelings as well as to sharpen the memory and 'activate' the interview.³³⁻³⁵ The moderator showed a visualised narrative (lifeline) with life events, such as stroke and discharge, as well as some photographs about daily activities, based on the Dutch Activity Card Sort³⁶ (see Figure 1). The photos helped participants to think of their own daily activities and to remember their experiences while managing themselves when preparing for and doing these activities. Furthermore, research assistants provided support in writing or summarising with participants when needed.

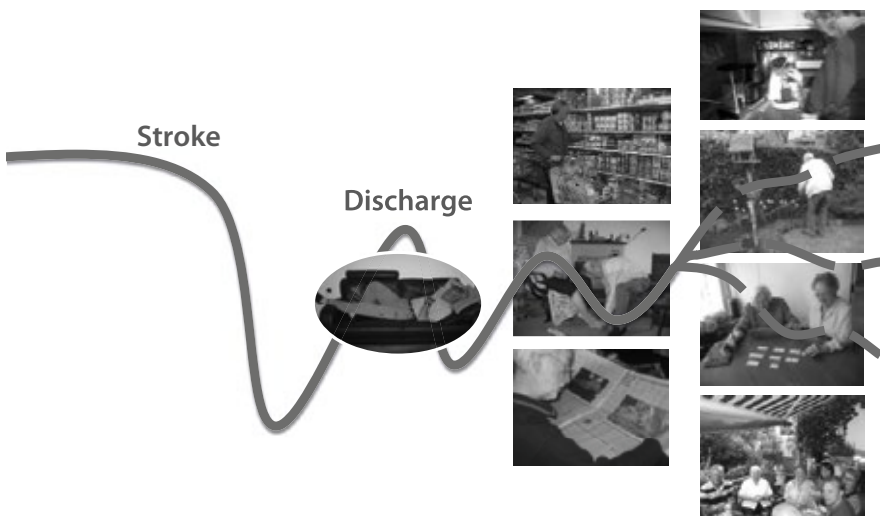


Figure 1 Life line with pictures of daily activities for photo eliciting: dressing, resting, making coffee, gardening, playing cards, reading newspaper, shopping, visiting family

Data analysis

The focus group interviews were audiotaped and transcribed verbatim, resulting in 192 pages of full text. To store, organize and retrieve data, transcripts and field notes were transferred to Atlas Ti 6.1.11 software. A constant comparative framework was used as a strategy for the analyses.^{31, 37} The objective of the constant comparative framework was to identify key issues and patterns in the data. Special attention was given to critical incidents to discover important events that had influenced participants' actions or decisions concerning their self-management^{31(p.125)}. Analysis of the data consisted of two phases.

In the first phase, the 'coders' independently coded the transcripts (TS and research-assistants MB+NH and AR+RV). They started with listening to the audiotapes and reading the transcripts to become familiar with them. After completing the coding of the first interview, the procedure and initial codes were discussed in a coders meeting to increase the rigour of the coding procedure. When coding, participants' comments and stories about the process of self-management post-stroke, generally and specifically, as well as important events, were labelled with a word or short phrase that expressed the key issues.^{37,38} Eventual differences were checked against the original transcripts. Subsequently, the other three interviews were coded. Then codes from all interviews were organized in coherent categories, and the categories were organized in recurring (sub)themes about self-management and the support and needs concerning self-management post-stroke.^{31, 37,38} In another coders meeting, the categories and emerging (sub)themes were discussed, refined and described; examples of these included 'Self-management, a difficult word', 'The process of self-management', 'The context', and 'The needs of stroke survivors'. Subsequently, the transcripts were reread to verify that the emerging (sub)themes were present in the data. The final step of this phase was the writing of preliminary findings.

In the second phase, the preliminary (sub)themes and findings were further discussed and refined in a separate meeting with the second author (EC) as well as in a reflective meeting with the entire research team (all of the authors). In this analytic reflection, the final four themes, as presented in the results section, were developed.

Trustworthiness

To enhance the trustworthiness^{39, 40} of the study, field notes and a research diary, as well as the written comments of the participants, were kept and used in the analysis process. Data were coded independently; categories and themes had been discussed in three coders meetings, discussed with the second author and amongst the whole research team. To verify findings, the preliminary (sub)themes were also presented at a meeting of the stroke support group two months after the interviews had been conducted.

The primary researcher and first author (TS), who previously worked as an occupational therapist in stroke rehabilitation and now works as staff lecturer and researcher with expertise in qualitative research, moderated the interviews. The co-authors were working

as an occupational therapist (EC), speech and language pathologist (BS), and physiotherapist and professor in Allied Health Sciences (RN), and were experienced researchers.

Results

The analysis led to four themes: (1) self-management: a difficult word, (2) self-management: a complex and long-term learning process, (3) influence of relatives on the self-management process, and (4) persons with stroke feel neglected in their needs. Each theme will be described and supported by quotes from participants. The addition of FG-1 or FG-2 after the quotations shows whether the quotations were from participants from focus group 1 or 2.

Self-management: a difficult word

The Dutch word 'zelfmanagement' is similar to the English word self-management. After some introductory questions, the participants were asked about their ideas of 'self-management' without further explanation. The immediate reaction of several participants was that they could not identify themselves with this word. Different participants said that it was a difficult word for them. One participant commented, 'Can't they think of a Dutch expression for it?' (FG-2), which indicated that he wanted a less difficult word to understand. For several participants, the word 'manager' was related to a position at work and was not perceived as something connected to their condition as stroke survivors. One participant stated, "*I was a manager at work, not as a patient*" (FG-1).

Although the participants could not identify with the word, they said that they did understand what was meant by the concept of self-management. When the participants were asked for alternatives or synonyms for the word self-management, many of the expressions that they provided had to do with '*organising your life*' (FG-2), '*sorting out*' (FG-1) and '*doing] it yourself*' (FG-2). These examples referred to the intentions of participants to solve their problems independently and only seek help if necessary. Indeed, self-management was apparently understood as something that people initially had to do for themselves, and they believed that they should only ask for help if needed—for example, when activities were too complicated or when communication was important. With a bit of humour, a participant stated that, for him, self-management meant that he was '*self-employed without staff*' (FG-2). Table 2 shows examples of expressions and comments of the participants regarding the word self-management.

Self-management: a complex and long-term learning process

When the participants talked about their own self-management, most commented that self-management was a long-term learning process. This started after discharge, and it had taken quite some time to adjust to the stroke and to manage their lives again. Many participants spoke about their adjustment after stroke when they explained their process of self-management.

Table 2 Understanding and Comments of Participants on Self-Management

Self-management is:
<i>"The director of your life in your hands"</i>
<i>"Do it yourself"</i>
<i>"Regulate it yourself"</i>
<i>"Self-employed without staff"</i>
<i>"Learning yourself to live"</i>
<i>"I can care about myself"</i>
<i>"Problem solving"</i>
<i>"Trying"</i>
<i>"Just go my own way as before"</i>
<i>"Put your life on track without too much interference from the environment"</i>
<i>"Let me do what I can"</i>
<i>"Mess around"</i>

Many participants reflected that they were not ready to self-manage immediately after discharge. A participant said this: *'If you're at home, then you still cannot do it alone. That takes much longer!'* (FG-1). To develop self-management post-stroke, participants expressed that there was a need to be selfish. One participant said, *'Well, it just happens to you. If you want to recover, then you have to work for it. Another person cannot do that for you'* (FG-2). Participants said that they even had to become a bit stubborn to learn to manage activities themselves.

To learn to manage the residual symptoms post-stroke and to do activities that were important to them, participants prioritized and planned their activities carefully. They used information about their illness and often tested the boundaries of their limitations with trial and error to learn how to manage their activities step-by-step. This was expressed by a participant, who said, *'You need to explore your limits until you bump with your head against the wall ... and then say, "Well, well, I have somehow gone too far!" That is a learning moment for the next time'* (FG-2). When prioritizing their activities, some participants stressed that they chose to do enjoyable things, such as a man who said the following about his visits to his singing choir: *'There are some things that are fun. There I am allowed to enjoy it and be tired'* (FG-2). Making these choices gave the participants the feeling that they were able to manage themselves and give meaning to their daily lives. In several examples, participants spoke about the consequences of medical conditions and about role changes, such as a woman who revealed the following about the changes in her role as a friend: *'You have changed as a friend; you can no longer do all the nice things together. Okay, you can walk a bit, but the friendship has changed ... What we first did together, I cannot do anymore'* (FG-1). The management of changes in her role as a friend (role management)

were consequences of the way she needed to cope with her fatigue (medical management), and this was difficult for her to accept (emotional management).

Although most participants were reluctant to fully accept the impact of their stroke, they expressed that reconciliation towards the varied impacts of their stroke on lifestyle was necessary before they could truly manage their own lives. Furthermore, it was apparent that participants' awareness of abilities and deficits promoted adjustment and learning towards managing life post-stroke. For example:

You regularly stumble—you experience different things. Every time that ... uh ... that you are brought to a halt, it is because you cannot go on. And then slowly, then you learn what you can and what you cannot, and then you adjust, uh—at least that is what you need to do; if you want it or not, you just have to adjust. (FG-2)

One outcome of the learning process was that participants had gained insight and had become more realistic and honest about their capacities. They experienced that activities often cost more time and energy, and they took this into account when it came to managing their own lives. They were listening to their bodies much better than before, and they perceived this to be part of their self-management. Related to fatigue, a participant said, 'It is heavy work to clean the whole house. But I can do a part of it. Yes, and every time I try a bit further—but you have to rely on yourself... Yes, the body gives a sign how far you can go' (FG-1). The participants who experienced limitations in their communication explained how they had learned to manage it and to advocate for themselves in being honest about their communication skills to others. One participant said, for example, 'If I make a call to a doctor or speak with a foreign person, I directly say, "Sorry, this conversation may be a bit weird. I've had a stroke". And then they understand' (FG-1).

The complexity of the process of self-management post-stroke had to do not only with the participant but also the social environment of the participant, which is explained in the next section.

Influence of relatives on the self-management process

Besides 'do-it-yourself', many participants indicated that their partners and children were important during their process of recovery after a stroke, and they expressed that they could not have learned and managed without them. One married participant indicated that, for her, self-management was not about management for one person but that it was more 'co-management', which meant that she managed her daily life and the symptoms post-stroke together with her partner. She said, 'If something like that [stroke, author] happens, you get it together ... that means "self-management for two' (FG-2). Another participant reacted to this statement by stating, 'My wife is my manager. Self-management is something you do together' (FG-2), which indicated that his wife was supporting him in planning and reminding him of activities or the necessity of resting.

Partners and children gave support, and they encouraged their loved ones to be proactive and to perform their daily activities. A participant explained how her partner supported her with an action list: *'We also have made a list of things for a while. What mattered most came first, and if that was fulfilled then it was crossed out. In such a way, the day came and went fine'* (FG-2). Sometimes, partners confronted the stroke survivors in regards to taking responsibility and becoming active, which helped in the development of self-management. A woman explained how a confrontation with her husband helped her to face the reality of her life post-stroke and prompted her to start managing herself:

He has really taught me to pick up the thread. I was actually in bed and on the couch, and I didn't get much further than that. When he came home from his work at some point, and the food was not ready...he said, 'If you're not getting up from that couch, then I'll take the children and then we'll leave.' (FG-1)

This confrontation helped her to resume her former activities in her daily life, and she said, *'And yes, of course, [it is] not as how it was before, but I'm there again'* (FG-1). She had the feeling that she was managing herself again, as well as the household activities.

The downside of the support of participants' relatives was that they often took over too quickly and encouraged them to participate in too many activities, which limited the self-management of the persons after stroke, as illustrated in the following statement: *'My wife is, of course, my "prop and stay", but I need sometimes to fight to be able to do something myself!'* (FG-2). When relatives took over too many activities, it prevented post-stroke individuals from learning and developing to self-manage. A way to cope with this was that participants became stubborn. One participant gave an example of what happened when her husband helped too quickly: *'Well... what is my husband doing when he joins me: "Come, I will just do it!" I always have to explain that I want to do that myself'* (FG-1). At the same time, different people in the focus groups expressed that they understood that their partners took over many things because participants could not do it alone, especially in the first phase after the stroke. Although the participants appreciated that their relatives helped with their activities, they emphasized that, even when activities were difficult for them, if they felt some involvement in the decisions that they made and the activities that they participated in, this would decrease their sense that their lives were being lived by others.

Persons with stroke feel neglected in their needs

Many participants felt they were not ready to manage themselves immediately post-discharge. They said that health care services like physical therapy or occupational therapy were stopped too early. Real recovery, regaining and managing their daily lives had just started in their own environment; during this time, they wanted more support to explore how to manage themselves and their daily life. Moreover, it was suggested that the

participants learned a lot during rehabilitation but that it was difficult for them to apply what they learned in their daily lives at home. A participant expressed, *'I missed [having] somebody to guide me after discharge—to stay active, to direct me'* (FG-1). After discharge, some participants received home care, physiotherapy, occupational therapy or speech therapy, but this was not described by the participants as particularly supportive for the development of self-management skills or competencies after a stroke. They perceived this care only as support in household activities, learning to walk or learning to speak.

When it came to emotional management, participants expressed that they had needed more support in coping with the changes in their roles and daily lives. Many participants missed having good, empowering talks with professionals, and they felt lonely in the process post-stroke. One participant revealed, *'The physical pain is bearable, but the emotions and grief ... There are no "emo-tablets" ... You just have to solve it yourself!'* (FG-2). If health care providers paid attention to the participants' grief, the participants did not always consider their providers' attention meaningful or 'deep enough' to talk about their real emotions. Moreover, empathy often was lacking, which one participant expressed in the following critical way: *'They become doctors—but the human behind the patient they don't see!'* (FG-1).

Some received support from their closest family members and friends, but mutual understanding was sometimes different with them, as was expressed by one participant who talked about her husband: *'He always says, "I do have sympathy for what happened to you, but I cannot understand" ... I say at those moments: I can't explain it either because I don't understand it myself'* (FG-2). Others stressed the importance of their peers. When they were with their peers, participants felt no need to be ashamed because they genuinely understood each other.

Participants suggested that having a coach visit people at home regularly would result in better knowledge about the development of their capabilities after a stroke, and it could also contribute to the development of self-management. A participant proposed the continuation of occupational therapy post-discharge and said, *'Why can an occupational therapist not be a coach? I have had a lot of OT during rehabilitation ... how to manage it ... and then you fall in a hole'* (FG-1). Home care professionals also were mentioned as possible key figures to support self-management because they knew the ins and outs of the individual after a while. Also, fellow sufferers could play roles as friends in the support network because they had experienced strokes themselves and understood the consequences. Meetings with peers could spark recognition and provide participants with trust. Also, support in how to cope with the shrinking social circle was needed—even linked with support in self-management.

Discussion

Self-management post-stroke is difficult. In regard to the word, participants had difficulties identifying with the term *self-management*. For some participants, being a manager was more likely perceived as a role at work than a role they had as a patient. The participants in our study described their post-stroke situation where they had to (learn to) manage themselves as a complex, long-term and personal learning process, in which they needed time to adjust to the consequences of the stroke itself and, besides that, learn how to self-manage.

The problems and needs of the participants changed over time, as they shifted from more practical issues in the beginning towards a need for psychological and emotional support in the later stages, which is supported by other studies.^{27, 41} Regarding the complex process, Jones¹ described how stroke survivors require time to learn to self-manage after being confronted suddenly with the multifaceted consequences of their stroke and that they do not learn step-by-step to self-manage in the same ways as people with other chronic diseases.

Post-discharge, our participants could not manage themselves immediately. Although they had received care that supported them in conducting household activities, learning to walk or learning to speak after returning home from a hospital or rehabilitation centre was more challenging than they expected. This supports the study of Turner et al.,⁴² which describes the transition from the hospital or rehabilitation centre as a period of great significance and uncertainty, which is particularly emotionally stressful and challenging. When persons post-stroke arrive home, they are confronted with the consequences of the stroke,^{43, 44} and especially during this time, they can benefit from a program that supports them in 'picking up the thread', enabling them to define their goals and make action plans.

The participants' process of learning to self-manage was related not only to the consequences of their strokes and the ways that they managed themselves but also to the roles of their relatives. The challenge here was finding a balance between adopting the 'do it yourself' approach and receiving support from their partners, which was a complex process. On one side, the participants stressed that their relatives sometimes limited their learning by taking over too quickly; on the other side, they appreciated and needed the support of relatives, to a certain extent. In respect to the role of relatives, participants spoke about 'co-management', which was about managing together with their relatives. This echoes the findings of a qualitative study amongst people with myotonic dystrophy, where co-management was called 'couple-management'.⁴⁵ The participants' need to have other people support them in their self-management was also reflected by Morelands⁴⁶ study showing that, in a cohort of 209 stroke clients, the family facilitated an average of 54% of the management of daily life again. As relatives, the 'co-managers' are important in the post-stroke process,^{12, 21, 46-48} and they influence the development of

self-management of stroke survivors. Self-management programs also should include relatives, particularly to address their attitudes in regards to the learning process of stroke survivors' self-management as well as changes in the spousal relationship.

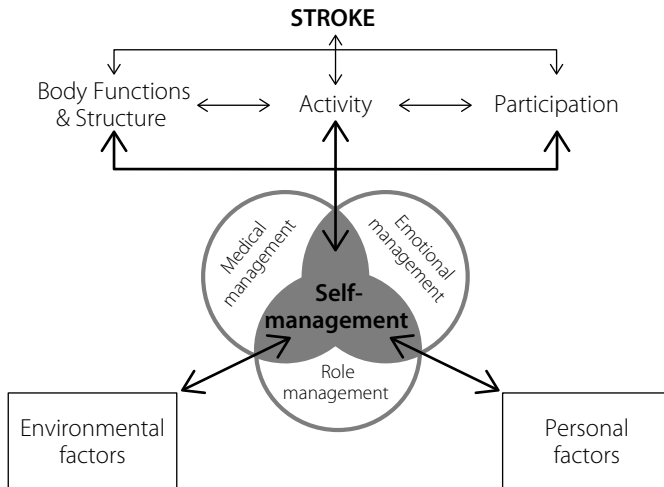


Figure 2 Self-management in the ICF

The complexity of self-management post-stroke is illustrated in Figure 2, where the International Classification of Functioning, Disability and Health (ICF),⁴⁹ a widely used framework in rehabilitation settings, is used to show the centrality of self-management. Self-management is broad and has different domains (medical, role and emotional management),¹⁸ and it is about the individuals taking ownership of their own health and (shared) decision-making.^{19, 22} On one side, the figure shows how the consequences of a stroke, together with personal and environmental factors, are related to each other and influence stroke survivors' capacities for self-management. On the other side, the two-sided arrows show how stroke survivors, in turn, can influence their own body functions, activities and participation as well as deal with their environmental and personal factors.

Strengths and limitations of the study

To increase the credibility of the study, participants who underwent rehabilitation in different settings were included. A strength of the study was the variation in length of time post-stroke—from one year to more than 10 years—meaning that the participants all had had long-term experiences in a 'life post-stroke'.⁴⁰ Credibility is also established by the adjustment of the method to the capacities of the participants.³⁹ The use of photo

elicitation evoked reflections of the participants on the concept and needs of self-management, and it may have added to the credibility of this word-based study.^{33(p.22)} A combination of verbal questions, supported by pictures (Figure 1) and visual questions, as well as the possibilities of writing down answers, gave participants the opportunity to react in different ways on the questions.

Although individual interviews might have led to more in-depth revelations about the experiences of individual participants regarding their self-management, the focus groups led to lively and critical discussions amongst the stroke survivors, resulting in their sharing rich information. It is possible that shared opinions within the stroke support group have influenced the opinions of some participants and that this has caused some bias. Nevertheless, there was not a real contrast between the opinions of the participants who had been selected via the stroke support group and those from the nursing home. In a meeting with the stroke support group, the members recognized themselves in the preliminary findings. A limitation was that the sample was rather small and that stroke survivors younger than 50 years old did not attend the focus groups.

Implications and recommendations

The results of this study can inform health care professionals about the concept of self-management from a stroke survivor's perspective. Attention should be paid to the naming and content of stroke self-management programs. Stroke survivors want to self-manage, but they should know that self-management is not 'do-it-yourself' but that life and health post-stroke can be managed in collaboration with relatives.

When developing and delivering self-management programs, an integration of medical, role and emotional management interventions can support stroke survivors to manage not only the stroke but also the social and emotional dimensions of their lives post-stroke. In the first phase post-stroke, programs could coach stroke survivors to take ownership of their health needs and support them in becoming experts about the best ways to deal with the stroke.^{19, 22} Understanding and recognizing limits, setting goals and taking action, problem solving, developing confidence and evaluating the effectiveness of their medical management are all important tasks and skills for persons to develop after a stroke.^{19, 22} After the initial phase, programs could focus more on providing social and emotional support and coaching stroke survivors to take ownership of creating a meaningful life post-stroke, which advocates interventions to support role and emotional management. This is also reflected in other publications.^{1, 6, 26, 50} Role management can even be the cornerstone of self-management programs, as it supports the focus on 'living with a chronic illness' and having a meaningful life,²² which means that valued activities and roles become the starting point of the assessments and goal setting as well as the guiding principle of the self-management process after a stroke.

Regarding the delivery of self-management programs, the findings of this study call for programs that are delivered in the communities or home settings of people following a stroke. This is supported by various studies, showing that managing one's life and oneself really starts once people are home again.^{21, 42}

For researchers, the challenge is to further study the complexity of the process of self-management not only when discharged to home but also in the long term. A longitudinal study design, involving not only the person after stroke but also the dynamic interaction with relatives and the environment, might be considered to deepen the understanding about the concept of self- and co-management.

Conclusions

Persons post-stroke might not fully identify themselves with the word *self-management*, and they can have a limited understanding about the concept. Participants reflected on their own self-management as a complex, long-term and personal learning process, in which they needed trial and error to learn to self-manage their lives again. Self-management was also considered as 'co-management', as persons post-stroke needed others to help them manage. Relatives were important in two ways: they could provide support, and they could limit the development of self-management. Coming home after being admitted to a hospital, rehabilitation centre or nursing home helped patients to face reality, but unfortunately, they also realized that they often were not ready to self-manage. This study helps us to understand the self-management of persons post-stroke as a complex and multidimensional concept that develops over time. Health care professionals can use this knowledge to reflect on the content, timing and place of delivery of current services. The challenge is to optimize the programs by integrating role and emotional management, besides medical management, in rehabilitation programs and to deliver stroke self-management programs not only during rehabilitation but also post-discharge in people's own environments.

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Chapter 4

The Perspectives of Spouses of Stroke Survivors on Self-Management – A Focus Group Study

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Abstract

Purpose: This qualitative study explored reflections of stroke survivors' spouses on their own self-management and self-management support of their partner post-stroke.

Method: Focus group interviews were conducted with 33 spouses of stroke survivors 34 to 79 years of age. A constant comparative framework supported the analysis.

Results: The stroke also affected the spouses. They experienced changes in their relationships and challenges to being a caregiver as well as a partner. They felt burdened, lonely, sad, and guilty. To manage themselves, many participants created time for themselves. For most spouses self-management was connoted with co-management because they perceived their partners were not able to manage themselves completely post-stroke. They often felt lost after their partners came home and reported that they learned how to coach their partners post-stroke by trial and error, without much professional support. Informal peer support was helpful for many spouses.

Conclusion: Involving the spouses of stroke survivors in stroke rehabilitation should start as soon as possible and continue at home post-discharge. In addition to enhancing the spouses' skills in caregiving and supporting self-management, stroke survivors' spouses also need support in their own emotional and role management. Moreover, peers can play a role in rehabilitation post-stroke.

Introduction

Stroke affects a growing group of people worldwide, with 16.9 million recorded cases in 2010.¹ Stroke affects not only the person with the stroke, but also the spouse or other family member.²⁻⁵ As stroke survivors are discharged earlier to their homes,⁶ healthcare services are increasingly delivered by the community, with the consequence that more and more informal care is needed. A stroke survivor's spouse is increasingly required to provide support and care to the partner.^{4,7}

Self-management is recognised as an important concept in stroke rehabilitation programs.^{8,9} Self-management is defined as an 'individual's ability, in conjunction with family, community, and the appropriate healthcare professionals to manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a chronic disease'¹⁰(p. 1145). Self-management encompasses medical management (dealing with the illness), emotional management, role management, and activating resources.^{8,11-15} The spouse often plays a role in how self-management of a stroke survivor develops.^{3,16}

To develop guidelines for stroke survivors' self-management interventions and educational programs for professionals, we wanted to explore the experiences, perceptions, and needs of stroke survivors, their spouses, and professionals regarding self-management support.¹⁷ Other focus group studies with stroke survivors and professionals have been published.^{3,16} Stroke survivors have expressed how self-management is a complex, long-term and personal learning process in which, in addition to the individual's self-management, relatives play a crucial role. However, they also recognised that sometimes their spouses were supportive, and at other times they found the spouse to be constraining. Regarding self-management support, stroke survivors indicated that more psychological and emotional support from professionals was needed.³ Allied health professionals in stroke rehabilitation saw different levels of self-management of stroke survivors, depending on the recovery phase, pre-stroke skills, cognitive abilities, and the attitude of the relatives. Regarding self-management interventions, professionals criticised stroke services as still being too medically oriented, and flexibility in the organisation and timing of delivery of services should be improved. Moreover, some professionals expressed difficulty in giving stroke survivors full responsibility for self-management, and some questioned the capacity of stroke survivors to self-manage on the highest level. Furthermore, collaboration between stroke survivors and their relatives was considered to be important in the development of self-management.¹⁶ To complete the exploration of the experiences, perceptions and needs of all stakeholders in self-management post-stroke in our project, we conducted a focus group study among Dutch spouses of stroke survivors.

Several qualitative and quantitative studies have been conducted regarding the experiences and needs of spouses of stroke survivors.^{4,5,7,18,19} Visser and colleagues⁵

described three roles of stroke survivors' spouses—caregiver, family member and client—and informal care may lead to emotional and physical burdens that need support. Furthermore, many spouses are poorly prepared for the role of caregiver.^{4, 7} Stroke survivors' spouses often experience a decreased quality of life.⁴ A longitudinal study on long-term psychosocial functioning showed that the perceived burden of the spouses decreased in the first 3 years after stroke. Although symptoms of depression decreased in the first year, symptoms increased between 1 and 3 years post-stroke.¹⁸ Furthermore, social relationships in general and the perceived quality of the relationship between the two partners decreased.^{4, 18, 19} Stroke survivors' spouses felt uncertain about the future^{7, 19} and reported social isolation.¹⁹ Spouses' challenges and needs were related to information and training in general and specifically regarding care tasks, local services and financial issues.^{4, 19}

Several coping strategies were identified in two reviews of qualitative studies about spouses of stroke survivors.^{4, 19} Those spouses took one day at a time, took time to manage their own wellbeing, put aside their own needs, tried to adapt to the changed role, tried to keep a positive focus and sought information and social support.^{4, 19} Although several of these coping and adaptation strategies can be related to the self-management of the spouses themselves, none of the studies focussed explicitly on the spouse's own self-management. Moreover, to the knowledge of the authors, no article yet published describes the perceptions of spouses of stroke survivors regarding self-management and self-management support post-stroke.

The aim of the current study was to explore the reflections of spouses of stroke survivors regarding their own self-management and that of their partner post-stroke.

Methods

Study design

We conducted a qualitative study during autumn 2013, consisting of four focus group interviews utilising a naturalistic study design²⁰ based upon a constructionist epistemology.^{21, 22} A group conversation to enable discussion between the group members was seen as more likely to give in-depth insights into the perceptions of the spouses of stroke survivors than individual interviews.^{23, 24} A regional medical ethical committee agreed with the study, which was conducted to conform to the Declaration of Helsinki.²⁵

Participants and context

Strategies such as social media advertisements, regional associations of caregivers newsletters, invitation letters from healthcare institutions and visits to 'Stroke Cafés' (voluntary meeting places for stroke survivors and their relatives) have been used to recruit spouses of stroke survivors. Interested potential participants received a letter about the aim, procedure and possible dates of the focus group study. Convenience sampling²⁰

was used, and spouses were included who lived together or had a long-lasting relationship with a person with a stroke. Another criterion was that the stroke survivor must have been living at home for at least 3 months after discharge post-stroke.

Thirty-five participants showed interest in participating in the study. Research assistants contacted them for additional information and made appointments for participation in the study. Two participants could not join the focus group interviews because of other appointments, so 33 participants gave verbal and written informed consent. All participants were living with their partners with a stroke except for one participant in focus group C (see Table 1). Four focus groups were composed and organized in a quiet room at a university of applied sciences.

The interviews were conducted by the primary researcher (TS), who worked previously as an occupational therapist in stroke rehabilitation and currently as staff lecturer and researcher with expertise in qualitative research. Four research assistants assisted in organising the interviews.

Data collection procedures

One interview of approximately 2 hours was conducted with each focus group, using a semi-structured interview guide with nondirective, open-ended questions.^{23, 24} First was a short introduction of the participants and the consequences for the partner who had the stroke. Following the introduction of a general definition of self-management, the moderator asked the participants to share their own perspectives. Self-management of both the stroke survivor and the spouse was discussed. In addition to verbal data, a mind map was made and discussed to identify the most important topics. After a short break, participants were asked to reflect on the support they received with their own self-management and that of their partner. Finally, we asked them what needs they had regarding self-management.

Data analysis

Audiotaped interviews were transcribed verbatim and transferred to ATLAS.ti to store and retrieve data (ATLAS.ti Version 6.1.11, Scientific Software Development GmbH, Berlin, Germany). The analysis was guided by the constant comparative analysis.²⁴

Analysis of the data consisted of two phases. In the first phase, the first author (TS) and four research assistants (VB, ZF, LK and MK), read the transcripts and listened to the audiotapes to become familiar with the data. In the next step (descriptive coding)²⁶(p. 87), TS and the research assistants independently coded one transcript and discussed the procedure and initial codes to increase the rigour of the coding procedure. The codes could be a word or short phrase that characterised participants' comments regarding self-management or reflections about stroke self-management support or needs. Subsequently, the other transcripts were coded, and codes were grouped into categories and recurring themes and sub-themes.^{24, 26} These were then checked against the

Table 1 Participants of focus groups (N = 33)

Focus group	Number of participants	Age of participants	Years of living with partner with stroke	Diversity of stroke consequences for different partners with stroke
A	N = 8 5 females 3 males	48–75 years	2–20 years All live with the partner with a stroke	Fatigue, short-term memory problems, fear, restlessness, hemianopsia, aphasia, apraxia, hemiplegia, limited mobility, unrestrained behaviour
B	N = 9 6 females 3 males	46–74 years	1–9 years All live with the partner with a stroke	Hemianopsia, prosopagnosia, increased emotional behaviour (crying), fatigue, disorientation, hemiparesis, hypaesthesia right side face, aphasia, apraxia, trivializing problems towards relatives, limited mobility, disturbed temperature regulation, disturbed smell and flavour, fear
C	N = 7 5 females 2 males	34–72 years	1–10 years One participant has not lived with the partner post-stroke	Hemianopsia, disabled writing and reading, epilepsies, fatigue, limited mobility, decreased concentration, disability in writing, emotional behaviour, hypersensitivity for visual and auditive stimuli, decreased visual abilities, depressed, decreased concentration, apraxia, aphasia, swallow problems, migraine, hypersensitivity for visual and auditive stimuli, cross-sight
D	N = 9 5 females 4 males	42–79 years	2–16 years All live with the partner with a stroke	Limited short term memory, hemiparesis, broca aphasia, limited mobility, neglect, limited mobility, aphasia

transcripts and the mind maps, and the first author started writing the preliminary findings.

After the first phase, the preliminary findings and themes were examined, refined and agreed upon in reflective meetings with the whole research team (all authors).

Trustworthiness

Several strategies were employed to ensure trustworthiness. We kept a research diary, and choices regarding the procedures of data collection and analysis were discussed with the

second author (EC). The data coding was done independently; categories and themes were discussed by the coders, with the second author and finally among the entire research team to support the rigour and transparency of the process.^{27, 28}

Results

A stroke also affects the spouse

All participants agreed that a stroke led to big changes for themselves as spouse and the person with a stroke. For most participants, the relationship was what changed the most. One participant stated, *'I lost my buddy'* (A5). Other participants indicated that they did not have an equal relationship anymore, that sometimes they no longer viewed the person with a stroke as their partner. In addition, several participants stressed the effect of aphasia on the relationship. A participant said, *'Not [being] able to have conversations is frustrating for both'* (D1). Moreover, participants with young children stressed that the stroke also affected their children.

Personality and behavioural changes were mentioned as examples of what made their partners different after a stroke. Although some participants were positive about the behavioural changes, such as a participant who said, *'I've got a sweeter wife than I had'* (D8), many participants were sad about the changes and losses. One of the participants said, *'I sometimes say that I have got a child in addition'* (D7), and another one said, *'He is sitting in the morning, he is sitting in the evening, and that's difficult to accept. I got a totally different husband, I lost him'* (A4).

Many participants were pessimistic about the future, for both the recovery of the person with the stroke as well as for themselves as spouse. They said about their partners, *'It will never be like it was'* (C2), and regarding the future, *'Gloomy picture of the future. I went to my retirement, and that future was falling in pieces'* (C1).

The stroke also affected the participants' roles. Besides being a spouse, they were confronted with the caregiver role, and this was confusing for most participants. One participant reported: *'You're a nurse, but you are also still a little bit a husband ... but mainly a nurse, yes, a nurse and therapist'* (A3). Moreover, some participants had to start working or increase their working hours as their partner was not able to work. One participant said, *'We have turned our roles. I am working now, and he is at home'* (A6). Most participants experienced this change in roles as a burden, emotionally, mentally and physically. One participant said, *'[The] mental burden makes me afraid ... that I cannot be myself anymore'* and *'You have to do everything alone. Different tasks than before which I also have to do alone'* (D6). Many participants experienced the burden of constant availability, even when they were not with their partners who had the stroke. This need for continued availability was compared with someone who works 24/7. The perception that one was constantly needed as a caregiver restricted the participants in other roles or activities, such as the inability to have hobbies or continue to work. One participant said, *'I have done a lot for the*

association, but all I did I had to quit. You always need to be on standby'(D2). Several participants mentioned that they are never on holiday anymore because of their partners' limitations. A participant said, *'I've still not been on holiday ... they say you have to choose for yourself, but where should he [partner with stroke] go? Then he must go to a nursing home ... and I cannot accept that in my heart, so then I also stay at home'* (A4).

Several participants indicated that life took on a different meaning and was often accompanied by feelings of helplessness, loneliness and sadness. They indicated that family and friends could not handle the situation and that only a few friends and family members were left. One participant said, *'You lose people around you because others feel anxious'* (A2). In addition, several participants expressed frustration with misunderstandings about the stroke consequences in their environment, and that their social circle was shrinking. One participant said, *'I sometimes say: you can borrow him [partner post-stroke], and not for a week but half a year, because then you'll understand how it works'* (A8). Also, guilt and anxiety were frequently mentioned. The balance they had in their lives and relationships changed after their partner's stroke, and the challenge was to find a balance for themselves as well as for their partners.

Stroke survivors' self-management is often co-management

When participants talked about self-management, their comments were mostly about the self-management of their partners, the stroke survivor. Only a few started with examples of self-management as a spouse. For most of the participants, self-management was almost automatically secondary to supporting their partner. Co-management and controlling things together was identified as important by most participants. Some spouses stressed that they made decisions together because their partners should always be involved. However, some indicated that they did things together only to keep peace in the relationship.

Some of the participants stated that stroke survivors could manage themselves well and were in charge of decisions. For example, a participant indicated that his partner could manage if he was gone for a few days, and that his partner was in charge of changing the medication: *'Then he changed his medication schedule. Just to manage this himself...'*(D6). Several participants described a process of developing stroke survivors' self-management. They supported their partners more in the beginning than later on. One participant said, *'The first year I [did] all things that could cause stress ... no he could not do that. He was only busy with his rehabilitation, dealing with emotions and trying to understand everything ... But recently he said, "You interfere with everything ..." and now I think, that is the moment where he shows he is able to do it himself again'* (B2). When they perceived that their partner was able to take decisions and perform activities more independently, they tried to reduce support. On the other side, several participants were cautious about the self-management of their partners post-stroke. Some were concerned about their partners' self-management abilities post-stroke; as a participant said, *'When they [partner with stroke] have to manage*

themselves, then I am in mortal fear'(D1). One participant said that his partner could do much on a physical level, but his memory was poor. Other participants admitted to having the ultimate control. They managed, planned and monitored whether the stroke survivor performed activities correctly, they made the most important decisions, and they arranged everything at times when the partner was not able to do this due to the stroke. One of the participants reported *'arranging everything and thinking about everything; otherwise, it does not happen or will not be good'* (C6).

Spouses' attitude: wait and see or take over, but often with concerns

The participants were very aware of their attitudes and the influence they had on their partners post-stroke. Several participants reflected that they took a wait-and-see attitude to stimulate their partners to do something themselves. *'Then I give a hint like "there it is" to motivate her to find something herself'* (A1). Alternatively, some participants deliberately took over tasks their partner could not do anymore so that the stroke survivors did not have to worry about it and were able to focus on tasks that were possible. A participant expressed: *'At the moment that she says "It is woolly in my head," that is actually a moment where she stays in the car. Then I do the shopping alone because everything is too much for her'* (C7). On the other hand, according to several participants, providing too much support or taking over could be a pitfall. Some participants said that when caring for their partners, they probably hindered them. *'My concern turns towards a kind of discouragement like "Well, better not to do that," although I know that that restricts him'* (D6). Other participants indicated that they had to let go of their concerns: *'I must learn to take risks that something happens when he is doing things'* (C2). Some participants stressed that it was important to leave the person with the stroke to their fate and to let them make mistakes when they tried to self-manage.

Prerequisites for stroke survivors' self-management

According to the participants, there were a number of conditions for stroke survivors to self-manage, taking the responsibility and being in charge: memory, learning ability, self-knowledge and self-reflection, planning, organization, communication and physical skills. A participant reflected on the ability of stroke survivors to self-manage: *'The more self-knowledge about what is going well or not, the more responsibility and control somebody can take'* (D6).

Furthermore, participants attached an important role to the social environment in supporting the stroke survivors' self-management. Topics such as support and stimulation from relatives and professionals, patience, and understanding from the environment were mentioned. Some participants indicated that spouses need to think 'out of the box' and offer alternative daily activities their partner is still able to do after a stroke. Besides this, the participants also mentioned the value of a positive attitude and confirmation towards their partner, the confidence to letting go, encouraging or slow down, providing structure

and sometimes pushing activities to support the development of the self-management of a stroke survivor.

Spouses create their own moments in order to self-manage

The participants in this study reported different strategies to self-manage as the spouse of a stroke survivor (see Table 2). A few strategies were related to medical management, but most were about emotional and role management. Mostly, the self-management strategies consisted of creating moments for themselves to do joyful and meaningful activities. Several spouses were trying to keep on as they used to do before the stroke. Others tried to create time and space for themselves, for example, to go on holiday with a friend, take the dog for a walk or go to the gym. Some participants had such moments for themselves thanks to professional services such as outpatient rehabilitation, activity centres, domestic help or support from relatives. *'My wife goes twice a week to a day-care centre ... that is for me the salvation. I go to the gym and that's my day off'* (D2). Several participants reported that finding time for themselves was a way of taking a break from their partners: *'I visit my sister two weekends a year, to go for a drink. This is actually enough for me, but I am deliberately going without my husband'* (A8). However, several participants expressed a sense of guilt when they did something for themselves, such as one participant who expressed his feelings when he was away for a short bicycle tour: *'Cycling is still nice ... but when I do that, I have a sense of guilt like "I am cycling here, but yes, she is at home" ... 'Then I'm going back soon, the shortest way home'* (C1).

A few participants try to stay positive to manage themselves, but one participant stressed: *'The first thing of self-management is to manage yourself as a spouse. If you cannot manage yourself, then you are also not able to manage another person'* (B8). In addition, it was indicated that recognition, support, understanding, patience and remaining true to yourself were important factors to keep going.

Disappointment regarding self-management support post-discharge

The majority of the participants had little or no coaching after their partner was discharged home. Many of them had been discharged rather quickly. The spouses had all sorts of questions, and the care and support they received post-discharge left a lot to be desired. Many participants expressed the need for better services. *'It is a shame that there is not some kind of standard service'* (C2). *'A warm blanket and understanding are important in the support'* (D1). Specific interventions to support the self-management of their partners or themselves post-stroke were not reported by the participants.

Many of the participants indicated they were not satisfied with the professional support for their partners or themselves, in both information about stroke and stroke services and support in self-management post-stroke. Only a few participants had positive remarks: *'Best support ... was the usual therapy in primary care'* (A2). However, many participants expressed that they eventually had to arrange much care themselves, like a

Table 2 Participants regarding their strategies to manage themselves

A5: I recently just went swimming	B7: We have talked about it: he [partner with stroke] goes out one extra night a week
A5: Holiday with a girlfriend	B7: Jogging, and my work is indeed very important
A6: Having lunch with friends	B8: When I think "I am just sitting too many evenings alone", then I'm going to see our son for a cup of coffee or a glass of wine
A6: I try every day to do something fun	B9: Fighting not to get in jail
A8: I go twice a year into town without my husband	C5: I live not with my friend, we are having a LAT relationship, so I have some days I really do not see him
A8: I am consciously working outside my home	C7: Trying to divide my energy over the day
B1: On medical grounds, I started with yoga	D2: My wife is two days a week to a day care center. I go to the fitness and then I have "my day"!
B2: Working and learning. Just not to be busy with my partner	D2: I'm going fishing
B3: Biking and I go hiking	D3: When it is too much to me, I'm going into nature on my bicycle
B3: We have a household help 4 hours a week. She ensures that I can do what I want, and that is wonderful. That's just a moment for yourself	D4: Walking the dog. Then your thoughts are free and you get peace with the situation
B3: Working in the garden	D5: When my husband is sleeping, I sit with a book on the couch
B4: You have to say to yourself: "This is my afternoon"	D5: He sleeps in the morning and 2 hours in the afternoon. Then I sit to enjoy reading
B4: Work is also time for yourself	D6: I work four days a week, and I'm going to a choir
B5: My husband was at the daycare, I had a pedicure and when I came home I made myself a nice cup of hot onion soup. That was again a "care-of-myself-moment"	D7: The only day I can do something for myself is when I go to my granddaughter
B5: Putting messages on Facebook. And then you get so much feedback again, and that relaxes	D8: The gym. Really to clear your head. The marathons are simply a way to empty the head and recharge the battery
B5: My husband goes every year to a care hotel. I really need that week for myself	
B6: Very active in our village	

participant reported: '*... when I had to figure things out for the WMO [Dutch national service to reimburse help and assistive devices], the lady of the office only showed me a website ... I just had to find out all by myself*' (D6). In terms of knowledge about stroke or stroke services, participants expressed no previous knowledge or experience regarding a stroke and its consequences. They felt lost at home. About asking for information, one participant reported: "*How can you ... ask anything if you do not know what to ask?*" (C2). Several participants ultimately sought help '*because I felt that it could not go on like this*' (D2). A few participants only found out later that stroke nurses could provide information and support: '*No information, absolutely nothing. We [were] just sent home. And only after a few months we*

heard something like "Oh there is something of a stroke nurse and there are associations that can help us"(C7).

The value of peer support

Informal support and care were received mainly from relatives or from volunteers who took the person with a stroke for a walk or other activity. Support also came through face-to-face contact and information from peers, both fellow partners and fellow stroke survivors. A participant appreciated being able to *'Listen to each other [in the same situation post-stroke] and have a day-trip with the peer support group'* (B1). However, some younger participants indicated that the peer support group did not match their age and that they had other issues. Several participants were active on social media. Facebook played a major role when participants wanted to share emotions with other peers. Support from other spouses on Facebook made them feeling less lonely. As one participant said, *'I have there [on Facebook] a big network of other caregivers, that's great'* B5). Although the input of professionals was perceived as important, advice from most participants was to appoint a fellow stroke survivor and a fellow spouse of a stroke survivor to share experiences and give support in self-management at home.

Discussion

The dominant finding in this study is that relationships changed between partners after a stroke. Spouses experienced feelings of loss and burden, especially caused by the new role as caregiver in addition to the role of partner. The changes caused helplessness, loneliness, sadness and guilt, and many participants needed time for themselves to self-manage, which is also found in other studies among caregivers of stroke survivors.^{4,6, 19, 29-31} Several participants missed professional support for their partner post-stroke as well as for themselves. Many participants felt that complete self-management by stroke survivors was not possible, and they preferred to speak about co-management.

Several reflections can be made when we compare the results of this study with our other focus groups with stroke survivors and professionals regarding self-management post-stroke.^{3, 16} Compared with our the reflections of the stroke survivors in a focus group study we conducted earlier,³ the spouses' reflections in our current focus group study on self-management differ slightly. Stroke survivors were focused on themselves and considered the idea of self-management as having to do with their own self-management. When the stroke survivors spoke about their spouses, it was mainly about how their spouses could help them in self-managing. The spouses, on the other hand, reflected first and foremost as caregivers when they talked about self-management. Only at a second stage did they reflect on their own self-management. This may indicate the manner in which spouses deal with a situation by effacing themselves.³² Professionals in stroke rehabilitation should acknowledge that spouses may wish to support partners' self-man-

agement after a stroke, but spouses should also be informed and encouraged to take care of their own health and wellbeing.

Although they used other terminology, many participants reported the same important elements in stroke survivors' self-management as was mentioned by professionals,¹⁶ such as the need for sufficient cognitive skills, self-knowledge and an ability to learn. The same can be said about participants' understanding of their own attitude in supporting stroke survivors' self-management. They developed their expertise and understanding gradually; the way they reasoned about coaching, supporting, letting go or structuring the situation for their partners post-stroke was comparable with the way professionals reason.¹⁶ The participants developed their expertise without much professional support. They had just learned by doing. These findings strengthen the findings of our other two focus group studies in which stroke survivors and professionals reported that more support in self-management post-stroke was needed.^{3, 16} Moreover, professionals expressed the need for self-management programs for both the stroke survivor and the spouse,¹⁶ which the participants of our current study mentioned as well. These interventions should start as soon as possible in the rehabilitation phase but especially post-discharge at home. A recent longitudinal study about follow-up care after a stroke with home visits showed that 76% of caregivers reported that their daily life improved after home visits, and 68% of the caregivers reported that if the care had been provided at a health centre, it would have been inaccessible for them.³³ When providing programs for stroke survivors and their spouses, professionals in stroke rehabilitation should also consider adopting some principles of Community Occupational Therapy in Dementia.³⁴ This program focuses on both patients with dementia and their informal caregivers, with the aim to sustain patients' and caregivers' autonomy and social participation.

The confusion and struggle of participants in managing the demands of their old and new roles as spouse, caregiver, therapist and family member reflect the findings of other studies.^{4, 5, 32} Proper support in the competing roles is desirable, preferably as soon as possible,³⁵ and can be addressed by professionals in role-management interventions. Research shows that spouses of stroke survivors need time for themselves to take care of their own health and wellbeing and socialize with friends and family.^{4, 5, 32, 35} On the other hand, spouses also want to be involved in their partners' rehabilitation. Moreover, due to changes in society and healthcare, spouses are increasingly expected to provide support to their partners post-stroke.⁴ For example, in a Dutch stroke rehabilitation program,³⁶ caregivers are coached to provide complementary exercise therapy to their partner with a stroke, in addition to usual therapy. The clinical implications of our findings are that professionals should explore whether stroke survivors' spouses can be loaded with extra roles as caregiver and 'therapist' in addition to being the spouse. Role and emotional management interventions can call attention to the roller coaster spouses are on and support them in the different roles. This might include discussing with spouses the

meaning and responsibilities of each role and the need to maintain their own social roles in the interest of their own health and wellbeing.³⁷ Moreover, to support the families of stroke survivors, a family-centred approach can be adopted by professionals to consider the different roles of all family members across the rehabilitation continuum.^{5, 35}

Finally, the use of peers and social networks such as Facebook are important to integrate in existing stroke self-management programs. This supports a study of the value of peer groups during in-patient rehabilitation³⁸ and a case study in which peer support was perceived as encouraging, motivating, validating and decreasing feelings of loneliness of stroke survivors and their care partners.³⁹ Moreover, peer support also promotes community reintegration of peer volunteers themselves.

Strength and limitation of the study

A strength of the study was that the participants varied in age and gender and had many years of experience living with a person with a variety of stroke consequences. However, the young spouses of stroke survivors were less present in the focus groups. Furthermore, spouses with a non-Dutch background were lacking in the focus groups. A limitation of the focus group methodology might be that some participants vocalized disagreement less due to the social context of the discussion. The separate data analysis by the first author and four research assistants and the debriefing of procedure and content with the second author and whole research team enhanced credibility and confirmability.^{27, 28} Preliminary findings have been presented and confirmed during a meeting with a selected group of spouses and professionals in stroke rehabilitation. One remark was that several spouses were divorced from their partner post-stroke and that this group was not present.

Conclusions

Stroke affects stroke survivors and their spouses. Stroke survivors' spouses reported changing roles, experienced feelings of burden, sadness, loneliness and guilt. They expressed how they quickly effaced themselves to support their partners post-stroke. They also expressed a need for time to themselves to self-manage. Development of stroke self-management programs in which stroke survivors and their spouses are involved from the beginning are needed and should continue at home. The focus should be not only on enhancing the skills of spouses in caregiving or providing additional therapy, but also on support and coaching stroke survivors' spouses in their own emotional and role management. Moreover, the value of peer support in self-management programs should be taken into account by professionals.

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Chapter 5

Self-Management: Challenges for Allied Healthcare Professionals in Stroke Rehabilitation – A Focus Group Study

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Abstract

Purpose: Self-management has become an important concept in stroke rehabilitation. This study explored allied healthcare professionals' (AHPs) perceptions and beliefs regarding the self-management of stroke survivors and their knowledge and skills regarding stroke self-management interventions.

Method: Four focus group interviews were conducted with 27 professionals. Verbal questions and mind mapping were used to collect data. A constant comparative framework was used for analysis.

Results: The AHPs discussed different levels of post-stroke self-management, depending on factors such as pre-stroke skills, recovery-phases post-stroke and cognitive abilities of the stroke patients. They hesitated about stroke clients' capacities to self-manage. AHPs questioned whether their own attitudes and skills were really supportive for stroke clients' self-management and criticised stroke services as being too medically oriented. They recommended that self-management programs should focus both on clients and caregivers and be delivered at peoples' homes.

Conclusion: Professional perceptions and beliefs are important factors to take into account when implementing stroke self-management programs. Before professionals can enable stroke survivors to self-manage, they first need support in acquiring knowledge and skills regarding post-stroke self-management. Moreover, professionals could benefit from behavioural change models, and professionals recognised that stroke self-management interventions would be most beneficial when delivered post-discharge at people's homes.

Introduction

Self-management is recognised as an increasingly important concept in stroke rehabilitation programs.¹⁻³ Self-management is defined as an 'individual's ability, in conjunction with family, community, and the appropriate healthcare professionals to manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a chronic disease'.^{4(p.1145)} Self-management interventions encompass not only dealing with the illness (medical/behavioural management), but also include emotional and role management.^{1, 5-9} Most interventions to support self-management are based on behavioural change theories^{1, 6, 7} and are intended to support clients in taking ownership of their health and well-being. When healthcare professionals apply self-management interventions in practice, clients are considered experts, professionals are supposed to work in a client-centred manner, and goal setting and decision making is done collaboratively.^{2, 6, 7} The Salzburg Statement on Shared Decision Making¹⁰ even '*calls on clients and clinicians to work together to be co-producers of health*'.

When one is designing and implementing self-management interventions in stroke rehabilitation, the attitudes and beliefs of stroke survivors and their caregivers need to be analysed. In addition, professionals' knowledge, beliefs, skills, attitudes, and motives to implement a self-management intervention in practice because these factors influence the way self-management is introduced to persons after a stroke.^{2, 11, 12} Different theories, like the illness script theory and the model of planned behaviour, can provide a framework for understanding healthcare professionals' reasoning, decision making, attitudes, and beliefs.¹³ Illness scripts are cognitive representations based on knowledge about an illness combined with previous experiences with clients that are used by clinicians when they are reasoning and making decisions about their clients.^{14(p.56)} Illness scripts organise information (patterns emerged from continuing exposure to clients, e.g. client characteristics, signs and symptoms, and underlying processes) in memory. When healthcare professionals are reasoning about clients, illness scripts are 'activated' and used. Experiences with previous clients seem to be influential in illness scripts and affect how professionals think and act in clinical practice with their (new) clients.^{13, 15} Illness scripts can vary from general disease-oriented scripts to scripts of individual clients.¹⁶ Furthermore, the theory of planned behaviour explains how professionals' behaviour (e.g. therapist, nurse, client) is shaped by their intentions¹⁷ and how these intentions, in turn, are influenced by professionals' perceptions and beliefs towards the behaviour, subjective norms about the opinion of their significant others (e.g. a client), and perceived behavioural control.^{13, 17}

De Silva¹⁸ discusses that healthcare providers' attitudes and skills can have a significant effect on the extent to which clients feel engaged and supported in their self-management.^{18(p.18)} Related to self-management in stroke rehabilitation, two recent qualitative

studies have described how professionals who applied self-management interventions were searching for a balance between relinquishing control and encouraging clients to make choices.^{19, 20} Moreover, Jones¹⁹ shows how the practitioners' belief in the program was felt to be critical to how much self-management interventions were applied by practitioners to clients in stroke rehabilitation programs.

In the Netherlands, the concept of self-management is not yet a commonality in stroke rehabilitation, although some self-management programs are delivered by expert-patients of regional divisions of the national client organisation *Samen Verder* (stroke survivors and their partners). A few rehabilitation centres have developed practice-based stroke self-management programs (a clinical program as well as a program 1–2 years post-discharge), but the effectiveness has not yet been proven and published. This paper describes a focus group study among Dutch allied healthcare professionals (AHPs) in stroke rehabilitation and is part of a bigger project. Based on data of the main stakeholders in stroke rehabilitation, being the persons after stroke, their partners, as well as the professionals in stroke rehabilitation, the project aims to develop guidelines for stroke self-management interventions and educational programs for professionals. As other studies in this project focussed on stroke survivors' perceptions regarding self-management post-stroke²¹ and partners (in progress), the aim of the current study was to explore AHPs' perceptions and beliefs regarding the self-management of persons after a stroke and their skills and attitude regarding stroke self-management interventions. The main questions addressed in this study were How do AHPs perceive and think about self-management of people post-stroke? and How do AHPs reflect on their skills and attitude in regard to self-management interventions?

Methods

Study design

During the spring and summer of 2012, we conducted a qualitative study consisting of four focus group interviews utilising a naturalistic study design²² based upon a constructionist epistemology^{23, 24} for the study's exploratory aims. A constructionist epistemology assumes that reality is socially constructed and research should be conducted through interaction between researchers and participants. We expected that discussions between the group members would give more in-depth insights into the perceptions and beliefs about the concept of self-management and the self-management of stroke survivors than individual interviews.^{25, 26} A Regional Committee on Research involving Human Subjects was informed; the committee stated that no approval was needed but that the general rules of privacy and ethics needed to be applied.

Participants and context

Occupational therapists, speech therapists, and physiotherapists were recruited via a list of addresses of institutions that delivered neurological services for the HAN-University of Applied Science for allied health professions where the first author works as a lecturer. Potential participants received a letter with information about the aim, procedure, and possible dates of the focus group study. Convenience sampling²² was used, and AHPs were included when they were working in stroke rehabilitation for at least two years.

Thirty-three participants, working at neurology departments of hospitals, rehabilitation centres, nursing homes, and private practices in the community, were interested in participating in the study. They were contacted by research assistants to provide additional information and make appointments for participation in the study. Six participants withdrew because they were too busy or ill at the time of the focus group interviews. Finally, 27 participants, mainly occupational therapists, participated in the focus groups. Table 1 shows the background of the participants.

Based on the preference for a certain date and place of the focus group meetings, four focus groups were composed. Three focus groups were organised in the east of the Netherlands and the other one in the west of the Netherlands. The interviews were located in quiet rooms at schools of allied health professions.

The primary researcher (TS), who previously worked as an occupational therapist in stroke rehabilitation and currently as staff lecturer and researcher with expertise in qualitative research, conducted the interviews. Two research assistants assisted in the organisation of the interviews. The co-authors were working as an occupational therapist (EC), speech therapist (BS), and professor in Allied HealthCare Studies and physical therapist (RN), and were all experienced researchers.

Data collection procedures

One interview that took about 2 hours was conducted with each focus group. For the interviews, we developed a semi-structured interview guide with nondirective, open-ended questions.^{25, 26} The first part of the interview focussed on participants' own definition about self-management, and a mind map was subsequently made to collect the most important topics that they related to self-management. The topics of the mind map were further discussed and refined. No framework or definition was introduced because the aim was to get open reactions and insight into the perceptions of the participants regarding self-management. After a short break, the participants were invited to describe their current way of working with regard to self-management and to reflect on the skills and attitudes needed to deliver stroke self-management interventions.

Data analysis

Interviews were audiotaped and transcribed verbatim. To store, organise, and retrieve data, transcripts and field notes were transferred to an Atlas.ti software management

Table 1 Participants of focus groups ($N=27$)

Focus group	Number of participants	Profession	Years of work (previous) experience	Experience in treatment area/ setting	Current workplace
1	N = 6 4 females 2 males	1 Occupational Therapist 2 Physiotherapists 3 Speech therapists	9-41 years	Primary care = 6 Clinical = 2 Outpatient = 2	Private practice
2	N = 6 6 females	6 Occupational Therapists	3-34 years	Primary care = 3 Clinical = 6 Outpatient = 4	Rehabilitation centre
3	N = 8 8 females	7 Occupational Therapists 1 Physiotherapist	4-30 years	Primary care = 7 Clinical = 8 Outpatient = 5	Nursing home
4	N = 7 5 females 2 males	6 Occupational Therapists 1 Physiotherapist	3-27 years	Primary care = 4 Clinical = 2 Outpatient = 2	Private practice Rehabilitation centre Nursing home

package (ATLAS.ti Version 6.1.11, Scientific Software Development GmbH, Berlin, Germany). Constant comparative analysis was used.²⁶

Analysis of the data consisted of two phases. In the first phase, the first author (TS), together with two research assistants (NH and EI), listened to the audiotapes and read the transcripts to become familiar with the data. The next step was descriptive coding.^{27(p.87)} TS, NH, and EI independently coded the different transcripts. The codes could be a word or short phrase that expressed participants' comments about the concept of self-management and examples about stroke clients, as well as reflections about stroke self-management interventions. After completing the coding of the first transcript, the procedure and initial codes were discussed in a coders meeting to increase the rigour of the coding procedure. Eventual differences were checked against the original transcripts. Subsequently, the next transcripts were coded, and codes were organised in categories and recurring (sub)themes about self-management after stroke.^{26, 27} Finally, the different files were merged to one file of Atlas Ti, and preliminary categories and (sub)themes were compared and refined by TS, NH, and EI.

After the first phase of the analysis procedure, the second author (EC) read a set of quotations (e.g. the ones related to professional beliefs) and discussed the categories and (sub)themes with TS. Additionally, the final themes were discussed and agreed upon in a reflective meeting with the whole research team (all authors).

Trustworthiness

We employed several strategies to ensure the trustworthiness of this study and kept a research diary. Choices regarding the procedures of data collection and analysis were debriefed in regular meetings with the second author (EC). Furthermore, we used the mind maps developed during the focus group interviews in the analysis as a supplement to the transcriptions. Data were coded independently; categories and themes had been discussed in coders-meetings and discussed with the second author and among the whole research team to support the rigour and transparency of the process.^{28, 29}

Results

The analysis led to four themes: (1) professionals' nominations of different levels of post-stroke self-management; (2) professional beliefs about post-stroke self-management; (3) factors influencing post-stroke self-management; (4) critical reflections on professional practice. Anonymous quotes from participants will be used. In brackets a code of the participant is shown; i.e. the code (OT-fg1-P2) refers to an occupational therapist (OT) in focus group 1 (fg1) and is participant 2 (P2) of this focus group. Table 2 shows the codes and background of all participants.

Professionals' nominations of different levels of post-stroke self-management

The initial reflections of the allied health professionals (AHPs) about stroke self-management in general were that clients should be able to direct and arrange their own life after stroke by setting their own goals and taking ownership of decisions in *rehabilitation processes* in different settings. Some physiotherapists also perceived 'doing exercises yourself' to be self-management. Some participants used a concept as autonomy as synonymous for self-management.

During the reflections about self-management, participants used different examples of clients in which they mentioned different levels of self-management. An occupational therapist said, '*Self-management can be big or small...managing your whole life and everything around it. Only a few stroke patients can do that. But you can also manage small areas, like choosing which clothes you want to put on in the morning; this is also a piece of self-management*' (OT-fg1-P2). Another occupational therapist said that for her, self-management could vary from '*sometimes totally 100%, and for some people 0%, and then everything in between*' (OT-fg4-P7). A physiotherapist mentioned that '*there might be "sub-self-management", which can be lifted up with several strategies or using resources*' (PT-fg4-P2). Other participants questioned whether one should talk about self-management if it were in small areas like choosing what to eat or drink. In the examples of clients in which illness scripts were recognizable, AHPs talked about the 'different levels' of post-stroke functioning. One occupational therapist said that the levels of Claudia Allen³⁰ were useful

to help her reflect about the levels of self-management after a stroke. Level 1 (automatic reactions) to level 3 (manual actions) are seen as levels with no or very low levels of self-management, while level 4 (goal directed actions), 5 (explorative actions) and 6 (planned actions) are associated with average to normal self-management.

Professional beliefs about post-stroke self-management

In all interviews, the therapists reacted with hesitation when they talked about the self-management capacities of persons after stroke like *'Difficult'*, *'Yes, but'* or *'I don't know'*. In their conversations, participants used at least two examples of clients in which an illness

Table 2 Background of participants per focus groups ($N=27$)

Focus group Participant	Profession	Sex	Work experience (years)	Setting	Phase stroke
ST-fg1-P1	Speech Therapy	F	30	Home-based, Clinical & PoliClinical	Rehabilitation Chronic
OT-fg1-P2	Occupational Therapy	F	9	Home-based	Rehabilitation Chronic
ST-fg1-P3	Speech Therapy	F	41	Home-based	Rehabilitation Chronic
PT-fg1-P4	Physiotherapy	M	23	Home-based	Chronic
ST-fg1-P5	Speech Therapy	F	19	Home-based	Rehabilitation Chronic
PT-fg1-P6	Physiotherapy	M	18	Home-based, Clinical & PoliClinical	Rehabilitation Chronic
OT-fg2-P1	Occupational Therapy	F	14	Clinical PoliClinical	Rehabilitation Chronic
OT-fg2-P2	Occupational Therapy	F	3	Home-based Clinical & PoliClinical	Rehabilitation Chronic
OT-fg2-P3	Occupational Therapy	F	31	Clinical PoliClinical	Rehabilitation
OT-fg2-P4	Occupational Therapy	F	3	Clinical PoliClinical	Rehabilitation
OT-fg2-P5	Occupational Therapy	F	6	Clinical Home-based	Rehabilitation Chronic
OT-fg2-P6	Occupational Therapy	F	34	Home-based Clinical	Rehabilitation Chronic

Table 2 Continued

Focus group Participant	Profession	Sex	Work experience (years)	Setting	Phase stroke
OT-fg3-P1	Occupational Therapy	F	24	Clinical Home-based	Rehabilitation Chronic
OT-fg3-P2	Occupational Therapy	F	7	Clinical PoliClinical	Rehabilitation
OT-fg3-P3	Occupational Therapy	F	15	Clinical Home-based	Rehabilitation Chronic
OT-fg3-P4	Occupational Therapy	F	4	Home-based, Clinical & PoliClinical	Rehabilitation Chronic
OT-fg3-P5	Occupational Therapy	F	30	Clinical Home-based	Rehabilitation Chronic
PT-fg3-P6	Physiotherapy	F	6	Home-based, Clinical & PoliClinical	Rehabilitation Chronic
OT-fg3-P7	Occupational Therapy	F	6	Home-based, Clinical & PoliClinical	Rehabilitation Chronic
OT-fg3-P8	Occupational Therapy	F	9	Home-based, Clinical & PoliClinical	Rehabilitation Chronic
OT-fg4-P1	Occupational Therapy	F	5	PoliClinical	Rehabilitation Chronic
PT-fg4-P2	Physiotherapy	M	27	PoliClinical Home-based	Rehabilitation Chronic
OT-fg4-P3	Occupational Therapy	M	9	Home-based	Chronic
OT-fg4-P4	Occupational Therapy	F	5	Clinical	Rehabilitation Chronic
OT-fg4-P5	Occupational Therapy	F	3	Clinical	Rehabilitation Chronic
OT-fg4-P6	Occupational Therapy	F	13	Home-based	Rehabilitation Chronic
OT-fg4-P7	Occupational Therapy	F	8	Home-based	Chronic

script was recognizable when they reflected about self-management. One example was about stroke survivors in general, and the other included scripts of stroke survivors with cognitive disabilities. Related to the first 'general' stroke-illness script, a physiotherapist reacted spontaneously with, *'That is a difficult thing, self-management. Especially for neurological clients it is not so obvious'* (PT-fg1-P6), which was representative of the reactions of other participants. Related to the second type of examples about persons with problems due to cognitive disabilities, professionals seemed to have even more negative thoughts about the capacities for self-management. In their reflections most participants stressed the inabilities of the stroke survivors. An occupational therapist working in a rehabilitation centre said, *'If they do not have insight in their illness, so if you don't know your abilities, then it might be difficult to have control'* (OT-fg2-P6). A physiotherapist expressed: *'I found this very difficult... to direct and arrange, to organise, making your own choices, having insight yourself about what is good for yourself? They (clients) have never experienced this'* (PT-fg3-P6). There were also doubts about the ability of making realistic goals and choosing for stroke survivors. An occupational therapist said, *'But it is a fact that they (clients) often... eh... cannot make a choice...especially to consider ten different options. So I think that the therapist is the one who is guiding'* (OT-fg3-P8). Another occupational therapist expressed, *'I have the idea, it might be generalization...but that stroke survivors just have difficulties to oversee the long term. Well, and then you are talking about cognition'* (OT-fg2-P1).

According to all AHPs in the focus groups, there were several prerequisites for self-management after a stroke, especially cognitive abilities. A participant expressed, *'If the definition is to give direction to my medical treatment, then you need at least some cognitive skills to make a decision, to develop insight, and so on'* (OT-fg4-P6). Insight, reflections, awareness of problems, realistic goal setting, problem solving, and executive functions were considered by the participants to be prerequisite for self-management. Also, self-efficacy, a supportive social environment (partner, family, relatives), insight into the resources in the environment, and being able to apply strategies in other situations were mentioned as preconditional for self-management. Knowing what one wants, taking initiative, and communication skills were also mentioned as important, as expressed in the following: *'people should be able – if you're talking about self-management – to ask for help if they need it from the people around them'* (OT-fg1-P2).

Factors influencing post-stroke self-management

All participants agreed that, beside the actual disabilities of the person after the stroke, the level of self-management also depended on the phase after the stroke, the setting, and the attitude of the relatives of the person post-stroke. One occupational therapist stressed that it was important to know the clients' self-management skills they had before the stroke and *'also what kind of learning style they had ... If you offer a program, you want to know their skills so that they can be optimally used'* (OT-fg3-P1). A physiotherapist who had previously worked in a hospital said about the acute phase, *'In a hospital it's difficult ... you're*

dependent on medical professions ... you recover step by step. And then you are still a real patient because you have lost yourself, because you are a patient' (PT-fg1-P6). An occupational therapist said about the acute strokes and the hospital, *'In a hospital you see the real acute strokes; the development is sometimes so fast [that] there is nothing to manage'* (OT-fg3-P5). When talking about possibilities for self-management, participants were more positive about being home, where *'you can expect that people have gained more insight in their own disease, disabilities and impairments, and that somebody is better able to self-manage than somebody with an acute stroke'* (PT-fg3-D6).

Some participants were critical about their own role and that of other professionals in relation to the self-management of clients and said that they often did too much and did not give the people a chance to manage the situation by themselves after the stroke. A critical remark of an occupational therapist was, *'Yes, I wanted to say that we as professionals might limit self-management'* (OT-fg2-P6). Regarding a hospital and nursing home, some participants said that the level of self-management of stroke clients was very much influenced by nurses: *'In the clinic, the first who takes away independence are the nurses who put a bed pan below a patient instead of helping them to go to the toilet'* (PT-fg1-P4).

Collaboration between the person after stroke and the relatives was considered to be important in relation to the level of self-management and was called system management. After having a stroke, people had to learn how to work together with their partner in various ways, such as in developing a new balance in life. Related to the influence of the environment it was stressed here that *'Partner and client have to be coached as good as possible about the things they can do together, but also that the client does not cling to the partner, or that the partner does not cling to the client'* (ST-fg1-P5). A speech therapist was hesitating about the positive role of the partner regarding the support of self-management of a stroke client and said, *'and then you go home and then the family "takes care" of you'* (ST-fg1-P1), and an occupational therapist said that *'Maybe you have to see it broader because partner and client have to find a new balance in tasks, but maybe you also have to include the children or other people in order to take care of the caregiver'* (OT-fg1-P2).

Critical reflections on professional practice

Several participants hesitated about their professional models in stroke rehabilitation in regard to self-management. Many agreed with each other when a therapist said that *'We are working in established protocols, and we take over rather quickly'* (OT-fg3-P3). A physiotherapist stated, *'I think that in general we are focussed to treat within medical-technical frameworks, but when you talk about self-care...self-management, then it is not directly related to that framework. So you should think from another perspective and that is more a social framework'* (PT-fg1-P6).

Related to their attitude, many participants said that they tried to work in a client-centred manner to support self-management. However, some physiotherapists reflected and questioned whether their attitude was really client-centred and said in different focus

groups that they *'still have the tendency to "drop" the treatment plan to their clients, that they (PT's) still have difficulties to work client-centred, especially when a client has cognitive problems and in the acute phase after stroke'* (PT-fg3-P6). Other participants perceived themselves as a coach: supporting the client and *'walking alongside'*, but others were not sure and even questioned whether they could be really equal.

Several people stressed that as a professional, you should dare to let go and let the clients do things by themselves. Yet a speech therapist questioned the language skills and general understanding of the stroke survivors, which influenced her in discharging clients: *'How can you make clear to people what is happening to them, and how can you let it go? You understand... this is a shaky balance'* (ST-fg1-P3). Other AHPs believed that *'as a professional, you have make yourself redundant'* (OT-fg4-P6), but hesitated because it was *'difficult to let it go, to give the responsibility back to the person him/herself'* (OT-fg3-P4). Furthermore, there was hesitation because of the possibilities they still saw for further treatment: *'at some point you come to the point that someone can do it himself, then you actually want to continue visiting them, but then you really have to let go!'* (OT-fg4-P3).

Different occupational therapists expressed that they had always focussed on people's self-management, although often indirectly. An occupational therapist working in rehabilitation said, *'Isn't this [self-management, TS] more or less a starting point of our profession?... something we do automatically?... when you talk about autonomy, independency, it is all so ingrained in the way we are educated that it becomes so obvious. It is good to think about it, but it is difficult to specify what I do specifically'* (OT-fg2-P1).

None of the participants had developed explicit self-management programs for the rehabilitation of stroke survivors. Nevertheless, they mentioned different interventions which, according to the participants, supported self-management, such as providing information and maintaining a good dialogue between the client, the partner, and the therapist. One participant stressed that there was always a *'client-related'* part, and a *'partner-related'* part within the interventions.

Much attention was paid to goal setting. In some rehabilitation centres, they had interviews every six weeks to evaluate or refine goals. Speech therapists used the BIPAC (Behoeften-Inventarisatie en Probleem Analyse van Communicatieve activiteiten)³¹ and BEBA (Birkhovense Evaluatieschaal Behandeldoelen Afasie)³² Dutch instruments to assess the experienced problems and needs of people with aphasia. Occupational therapists often referred to the Canadian Occupational Performance Measure (COPM) as the obvious way to explore client-centred goals with their clients, and a few mentioned a self-developed pain-management method to explore activities. However, several therapists questioned if they had sufficient skills to explore goals: *'I think that you should look from another perspective...I don't think that we are all so skilled to explore the question of the client'* (PT-fg1-P6). Although motivational interviewing is described in the literature¹⁸ as an important approach to support self-management, only a few participants used motivational interviewing with their clients.

The organisation of care was perceived by several participants as a barrier. Most participants agreed that self-management was difficult for clients admitted in a hospital. An occupational therapist said, *'What is permitted by the system? Look... you have suffered an acute stroke, then the whole environment decides for you what you are allowed to do or not, how late you have to go to the toilet, and how late the bed pan is taken away'* (OT-fg4-P6). A therapist working in a rehabilitation centre questioned the timeframe: *'If you look in literature, and find that only after 1-2 years people are really able to manage themselves... well, what can you do with rehabilitation programs then?'* (OT-fg2-P3). More flexibility in interventions instead of holding on to the established protocols was suggested, as well as regular appointments to evaluate changes in the life and self-management of their clients. A multidisciplinary approach was considered important but not easy in primary healthcare. A speech therapist described that in the community *'you have to look for other professionals... search for a PT and an OT...whoever. ... Creating a new team is not easy ... at least for stroke patients at home who recently had had a stroke. They are visiting different therapists, so different teams. That costs a lot of time'* (ST-fg1-P1). Although many participants stated that 'real' self-management started after discharge, they admitted that there was often not enough time to support persons at home who have had a stroke.

Discussion

The analysis revealed how the AHPs' reflections on stroke survivors were merely focussed on disabilities and how capacities of stroke survivors to self-manage were doubted. Different levels of self-management of stroke survivors were perceived, and, according to the AHPs, several factors affected self-management, such as the recovery-phase post-stroke, the relatives of the stroke survivors and the professionals themselves. The participants stressed that their own professional behaviours and skills, such as client-centred goal setting, were important to support self-management, but at the same time, several AHPs expressed difficulties applying this in practice. They reflected that current models in stroke rehabilitation are still too biomedical and considered that a social framework might fit better with self-management support, a position which echoes the paper by Jones et al.¹⁹ Moreover, several participants stressed that the timing and setting of stroke rehabilitations services insufficiently supported self-management of stroke survivors because there was a lack of flexibility. The participants expressed a need for support in self-management post-discharge at their own homes. This is consistent with other articles where health systems and flexibility of rehabilitations services were mentioned as barriers for client-centred goal setting in inpatient stroke rehabilitation.^{2, 33}

Participants in our study perceived a client-centred attitude and goal setting as important in relation to self-management interventions. The OTs used the COPM,³⁴ and some other participants mentioned goal-setting interviews and evaluations. When we asked more in-depth about their interventions, none of the AHPs seemed to use theories

or models about self-management. Levack et al.³³ stated that simply using goal terminology is insufficient to ensure that goals influence the rehabilitation process of clients (and family) post-stroke. In our study, several AHPs said that goal setting was difficult and that clients' goals were sometimes unrealistic. Levack et al.³³, however, also stated that clinicians should be more open to clients' goals, even if the goals were seen as unrealistic. The challenge is just to explore the deeper meaning of the so-called 'unrealistic goals'. This negotiation about the content of the goals can support clients to reformulate them as realistically attainable goals, and might decrease the gap between clients' goals on social level while professionals still formulate biomedical goals.^{8, 33} The CO-OP,³⁵ a novel cognitive-based approach based on enabling principles and client centeredness, could be used by professionals to support stroke survivors in a guided discovery and use of (cognitive) strategies to develop self-efficacy in self-management in daily life in a way that is realistic, attainable, and meaningful. However, the CO-OP³⁵ is especially useful with clients with only mild cognitive problems.

In AHPs' reasoning about stroke survivors' levels of self-management, we could distinguish the influence of professional perspectives, illness scripts, and clinical mindlines.¹⁴⁻¹⁶ According to Gabbay and le May,^{14(p. 56)} clinical mindlines encompass a wider range of variables and factors when compared with illness scripts. Clinical mindlines are 'internalised, collectively reinforced, tacit guidelines in the head,³⁶ informed by clinicians' training and reading by working with clients in clinical settings and by interaction with other professionals. Mindlines are built up as a 'bank of personalised, flexible syntheses of all the different types of theoretical and experiential knowledge',^{14(p. 44)} and affects professionals' reasoning and decision making. In analysing AHPs' reasoning about stroke survivors' self-management, we could distinguish the influence of professional perspectives, like the speech therapist who felt hesitation about stroke survivors' self-management as she looked at language skills, and an occupational therapist who used the cognitive disability model of Allen³⁰ to reflect on the different levels of self-management.

Based on the illness script and mindlines theory,¹⁴⁻¹⁶ we assumed that the participants' reflections were informed by their beliefs about self-management after a stroke, their 'stroke-illness scripts', and mindlines. Beliefs, illness scripts, and mindlines affect how professionals reason, how they make decisions, and subsequently how they act.^{13, 14} One thing that needs to be considered is how the AHPs in this study doubted the capacities of stroke survivors with cognitive disabilities to manage themselves. Although we agree with the participants that stroke survivors with cognitive disabilities might need more support in self-management post-stroke, we still have interpreted several expressions of the AHPs in the focus group interviews as doubtful. If AHPs believe that stroke survivors with cognitive disabilities are not able to self-manage, this will unconsciously affect professionals' decisions and actions regarding people post-stroke with cognitive disabilities. We consider this negative belief to be a 'disabling belief', meaning that the professionals were doubtful about stroke survivors' capacities to self-manage, especially

people with cognitive disabilities post-stroke. This negative belief might have led to decisions by the professionals that negatively affected the process with their clients. Doubts whether people with cognitive disabilities after they have had a stroke could manage themselves were also described in a study by Jones et al.,¹⁹ which evaluated the application of a stroke self-management program. In Jones' study,¹⁹ professional doubts were related to the moment and the sensitivity needed when introducing self-management to clients who were in a time of great change and might feel the pressure to take responsibility, while in our study, the participants related their doubts to the cognitive capacities of people after they have had a stroke. Our interpretation of the professionals' doubtful and sometimes disabling beliefs was confirmed in a meeting with a rehabilitation team where the preliminary findings of our study were presented and discussed. When the team members were asked about the capacities of stroke survivors to self-manage, the team members reacted similarly to participants in our focus group interviews. They first started with discussing reduced functions and were hesitant about whether a person with cognitive disabilities could self-manage. The AHPs' professional beliefs in our study echoed the discussion in literature that it is important to study professionals' beliefs further.^{2,37}

The challenge is how AHPs working with stroke survivors in general, and especially AHPs working with clients with cognitive disabilities, can be supported in the development of their professional beliefs, skills and attitudes regarding stroke self-management interventions and how the slightly negative beliefs regarding people post-stroke's capacities to self-management might be positively changed. It is possible that the illness scripts and mindlines about stroke clients who manage themselves post-discharge in a good way have not been sufficiently developed in the minds of the professionals. In order to adapt old and develop new stroke-illness scripts and mindlines, AHPs should be further informed about self-management as a long-lasting learning process^{9, 21} with different levels of self-management, as well as about the supportive role of caregivers (co-management).²¹ Furthermore, successful examples of stroke survivors in the chronic phase (3–4 years post-stroke) who demonstrate abilities to use strategies in daily life could be shown in education and post-graduate courses. Successful cases with a focus on abilities of stroke survivors, might develop 'ability oriented' stroke-illness scripts, and enhance professionals' beliefs in the capacities and abilities of stroke survivors, instead of focussing on disabilities as a result of the biomedical models with pathogenic paradigms in professional education.^{2,38} If AHPs are able to approach stroke survivors with cognitive disabilities as the ultimate challenge to target self-management support to the specific problems in daily life, then the focus is on enablement instead of on the disabilities. Last but not least, the explanation of professionals' enabling skills, such as negotiating with and coaching of stroke survivors in choosing, organising, and performing useful and meaningful occupations,³⁹ would further support and empower AHPs to develop and apply self-management interventions.

Strength and limitation of the study

To increase credibility and confirmability, analysis was conducted separately by the first author and two research assistants, and the procedure and content of the analysis has been debriefed with the second author and with the whole research team.^{28, 29} Moreover, the preliminary findings have been presented to members of a stroke rehabilitation team, which confirmed the theme about professional beliefs. A strength of the study was that the participants had many years of experience in stroke rehabilitation, in addition to their work experiences in different settings. Within the 27 participants, which is of course a small group of the 'stroke professional population, a limitation was that occupational therapists outnumbered the other professions in the focus group meetings. An explanation can be that the occupational therapists saw self-management as a concept that was ingrained in their profession. This limitation makes that the beliefs of other disciplines may not be fairly represented. However, in this group no real differences in perspectives could be established.

Implications and recommendations

Although professionals are willing to apply stroke self-management interventions, they can benefit from theory and models about self-management interventions. Knowledge about self-management as a learning process,^{9, 21} as well as possible levels in self-management with a supportive role of caregivers (co-management),²¹ might help professionals to develop a deeper understanding of stroke self-management and adapt their stroke-illness script. Furthermore, motivational interviewing as a non-judgmental counselling approach,^{18, 40} together with enabling skills³⁹ might support and empower professionals in their skills to deliver stroke self-management programs and negotiate with and coach clients regarding their goals. Professionals could use the CO-OP³⁵ to guide stroke survivors to apply cognitive strategies in attainable and meaningful goals.

In addition, different illness scripts of stroke survivors and their self-management, not only representing the acute and rehabilitation phase, but also later phases, e.g. 3–4 years post-stroke, should be addressed in bachelor and post-graduate education. This can give students and professionals a broader picture of the possibilities of stroke survivors to self-manage. For research this means that more longitudinal qualitative studies about self-management post-stroke in the chronic phase is needed. Furthermore, the usefulness of Allen's³⁰ cognitive disability model to describe different levels of self-management and possible support by caregivers could be explored and used in the development of self-management programs fitting different levels of self-management.

This study also suggests that AHPs in stroke self-management programs should reconsider the use of social models, besides biomedical and professional models. Furthermore, professionals and policymakers should consider their organisational models. Although the principles of self-management should be applied as soon as possible,⁶

stroke survivors benefit most from self-management interventions post-discharge in their own homes not only for stroke survivors, but also for their next of kin.^{8,21}

Conclusions

Dutch allied health professionals in stroke rehabilitation are willing to support stroke survivors in their self-management, but they are critical about their own attitudes, skills, and organisation of care. Their professional perceptions and beliefs regarding stroke survivors' self-management seemed influenced by stroke-illness scripts, particularly with clients with cognitive impairments. Before professionals can really support and enable stroke survivors and their next of kin in self-management or co-management, they first need to be supported in their own knowledge, understanding, and skills regarding post-stroke self-management. Illness scripts of people post-stroke with successful self- and co-management on the long term can enhance this understanding. Furthermore, professionals can benefit from social frameworks and behavioural change models when developing and implementing self-management programs. Moreover, stroke self-management programs should be delivered post-discharge at people's home.

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Chapter 6

Self-management Develops Through Doing of Everyday Activities – A Longitudinal Qualitative Study of Stroke Survivors During Two Years Post-stroke

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Abstract

Background: A description of the complexity of the process of self-management and the way stroke survivors give meaning to their process of self-management post-stroke is lacking. This study explores how stroke survivors managed their lives, gave meaning to their self-management post-stroke and how this evolved over time.

Methods: Data was generated through participant observations and interviews of 10 stroke survivors at their homes at 3, 6, 9, 15 and 21 months post-discharge. A constant comparative method was chosen to analyse the data.

Results: 'Situated doing' was central in stroke survivors' simultaneous development of self-management and their sense of being in charge of everyday life post-stroke. Doing everyday activities provided the stroke survivors with an arena to explore, experience, evaluate, develop and adapt self-management and being in charge of everyday activities and daily life. The influence of stroke survivors' partners on this development was sometimes experienced as empowering and at other times as constraining. Over time, the meaning of self-management and being in charge changed from the opinion that self-management was doing everything yourself towards self-managing and being in charge, if necessary, with the help of others. Moreover, the sense of self-management and being in charge differed among participants: it ranged from managing only at the level of everyday activities to full role management and experiencing a meaningful and valuable life post-stroke.

Conclusions: The findings of this study indicate the doing of activities as an important arena in which to develop self-management and being in charge post-stroke. Stroke self-management programs could best be delivered in stroke survivors' own environment and focus on not only stroke survivors but also their relatives. Furthermore, the focus of such interventions should be on not only the level of activities but also the existential level of self-management post-stroke.

Background

Self-management is recognised as an increasingly important concept in stroke rehabilitation programs.¹⁻³ Self-management is defined as an 'individual's ability, in conjunction with family, community, and the appropriate healthcare professionals, to manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a chronic disease'.^{4(p.1145)} Self-management encompasses dealing with the illness (medical management), but importantly also includes activating resources and living with a chronic illness in which emotional management and adjusting, meaning making and integrating illness into daily life (role management) are important processes.^{1, 5-8} Stroke survivors described their self-management as a complex and long-term learning process during which they finally learned to live again with the of their next of kin.⁹ Aside from individual self-management, stroke survivors stressed the importance of co-management with relatives.⁹ To optimise the delivery and content of stroke self-management programs, longitudinal studies are needed to further explore the complexity of the process of self-management post-stroke.^{1, 9}

Several longitudinal qualitative studies with stroke survivors reported how the process post-stroke involved restructuring and adapting physical, social and emotional aspects of an individual's life; social and emotional consequences were identified as the largest problems in daily life for stroke survivors during this process.¹⁰⁻¹² Stroke survivors' return to daily life is complex; they see it as a challenging process of change with uncertainty and struggle to regain important roles and tasks in daily life.^{11, 13, 14} Robison and colleagues¹² described after a one-year longitudinal qualitative study how stroke survivors had difficulties resuming valued activities post-stroke and how some stroke survivors were more adaptable than were others. Moreover, Kubina et al.¹⁵ described in their longitudinal study how the process of stroke survivors' re-engagement in valued activities over a two-year period was characterised by social connection and being in charge. In another longitudinal qualitative study with Norwegian female stroke survivors up to two years post-stroke, four phases were described: in the first phase participants' main concerns were their bodily changes (0-2 months post-stroke); in the second phase they focussed on functioning in everyday activities (2-6 months); in the third phase most participants experienced a deeper self-understanding when they realised that the stroke represented a shift towards a new life (6-12 months) and in the fourth phase the participants were going on with their life, despite feelings of frailty and bodily ailments, which led to a decrease in activities (12-24 months).¹⁶

Although several findings of the aforementioned qualitative studies can be linked to stroke survivors' self-management, none of them focussed specifically on the complex process of self-management post-stroke from a stroke survivors' perspective. Furthermore, many longitudinal qualitative research projects studied stroke survivors up to one year after the stroke,^{10-12, 17-19} while the process of adaptation and self-management post-stroke

often takes longer. Moreover, Robison¹² indicated that after only one year, stroke survivors are beginning to discover the extent to which they may or may not be able to resume valued activities; other authors have also recommended studying the process of self-management for stroke survivors beyond one year post-stroke.^{18, 20}

It appears that an explicit description of the complexity of the process of self-management and the way stroke survivors give meaning to their process of self-management up to two years post-stroke is lacking. To unravel the complexity of self-management in stroke survivors' everyday life, we designed a prospective study with multiple points of data generation over a period up to two years post-discharge. This offers the possibility of analysing the process of self-management more in depth, as serial qualitative interviews offer considerable advantages over the more typical single 'snapshot' techniques in understanding patients' changing experience of illness.²¹ Moreover, we also wanted to collect observational data in addition to interviews. Participant observation could ground the study in daily life²²⁻²⁴ and further unravel the complexity of self-management of stroke survivors in their own context. The present article draws on a research project that studied 10 stroke survivors up to two years post-discharge through participant observations and interviews. The current article presents the longitudinal qualitative study with the aims to explore how stroke survivors after discharge managed their lives, how they gave meaning to their self-management post-stroke and how this evolved over time.

Methods

Study Design

To understand how stroke survivors manage their lives and give meaning to their self-management in the first two years post-discharge, a longitudinal qualitative study has been conducted by applying a constructivist paradigm.²¹ The study was conducted between summer 2012 and winter 2014. The prolonged involvement in stroke survivors' lives built trust with stroke survivors (and their context) and developed an accurate insiders' understanding of the stroke survivors' perceptions and experiences about their self-management of daily life after stroke in a narrative form.^{21, 25, 26} Ethical approval for the research project was given by a Regional Committee on Research involving Human Subjects (ref no. 2011-542). The researchers followed ethical principles in accordance with Dutch research ethics regulations.

Participants and context

Participants were recruited via two rehabilitation centres. Potential participants received a letter with information about the aims and procedures of the study. Purposive sampling²² was used, and participants were included who had experienced a first-time stroke, were living at home at least three months after discharge, were able to communicate in Dutch and had a score lower than 8 on the Hospital Anxiety and Depression Scale (HADS).^{27, 28}

Twenty participants living in the east and south of the Netherlands have been approached for the study, and fourteen participants were interested in participating in the study. These participants have been visited by the first author and researcher (TS) and additional information was provided. Three participants did not meet the inclusion criteria: two participants had a HADS score higher than 8, and one participant had insufficient communication skills to participate in the interviews. One participant dropped out after the first moment of data generation. Ten participants participated in the study and represented a heterogeneous sample in terms of gender, living alone or with a partner, and left- and right-sided stroke (see Table 1). The participants received written and verbal information about the study and also gave their verbal and written informed consent to participate.

Data generation

Researchers visited participants four to five times around 3, 6, 9, 15, and 21 months post-discharge. Most of the encounters started with a participant observation during a self-chosen everyday activity, followed by an interview. The first and third author (TS & JZ) generated the data. Both were occupational therapists with experience observing persons with neurological conditions in daily activities at home and expertise in qualitative research.

The participant observations were mainly in or around participants' homes but also at other locations, such as a workplace, health care centre, local park, supermarket, or a lunch room. A variety of daily activities and situations were observed (see Table 2). Some participants invited TS to join a therapy session, as this was for them an important activity. A few days before the visit, participants were phoned to remind them of the upcoming participant observation and interview. When conducting the participant observations, TS and JZ joined the participants in their self-chosen daily activities and situations. Extensive field notes of the encounters with the participants were made on completing the participant observations.^{23, 24} Sometimes the participants' partners were involved in the activities. TS or JZ helped with small steps if this was requested or needed, which supported the process of building rapport.²³ Subsequent to the observations, researchers interviewed participants to elicit narrative material regarding the stroke-survivors' self-management post-stroke. Although a set of general questions and topics were prepared (see Table 3), the interview followed a conversational style.²⁶ Previous interviews with the participants and their observations shaped each subsequent interview. All interviews were tape-recorded and transcribed verbatim. Most encounters lasted between two and four hours. In total, 42 interviews and participant observations had been conducted during home visits as well as three telephone interviews instead of visits. Research assistants helped transcribe and organise the empirical data.

Table 1 Characteristics of participants

No. participant sex - year of birth	Diagnosis	Living conditions	Housing	Employment status
1 F - 1935	RCVA	Married No children	House Service flat, 1 year post-stroke	No paid job
2 M - 1958	LCVA	Married Children living away from home	House	Long-term disability
3 F - 1942	RCVA	Widow Children living away from home	House Flat, 1½ year post-stroke	Retired pre-stroke
4 M - 1946	RCVA	Married Children living away from home	Flat	Stopped working post-stroke
5 F - 1946	RCVA	Living together with partner Children living away from home	Flat	Stopped working post-stroke
6 M - 1951	RCVA	Living together with partner Children living away from home	Flat	Reintegrated in new job post-stroke
7 F - 1948	LCVA	Widow Children living away from home	Service flat	Retired pre-stroke
8 F - 1946	LCVA	Married Children living away from home	Flat	Retired pre-stroke
9 F - 1957	RCVA	Widow Son and daughter living at home	House	Reintegrated post-stroke Stopped working 1 year post-stroke
10 M - 1945	RCVA	Living together with partner Children living away from home	House	Retired pre-stroke

(M: male; F: female; LCVA: left cerebrovascular accident; RCVA: right cerebrovascular accident)

Leisure activities pre-stroke	(Dis)Abilities post-stroke after discharge
Cycling, creating postcards, baking, physio fitness, reading, holidays	Walking with rollator outside house Decreased coordination left arm/hand—fatigue
Doing odd jobs and woodwork in garden, computer, visiting antique markets with wife, walking	Walking without devices Decreased coordination right arm/hand—fatigue
Playing cards, social activities with friends, activities of elderly association, aqua jogging	Walking with rollator outside house Decreased coordination left arm/hand—fatigue
Visiting friends and family, attending soccer	Wheelchair inside house; mobility scooter outside Spastic left arm
Creating postcards, playing badminton, playing saxophone, physio fitness	Walking with rollator outside house Decreased coordination left arm/hand Decreased concentration and attention—fatigue
Visiting cultural activities, referee in rugby, position in board care institution, jogging	Wheelchair inside house; mobility scooter outside Walking few meters—paralysed left arm
Cycling, voluntary work (primary school)	Walking with rollator in and outside house Decreased concentration
Walking, visiting theatre and museums, tennis, baby-sitting grandchildren	Walking with rollator in and outside Wheelchair, mobility scooter and adapted bicycle outside Hemiparesis right arm—moderate fatigue Moderate attention in groups of people
Visiting friends, church, singing in choir	Walking, cycling and car driving without devices Moderate fatigue Decreased processing of visual and auditive stimuli
Gardening, horse riding, cycling, doing odd jobs	Walking with stick few meters in and outside Wheelchair and mobility scooter outside Hemiparesis left arm

Table 2 Diversity of observed activities and situations

Participant	Observed activities and situations
1	Baking a cake Doing the laundry Walking to the chemistry and shopping Showing new apartment, preparing and drinking tea Walking in environment of new apartment Making postcards Preparing and drinking tea with participant and spouse
2	Preparing and drinking tea; woodworking in garden Joining occupational therapy session: exercises handwriting and woodwork Walking to garage and show repaired cars Walking in neighbourhood and drinking tea
3	Coffee, showing garden Preparing and having lunch at home Working in garden Preparing soup and having lunch at home Preparing and drinking coffee with pastry
4	Drinking coffee with both spouses Showing pictures of jobs in past on computer Driving mobility scooter into park Visiting and training local soccer team Driving towards and shopping in builder's store Showing new car with adaptations
5	Drinking tea with both spouses Making shopping list and shopping in supermarket Joining physiotherapy session Showing self-made postcards and making tea Touring in surroundings with mobility scooter Preparing and drinking tea with participant and spouse
6	Preparing and drinking coffee Using wheelchair to get to city centre and shopping Going to market with mobility scooter Showing adaptations and activities in kitchen Visiting and touring at new workplace Preparing and drinking tea 'Walking and talking' in environment in wheelchair
7	Preparing and drinking coffee Shopping in supermarket Having lunch in lunchroom in city Walking and talking, and showing car Performing little household activities, tea and talk

Table 2 Continued

Participant	Observed activities and situations
8	Preparing and serving tea, coffee and cookies Folding laundry Preparing coffee and drinking coffee with participant and spouse Walking to garage and showing adapted bicycle
9	Visiting physiotherapy session Walking to and shopping in supermarket Preparing and having dinner with family Cycling in surroundings Driving with car through city Joining neuro-feedback therapy session
10	Preparing and drinking tea with participant and partner Showing garden and explaining activities pre-stroke Preparing and drinking tea with participant Trying out home trainer (cycle)

Data analysis

The method used for data analysis was informed by the constant comparative method.²⁹ ³⁰ General analysis started after each encounter with participants to prepare for the next visit. In-depth data analysis began after all data was generated. The Atlas.ti software package (Atlas.ti Version 7.5.2) was used to assist in the process of data analysis. Initially, each separate case (all empirical data of one participant) had been analysed, followed by an analysis across all cases and finally a synthesis of the findings. During the close reading and comparison of the different categories, we paid extra attention to how participants reflected on their self-management to detect changes over time. Repeatedly emerging concepts were further analysed in their relation to self-management.

The use of memos and mind maps supported our analytical interpretation regarding participants' meaning of their self-management post-discharge.^{30, 31} During the entire analytical process, analysis and refinement of categories and themes was ongoing between TS, JZ and SJ (second author). Moreover, the analytical process and the preliminary and final themes were discussed and agreed upon in reflective meetings with all authors. For a description of the analytical process, see Table 4.

Table 3 Main topics for observations and interviews

<ul style="list-style-type: none"> • Self-management of participants • Performance of daily activities • Problem solving • Use of strategies • Roles 	<ul style="list-style-type: none"> • Decision making • Support or help of others • Interaction with environment • Changes compared with previous moment of data generation
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Table 4 Analytical process

Data analysis:

- **Reading** of interviews to form an overall impression of the separate cases (TS & JZ).
 - **Preliminary coding** of two different interviews of two different cases, followed by a coders' meeting to discuss the coding procedure and content of codes (TS & JZ).
 - **Initial coding** of all interviews and field notes of each separate case, and subsequent grouping of codes into categories (TS & JZ).
 - **Memos of each case were written**, as well as general memos to catch thoughts, reflections on possible similarities and differences between cases (TS & JZ). Discussion of memos among TS, SJ and JZ.
 - **Longitudinal comparisons** within cases and categories. Quotations of the participants were ordered chronologically to detect whether there was a change in participants' expression regarding their self-management during the course of the post-stroke period (TS & JZ).
 - **Focused coding**: examining the categories from the perspective of emerging concepts (TS).
 - **Developing final themes** (TS, SJ & JZ with other authors).
-

Results

Six themes were developed in which the doing of everyday activities was a central element (see Figure 1). To protect anonymity, quotes exemplifying the themes include the number of the participant and the moment of data generation (e.g., [3-4] means participant 3 in the fourth encounter).

Self-management develops through involvement in activities

Self-management post-stroke developed gradually and was closely related to participants' doing of everyday activities. However, doing activities was more than only performing an activity. Doing activities situated the participants in their everyday life, and through 'doing', participants interacted with their environment. 'Doing' encompassed exploration, adaptations, challenges and rewards (for example, when participants were able to fulfil pre-stroke roles), but doing also involved fear, saying farewell and grief (for example, when they had to decide that certain activities were not possible anymore).

While the participants were doing daily activities, different processes of self-management happened simultaneously, and through the 'doing', the participants experienced what self-management meant for them. 'Doing' provided participants with experiences that related to stroke—consequences, possibilities and disabilities in activities and situations, interaction with other persons, or receiving or asking for help. The 'doing' was the gateway to these experiences, and through these experiences most participants could learn. For example, one participant expressed: *'So that's what you experience, and that's what you have to deal with...that's how it goes. Without facing it you can't know it'* [7-2]. Not all participants reacted or learned from their experiences. During some participant observations, a few participants showed minor disabilities which they did not notice or correct, such as

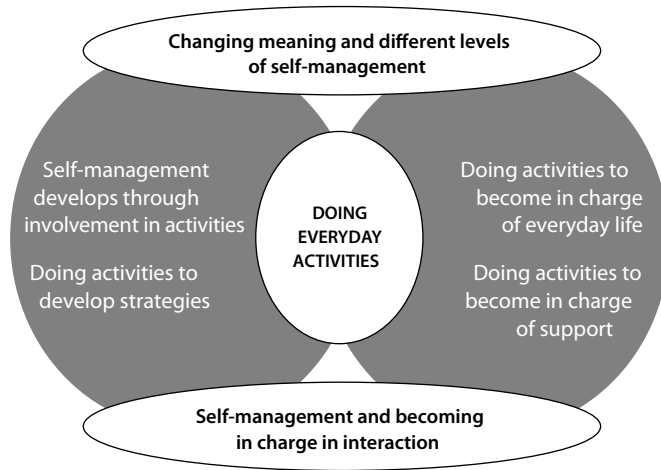


Figure 1 Doing everyday activities as a central element in self-management and becoming in charge

the participant [3-1] who did not use a new coffee pad in her single serve coffee machine whilst she was preparing coffee while at the same time talking to the researcher. During the interview, the participant trivialised this and said that she had not noticed this and that it was not a big problem for her because she could still manage to make coffee.

However, daily activities helped most participants understand how to manage their own situated doing: *'Within your familiar context you do things in a certain way, and then you realise that that method doesn't work anymore. Not only because of physical limitations but also because of the context, the others around you, the practical aspects of the situation being different than what you had in mind. The context does not allow you to do what you had in mind'* [10-2]. Based on the experiences and appraisal of their 'doing', participants could decide to adjust their activity performance. One participant expressed: *'Just trying to do the things you used to do, and if it doesn't work out, it doesn't work out. Then you try to do it in a different way'* [4-5]. Through experimenting with alternative ways of performing activities, several participants experienced how they could still manage their daily activities but often differently than they did pre-stroke. One participant told how the housecleaning had changed over time post-stroke: *'I have become much more calm. First [pre-stroke-TS] I cleaned the silver or the copper very often, now I only polish it when it is dirty'* [3-3]. Through involvement in activities, participants learned how to self-manage, and this consequently supported participants' sense of being a self-manager who could do everyday activities. This developed gradually, and through the 'doing' the participants experienced a sense of relative mastery. These experiences gave the participants access to further development,

meaning that they could change and become the person who could manage disabilities, activities and, finally, self-manage their everyday life again.

Changing meaning and different levels of self-management

With the 'doing' as a facilitator, the participants experienced and developed their self-management abilities in different ways. Over time, the meaning of self-management changed. Initially self-management connoted '*Independency and being able to practice it*' [6-1] and '*Try to manage everything yourself*' [2-2]. This transition was not easy for participants, many of whom felt lost post-discharge because they had missed coaching and support in self-management in their own environment directly after discharge.

The value attributed to independence in the context of self-management became less whilst the importance of meaning in choice attributed by participants in everyday situations increased. For example a participant said: '*Self-management gets more and more meaning. Before, self-management was planning...now I touch upon a deeper sense. Choosing between what comes on your path, does it feel right? What will it bring me? ...in relation to my recovery to feeling better*' [9-3]. Finally, for most participants self-management meant that they could manage and direct their everyday life and do the things they wanted to do, like how one participant expressed that '*Self-management is about doing what matters to me. That I can do what I want and that that is okay*' [3-5]. Knowing what they were able to do post-stroke made most participants more confident in managing themselves; however, some participants discovered that that they could not do what they wished to do. During an observation, Participant 5 said she used to be able to manage several single activities, but that, eventually, she was not as active and could not do what she wanted as she used to do pre-stroke. She pointed to the Christmas tree in her living room and expressed that social activities around Christmas were fewer than what she did pre-stroke and that she was only sitting at home during the holiday. In the interview that followed, she said that she really missed having access to a person who could assist in finding new meaningful activities post-stroke.

Individuals varied regarding the scope and level of self-management. The sense of being a self-manager differed per participant and depended on several factors, such as participants' abilities to self-manage, their perception of self-management, their personality pre-stroke and the interaction with their environment. Some participants talked about self-management as self-managing on the level of activities. Other participants perceived it more broadly, as they strived to be engaged in a meaningful life and meaningful roles. One participant who, despite her severe stroke, was able to self-manage together with her partner and focused more on managing and directing her own life said: '*Self-management is taking charge of your own life*' [8-4]. Through the 'doing' she became a self-manager and felt empowered to direct her own life. Moreover, the participants who expressed a strong sense of self-management showed during observations that they interacted fairly well with their environment. They dared to ask for

help and arranged facilities to optimise their mobility. Furthermore, they dared to decide not to do certain activities, even when it was still possible, as participant 7 expressed about her administration. During an observation, she presented letters from several authorities and reported that she had asked her daughter-in-law to do her administration. This participant perceived herself as a good self-manager and said that deciding not to do something any longer was also part of that.

Doing activities to develop strategies

'Doing' was also essential to develop strategies. Through the 'doing', the participants became aware of their limitations post-stroke and possibilities to manage them. Several participants stressed that doing activities at home was needed to experience and learn strategies, like the woman who reflected on exercises and strategy training in the rehabilitation centre and explained that she had to experience it herself: *'Because my whole life is turned upside down... So how can I answer how I am going to approach it. I don't have a clue; I have to experience it all, in order to know what works or doesn't work'* [7-2]. Although individuals varied in the type and timing of strategies, medical, role and emotional management strategies were mostly interwoven. However, in the first post-discharge period, self-management strategies were more related to medical management of the stroke consequences. The most often-heard strategies involved pacing to manage fatigue and using a shopping list and agenda to compensate for the minor memory problems. Regarding 'invisible problems,' such as concentration loss or hypersensitivity for sensory stimuli, the 'doing' also provided the participants with experiences and consequently with a better understanding of the real stroke consequences and possible strategies to cope. Remarkably, several participants who experienced invisible problems did not explicitly talk about them during the first encounters. It seemed that it took some time before the participants became aware of and understood their invisible problems. Moreover, only one participant had received additional coaching to manage the invisible problems. None of the others had received professional coaching but had just learned to manage their invisible problems by trial and error in daily life.

Gradually, the understanding about their stroke consequences and their strategies to cope increased. In the first interviews post-discharge, several participants expressed how their limitations were not clear and sometimes just happened to them. During the last interviews, the participants expressed that they had learned which strategies worked for them to compensate for the limitations. Instead of being surprised and reactive, most participants became proactive and were able to manage themselves and their activities: *'So when I go see my family, I ask myself the question: what is the easiest and safest way to get there?'* [4-3]. Many participants mentally planned the activity before the actual 'doing'. Although most participants learned step by step to self-manage their everyday activities, there were also situations where participants were not successful in self-managing. An example of this occurred when a researcher arrived for a visit at a participant's home and

the participant was in panic [9-5]. At the same time the researcher arrived, her new cat had knocked over several objects in the kitchen and the phone rang. The participant needed the researcher's help to calm down and get a grip on the situation again. Later on in the interview, the participant explained that post-stroke it took her more time to solve problems, to self-manage these situations and to relax afterwards.

After participants had learned strategies to self-manage the stroke-consequences, the participants gradually related their strategies to the performance of more demanding activities. One participant expressed how he cooked again for his wife and friends, but the recipes and ingredients had changed: *'On a regular basis I take out something ready-made ... typically stew, stir-fried or vegetable dishes, so always meals you can prepare with one hand'* [6-3]. After a while the strategies became part of participants' routines in daily life. Eventually, all participants related their self-management strategies to activities of daily life. Self-management strategies were embedded in and got meaning out of everyday activities. Participants rested before going to the theatre; they asked for help in a shop to buy their groceries for cooking or they switched off their emotions to be present at a birthday party. Although the strategies eventually helped the participants manage and do their everyday activities, several participants still felt that the strategies were insufficient to fulfil all valued roles as they did pre-stroke. Participant 8, for example, expressed sadly how she could not be the grandmother she was before the stroke.

Some strategies took on other meanings over time, especially that of taking rest. Initially, rest was perceived as an extra activity performed before or after a daily activity; participants had to get used to it. In later interviews, participants' resting had become integrated in their daily routines. Rest now had a positive meaning; one participant expressed: *'It happens on occasions that I am too tired, and I am just lying down with a book on the sofa. When I do that because I am too tired to do something, I enjoy the rest'* [1-5].

Doing activities to become in charge of everyday life

When the participants talked about self-management, many simultaneously talked about their sense of becoming in charge. One participant stressed in her last interview *'Self-management ... it is all about directing your own life'* [7-4]. Participants became in charge in different areas. First, by using strategies, the participants became in charge of their stroke consequences during their 'doing'. Subsequently, the 'doing' supported participants' sense of being in charge of their daily activities, like a participant expressed in relation to his self-care: *'A fundamental transition was regaining the ability to choose myself when I go to the restroom because it became physically possible again'* [6-1]. The experience of mastery of activities was satisfying for most participants: *'For example, doing stuff in the house that requires some efforts, e.g., sorting out clothes ... that gives me satisfaction. The ability to do things for myself and by myself'* [8-2]. Moreover, the sense of being in charge of activities also gave the participants the confidence to create, manage and become in charge of other new and engaging activities. A participant who had woodwork as a hobby said: *'I*

appreciate discovering something new again, like new tools, how do you use them ... what is the mechanism behind them, how do you make it, how can you improve it?' [2-2].

Another way participants became in charge of activities was doing activities earlier than their partner did them. They related this to attaining ownership of single activities through 'doing'. When they did the daily activity before, it could have been taken over by their partners; it gave them a feeling of ownership and sense of being in charge of the activity again. One participant said: *'The last thing I reclaimed was the coffee machine ... and I have done that all by myself. When she comes home from her work coffee is ready, and that ... she can't take that away' [2-3].*

With regard to becoming in charge and directing their lives, most participants expressed that they gradually had become the ones who decided what, when and how they could do something. However, for some participants, being in charge was easier said than done, such as a participant who explained: *'In the morning I am full of energy and do a lot of things. In the afternoon I am just too tired to do things' [6-4].* Being in charge of single activities was one thing, but being in charge and finding meaning in post-stroke everyday life was something else. Several participants had expressed in interviews how their *'life was ending'* [2-2] or had lost meaning and was *'just babbling on'* [6-2], although participant observations had showed how they self-managed and were in charge of single activities independently.

Regarding the sense of being in charge and directing their lives, mobility was a specific aspect. Mobility was not only the ability to walk, but also, for example, the ability to drive a mobility scooter or a car. Increasing mobility gave the participants possibilities to broaden their world and to decide and feel in charge of when and where to go. The ability to go outdoors independently was for some participants related to their physical recovery, and for others also to the use of resources and arranging mobility scooters, adequate wheelchairs or adapted cars. One participant expressed how the mobility scooter had empowered her to expand her social life again: *'In the end you do meet new people again. Slowly but surely your little world expands, and I am proud to say out loud: that's my own merit' [7-4].* Through increasing mobility, the participants could more easily decide themselves when and where to go, and this gave the participants a sense of being in charge of their social life. To the contrary, not all participants could easily arrange assistive devices such as a mobility scooter or an adapted car. Often participants needed good interactive skills and an understanding of their insurance or municipal regulations, which was not easy for every participant.

Doing activities to become in charge of support

Receiving support as part of self-management was a topic that came back in all encounters. How much support was needed was only determined in the actual 'doing'. In the first period post-discharge, several participants perceived the help of others as necessary. Although most participants felt uncomfortable receiving or asking for help, they realised

that without the help of others, they could not manage and complete an activity or go outside their house. However, over time, participants' attitudes towards the support of others in relation to their own self-management changed.

Gradually, the support of others was perceived differently by the participants: from help which was needed in the beginning post-discharge towards help which was not necessary or sometimes even unwanted. Moreover, through their 'doing' and interaction with others, the participants developed another sense of being in charge of support, compared with the feeling they had just after their stroke. In the last interviews, several participants who still needed certain support expressed that asking for help still felt uncomfortable, but that they now perceived themselves as the ones who were asking for help or who could even instruct their partners how to do activities. Like one participant reflected: *'Of course I'd prefer to do everything myself, but when I can't, then I find it easy to delegate it and to give somebody else the instructions how to do it'* [1-5]. For most participants, asking for help or getting help no longer denoted dependency on the other person, but asking for help was part of their self-management, like another participant expressed: *'Asking for help is a learning process. I decide when and how much help I receive. Support is part of the game'* [6-4]. They asked by choice and not as a result of need.

Self-management and becoming in charge in interaction

In and through their 'doing', participants interacted with other persons and developed ways to self-manage or to co-manage with their partners. Most couples needed time to share experiences and discuss how to co-manage certain situations together. One participant expressed: *'It is about having a dialogue about it, I mean, I just can't decide on my own to do one thing or another. And when she [partner—TS] wants to do something, then share what the plans are. I believe we both found a good balance between us again'* [6-4]. In most cases, both partners were involved in co-managing daily life and out of reciprocity they also considered how to take care of each other. It was a give-and-take, and often the balance was experienced as positive and supportive. However, a few participants explained how they did not always feel supported to self-manage and become in charge. They related this often to their partner who helped too quickly. In most cases, the spouses could discuss this, like a participant expressed: *'I tell him: 'I want you to give me more space to do things myself. Instead of encouraging me to do something, you are telling me that you will do it... and I want to do it myself''* [1-2]. On the other hand, some participants felt less empowered to self-manage and be in charge of daily activities by their partners. In the last interview, participant 5 expressed that she did not do so much at home, but in a joint interview, her husband expressed that he had taken over the household and shopping because that was his way to self-manage. There was not much interaction about each other's experiences, and the participant said that they had stopped talking about it.

Regarding the interaction in relation to self-management, several participants expressed that communication was an important skill in self-management, especially

communication in relation to arranging resources and asking for help. One participant expressed that *'If you have difficulties to ask for help, then self-management will get difficult'* [6-3].

Discussion

The current findings support the individual, dynamic and contextual nature of self-management.^{7-9, 32, 33} However, this research adds to this knowledge how participants' self-management and sense of being in charge were interwoven, and developed and attained meaning through 'doing'. For stroke survivors the value of doing activities is described in several other publications,^{12, 15, 16, 19, 34, 35} but the current findings show how doing everyday activities provided the participants with experiences on different levels in relation to their sense of self-management and being in charge. Through everyday activities the participants experienced their stroke consequences, and, subsequently, the participants learned to self-manage the stroke consequences in light of everyday life. This 'feedback from doing'³⁵ helped participants to explore (new ways of) everyday doing, adapt their performance and expectations regarding their everyday doing and re-engage in valued everyday activities. An implication from the findings is that professionals in stroke rehabilitation should use the value of doing everyday activities³⁶ in stroke self-management programs to create an arena where stroke survivors can self-manage and become in charge of the stroke consequences and daily activities on a practical level.

Several participants used strategies proactively to self-manage stroke consequences when preparing and exploring new or challenging activities. This finding supports the assumption of Tielemans and colleagues³⁷ about the value of proactive action planning in self-management programs. The current study adds to this assumption that our participants related their proactive planning to meaningful activities. This suggests to rehabilitation professionals that the delivery of self-management programs should be situated in meaningful context. In addition to information provision, goal setting and action planning, pro-active self-management strategies should be learned, applied and evaluated in the context of the everyday life of stroke survivors to do justice to the complex nature of self-management.

Another finding of the current study is how the meaning of self-management and being in charge changed over time. Initially, our participants connoted self-management with doing everything themselves, if possible, without any help. Eventually they experienced asking for help not as a result of need, but as a result of choice and felt in charge. Regarding the sense of being in charge, our findings support the study of Kubina et al.,¹⁵ who described how 'doing' supported participants' sense of personal agency³⁸ in daily activities and meaningful life. However, Kubina et al.¹⁵ presented being in charge only as considering oneself a primary decision maker regarding how and when to resume personally valued activities. In this study, we found that being in charge was also about

being in charge of stroke consequences, one's own life and requesting the help of others.

As in other studies,^{9, 12, 14, 39} the current findings revealed the influence of the partner on participants' ability to resume pre-stroke activities, self-management and their sense of becoming in charge. Our findings showed on one side how partners facilitated the self-management process, but on the other side how they sometimes were a barrier for stroke survivors' self-management by taking over everyday activities too quickly. Furthermore, being in charge didn't mean that the participants were independent and totally self-managing, but often that they were interdependent and co-managing with their partners in various situations which changed over time.^{39, 40} Interaction with others in the network of participants, exchanging experiences, and asking and receiving support were important elements. This suggests that rehabilitation professionals should include the relatives of stroke survivors as soon as possible in the stroke self-management programs. This will assist in addressing topics such as being in charge, interdependency, the value of supporting the stroke survivor, asking for help, and co-management in relation to participants' empowerment.

Concerning the scope of self-management and being in charge, there were differences among the participants. The findings of this study revealed that creating meaning in life after stroke was not easy for every participant. Although several participants felt able to self-manage a new life with meaningful activities post-stroke in the second year post-discharge, this was not experienced by all participants. Some participants only experienced 'self-managing the practicalities of life', but not on an existential level of living with a stroke and creating meaning in life. The different levels of self-management post-stroke reflect the findings of a focus group study among allied health professionals about stroke self-management.⁴¹ However, the current findings emphasise that becoming a self-manager at different levels from single activities to the existential level takes time.^{7, 16} It appears therefore that in addition to post-discharge self-management programs that focus on practical issues in everyday life, longer term programs that facilitate self-management on a more existential level are needed. These should focus on role management rather than the illness or impairment (medical management), and should start once the stroke survivor has spent a considerable number of months at home, for example twelve months post-discharge. The timeframe will vary depending on the state of readiness of the stroke survivor and the nature of their questions about their roles post-stroke.^{5, 7, 8, 42} Moreover, the doing of everyday activities as part of a defined role, can help stroke survivors learn from experiences, recognise oneself, define (new) meaning in their 'doing'^{12, 16, 19} and address the existential dimension of self-management.

Methodological considerations

The number of participants is limited and restricts the generalisability. Although diversity was achieved in gender, living conditions and disabilities, the sample does not represent the general population of stroke survivors. Participants with severe cognitive impairments

and severe communication problems, or participants who were dependent on others for their mobility, were not represented. However, the findings of this study reveal how a certain group of stroke survivors self-managed and gave meaning to their self-management post-stroke. This can be applied to other stroke survivors or contexts. One strength of this study was the extended period of data generation which provided the stroke survivors with the possibility to reflect on their own process of self-management post-stroke.²¹ Triangulation through the use of interviews and participant observations enhanced the completeness and credibility of the findings. However, some participants may have altered their behaviour because they were being observed. A few participants initially expected that the observations would be an assessment of problems and disabilities, but the researcher explained that the intention was to 'be part of their daily life' to observe how they self-managed, and, for example, asked for help as part of their self-management instead of focussing on disabilities or independence. Another strength of the study was that its design grounded it in the everyday life of stroke survivors. This might have influenced our findings, as the participant observation during the doing of activities was part of the method and, therefore received extra attention. However, during interviews, the participants, without being prompted expressed in various ways the value of their everyday doing in relation to self-management and the process of becoming in charge.

On occasions where partners were present, data generation was adapted to include the partner in the interviews or observations and to capture the interaction between the stroke survivor and the partner. Furthermore, reflective meetings with all authors to discuss the analytical process and the preliminary and final themes enhanced the credibility of the study.^{43,44}

Conclusion

This study aimed to explore stroke survivors' self-management post-discharge. The findings indicated that situated doing was central in stroke survivors' simultaneous development of self-management and the sense of being in charge of everyday life. This process was individual, dynamic and contextual, in which the interaction with the partner was experienced empowering in some situations and as a constraining factor in others. It did not appear possible to describe a general scenario for the development of self-management and becoming in charge of everyday life. Experienced levels differed among participants, ranging from only managing at the level of everyday activities to full role management and experiencing a meaningful and valuable life post-stroke. Individualised self-management programs for stroke survivors, together with their relatives, should be offered post-discharge in stroke survivors' homes to coach stroke survivors and their relatives in the development of self- and co-managing with the doing of everyday activities as an essential determining part of everyday life. Moreover, stroke self-management programs

with more existential content should also be considered after about one year of living at home to address the need of stroke survivors to live a meaningful life post-stroke.

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Chapter 7

Negotiating Role Management through Everyday Activities: Narratives in Action of Two Stroke Survivors and Their Spouses

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Abstract

Purpose: To manage social roles is a challenging part of self-management post-stroke. This study explored how stroke survivors act as role managers with their spouses in the context of everyday activities.

Method: Two stroke survivors with a first time stroke living at home with a spouse were included. Data were generated through participant observations at their own environment at 3, 6, 9, 15 and 21 months post-discharge. The narrative analysis focused on the actions of participants.

Results: Daily activities can be understood as an arena where role management and a meaningful live is negotiated and co-constructed with others. Everyday activities gave stroke survivors and their spouses insight to stroke survivors' capacities in daily situations. This was sometimes empowering, and other times conflicting when a spouse had negative perceptions of the abilities of the stroke survivors.

Conclusion: The findings add to the current understanding of self-management and role management with regard to how these are situated in everyday activities. Daily activities can help both spouses to reflect and understand about self-management, role management and co-management in daily life. Moreover, observing stroke survivors in everyday situations provides professionals with concrete pictures of stroke survivors' performance and self-management in interaction with their spouses.

Introduction

Most people manage themselves by routine, fulfil their roles in the community, and try to find meaning in life.^{1, 2} Like with other acute health events and chronic illnesses, a stroke leads to drastic changes for a person in terms of biographical disruptions of a desired, meaningful life, particularly in terms of roles, responsibilities, sense of self, and identities.³⁻⁹ A stroke often affects the fabric of predictable everyday life,¹⁰ and self-management post-stroke is not as it was before the stroke.¹¹ Depending on personal and environmental factors and the severity and the phase after a stroke, patients may experience disabilities in physical, cognitive, social, and emotional functioning.^{7, 12-17} Together with their spouses, they have to deal with these changes and find a new balance in their everyday lives.^{18, 19} Interventions supporting self-management have been recommended as methods to support stroke survivors in adjusting and coping with the consequences of the stroke.²⁰ To date, different stroke self-management programs have been designed and researched.^{21, 22} Self-management can be defined as “an individual’s ability, in conjunction with family, community, and healthcare professionals, to successfully manage the symptoms, treatment, physical, psychosocial, cultural, and spiritual consequences and inherent lifestyle changes required for living with a long-term chronic disease”.^{23(p.1145)} Self-management has three interacting domains: medical management, role management, and emotional management.²⁴ However, in the literature, there is not much of a differentiation made among medical management, role management, or emotional management. Alternatively, Schulman-Green et al.²⁵ have identified three processes of self-management in chronic illness: focussing on illness needs, activating resources, and living with chronic illness.

The post-stroke process has been described as a transformation and adaptation for stroke survivors and their spouses in their daily activities, their relationship, and changes and limitations in other social roles. Stroke survivors are often not able to perform daily activities or fulfil social roles the way they were used to do pre-stroke. Furthermore, spouses are mostly confronted with a new role of caregiver besides their role as partner. This causes feelings of uncertainty and changes in self and roles, as well as physical, emotional, and informational needs.^{5-9, 18, 19, 26-31} With regard to self-management, stroke victims have described self-management as a complex, long-term learning process and expressed that self-management is influenced by their relatives.¹¹ However, there is a need for further research on how stroke survivors self-manage and act in their roles in the context of their everyday life activities.

Activities of everyday life are important for persons. It characterizes who they are, how they daily use of time and energy, such as cooking a meal, shopping, dressing, a phone call to arrange services, or driving a car.¹ Role management refers to the way people regain, adapt or maintain roles within their lives.^{24, 32} In order to understand how people act in order to manage themselves and their roles in everyday life, agency is a

useful concept to study. The concept of human agency is about a person's ability to act in different situations.^{33, 34} It can be seen as a means for and as a result of participation in everyday activities.^{1, 35-37} Agency is situated in daily activities, and can be related to the way persons manage to negotiate challenges and find solutions in everyday life.³⁸ Agency is described as temporal, multifold, and co-constructed.^{37, 39-41} Temporality can be related to an ongoing development of agency of a person in a changing life line; some persons post-stroke might experience differences in their agency when they compare themselves to their former capacities, their pre-stroke selves, lives, and roles.⁸ Agency is multifold, as it not only relates to acting, but also to identity. It is the aspect of the performance of everyday activities, the doing, that helps people to make meaning of their lives and shape their identities.³⁵ Although agency initially refers to human acts done intentionally,⁴² it is also about getting others to act. So agency is constantly co-constructed with others and negotiated in the everyday activities and environments, particularly the social ones.^{39, 40} However, although an agentic perspective on role management can offer a deeper understanding of the how and why questions regarding self-management post-stroke, such agentic perspective on role management post-stroke is largely absent from existing research.

Within this study, we have used a narrative theory to conceptualize everyday activities and role management. Ricoeur^{43, 44} has described how narratives can be observed when people "act." In an "enacted narrative," people can act out their narratives by performing everyday activities. Ricoeur⁴⁴ proposes that the actual doing in daily life produces images that people might connect to past experiences or to future events. For example when a stroke survivor is making the first steps with the therapist; these first steps can be linked with images about possible scenarios as "when I am able to make these steps, I might be able to walk stairs and go home". By doing this, people try to interpret their experiences by creating meaning in form of possible storylines or scenarios. Furthermore, when people act, they try out possible interpretations of their acts and their situations. This testing of possible interpretations is part of peoples' ongoing negotiating of meaning.⁴³⁻⁴⁵ By their engagement in different situations people play (and test) with possible scenarios in different situations; they receive responses from spouses, family, or friends; and develop further understanding of their own situations. In relation to daily activities and role management, people develop interpretations of possible ways (scenarios) how they can manage their roles in the context of everyday life. The plots people develop through this process serves as a possible meaning that captures how certain processes of life have been and how life might develop; it supports in a further understanding of their own daily life.⁴⁵

From a narrative perspective, the process of role management post-stroke can be viewed as a personal and contextual narrative with plots, events, daily activities, roles, and turning points. Consequently, everyday activities can be viewed as narratives-in action or enacted narratives⁴⁶ where the role manager acts.^{46, 47} For persons who are living with a

spouse, role management is embedded and constructed primarily with their spouses. However, although several qualitative studies^{29, 48-50} have documented the ongoing post-stroke recoveries with their transformations and adaptations, less work has been done on the exploration of the way role management is enacted in everyday activities by stroke survivors and their spouses and how this evolves over time. Therefore, the aim of this study was to explore how post-stroke persons act as role-managers along with their spouses in the context of their everyday activities over time.

Methods

This study was informed by a narrative theory, which has been described as a useful perspective for studying human action, experiences, and meaning over time.^{44-47, 51} We were drawing upon 'narrative-in-action' as a theoretical resource, as we were interested in how meaning was negotiated and developed in everyday actions.⁴⁶ In doing so we altered from viewing narratives as verbalized, storied text about people's experiences in daily life.^{46, 52} and focused on observation of participants' narratives as embedded in action.⁴⁶ This 'narrative-in action' approach is a useful way to study how meaning is created during acting in everyday activities.⁴⁶ Based on the reasoning that narratives and experiences are socially constructed, this study followed a socio-constructivist epistemology.^{47, 51}

Participants and context

Two participants were drawn from a larger longitudinal study where participants have been included after experiencing a first-time stroke, living at home at least three months after discharge, living with a spouse, and having a score lower than 8 on the Hospital Anxiety and Depression Scale (HADS).^{53, 54} With the requirement of a HADS score below 8 we wanted to exclude participants with a post-stroke depression, as we wanted to focus on the self-management of stroke survivors with mainly physical stroke consequences. The two participants were also selected as we also wanted to include one male and one female participant. Moreover, both participants showed in the first encounter that they could provide us with rich information. Furthermore, both the participants and their spouses, agreed to welcome the researcher several times for the participant observations. Ethical approval for the research project was given by a Regional Committee on Research involving Human Subjects (ref no. 2011-542) and followed ethical principles in accordance with Dutch research ethics regulations.

The participants in this study were 67-year-old Betsy (pseudonym) and 68-year-old Martin (pseudonym); their spouses were Jan and Annie (pseudonyms), respectively. Basic descriptions of the participants are given in Table 1.

Table 1 Demographic Data of the Participants

Participant & Partner	Marital status, children Daily activities pre-stroke Stroke and consequences
Betsy, 67 years old <i>Partner: Jan</i>	<p>Divorced, now cohabiting and living with Jan in a sixth-floor apartment; three grown children.</p> <p>Worked in a patisserie, voluntary language teacher of asylum-seeking family, played saxophone in a music band, played badminton, made post cards, and was involved in physio-fitness.</p> <p>Stroke left; mild senso-motoric problems, right side; mild memory problems; mild problems in orientation in time and place; lowered ability to maintain attention and to concentrate; mild hemi-inattention, for left side. Independent self-care. Independent walking inside the house and outside with rollator.</p>
Martin, 68 years old <i>Partner: Annie</i>	<p>Married with Annie and living in a fourth-floor apartment; two grown children.</p> <p>Retired, but still working as an ambulance nurse and community nurse.</p> <p>Stroke right; hemi paresis, left side; spastic left arm; self-care with help; walking maximum 20 meters with walking aid; using wheelchair inside and outside the house, as well as a mobility scooter outside.</p>

Data generation

The first author and main researcher (TS) generated the data through participant observations in everyday activities initiated by the participants.⁵⁵ Repeated participant observations, five times with each participant over 21 months post-discharge, made it possible to be a part of the participants' enacted narratives in their ongoing everyday lives. Most encounters lasted from two to four hours and took place at the participants' homes or if appropriate in the surrounding areas. Encounters were planned approximately around 3, 6, 9, 15, and 21 months post-discharge.

Two weeks before each encounter, participants were phoned to make appointments and to explain the purpose of the home visit. TS joined the participants while they performed everyday activities, such as grocery shopping, visiting the physiotherapist, having coffee with spouses, or taking a walk. Sometimes the participants' spouses were engaged in the activities. The researcher had 'informal' talks with the participants (and the spouse if present) about what was going on at that time and sometimes how this could

be interpreted, and helped with small steps of activities if needed, which supported the process of building rapport.⁵⁵ After each encounter, TS made field notes about the actions of the participants in everyday situations, followed by reflections.^{46, 55, 56} Reflections were about remarkable, unexpected, or specific situations and actions in general, and in relation to role management in particular.

Data analysis

The narrative analysis was an interpretative, inductive, and iterative process of moving between the data from observation and informal talking, and followed the principles of the hermeneutic circle, meaning that the analytical interpretation involved a constant back- and forth movement between the data from each encounter and the emerging analytical results from the period as a whole.^{45, 46, 55, 57} Moreover, existing theory was brought into the interpretative process, characterizing the hermeneutical interpretation.⁵⁷ See figure 1.

First, the field notes and reflections of encounters with Betsy and Martin were read and discussed separately among TS and the second and third authors (SJ and JZ, respectively). Significant events and actions were identified through close readings of the field notes and reflections, and preliminary plots were identified. Plots are context bound,

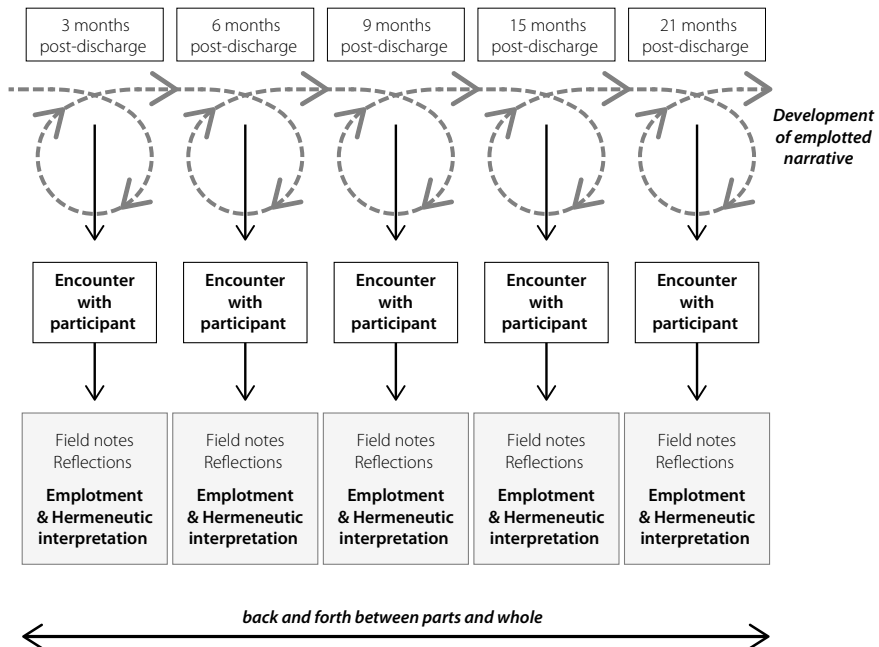


Figure 1 Process of data generation and analysis

depending on the situation (e.g., the consequences of the stroke, relatives, other people, time, and the environment), and give possible meanings to a life post-stroke. Links between different events and actions of the participants, the interactions with their spouses, and the possible meanings of these events and actions were investigated. In this process of emplotment,^{44, 45} further interpretations about actions of participants with regard to role management were processed into possible story lines and plots by TS, SJ, and JZ.

After the step of emplotment, following the encounters with each participant and their spouses, theories and literature about self- and role management, agency, and meaning making in daily activities were brought into the interpretation and refinement of possible storylines and plots. Together with the process of emplotment, hermeneutical interpretation took place after every encounter with each separate participant.⁵⁷

The generated data and possible storylines and plots were re-interpreted several times while moving back and forth between the field notes, reflections, and the literature. This process stopped when possible storylines and plots were developed for each separate participant.

The analysis resulted in a storied outcome where empirical data and theoretical perspectives are presented together in order to enhance transparency. The two narratives presented below must be viewed as co-constructions of the participant, the spouse, and the researcher,^{46, 47, 57} and are the authors' interpretations of these co-constructions.

Findings and discussion

Betsy: "I need him, but without him I could do more."

Betsy, 67 years old, and cohabiting with her spouse Jan, expressed that she had mixed feelings about the way Jan supported her after her stroke. During various encounters with Betsy, she repeatedly expressed to the researcher that she needed her spouse, that she was glad for his support in different situations and how he organized the household in general. However, she also said that he was too careful with her and in some ways even limited her. Two situations will be further described with possible explanations.

"I need him, but he always cooks the same!"

During the first encounter, Betsy was sitting with Jan at the dinner table preparing a shopping list. She had planned to go to the supermarket and the researcher (TS) was scheduled to join her. She stood up and put her coat on, and put her bag, wallet, and keys in her walker, then she walked with the researcher to the supermarket around the corner. Outdoors Betsy said, *'You know, I welcome his help, but he can only cook three meals. It's often the same.'* Betsy expressed to the researcher that she had always been the one who did the cooking and that she really wanted to cook again. Once in the supermarket, Betsy collected all groceries from the shopping list. She could find everything, looked at the

prices, and decided what to buy. She also took a few other vegetables and mentioned that she always had done so: *'I often take extra vegetables. It means that you can choose, and create different meals every day. A little wok is always delicious.'* When Betsy came back from the supermarket, she gave the bag to her partner. After Jan responded surprised that she had bought too many vegetables, she said, *'But I can help you with cooking! Maybe we can use the wok.'*

One possible interpretation is that Betsy explored new possibilities and tried to negotiate with her spouse about the possibility of cooking together. Based on the past, where she was always the one who cooked, and based on positive experiences in other activities she had done recently, she might have created a future storyline where she saw herself cooking again. Knowing that past and future influences present actions,^{43, 47} she might have bought extra vegetables to explore and negotiate the possibility of doing something she did before the stroke: cooking a meal.

Almost two years post-stroke, Betsy was not cooking anymore and rarely went to the supermarket. During the last visit, she told the researcher that Jan was often not amused when she came home with more groceries than he had written on the shopping list. At the time of the visit, Jan was doing most of the shopping. In contrast, Jan said the new situation had been overwhelming for him, and that he had lost his 'pal' at home. He expressed how difficult it was to cope with the changes at home, and he didn't exactly know where to start to solve the challenges in the household himself. On one hand, he was devoted to assist Betsy in everyday activities, but on the other hand, he explained, he could often do these activities easier and quicker himself. Jan perceived this as the best way to manage himself: *'I also have to take care of my own time. Activities like grocery shopping, cooking, or household activities I can do much faster than her. Beside these activities, I also have other things to do.'* Jan said they had stopped talking about it with each other and that they both tried the best they could in their new situations.

From the perspective of co-management and role management,^{11, 58} one possible interpretation of the situations described above is that each person tried to manage the situation in her or his own way, but both were taking care of their own daily business without a dialogue with each other. Both persons might have had different understandings and expectations of their everyday activities and roles, but there was no dialogue about their perceptions of the changed situation and roles post-stroke. A dialogue between Betsy and Jan about the meaning of activities and finding a new balance in role management could have been a way to negotiate capabilities and expectations about future roles and the best ways to perform activities. Moreover, a dialogue could have helped them to tune in to each other instead of maintaining the current gap between them, and it could support both persons in doing the everyday activities they really wanted.^{59, 60}

Concerning the cooking, Jan argued that it was best for both that he prepared everything, and that, at the end, Betsy could sit in the kitchen and check the potatoes and

vegetables when they were boiling. Jan explained his internal conflict: he wanted to help Betsy, but he also wanted to prevent any mistakes she might make, as he experienced sadness when Betsy struggled in activities. Jan said, *'I sometimes have to leave the kitchen because I cannot stay close to Betsy and face her struggles during household activities.'* To prevent that Betsy would struggle during household activities, he took over everything. If he felt too frustrated or sad, he sometimes left the kitchen and asked Betsy to do some easy activities herself. However, the activities that Betsy was asked to do had no meaning for her. She explained, *'Jan proposed that if he first prepares everything and puts it on the gas, I could sit in the kitchen beside the gas cooker and control the potatoes when they were boiling. But well, I can better read a newspaper. I stopped cooking.'* The consequence was that Betsy was not engaged in cooking anymore. The steps of the cooking she was allowed to do were too simple and meaningless for her. Furthermore, it also resulted in a situation where Jan wished to see a 'happy Betsy' who could do simple activities without mistakes, while Betsy said she was actually less happy because of his way of supporting her. She said she had accepted her mistakes while doing everyday activities. She just wanted to cook. Jan argued that he was critical regarding the way Betsy performed activities. He said he thought that the best way to help her was to give feedback about the failures and to structure or take over the activities when she was trying out everyday activities.

The stories and actions of both Betsy and Jan can be interpreted in different ways. Based on Vik et al.³⁷ and Kessler et al.,⁶¹ who described the importance of developing a sense of agency and building competences in participation in meaningful occupation in the years following stroke, one possible interpretation is that a vicious cycle started. We imagined how Jan, Betsy's spouse, did not stimulate her to perform different activities or to relearn by doing. As a result, her sense of agency decreased. If we link this to the process of role management, Betsy is an active agent in the beginning of the post-stroke process where she did the shopping and cooking. Initially, she negotiated with Jan to do more everyday activities step by step. However, during the last encounters, Betsy was a more passive agent who was not creating new situations or activities. She rarely participated in meaningful activities like cooking. Consequently, she was not able to redevelop her competences in cooking in order to regain this important role.

"I need him, but without him I could do more."

Almost a year after the stroke, Betsy said that she'd had a very good day when Jan was away for a full day with friends. She said, *'We had made a list with different household activities that I could do. I was really happy at the end of the day. I had done all the household activities by myself, in my own way and own pace.'* When Jan had returned home, she had shown him what she had achieved at home. Betsy later told the researcher how she wanted to share her success of completing the household activities by herself and had hoped that she could do this again, but Jan had responded stoically to her achievement. Ricoeur^{43, 44} described that, when performing everyday activities, people interpret their

experiences and produce images that are connected to past or future events. By doing this, people create possible storylines or scenarios which are used in their negotiations about future situations. Related to this, role management and Betsy's different actions as her own agent can then be seen as a negotiation between Betsy and Jan about future activities and each other's roles. Moreover, role management was also Betsy's internal dialogue about her future scenario, her 'self' and her identity, and about the roles she had and which roles she was able to regain.^{35, 62, 63} In this case, she might have interpreted her recent experiences as not only being able to do the household activities, but also as a possibility to negotiate with her spouse about doing more activities in the future.^{43, 44}

Betsy was also engaged in activities outside her home in the community. She repeatedly talked about her visits to an African family to coach them in the Dutch language and culture and her time at the local activity centre where she helped to serve lunch once each week. She explained, *'The people at the activity centre take the time for me. I know that it costs them time, but they tell me when things are not going as it should go. I know that I'm not so quick. I can only serve two meals per time with my walker, but that is okay for them.'* Betsy said that she really liked to go there, that she had accepted that she made little mistakes, but she could let it go. Helping other people in the activity centre was more important for her.

In general, we have interpreted how cooking and household activities, even when these went differently before the stroke, were possibilities for Betsy to reconnect to her important pre-stroke roles. Betsy had accepted that trial and error were part of the process of self-management. For her, the experience of mastery in activities was more linked to the meaning of an activity and the satisfaction of the 'self'.⁶⁴ Cooking and household chores were her pre-stroke roles, and starting to do them again was a way to regain these roles as well as a sense of self and identity.^{2, 35, 63} Betsy's self-management was embedded in the management of the 'self', roles and identity, which we have interpreted as role management.^{11, 24}

Martin: "I can still orchestrate my life."

Orchestrating the people around him to reconnect to roles.

Martin was sitting in his wheelchair during the first encounter. He told the researcher that even after his retirement he had been working as an ambulance nurse and community nurse. He shared pictures of the time he had worked as an instructor in the army before the stroke and showed how he still could track the ambulances on his computer when they had to go to an accident. Martin talked mainly about work-related issues and not about his stroke. His wife said during the first encounter that work was *'his everything'*. When the researcher asked Martin 21 months later about the biggest changes post-stroke, he responded immediately, *'Not being able to work again. That is the biggest change!'* However, in the various encounters, Martin often told how he had visited some people in the flat he knew from the time he worked as a community nurse. He said, *'Of course, I was*

not visiting them as a nurse, but I can still have a talk with them.' He had also become a member of the residents' association and had recently organized an event for the residents of the flat where his old ambulance mates had given a presentation about first aid for elderly.

One possible interpretation of Martin's story is that he tried to reconnect through these activities with his pre-stroke role as nurse.^{8, 65} Although he was not a professional nurse, being with others and talking and giving advice to others was still meaningful for him. Martin tried to reconnect with this through new activities in and around his building in order to reconstruct his sense of self and continuity of his roles.^{65(p. 88)} When he performed these activities, he might have created possible future storylines;^{43, 47} these storylines could have helped him in the negotiation with and reinvention of his social self, his roles, and his identity.^{62, 63}

During the third encounter, Martin wanted to go to the park to take the dog out for a walk. His wife, Annie, helped him with his jacket and put the dog on a leash. Once in the garage of the flat, Martin made the transfer from his wheelchair to the mobility scooter, and Annie connected the dog leash to the mobility scooter. Martin and the researcher went to the park and a conversation began about the possibilities for him to go out independently. Martin said he had to get used to the fact that his wife had to help him with dressing and washing, but that it felt normal now. Later on in the conversation he expressed that he needed her and that she was really important for him because Annie's help made it possible for him to go out to see his friends or visit people in the flat. For Annie, it was normal to do this. She said, *'In the period that I was ill, he helped me so much. It is normal to do this for him now.'* She also said Martin had not changed after the stroke: *'He is still orchestrating the people around him. He has people for all kinds of activities and knows how he can approach them.'* An example was given in another encounter where Martin told how he had asked a friend for help because he wanted to create a flower box on the balcony. Martin had phoned his friend, and his friend bought pots, sand, and flowers for the flower box. Martin showed the researcher his balcony and how he could water the little plants. He said, *'You know, I cannot sit the whole day inside my house. I want to go out or sit on the balcony.'*

From an agentic perspective, we have interpreted Martin in these situations as an active agent. He was the one who had the lead, but was able to ask other persons for assistance when he needed it. He used the capacity of others in order to control and manage the situation with others, which can be viewed as proxy-agency.^{33, 42} Role management for Martin was to organize people around him to help him and fulfil his role. Role management was situated and co-constructed by Martin through everyday activities, which is referred to in other studies as co-management.^{11, 58} Moreover, role management for Martin meant considering different scenarios with regard to future roles and possible adjustments he had to make.

Another situation where Martin organized services in order to be able to go out and fulfil his social roles was when he made a phone call with someone from the municipality

during the first encounter. Martin explained on the phone that his current mobility scooter was not good enough to drive into the hilly area of the city where he lived and that he could not go out with his dog or meet other people. He expressed to the researcher that arranging things like phoning people from official bodies and arranging services for himself was not difficult for him. His wife said later, *'That is typically Martin. He knows how to do this. He has always done this!'*

One possible interpretation is that Martin was an active agent and a good medical manager, as he arranged the care and resources in order to deal with the consequences of the stroke.^{8, 32} We have interpreted this as an action of a role manager, meaning that Martin managed his surrounding situations in order to be able to perform his social roles.^{8, 32} Having a better mobility scooter would mean that he could go out with his dog and play his desired role in his social network. We saw a person who was able to negotiate with people to create situations as he wanted them to be. Moreover, Martin's wife trusted him and gave him space to explore possibilities. Although Martin was dependent on his wife and other persons, he was in charge. He was orchestrating the people around him in order to reconnect to and fulfil the roles as he wanted to fulfil the roles.

"There is still a life with only one hand."

In various encounters, Martin often reflected on everyday activities. He tested future possibilities with his wife and the researcher. One example is how Martin talked about his physiotherapist. He often said that she was a good professional who challenged him, knew how to handle him, and trusted him. On a certain moment, almost one year after the stroke, Martin talked about the moment he had walked a few meters with the physiotherapist. He explained how good it felt to take the first steps, and how it gave him hope about his possibilities for the future. He said, *'Well you know, if I can walk again, I might also be able to drive a car again, go to the shop myself, or visit people outside my own village.'*

One possible interpretation here is that the experiences he had and the meaning he gave to the first steps with his physiotherapist were much more than a step with a walking aid. From a narrative perspective, where the past and present can shape future storylines,^{43, 47} Martin could have created different scenarios around the possibilities of walking again or even driving a car. Through Martin's positive experiences of relative mastery while walking,⁶⁴ he gained access to the world of "as if",⁴³ which enabled him to continue stories such as walking and driving a car. Driving a car would not just be 'driving a car', it would open up new possibilities and allow him to regain old roles.

A similar interpretation can be made about the following situation: Martin, who had just gotten his driver's license back, had just bought an adapted car, and he and Annie had been driving in the city. When the researcher had coffee with the two of them, Annie said, *'He drives safer than me!'* A bit later, Martin started to joke about travelling by car to a fisher's village the next weekend. He referred to the delicious fish they had always bought there in the past. Suddenly, he said, *'And if we go to the fishers village, we might also go to [our son]*

Jeroen. His wife laughed and said, "Well, if you have something on your mind, it will happen."

One possible interpretation of this situation is that the positive experience of driving the car in the city had opened up the idea of going to a fisher's village and buying some fish. It was something they had done in the past, and the idea and possibility had come alive again. Martin said that he always got his first ideas when he was doing activities. We interpreted that, through the experience of relative mastery in everyday activities, Martin created images of future activities and ways to fulfil roles.^{43, 44, 64} He tested the possibilities of future activity and negotiated with his wife. Through the activities, either by doing or by talking about them, Martin tested new scenarios. He talked about his dreams and considered possibilities of how to manage, continue, and reconnect to old roles. We interpreted Martin as an agent who had sufficient confidence to take action, to negotiate with others, and to manage his old and new roles. Although he had limitations, he was an agent with the ability to create meaning in life post-stroke. As he said, *'there is also a life with only one hand.'*

Methodological considerations

Our method to generate knowledge challenged the trustworthiness of the study by its interpretative mode, so we tried to enhance the trustworthiness using several strategies. The dialogues with the participants were not recorded, but extended field notes were written by the researcher. During data generation and interpretation, TS had ongoing conversations with SJ and JZ to reflect on the empirical data, as well as on the emerging plots, and hermeneutical interpretation of the data. Furthermore, procedures for data generation as well as the interpretation and emplotment of the storied outcomes were considered in regular team meetings with the other authors in order to establish trustworthiness.⁵⁷

The adoption of a socio-constructivist epistemology and a narrative approach for this study meant that the empirical data of this study should be viewed as a co-construction between the participants and TS, who is an occupational therapist, experienced in supporting persons in their daily activities after they had suffered from strokes. To enhance trustworthiness, situations and preliminary findings were discussed during encounters with the participants. Nevertheless, the storied outcomes of this study are the researchers' constructions and the researchers' interpretations.^{47, 51}

The longitudinal aspect with various moments of data generation and the use of theory during the interpretation of the empirical data enhanced the credibility of this study. Moreover, the rich descriptions of the research situation and its dynamics, along with the outlined theoretical resources, provide information for the readers to judge the plausibility of the storied outcome.^{66, 67}

Conclusions and implications

This study demonstrates how role management is embedded in everyday activities of stroke survivors and their spouses. Performing daily activities gives stroke survivors an experience of relative mastery with regard to their abilities, which can give them different scenarios and understandings of future possibilities.^{68, 69} Performing daily activities and experiencing relative mastery can facilitate stroke survivors' internal dialogues as role managers with regard to questions like, "Will I be able to manage this activity myself?" or "Will I be able to fulfil this role again?" Considering the possibilities of reconnections with meaningful past roles helps the stroke survivor as role manager.^{35, 43, 44, 62, 63} Furthermore, to experience the ability of doing the activities they want, to reconnect to their pre-stroke roles, and to ask support from others when needed will also influence the sense of agency of stroke survivors.^{37, 61, 68} Besides, stroke survivors' doing gives spouses an impression about their partner's abilities post-stroke in an everyday context. Moreover, stroke survivors' activities can generate and support the dialogue between them and their spouses about each other's scenarios and future images about their roles and possibilities in co-management. This can help spouses to adjust their future expectations and understanding with regard to the self-management of the persons post-stroke in everyday life.^{43, 44, 64}

This study adds to the current understanding of self-management how it is situated in everyday activities through role management. Self-management is easily perceived as an individual responsibility with a focus on medical management. However, role management cannot be ignored. Role management is the revisioning and management of an acceptable meaningful future life through everyday activities and roles.^{24, 32} Consequently, daily activities can be understood as an arena where role management is negotiated, created, and co-constructed with others. Sometimes this is conflicting, like with Betsy and Jan, and other times it is self-empowering like with Martin and his wife.

This study also informs healthcare professionals about the value of the performance of daily activities for stroke survivors in their own contexts. Therefore, we advise healthcare professionals to give stroke survivors the opportunities to perform everyday activities in their own environments as a tool in self-management programs. Doing daily activities gives stroke survivors' experiences of relative mastery of the activities when performing these activities, which can facilitate the internal dialogue of stroke survivors with regard to their capacities as role managers. Moreover, observing stroke survivors in everyday situations provides a richer picture of the way they act and react as agents and how they manage themselves in interactions with their partners instead of an interview only. Knowledge about their process of self-management, as well as knowledge about the "battle and alliance" between stroke survivors and their spouses,⁵⁹ can be used to offer support in terms of a realistic and meaningful balance in their everyday activities.⁶⁰ Professional support in performing daily activities, and subsequently the dialogue between both spouses about the meaning of roles and activities, as well as the balance

between taking over, or enhancing participating in activities, might support them in finding a meaningful balance in daily activities. Moreover, this can prevent spouses or other family members from becoming the second patient in the family.⁷⁰

Concerning future research, the approach of narrative in action is a useful framework for unravelling the complex processes of self-management and specifically role management in interaction with the environment. An observation of a narrative in action generates richer empirical data in relation to role and self-management in daily life.

Finally, we encourage healthcare professionals to deliver stroke self-management interventions not only to assist stroke survivors in managing their health conditions and healthcare services, but also to support stroke survivors and their spouses in their role management. Stroke self-management programs can assist stroke survivors and their spouses with exploring different scenarios in order to find meaningful post-stroke lives and to become a couple that can put their life back together.

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Chapter 8

General Discussion

Introduction

The objective of this thesis was to improve the understanding of self-management post-stroke from the perspectives of the stroke survivors, spouses, and health professionals. Six studies with a variety of designs and samples were conducted. Chapters 2, 3, 6, and 7 described the experiences of stroke survivors regarding the impact of the stroke and the process of self-management post-stroke. Chapters 4 and 7 addressed the spouses' experiences. Chapter 5 described the perspectives of allied health professionals on stroke rehabilitation and self-management post-stroke. The next paragraphs present the main findings of this thesis, their interpretation and discussion, and some methodological considerations. This chapter will end with the conclusions and implications for practice and future research.

Main findings

The impact of a stroke on stroke survivors and their spouses is large. Beside physical and emotional problems, many stroke survivors experienced discontinuity in their roles and their sense of self after their stroke (Chapter 2). To manage an uncertain self (*'I am half a person'*) was not easy and caused feelings of uncertainty. For most stroke survivors, regaining or developing (new) roles and a sense of self was a difficult, long-term process that involved ongoing questions about the possibilities of continuing or adapting roles. The stroke also affected spouses who experienced changing relationships and challenges as caregivers in addition to their role as spouse (Chapter 4). These changes caused feelings of burden, loneliness, sadness, and guilt for the spouses. Furthermore, spouses expressed a need for time and attention regarding their own self-management.

Stroke survivors, spouses, and allied health professionals all viewed self-management as a complex and dynamic learning process. The process was personal, situated, and temporal. Initially, many stroke survivors did not feel ready for self-management post-discharge. They perceived that they had learned by trial and error and that 'real' self-management could be developed best at their own homes post-discharge. During the recovery, post-discharge stroke survivors went through different phases of self-management (Chapter 6). First, stroke survivors learned to manage stroke consequences such as fatigue. Second, they were able to self-manage (parts of) everyday activities (e.g. adapting activities to perform them successfully). The third phase of self-management for stroke survivors involved their attempts to engage in meaningful roles and a meaningful life. The degree to which they experienced self-management was associated with the extent to which they experienced a sense of control. Knowing how to self-manage or co-manage with others also gave the stroke survivors a feeling of being in charge.

Stroke survivors were often not familiar with the term self-management (Chapter 3). Initially, most of the stroke survivors interpreted self-management as 'do-it-yourself'. However, over time stroke survivors' perception of self-management changed.

Aside from individual self-management, stroke survivors expressed later in their recovery process that self-management could also mean managing together with other persons, which we have described as co-management. Co-management means that stroke survivors can ask other people for support or to arrange things for them or that relatives give support or arrange things for the stroke survivor on their own initiative. The way stroke survivors and their spouses reflected on self-management post-stroke differed. Stroke survivors reflected mainly on their own self-management. Even when stroke survivors talked about their spouses, it was about the value of their spouses in regard to performing or arranging activities for them. Alternatively, when the spouses of stroke survivors reflected on self-management, they spoke about the stroke survivors' self-management in the first instance and only about their own self-management thereafter (Chapter 4).

Spouses and allied health professionals indicated different levels of self-management and expressed concerns regarding stroke survivors' abilities to self-manage (Chapters 4 and 5). Professionals talked about big or small self-management. 'Small self-management' referred to individuals who could perform some steps or a whole activity independently, while 'big self-management' referred to stroke survivors' ability to manage and shape their own lives. The professionals' concern was whether stroke survivors had sufficient skills to be fully in charge of their own life, and they were especially worried about the self-management skills of stroke survivors with cognitive problems. Spouses, in turn, also expressed their concerns but differentiated more between self-management and co-management. They indicated that, ultimately, it was often co-management instead of independent self-management that took place. The spouses reported that some stroke survivors needed support on a functional level but could still fulfil their social roles, while other stroke survivors could manage themselves sufficiently during daily activities, but were ultimately not able to be completely in charge of their own life. In the latter cases the spouses were needed to keep the overview, arranging things and taking decisions. According to the professionals and spouses, important factors in relation to self-management were the ability to set goals; take decisions; direct, arrange, and solve problems; and take action. Moreover, the professionals perceived the pre-stroke skills and the recovery phases as other important factors that influenced self-management post-stroke.

Situated doing in everyday activities was important in the development of self-management (Chapters 3 and 6). Performing daily activities provided the stroke survivors with an arena to explore, experience, evaluate, develop and adapt the self-management of their everyday activities, roles and life. They often tested the boundaries of their limitations with trial and error to learn how to manage their activities. Everyday activities gave stroke survivors images about possibilities and disabilities, which helped them negotiate with their inner selves about regaining, adjusting, or stopping meaningful activities and roles or negotiating and interacting with others.

The way the co-management was carried out varied among couples. Interaction and co-management was empowering at some times and conflictual at others (Chapters 3, 4 and 7). When the spouse had negative perceptions of the stroke survivor's abilities, the interaction could even be disabling. Furthermore, several spouses also reported that they realized that providing too much support or taking over could be a pitfall for their partners' development of self-management post-stroke.

Practical and existential self-management support for stroke survivors. Across the trajectory, post-discharge stroke survivors had varying needs for self-management support, ranging from a need for 'practical self-management' in the period immediately after discharge to 'existential self-management' in later periods post-discharge (Chapter 6). When stroke survivors were at home for a reasonable amount of time—about a year, for example—their questions were more related to existential issues, such as their potential to fulfil meaningful roles and live meaningful lives.

Stroke survivors, spouses, and professionals criticized current stroke self-management services. Stroke survivors and spouses both reported that they had missed support post-discharge. Together with the professionals, they reported that stroke self-management programs could best be delivered in stroke survivors' own environment and focus on both stroke survivors and their spouses (Chapters 3, 4, 5). Professionals criticized current programs as being too medical and not flexible enough to provide optimal support of self-management. They mentioned client-centred goal setting as being important for supporting self-management, but some questioned whether their attitude was really client-centred. On one hand, several allied health professionals stressed that, as a professional, one should dare to let go and let clients do things by themselves. On the other hand, some professionals expressed difficulty in doing so. Furthermore, both stroke survivors and spouses expressed that informal support and peers were almost as valuable as professional services.

Interpretation and discussion of the findings

The following section presents the interpretations and discussion of this thesis's main findings. Because the main findings were interrelated and overlapping, this section is structured around five main topics: (1) meaning of self-management; (2) different forms of self-management; (3) processes of self-management: phases and levels; (4) self-management as negotiations; and (5) self-management and the value of everyday activities.

1. Meaning of self-management

An important objective of this thesis was to explore self-management after a stroke. The question 'what is self-management?' can be discussed from different perspectives. The literature presents different meanings of self-management, ranging from a narrow meaning involving managing the symptoms and consequences of a chronic disease to a

broader meaning involving fitting the chronic condition into the client's life.¹ From a psychological perspective, and based on the findings of this thesis, one can question where the 'self' in self-management is located. Together with Koch et al.² we conclude that the role of the 'self' has been sparsely addressed in the literature on self-management and almost excluded when self-management has been discussed. This raises questions such as what this means for the 'self' in self-management interventions and whether the 'self' is sufficiently addressed. The findings of chapter 2 revealed that stroke survivors experienced a disrupted 'self' and ultimately aimed to recapture their 'self'. When we relate these findings to Koch and colleagues'² conclusion that self-management literature hardly addresses the 'self', one may doubt whether stroke survivors are really supported in becoming an expert at the level of 'self'-management or just managing their disease, emotions, and everyday activities. Thompson et al.³ proposed that people who have sustained a life-disrupting injury need to find a new 'I am' in addition to a new 'I can'. To date, however, rehabilitation is still focused on the 'I can' but has paid sparse attention to coaching people in 'who I am' in the face of the consequences of a disease.⁴ For professionals in stroke rehabilitation, the findings of this thesis and these considerations suggest the need to refocus interventions for stroke survivors. Using a broader perspective on self-management interventions, one that goes further than a focus on behavioural change and on patients who are expected to manage the chronic condition may better address patients' needs. Moreover, a focus on the 'self' may also create space for relating existential issues as part of interventions.

When we view the meaning of self-management from a patient's perspective, the findings of chapter 3 have shown that the term self-management was unfamiliar to the participating stroke survivors. This is confirmed by literature that concluded the abstract terminology, with a variety of definitions, confuses many patients.⁵⁻⁸ They do not recognize themselves in the terminology and associate self-management with something new to them.⁵ Initially, many patients associate the word 'self' in self-management with 'do-it-yourself'⁶, as happened also among the participants in our focus group study (Chapter 3) and British stroke survivors identified in a British study.^{9, 10} They connoted self-management with independence in activities, independence from others and independence in decision making.

The findings of chapter 3 raise the question of the considerations for practice to which patients' unfamiliarity with the term self-management may lead. Although the term is used largely by policymakers and health professionals, it highlights a lack of common understanding of what self-management means for patients.⁹ This may suggest that health professionals in stroke rehabilitation should be careful when using the term self-management or when referring to self-management interventions in information leaflets.¹¹ Moreover, when professionals approach their work as client-centred and expect clients to be involved in their own treatment,^{8, 12, 13} the terms they use must be relevant and understandable.

2. Different forms of self-management

From the findings of this thesis, we may conclude that self-management post-stroke should be explained carefully. Chapters 3 and 6 suggest that professionals should explain self-management as a learning process situated in daily life. In the beginning of the trajectory, the focus is more on the practicalities of everyday life and, later, on the existential dimensions of life and stroke survivors' engagement in meaningful roles. Furthermore, the findings in several chapters showed that within self-management post-stroke we can distinguish different forms of management. Based on these findings, professionals may consider elaborating on co-management, the spouse's self-management, and couple- or family management.

Our focus group studies of the stroke survivors and their relatives (Chapters 3 and 4) demonstrated that they often managed together rather than independently. Based on these findings, we recommend that professionals in stroke rehabilitation address **co-management** and explain its implications for both stroke survivors and their relatives. The term co-management is sparsely used in the literature about self-management. Articles addressing co-management describe it as a process between the patient and the physician that is related to the role of the patient in his or her treatment.^{14, 15} However, when talking about co-management with stroke survivors and their relatives, professionals may want to start a conversation about how families may wish to manage and take decisions together that might support equal responsibility for managing daily life. Moreover, the term co-management might prevent an interpretation as 'doing-everything-yourself'.

Furthermore, the findings of chapter 4 suggested that professionals need to acknowledge **spouses' own self-management**, for which the spouses also need time and coaching. Would it not be ideal when spouses are viewed as full participants of stroke self-management programs? Doing so would support them in their own process of emotional and role management and, in addition, help coach them in supporting their partners in self-management and co-management post-stroke.

Another form of self-management identified in the literature is **couple- or family management**, which, for stroke survivors who are living alone, can be seen as management of and within the social network. Using a whole-system or family-centred approach^{7, 16-18} may complement the concept of self-management and would make it possible to address goals for stroke survivors and their spouses as well as 'joint goals'. Moreover, as participating stroke survivors in chapters 3 and 6 reported that their relatives could be overprotective, a family approach could also support the negotiation between the stroke survivor and relatives in regard to trial and error and the development of self-management.

In addition to coaching sessions for stroke survivors and their relatives, the different forms of management post-stroke may also be used to revise professional guidelines to support stroke survivors and their caregivers.^{19, 20}

3. Processes of self-management: phases and levels

The literature describes the process of self-management as a learning process²¹⁻²³ but does not further differentiate it. In our longitudinal study (Chapter 6) we found that the participating stroke survivors went through three interrelated and sequenced phases of self-management (see figure 1). The phase of self-managing stroke consequences was the first phase many participants went through. Subsequently, they went through the phase of self-managing parts or whole activities and, finally, through the phase of self-managing to participate in meaningful roles and engage in a meaningful life.



Figure 1 Phases of self-management post-stroke in relation to experienced functional recovery

The three phases of self-management as identified in chapter 6 raised the question of whether these phases followed a particular sequence. While this seems apparent, the findings showed that although participants might ‘pass’ the first phase, they could return to that phase because self-managing stroke consequences was needed to manage daily activities. Based on literature describing processes of self-management in general,^{24, 25} we conclude that the three phases as described in chapter 6 can fluctuate and vary in importance to patients over time, depending on their life situations. For example, a stroke survivor who is attempting to reorganize everyday life to manage the hyper-sensitivity for visual input post-stroke may simultaneously have to prioritize family and leisure activities and consider the meaning of the different activities.

When we compare our findings with other longitudinal studies that describe recovery phases post-stroke,^{26, 27} a similarity is that the final phases presented in the different studies are about ‘real living’,²⁷ ‘going on with life’²⁶ and ‘engaging in meaningful roles

and life' (chapter 6). A difference between Eilertsen's²⁶ study and our study is that they present the phases as being related to a certain timeframe. For example, in Eilertsen's study, the second phase where stroke survivors focused on activities is presented as taking place 2-6 months post-stroke. We did not relate the phases to a timeframe because we heard too much variation in participants' stories and because the phases fluctuate. We also compared our findings on the three phases with the work of Corbin and Strauss,²⁸ who described medical, role and emotional management as dimensions of self-management. Our first phase of self-managing stroke consequences can be viewed as medical management^{23, 28} and as a way to control the illness.^{24, 29} The second and third phase, self-management of activities and roles and life, may be related to role management.^{23, 28} Emotional management is less explicitly described in our phases, but the stroke survivors and their spouses actually needed it throughout the entire process.⁷ Emotional management is described in more detail in theories on how people react to trauma or crisis.³⁰⁻³² Horowitz³¹, for example, described how after an event people initially experience bewilderment, helplessness, denial and go on with life after each other, and that, finally, the event is integrated in a life narrative. The process is considered as 'working' and has reached completion when the event is no longer at the forefront and when people experience emotional balance and go on with life. As in both the other longitudinal studies^{26, 27} and ours, the last phase of this process is also about going on with life.

Different levels of self-management was another a topic that the participating spouses and allied health professionals in the focus group studies discussed. They talked about levels of self-management mainly from the perspective of independence. Independence is still an important goal of rehabilitation, and professionals working in rehabilitation encourage patients to regain as much independence as possible.⁴ Independence is also a desired initial outcome of self-management for many stroke survivors.^{33, 34} From the perspective of independence, self-management might be viewed as a higher-level goal than co-management. However, patients with chronic illnesses ultimately value autonomy and the ability to live meaningfully with an illness above independence.²⁴ It is more important for them to be in charge of their lives, to re-engage in valued roles, and restore continuity in a meaningful life, than to perform activities independently.³⁵⁻³⁸ Our longitudinal study also identified that participants' beliefs regarding support changed. At a certain moment, they accepted support from others because it helped them to engage in meaningful activities and roles. These considerations suggest that professionals should discuss beliefs about independence with stroke survivors and their spouses, first to understand how their beliefs might affect their reasoning about self-management in general, and second, how their beliefs might affect their reasoning about receiving support from others.

4. Self-management as negotiation

An alternative way to understand the findings of this thesis is to consider that within each phase of self-management, stroke survivors are in ongoing negotiations with different aspects of relevance when they manage themselves. In chapters 6 and 7 we mainly described how the participants negotiated with their inner selves (What is meaningful? What do I want?), their beliefs about support (What kind of support do I want?), and how they negotiated with their spouses. These negotiations can be viewed as part of the decision-making process of self-management.³⁹ People negotiate and make decisions against the background of several aspects, such as assessing the effects of self-management, evaluating their own capacity, perceiving normality, meaningfulness, and experiencing support and access to external resources.³⁹ In this negotiation the different aspects might conflict: for instance, during a birthday party of a grandchild. We use this situation, which we borrow from an example that was described by a participant of the longitudinal study, to reflect on negotiating and decision making in self-management. On one hand, a birthday party is a meaningful activity that might lead to the strong feeling that one wants to go. On the other hand, stroke survivors might be aware that the situation could give too much sensory input that challenges the management of stroke consequences, or that they need too much support from family members to travel to the birthday party, which might challenge their ideas of normality and independence. Depending on their awareness of the situation's challenges, the possible self-management strategies, and the negotiation between the different aspects, a stroke survivor will consider different aspects and prioritize certain activities over others. One day, this may result in the decision to visit a birthday party and to take rest before or afterwards (because they feel it is possible and normal to do so), while on other days the decision might be not to go to the birthday party because they have other priorities.

5. Self-management and the value of everyday activities

The findings from the studies presented in chapters 6 and 7 highlight how the doing of everyday activities provided the participants with different experiences in relation to their sense of self-management and being in charge. This finding relates to what the literature often refers to as a perceived success or failure in certain activities.⁴⁰ However, from the findings of the studies in chapters 6 and 7, doing can be viewed as more than performing activities and experiencing mastery. Doing also gave the participating stroke survivors an impression about their sense of agency, the meaning of the everyday activity and their sense of self in the context of the post-stroke situation, which confirms ideas presented in other literature about the value of daily activities.⁴¹⁻⁴³ Furthermore, the literature described how everyday activities helped stroke survivors recapture and reclaim feelings of belonging, enjoyment, autonomy and independence.^{37,44}

A question worth considering is why daily activities, or more simply, just 'doing', can have value for the development of self-management. The findings from the studies in

chapters 6 and 7 showed how experiences received through doing were important for the development of self-management and could be even stronger than the insights participants received through verbal or written information. From the perspective that 'knowing' does not mean that people can change and self-manage,⁴⁵ our research findings suggest that doing can be viewed as a way to receive additional experiences about one's own capacities and limitations with regard to the self-management of activities.

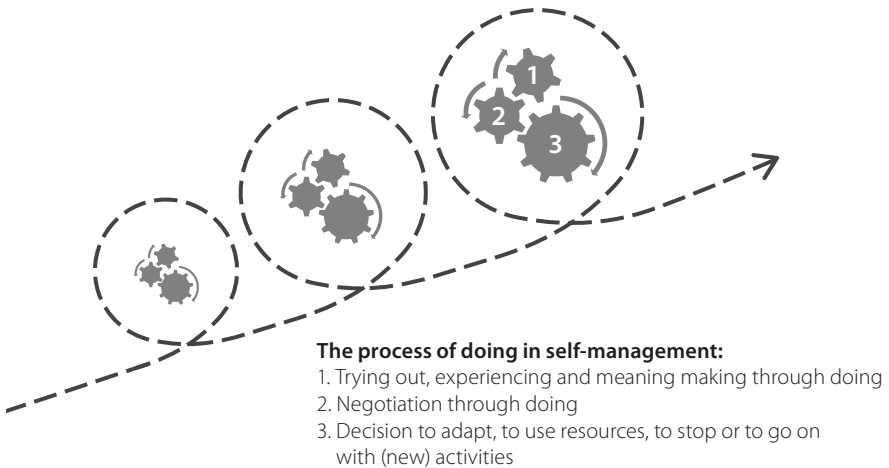


Figure 2 The process of doing in relation to self-management

In the context of self-management, doing may give stroke survivors the arena to develop their self-management: they can try out, experience and make meaning through doing; negotiate through doing; and decide to adapt activities, use resources, stop or go on with (new) activities when managing.³⁷ Figure 2 depicts this process of doing in relation to development. Through doing, stroke survivors can explore, consider occupational challenges, and re-evaluate the personal meaning of everyday activities.^{37, 46, 47} Doing helps people to give meaning to certain situations by making links between meaning and action.^{48, 49} Experiences through doing can give stroke survivors new possibilities and may help them to negotiate with their inner selves or about other aspects and make their own decisions.⁴⁴ Doing in this context gives them the optimal situation for what David Krech⁵⁰ calls 'perfink', meaning that people perceive, feel and think simultaneously when they act.

Furthermore, doing might also provide the relatives of stroke survivors with important impressions. Through doing, stroke survivors may show others how they successfully self-manage in certain activities and situations, which can help relatives adjust their expectations in regard to their partners' self-management skills. This can support dialogue

and negotiation between stroke survivors and their relatives about abilities, limitations, and responsibilities in activities and roles.

The value of engagement in everyday activities may inspire health professionals to use the 'doing and perinking' in programs to support the development of stroke survivors' self-management and to create dialogue between the stroke survivor and relatives about self- and co-management. As occupational therapists are experts in enabling people to participate in everyday activities, they may be involved in the development of such programs.⁵¹

Methodological considerations

This thesis aimed to explore self-management post-stroke from the perspectives of stroke survivors, their spouses, and health professionals. The studies in this thesis employed a variety of samples and qualitative designs. We consider this to be a strength because it made possible, using different methods, the exploration of personal experiences and reflections about the way people made sense of their self-management in everyday life. This has increased the credibility and confirmability of the findings within this thesis.⁵²⁻⁵⁵ Furthermore, these qualitative studies have yielded a wealth of findings that could not be easily collected through quantitative studies. The findings are not generalizable as is the case with quantitative studies; however, 'generalization through the recognition of patterns'⁵⁶ might be possible. The findings and conclusion may be recognized by professionals and may be applied to other stroke survivors or contexts. In addition to discussing the methods in the previous chapters, we would like to reflect on some other methodological issues.

Participants and designs: providers of high-quality data?

The success of the different studies depended on, among other factors, generating rich data. In this regard, we consider the participants in all studies to be appropriate candidates. The sixteen community-living stroke survivors and thirty-three spouses all had long-term experience, respectively, with a life post-stroke or with living with a partner post-stroke. Furthermore, the allied health professionals had long-term experiences in treating and coaching stroke survivors in different settings (e.g. clinical settings and community settings). However, as stroke survivors, spouses and professionals in our studies reported that 'real' self-management happens at home, future studies could also be conducted among health professionals working in the community to capture their experiences and reflections about self-management post-stroke in the community. Stroke survivors with severe cognitive impairments and communication disorders were not represented in neither the focus groups nor the sample of the longitudinal qualitative study. Furthermore, hearing more about their experiences could have added extra insight regarding the way they managed with or without the support of others. Nevertheless, their 'voice' was partly

expressed in the focus groups with the spouses, as this sample did represent several spouses of stroke survivors with cognitive and communication problems.

In chapter 2 we described our thematic synthesis of qualitative studies to gain a better understanding of stroke survivors' perspectives on the impact of the stroke on their roles and self.⁵⁷ The thematic synthesis is an example of a relatively new review methodology that gains importance through building evidence using the perspectives of patients.⁵⁸ While a summary of the literature would have been possible,⁵⁹ this method made it possible for us to undertake a meta-analysis and synthesis based on the different findings from primary qualitative studies.

In chapters 6 and 7 the designs of the longitudinal and narrative studies grounded them in daily life and supported exploring stroke survivors' self-management in their own context. Narratives in themselves offered us a method for addressing existential issues that frequently accompany people's illness.⁶⁰ Moreover, the method of narrative-in-action of chapter 7 enriched our study with narrative data regarding everyday situations. As this method entailed the observation of participants' narratives-in-action,⁴⁸ we were provided with situated real-time data and could really focus on the way that participants, sometimes together with their spouses, self- and co-managed in everyday life.

The challenge of data generation

For chapters 3, 4, and 5 we used focus groups, each with different stakeholders, which made it possible to explore opinions on self-management post-stroke from three perspectives. The group dynamic, the explicit invitation to react to each other, and the use of visual material (e.g. photographs) produced lively discussion among the participants.⁶¹ For the focus group studies, we initially had considered inviting stroke survivors and their spouses to the same focus group to hear views on self-management post-stroke from both perspectives. However, eventually we decided to interview them separately, as the presence of a stroke survivor or spouse could constrain the way participants talked about their own feelings or about the other person's emotions. Retrospectively, we believe this was a good choice. In particular, the spouses often began their reflections by saying, 'Well... here, without my partner, I can say that...!', meaning that they might have felt more free to talk about their own experiences. Our choice to interview stroke survivors and their spouses in separate groups was confirmed by a recent paper reporting a focus group study about self-management post-stroke with stroke survivors and carers. They discussed how including carers and stroke survivors in the same focus group might have influenced the stroke survivors.⁹ On the other hand, they reported that without their inclusion, the views of stroke survivors with communication problems would have been difficult to elicit.

With respect to the capacities of stroke survivors we adapted the interview length and topics, organized two relatively shorter meetings instead of one longer meeting, and used photographs to support our questions. We held only one meeting with the different groups of spouses and allied health professionals.

A strength of the longitudinal and narrative studies was the extended data generation period, which provided the participants with the ability to reflect on their own process of self-management post-stroke.⁶² The longitudinal design enhanced rapport during repeated visits and limited the risk of recall bias. We could prospectively follow the stroke survivors as their post-stroke process changed and ask them to reflect on changes since the last visit. Although inevitable with regard to a longitudinal qualitative design, a possible limitation of our study is the risk that the researchers might have influenced the participants and spouses during their repeated encounters. However, the participants appeared pleased with the researchers' visits and continued providing extended and personal stories about their life post-stroke and the way they tried to self-manage.

In the longitudinal qualitative study, we have used both individual interviews with a conversational style⁶³ and participant observations. Sometimes we adapted our data generation to include the spouse in an interview or observation: for example, when they came home after being away and joined an activity or interview. Separate interviews with the partner might have given new perspectives on stroke survivors' self-management, but this was not done in the present study.

For the narrative study (Chapter 7), we selected two of the ten participants included in the longitudinal qualitative study. We considered which participants could provide rich data.⁵² For the narrative study only observational data was used to analyse the narratives-in-action of the two stroke survivors and their spouses. Narrative analysis is useful to study how meaning is enacted and constructed in everyday life.⁴⁹ The method of narrative-in-action is rather new in the field of qualitative research. However, together with Frank and Polkinghorne,⁶⁴ we believe that observational approaches have great potential to unravel complex processes of participants in daily life⁶⁵ and help researchers and practitioners to understand what people do and why.

Position of the researcher

For both the focus group studies and the longitudinal and narrative studies, we took careful preparations to enhance data generation. Besides developing interview guides and preparing formats for field notes, it was also important to reflect on the researcher's positioning.^{52, 61, 63, 65, 66} In qualitative research a researcher is, per definition, part of the context in which data is generated, and especially when using participant observations as a method for data generation, the researcher becomes a part of what happens and what is being studied.^{67,68} To be aware of this reality, reflexivity⁶⁹ was important throughout the whole project. The main researcher and author of this thesis, who is around 50 years of age with a variety of lived experiences, has reflected on his pre-understanding about stroke and self-management as well as his background as an occupational therapist.

Being an occupational therapist might have influenced the data generation and interpretations in a variety of ways. On one hand, being an occupational therapist with knowledge of everyday activities might have enhanced data generation: for example,

when participants talked about the meaning of mundane activities such as playing cards, a regular trip to the supermarket, or self-care activities with or without help. On the other hand, having an occupational therapy background might have influenced interpretation, as there might have been more attention paid to everyday activities than other factors.

Establishing trustworthiness

Throughout the different qualitative studies, we aimed to enhance the trustworthiness in different ways.^{53, 54} Although there is a variety of methods to conduct thematic synthesis, we have tried to enhance the quality of the synthesis by using well-established applied methods for reviewing, appraisal, analysis and synthesis of qualitative studies.^{57, 70, 71} We conducted analytic procedures for the thematic synthesis as well as all the focus group interviews with other researchers (co-authors); all authors discussed the preliminary findings.

Regarding the trustworthiness of the longitudinal and narrative studies, the quality of the procedures was established through ongoing conversations with the primary supervisor of the longitudinal and narrative studies, an experienced researcher with considerable knowledge of the chosen method. Moreover, cooperating with the second researcher of the longitudinal and narrative studies and holding regular meetings with the other supervisors of this thesis created in-depth discussions and helped refine interpretations. In line with a constructivist paradigm, we consider the findings of the studies not as 'the truth' but as one of several possible interpretations.^{65, 72, 73} The empirical data of the longitudinal qualitative and narrative-in-action studies should be viewed as co-constructions between the participants and the researchers and the storied outcomes are the researchers' constructions and interpretations.^{66, 72} The rich descriptions of the research situation and its dynamics, along with the theoretical resources outlined, provides information for the readers to judge the findings' plausibility.^{64, 74}

Conclusions and implications

The conducted studies of this thesis provided us with an in-depth understanding of self-management post-stroke from the perspectives of stroke survivors, spouses and allied health professionals. As self-management support interventions are usually complex interventions that should be tailored to the individual,^{7, 22, 75} a next step towards the development of a stroke self-management program would be a further intervention mapping.⁷⁶ Although current stroke self-management programs apply a variety of important intervention components such as goal setting, problem solving, action and coping planning, structured information, follow up and professional support,⁷⁷⁻⁸² some additional suggestions for practice can be derived from this thesis.

Invite spouses as full participants in stroke self-management programs

The findings of this thesis confirm the value of including spouses in stroke self-management programs.^{81, 82} Inviting them as full participants will

- support spouses in developing caregiving skills and feeling confident when supporting stroke survivors' self-management;
- encourage spouses to be involved in goalsetting and come to a consensus about realistic targets in the short and long term⁷;
- support the negotiation between partners and spouses about self-management and co-management post-stroke; and
- support spouses in their own emotional and role management.

Separate interventions for self-management of spouses of stroke survivors need to be developed

Beside the support of their partner post-stroke, spouses also need to be supported in their own self-management.

Pay attention to the 'self' in self-management programs

Beside general principles of self-management, professionals are advised also to pay attention to 'SELF'-management.

Be careful and transparent when explaining self-management

Prevent the assumption that self-management is understood as 'doing-everything-yourself'. This can be done by addressing co-management, couple and family management or management within the social network.

Distinguish three phases of self-management post-stroke

The findings of this thesis suggest three phases of stroke survivors' self-management: self-managing stroke consequences, self-managing daily activities, and self-managing to engage in meaningful roles and have a meaningful life. These phases can be used to tailor interventions to individuals and their changing needs over the trajectory of recovery post-stroke.

A gradual shift from medical management towards role management interventions

An ideal stroke-self-management program has a mix of medical management, role management and emotional management interventions.^{23, 28} However, when looking at the phases in the development of self-management post-stroke, a gradual shift from medical management interventions towards role management interventions is recommended (see figure 3).

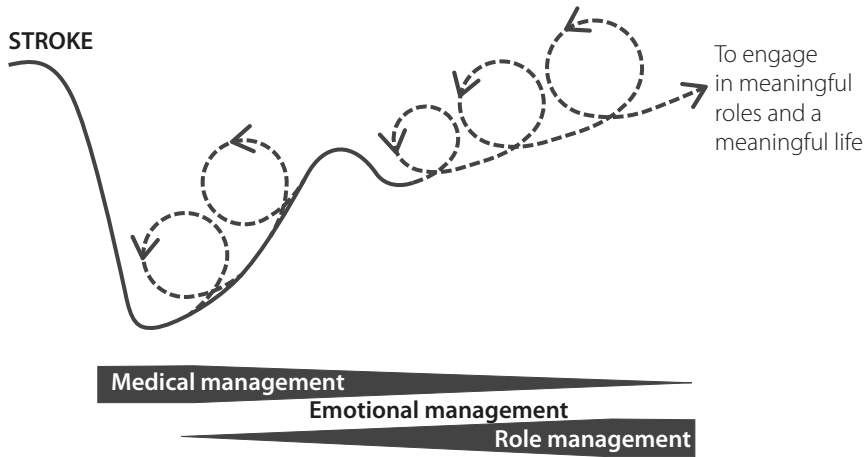


Figure 3 The gradual shift from medical management towards role management interventions

Depending on the phase and needs of the stroke survivor and relatives, professionals should adapt and refocus interventions.⁸³ At the beginning there is a need for medical management interventions to control the disease.^{23, 24, 29} Gradually more attention to role management interventions is recommended to support on-going activity and role needs, recourse activation and the help of others. In addition to medical and role management, emotional management interventions are recommended to address the psychosocial challenges and needs of stroke survivors and the close relatives in all phases.^{7, 84}

Home based stroke self-management programs in the short and long term

Although literature recommends to prepare stroke survivors and their relatives on self-management already in a clinical rehabilitation setting,¹⁹ the findings of our studies suggest that professionals develop and deliver self-management programs in stroke survivors' homes. Furthermore, we recommend considering two types of stroke self-management programs:

First, a 'practical' self-management program that stroke rehabilitation teams or stroke teams in primary care deliver. This program should focus on self-management of stroke consequences and everyday activities that helps stroke survivors re-integrate in society, beside some general self-management issues such as managing health services and activating resources.^{23, 24}

Secondly, an 'existential' self-management program for the long term to promote stroke survivors' and their relatives' psychosocial well-being.^{7, 84} The interventions should focus more on existential issues, the negotiation with their inner self in relation to the

values and meaning in their life post-stroke, the adoption or adjustment of meaningful societal roles, and a rebalancing of spousal roles and relationships.^{39, 84}

Use the value of everyday activities

This thesis also suggests that health professionals should use or at least address everyday activities in their interventions. The doing provides stroke survivors trial-and-error learning practice in the context of real life. Occupational therapists may be involved in this regard because they are known as experts in enabling everyday activities.⁵¹

The use of peer support

Together with other studies,⁸⁵⁻⁸⁸ the findings of this thesis suggest the use of peer support as part of stroke self-management programs. Peers can visit stroke survivors and their relatives at home and inform, empower and support them in understanding the challenges of self- and co-management.^{34, 89}

Implications for education

The findings of this thesis and their practical implications also have consequences for education and postgraduate courses. Historically, stroke rehabilitation focused on clinical rehabilitation but retained a biomedical orientation. Beside clinical rehabilitation, more attention in education should be paid on self-management interventions for stroke survivors and their relatives in the community. Moreover, the new perspectives on health as 'the ability to adapt and to self-manage in the face of social, physical and emotional challenges',⁹⁰ as well as an adoption of behavioural change models to support self-management post-stroke, can be used to educate professionals.

Implication for research

Future research is needed to study the complexity of the self-management process post-stroke. When possible, stroke survivors' relatives should be incorporated in these studies. Several topics need further attention.

Measuring

- An investigation is needed regarding which self-management outcomes all stakeholders consider important and can be applied in patients' everyday lives;
- The shifting understanding of health⁹⁰ requires a change in the way we measure. From a focus on measuring disability and recovery, measurements that measure patients' abilities and strength to self-manage are needed;
- In a mixed method and longitudinal design, qualitative and quantitative data can be linked to measure and further understand self-management in the long term; and

- As 'real' self-management takes place when stroke survivors are at home, we suggest future studies among health professionals working in the community regarding the concept of self-management and how it is organized.

Self-management programs

- Community health professionals should develop a vision of self-management support and, subsequently, a community-based self-management program for stroke survivors and their relatives;
- Professionals should develop programs to support stroke survivors' existential self-management on the longer-term;
- To address the needs of stroke survivors with severe cognitive and communication problems and their relatives in relation to self-management, professionals should develop self-management interventions for this group. The narrative-in-action might be useful to study their self-management capacities in everyday life.

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Chapter 9

Summary

Around 45.000 people suffer a stroke each year in the Netherlands. Among these, many people may well recover over time or retain relatively few disabilities. Some stroke survivors, however, must deal with permanent limitations in everyday activities and restrictions in participation due to sensory-motor, cognitive and emotional problems. Besides, stroke also affects the stroke survivor's spouse or other family members, who often take on the additional role of caregiver and for whom the new situation frequently causes emotional and physical burdens. To support stroke survivors and their spouses to better care for themselves and to live a meaningful life post-stroke, self-management is recognized as an important concept in stroke rehabilitation.

Although self-management principles have been applied in several stroke self-management programs, the viewpoints and experiences of the stroke survivors and their spouses on self-management post-stroke are rarely described. Moreover, the perspectives and readiness of health professionals in stroke rehabilitation should also be explored before a stroke self-management program is developed and implemented. The general objective of this thesis was to improve the understanding of self-management of stroke survivors from the perspectives of different stakeholders, namely the stroke survivors, their spouses and health professionals. Furthermore, the objective was to explore how stroke survivors and spouses self-manage post-discharge.

Chapter 1 provided an introduction of the topics under research. The chapter began with a brief overview of the consequences of a stroke for stroke survivors and their relatives. Subsequently, we introduced the concept of self-management and, for the purpose of this thesis, described self-management as an 'individual's ability, in conjunction with family, community and the appropriate health-care professionals to manage the symptoms, treatment, physical, psychosocial, cultural and spiritual consequences and inherent lifestyle changes required for living with a chronic disease'. Self-management is a multifaceted process consisting of three key domains: medical management, role or behavioural management and emotional management. Several programs in stroke rehabilitation have applied self-management principles in stroke interventions. Most of these programs focus on the initial period post-stroke, sometimes delivered as a clinical program and other times post-discharge. The chapter concluded that existing literature rarely describes the perspectives of the stroke survivors, their spouses and health professionals on self-management post-stroke. To explore these perspectives, this thesis addressed the following research questions:

- What is the impact of stroke on stroke survivors' roles and self?
- How do stroke survivors, spouses and health professionals experience and reflect on self-management post-stroke?
- How does self-management post-stroke evolve over time in everyday life?
- How do stroke survivors and spouses manage themselves post-discharge?

Chapter 2 presented a thematic synthesis focusing on stroke survivors' views on the impact of stroke on their roles and 'self'. A thematic analysis and synthesis of 33 qualitative studies provided insights into the post-stroke experience and identified three overarching themes: 1) Managing discontinuity is a struggle; 2) Regaining roles: to continue or adapt?; and 3) Context influences management of roles and 'self'. Regaining or developing valued roles and 'self' was an ongoing struggle and discontinuity and uncertainty were central to the adjustment process after stroke. In the process to regain their roles, stroke survivors constantly considered whether they could continue their pre-stroke roles or whether they should adapt or stop their roles. The context of stroke survivors influenced their management of roles and 'self'. Immediately post-stroke, survivors were often passive and took a 'wait-and-see' attitude. Gradually they became more active and increasingly took charge in the process of regaining roles. In this process, stroke survivors sometimes perceived family and health-care providers as paternalistic and a barrier to their becoming active and regaining autonomy while seeing them at other times as supportive in becoming more involved in everyday life and managing themselves. Regarding rehabilitation goals, stroke survivors experienced a gap between their own goals and those of health-care professionals. Stroke survivors ultimately focused more on meeting their psychosocial needs, regaining roles, making the transition to home life and managing practicalities at home, whereas health professionals focused more on biomedical goals.

Chapter 3 described a focus group study with 16 community-living stroke survivors who reflected on the concept of self-management, their readiness to manage themselves and their needs regarding self-management support. The participants initially had difficulties with the term 'self-management'. Most of them interpreted self-management as 'do-it-yourself'. When they reflected on their process of self-management, they described their self-management as a complex, long-term and personal learning process. In this process, they learned how to manage their activities step-by-step with trial and error. Aside from individual self-management, the stroke survivors also mentioned co-management with their relatives: Relatives could provide support, but they also limited the development of participants' self-management skills. Post-discharge, the participants were not ready to self-manage. They would have appreciated additional practical, psychological and emotional support.

Chapter 4 presented the findings of four focus group interviews with 33 spouses of stroke survivors about their own self-management and self-management support of their partner post-stroke and of themselves. Post-stroke, they experienced changing relationships and challenges to be both caregiver and partner, which caused feelings of burden, loneliness, sadness and guilt. To manage themselves, many spouses created time for themselves. They reported they often felt lost after their partner was discharged home and they reported learning by trial and error how to coach their partners post-stroke. The

participating spouses would have appreciated additional knowledge, skills and tools for coaching their partners post-stroke, beside more attention for their own self-management. Most spouses connoted self-management with co-management because they perceived their partners were not able to manage themselves completely post-stroke. Besides formal support, many spouses found informal support helpful and they suggested that peers could play a role in post-stroke rehabilitation.

Chapter 5 reported allied health-care professionals' perceptions and beliefs regarding the self-management of stroke survivors and stroke self-management interventions. We conducted four focus group interviews with 27 professionals. The allied health-care professionals nominated different levels of post-stroke self-management, depending on factors such as stroke survivors' pre-stroke skills, post-stroke recovery-phases and cognitive abilities. They used the term 'small self-management' when they referred to an individual who could independently perform some steps or a whole activity, while 'big self-management' meant for them that stroke survivors could shape their own lives. Regarding stroke survivors' capacities to self-manage, these health professionals were hesitant, doubting in particular whether stroke survivors with cognitive disabilities had sufficient skills to self-manage. Several questioned whether their own attitudes and skills were really supportive for the stroke survivors' self-management. While a few participants stressed that one should dare to let go and let clients try things by themselves, some expressed difficulties in doing so. The allied health professionals criticised stroke services as still being too medically oriented and not flexible enough; they recommended that self-management programs should focus both on clients and caregivers and be delivered at peoples' homes.

Chapter 6 described a longitudinal qualitative study on stroke survivors' self-management in daily life post-discharge and how self-management evolved over time. We conducted participant observations and interviews of ten stroke survivors at their homes at 3, 6, 9, 15 and 21 months post-discharge. 'Situated doing' was central in stroke survivors' development of self-management. Doing everyday activities enabled the stroke survivors to explore, experience, evaluate, develop and adapt their self-management strategies. Along with the development of self-management strategies, they simultaneously developed a sense of being in charge of their everyday activities and daily life. The degree to which they experienced self-management was associated with the extent to which they experienced a sense of being in charge. Over time, however, the meaning of self-management and being in charge changed. From the opinion that self-management was 'do-it-yourself, without any help if possible', the meaning shifted towards 'self-managing and being in charge with the help of others if necessary'. Regarding the process of self-management, the participants gradually went through three processes: a) self-management and being in charge of stroke consequences, b) self-managing at the level of everyday

activities and finally c) managing meaningful roles and a valuable life post-stroke. Self-management and taking charge developed in interaction with people in the environment—the stroke survivors sometimes experienced their spouses' influence as empowering and at other times as constraining.

Chapter 7 focused on how stroke survivors acted as role managers and how they interacted with their partners in the context of self-managing everyday activities. We used the data of the participant observations of two participants in the longitudinal qualitative study and focused on narratives in action. Self-management and role management were situated in everyday activities. Daily activities gave the stroke survivors and their spouses insight into stroke survivors' capacities in daily situations. For the participants, these everyday activities were an arena where they negotiated and co-constructed role management and a meaningful life with others. In some situations this was empowering; in other situations, however, it created conflict, particularly when a partner had negative perceptions of the stroke survivor's capabilities. Daily activities had additional value for both partners and could help them to negotiate about self-management, role management and co-management to develop a meaningful life post-stroke.

Finally, **Chapter 8** provided an overview and interpretation of the main findings, followed by methodological considerations along with implications for practice and future research. Several recommendations can be made:

- Spouses should be viewed as full participants in stroke self-management programs in addition to the stroke survivors;
- Separate interventions for self-management of spouses of stroke survivors need to be developed;
- Attention should be paid to the 'self' in self-management programs;
- Professionals should be careful about explaining and applying self-management interventions. Self-management is not 'do-it-yourself'; rather, co-management, couple and family management should also be aspects in self-management interventions;
- Self-management programs should address the practical (doing everyday activities) as well as existential issues (living a meaningful life post-stroke);
- The process of self-management post-stroke can be differentiated into three phases: self-managing stroke consequences, self-managing activities and self-managing to engage in meaningful roles and a meaningful life;
- Stroke self-management programs should have a mix of medical, role and emotional management interventions. Depending on the phase and needs of the stroke survivor and the relatives, the focus of the interventions should gradually shift from medical management interventions towards role management interventions later in the process post-stroke;

- Health professionals should use the value of daily activities as an arena to develop self-management competencies; occupational therapists can give advice about the use of everyday activities in interventions;
- At least two types of stroke self-management programs should be delivered at stroke survivors' homes. In the first period post-discharge, the interventions should focus on development of stroke survivors' self-management of everyday activities and reintegration into society. The second type, recommended for stroke survivors who are at home for a longer time, should focus more on existential issues and adjustment of meaningful societal roles.

The findings of this thesis also suggested education and post-graduate courses for health care students or professionals to pay more attention to rehabilitation and support of self-management of stroke survivors and their relatives in the community. Moreover, shifting from a biomedical focus towards the new perspectives on health as 'the ability to adapt and to self-manage' as well as adopting behavioural change models to support self-management post-stroke can be useful in educating professionals.

Future research is needed to study the complexity of the process of self-management post-stroke and, when applicable, stroke survivors' relatives and/or caregivers should also be incorporated in these studies. Several topics need further attention:

- which self-management outcomes are considered important and appropriate by all stakeholders and can be applied in patients' everyday lives;
- a change in the way we measure, with a shift in the focus of measuring disability towards measuring the abilities and strength of a patient to self-manage;
- measuring and further understanding self-management in the longer term would be benefited by a mixed-method and longitudinal design where qualitative and quantitative data can be linked;
- how health professionals working in the community view the concept of self-management and how stroke self-management interventions are organized;
- developing a vision of self-management support in the community and subsequently developing a community-based self-management program for stroke survivors and their relatives;
- developing programs to support stroke survivors' existential self-management in the longer term; and
- further addressing the needs of stroke survivors with severe cognitive and communication problems and their relatives, a group for whom special attention is needed to research and develop self-management interventions.

Studies on these topics would contribute to the further development of self-management interventions that would address the needs of stroke survivors and their relatives to manage themselves and find meaning in life in the longer term post-stroke.



Nederlandse Samenvatting

Dankwoord

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Nederlandse Samenvatting

In Nederland krijgen ieder jaar ongeveer 45.000 mensen een beroerte, ook wel CVA (Cerebro Vasculair Accident) genoemd. Veel mensen herstellen goed of hebben relatief weinig restverschijnselen. Sommige CVA-getroffenen ondervinden echter permanente beperkingen in dagelijkse activiteiten en participatie door sensomotorische, cognitieve en/of emotionele problemen. Voor deze groep heeft een beroerte ook gevolgen voor de partner of andere naasten. Zij krijgen vaak een aanvullende rol als mantelzorger, en de nieuwe situatie leidt regelmatig tot emotionele en fysieke overbelasting. Zelfmanagement wordt gezien als een belangrijk concept in de CVA-revalidatie om CVA-getroffenen en hun partners te ondersteunen in een betere zorg voor zichzelf en een betekenisvol leven na de beroerte.

Ondanks dat zelfmanagement principes in verschillende programma's worden toegepast, zijn de meningen en ervaringen van de CVA-getroffenen zelf en hun partners over zelfmanagement na een beroerte nauwelijks beschreven. Willen we effectieve zelfmanagement programma's voor mensen met een beroerte ontwikkelen, dan is het van belang en logisch om de opvattingen van CVA-getroffenen en hun partners te onderzoeken. De belangrijkste doelstelling van dit proefschrift was daarom om inzicht te krijgen in het zelfmanagement van mensen na een beroerte: wat houdt CVA-getroffenen en hun partners bezig? Wat zijn hun ervaringen ten aanzien van zelfmanagement na een beroerte? Wat zijn hun wensen en behoeften? En hoe managen CVA-getroffenen en hun partners zichzelf na ontslag naar huis? Daarnaast wilden we ook weten hoe de verschillende professionals in de CVA-revalidatie aankijken tegen het concept zelfmanagement en op welke manier dat nu aan bod komt in de revalidatie. Vanuit deze kennis kunnen aanbevelingen geformuleerd worden voor het ondersteunen van deze kwetsbare groep.

Hoofdstuk 1 geeft een introductie op het thema van het onderzoek. Het hoofdstuk begint met een beschrijving van de gevolgen van een beroerte voor de CVA-getroffene en de naasten. Vervolgens wordt het concept zelfmanagement beschreven. Voor dit proefschrift wordt zelfmanagement gedefinieerd als 'de individuele mogelijkheid om, eventueel samen met de familie, de naasten en professionals, de symptomen, behandeling, fysieke, psychosociale, culturele en spirituele consequenties en bijbehorende aanpassingen in leefstijl te managen om te kunnen leven met een chronische aandoening'. Zelfmanagement wordt onderverdeeld in medisch management, rolmanagement en emotioneel management. Verschillende programma's in de CVA-revalidatie gebruiken principes van zelfmanagement. De meeste programma's zijn gericht op de eerste fase na een beroerte en worden zowel aangeboden als klinisch of als poliklinisch programma. De introductie op dit proefschrift eindigt met de conclusie dat de opvattingen van de CVA-getroffenen, hun partners en de professionals in de CVA-revalidatie op zelfmanagement na een beroerte nauwelijks zijn beschreven in de literatuur. Daarom zijn de volgende

onderzoeksvragen opgesteld:

- Wat is de impact van een CVA op de rollen en het 'zelf' van een CVA-getroffene?
- Hoe ervaren CVA-getroffenen, partners en professionals het zelfmanagement na een CVA en hoe reflecteren zij hierop?
- Hoe verloopt de ontwikkeling van het zelfmanagement na een CVA in het dagelijks leven?
- Hoe managen CVA-getroffenen en hun partners hun leven na ontslag van de CVA-getroffene naar huis?

Hoofdstuk 2 presenteert een thematische synthese van de literatuur over de impact van een beroerte op de rollen en het 'zelf' vanuit het perspectief van de CVA-getroffene. De analyse en thematische synthese van 33 kwalitatieve studies geven inzichten in de ervaringen van CVA-getroffenen en zijn onderverdeeld in drie thema's: 1) Het managen van discontinuïteit is een worsteling; 2) Het herwinnen van rollen: een kwestie van doorgaan of aanpassen?; en 3) De omgeving beïnvloedt het managen van rollen en het 'zelf'. Het terugwinnen of ontwikkelen van waardevolle rollen en het 'zelf' was een continue worsteling waarbij discontinuïteit en onzekerheid belangrijke ervaringen waren in het aanpassingsproces van de CVA-getroffenen. Tijdens dit proces overwogen CVA-getroffenen constant of men rollen die men vervulde voor de beroerte kon blijven vervullen, of moesten aanpassen of misschien moesten opgeven. De omgeving van de CVA-getroffene speelde een rol in het managen van de rollen en het 'zelf'. Onmiddellijk na de beroerte waren CVA-getroffenen passief en namen zij een afwachtende houding aan. Gaandeweg werd men echter actiever en nam men zelf opnieuw regie in het oppakken en het terugwinnen van rollen. Tijdens dit proces ervoeren de CVA-getroffenen dat de familie en gezondheidszorg-professionals soms paternalistisch en beperkend waren in het oppakken van autonomie, terwijl men hen aan de andere kant ervoerde als ondersteunend en betrokken bij het managen van het dagelijks leven. Ten aanzien van de revalidatiedoelen ervoeren CVA-getroffenen een verschil in de eigen doelstellingen en die van de professionals. CVA-getroffenen waren uiteindelijk meer gericht op de psychosociale behoeften zoals het terugwinnen van de rollen, de overgang naar huis en het managen van de praktische zaken, terwijl de doelen van de professionals meer gericht waren op biomedische herstel.

In **hoofdstuk 3** beschrijven wij een focusgroep studie met 16 thuiswonende CVA-getroffenen die reflecteerden op het concept zelfmanagement, de vraag of zij voorbereid waren om zichzelf te managen en de behoefte aan ondersteuning. In eerste instantie hadden de deelnemers moeite met de term 'zelfmanagement'. Het merendeel interpreteerde dit als 'alles zelf doen'. Toen men vervolgens reflecteerde op het proces, gaven de deelnemers aan dat zelfmanagement na een beroerte een complex, langdurig en persoonlijk proces was. De deelnemende CVA-getroffenen leerden zichzelf stap voor stap te managen door trial en error. Naast zelfmanagement hadden de deelnemers het ook over 'samen

managen' of te wel co-management met hun naasten. De kanttekening die de deelnemers gaven was dat de naasten enerzijds ondersteuning konden bieden, maar anderzijds ook wel eens belemmerend konden zijn in het uitvoeren van activiteiten of het oppakken van eigen rollen. Na ontslag naar huis voelden de meeste deelnemers zich onvoldoende voorbereid om zichzelf te managen. Eenmaal thuis had men graag aanvullende praktische, psychologische en emotionele ondersteuning ontvangen.

In **hoofdstuk 4** zijn de resultaten beschreven van vier focusgroep interviews met in totaal 33 partners van CVA-getroffenen over het zelfmanagement van de partners en de ondersteuning die de CVA-getroffenen en de partners hebben gekregen. Na de beroerte ervaren de partners van CVA-getroffenen een veranderde relatie, met als uitdaging om naast partner ook mantelzorger te zijn. Dit veroorzaakte overbelasting, gevoelens van eenzaamheid, verdriet en schuldgevoelens. Om zichzelf te managen creëerden veel partners tijd voor zichzelf. Er werd aangegeven dat men zich vaak verloren voelde nadat hun partner weer thuis was gekomen na het CVA. Door vallen en opstaan had men geleerd om de CVA-getroffene te kunnen begeleiden. De deelnemende partners hadden graag meer kennis en vaardigheden gehad om de partner met een beroerte te kunnen begeleiden. Daarnaast gaven de deelnemers aan dat men ook meer aandacht voor het eigen zelfmanagement had willen hebben. De meeste partners relateerden zelfmanagement met 'samen-managen' omdat zij zagen dat hun partner met een beroerte zichzelf niet volledig kon managen na een beroerte. Naast formele zorg, gaven de partners aan dat informele zorg ook nuttig was. Men gaf de suggestie dat lotgenoten een rol zouden kunnen spelen in het revalidatie proces na een beroerte.

Hoofdstuk 5 rapporteert over de opvattingen en overtuigingen van paramedici over zelfmanagement van CVA-getroffenen en CVA-zelfmanagement interventies. Voor deze studie zijn 4 focusgroep interviews uitgevoerd met in totaal 27 professionals. De paramedici spraken over verschillende niveaus van zelfmanagement, afhankelijk van bijvoorbeeld de vaardigheden van de persoon voor de beroerte, de fase van herstel na de beroerte en de cognitieve mogelijkheden. Zij gebruikten de term 'klein zelfmanagement' voor iemand die enkele deelhandelingen van een activiteit kon uitvoeren, en over 'groot zelfmanagement' wanneer CVA-getroffenen het eigen leven weer vorm konden geven. De paramedici reageerden terughoudend ten aanzien van de capaciteiten van CVA-getroffenen om zichzelf te managen. Zij twijfelden vooral over de vraag of dit voor CVA-getroffenen met cognitieve beperkingen wel mogelijk was. Diverse paramedici vroegen zich af of hun eigen houding en vaardigheden wel voldoende waren om CVA-getroffenen goed te kunnen begeleiden in het zelfmanagement. Sommige deelnemers gaven aan dat je ook moest durven 'loslaten' en cliënten dingen moest laten uitproberen. Anderen gaven aan dit moeilijk te vinden. De paramedici uitten verder kritiek op de programma's voor CVA-getroffenen en gaven aan dat deze uiteindelijk vaak nog te medisch georiënteerd

zijn en te weinig flexibel. Men gaf verder nog aan dat de programma's zich moeten richten op de CVA-getroffene én de partner en bij voorkeur in de thuissituatie moeten worden aangeboden.

Hoofdstuk 6 beschrijft een longitudinale kwalitatieve studie naar zelfmanagement in het dagelijks leven van CVA-getroffenen en hoe dit ontwikkelt in de tijd. In dit onderzoek zijn participerende observaties en interviews uitgevoerd bij 10 CVA-getroffenen op 3, 6, 9, 15 en 21 maanden na ontslag naar huis. 'Het doen in de context' bleek centraal te staan tijdens de ontwikkeling van het zelfmanagement. Het doen van dagelijkse activiteiten maakte het mogelijk dat CVA-getroffenen zelfmanagement strategieën konden ontdekken, ervaren, evalueren, ontwikkelen en aanpassen. Gedurende het herstel proces veranderde de betekenis van zelfmanagement en het gevoel van eigen regie. De betekenis van zelfmanagement veranderde van 'alles-zelf-doen' naar 'zelfmanagement en eigen regie met de keuze om dit mét of zonder hulp van anderen te doen'. Tijdens de ontwikkeling van zelfmanagement gingen de CVA-getroffenen door drie fases: a) zelfmanagement van de CVA consequenties, b) zelfmanagement op het niveau van dagelijkse activiteiten en tenslotte c) managen van betekenisvolle rollen en een waardevol leven na een beroerte. Tijdens het ontwikkelen van zelfmanagement kreeg men ook een gevoel van regie over dagelijkse activiteiten en het dagelijks leven. De mate waarin men het zelfmanagement ervaarde had te maken met de mate van regie. Zelfmanagement en eigen regie ontwikkelden in interactie met de mensen in de omgeving, waarbij de CVA-getroffenen de partners soms ervaarde als stimulerend en soms als beperkend.

In **hoofdstuk 7** beschrijven wij hoe CVA-getroffenen in interactie met hun partners handelen als rol-manager in de context van dagelijkse activiteiten. Hiervoor hebben wij de data van twee deelnemers van de longitudinale kwalitatieve studie gebruikt en ons gericht op de 'narratives-in-action', dat wil zeggen 'de verhalen die mensen vertellen door wat zij doen'. Het zelfmanagement en rol-management vond plaats door middel van dagelijkse activiteiten. Alledaagse activiteiten gaven CVA-getroffenen en hun partners inzicht in hun capaciteiten in dagelijkse situaties. Voor de deelnemers waren deze dagelijkse activiteiten de plek waarin men samen kon afstemmen over het managen van hun rollen en een betekenisvol leven samen kon vormgeven. Soms was dit stimulerend, terwijl in andere situaties conflicten ontstonden, in het bijzonder wanneer partners negatieve verwachtingen hadden van de mogelijkheden van de CVA-getroffene en hen weinig ruimte boden voor het ontdekken van de mogelijkheden.

Tot slot geeft **hoofdstuk 8** een samenvatting en discussie van de belangrijkste resultaten, gevolgd door een methodologische beschouwing. Daarna worden de implicaties voor de praktijk en verder onderzoek beschreven. Op basis van de resultaten en de discussie worden de volgende aanbevelingen voor de praktijk gegeven:

- Beschouw partners als volwaardige deelnemers aan CVA-zelfmanagement programma's naast de CVA-getroffenen;
- Voor partners van CVA-getroffenen dienen aparte interventies te worden ontwikkeld voor het zelfmanagement van de partners zelf;
- Besteed aandacht aan het 'ZELF' in zelfmanagement programma's;
- Professionals moeten genuanceerd zijn in hun uitleg en toepassing van zelfmanagement interventies. Zelfmanagement is niet 'doe-het-zelf'; beter is het om tijdens interventies aandacht te besteden aan co-management: samen-managen met partner, familie en/of andere naasten;
- Professionals dienen aandacht te besteden aan zowel praktische (het doen van dagelijkse activiteiten) als existentiële aspecten (een betekenisvol leven na een beroerte) van zelfmanagement;
- Na een beroerte kunnen drie fases onderscheiden worden in zelfmanagement: het hanteren van de gevolgen van een beroerte, het managen van activiteiten en management van betekenisvolle rollen en deelname aan een betekenisvol leven na een beroerte;
- CVA-zelfmanagement programma's zouden een combinatie moeten zijn van interventies gericht op medisch, rol en emotioneel management. Afhankelijk van de fase en de wensen en behoeften van de CVA-getroffenen en hun naasten dient, naarmate men verder komt in het proces na een beroerte, de focus van de interventies te verschuiven van medisch management naar rol-management;
- Het uitvoeren van dagelijkse activiteiten blijkt bij uitstek een waardevol middel om zelfmanagement competenties te ontwikkelen;
- Minimaal twee vormen van zelfmanagement programma's zouden aangeboden moeten worden aan CVA-getroffenen in de thuissituatie. In de eerste periode na ontslag een programma waarbij de aandacht uitgaat naar het zelfmanagement van dagelijkse activiteiten en (weer) participeren in de maatschappij. Daarna, wanneer CVA-getroffenen een langere tijd thuis zijn, is behoefte aan interventies met aandacht voor existentiële aspecten en aanpassing van betekenisvolle rollen.

De resultaten van dit proefschrift geven ook implicaties voor de opleidingen en post-HBO cursussen van professionals. Allereerst is meer aandacht nodig voor ondersteuning van het zelfmanagement van CVA-getroffenen en hun naasten in de maatschappij. Daarnaast is een verschuiving nodig van de biomedische focus richting de nieuwe opvatting over gezondheid als 'de mogelijkheid om aan te passen en zelf te managen'. Tevens kan meer aandacht worden besteed aan gedragsverandering in de opleiding van professionals om het zelfmanagement van mensen na een beroerte te begeleiden.

Vervolgonderzoek is nodig om nader inzicht te krijgen in de complexiteit van het proces van zelfmanagement na een beroerte. Indien van toepassing zullen de partners en/of

andere naasten van de CVA-getroffenen betrokken moeten worden in deze onderzoeken.

Diverse onderwerpen verdienen extra aandacht:

- Onderzoek welke uitkomstmaten geschikt en belangrijk zijn voor alle betrokkenen en betrekking hebben op het dagelijks leven van patiënten;
- Overweeg een verandering in meten, waarbij een verschuiving van het meten van beperkingen naar het meten van mogelijkheden en de 'eigen kracht' van patiënten om zichzelf te managen wenselijk is;
- Mixed-method studies met een longitudinaal design, waarbij kwalitatieve en kwantitatieve gegevens gebruikt worden geven meer inzicht in zelfmanagement op de lange termijn;
- Onderzoek hoe eerstelijns' professionals het concept zelfmanagement zien en hoe de CVA-zelfmanagement programma's zijn georganiseerd;
- Ontwikkel een visie op zelfmanagement ondersteuning in de eerste lijn en ontwikkel vervolgens een eerstelijns' zelfmanagement programma voor CVA-getroffenen en hun naasten;
- Ontwikkel programma's om het existentiële zelfmanagement van CVA-getroffenen te ondersteunen; en
- Onderzoek de wensen en behoeften van CVA-getroffenen met ernstige cognitieve en communicatie problemen en hun naasten en ontwikkel hier zelfmanagement programma's voor.

Wetenschappelijke studies naar bovenstaande onderwerpen kunnen een bijdrage leveren aan de verdere ontwikkeling van zelfmanagement interventies en aandacht geven aan de wensen en behoeften van CVA-getroffenen en hun naasten om zichzelf te managen en op de langere termijn een betekenisvol leven te leiden.

Dankwoord

Wie verre reizen doet, kan veel verhalen (Mathias Claudius, 1740-1815)

Nu dit promotieonderzoek er op zit kijk ik dankbaar terug op een bijzondere reis. Een reis waarbij ik in verschillende werelden mocht kijken en waar mensen bijzondere ervaringen met mij wilden delen. Mijn promotieonderzoek was geen georganiseerde reis, een Lonely Planet was er al evenmin. Het was een aaneenschakeling van mooie reiservaringen: een trekking in relatieve onbekende (onderzoeks)gebieden, ontmoetingen met interessante mensen onderweg, nieuwe ontdekkingen op de landkaart of kleine survival tochten met vaak als einde een prachtig uitzicht boven op de berg als het artikel online verscheen! Maar reizen doe je niet alleen! Ik heb het geluk gehad om in goed gezelschap te hebben vertoefd. Sommige mensen reisden slechts een klein stukje met mij mee, anderen deelden een heel stuk van de tocht. Lang of kort, jullie hebben er samen voor gezorgd dat deze reis onvergetelijk is geworden.

Allereerst gaat mijn dank uit naar de deelnemers aan de focusgroep interviews met CVA-getroffenen, paramedici en partners van CVA-getroffenen. Daarnaast en in het bijzonder ben ik veel dank verschuldigd aan de mensen die ik bijna twee jaar lang heb mogen volgen in het kader van de longitudinale studie. Ik mocht een kijkje nemen in jullie leefwereld na een beroerte. En of het nu het tuinieren was, de houtbewerking in de schuur, een onverwachte lunch in het centrum van de stad of het uitlaten van het jonge hondje in het park, alle momenten waren leerzaam en bijzonder. Jullie persoonlijke verhalen en ervaringen zijn van grote waarde geweest voor dit promotieonderzoek.

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gegeven. De overlegmomenten vonden altijd plaats in een relaxte sfeer en gaven mij vertrouwen in bepaalde keuzes op sommige kruispunten. Naast mijn promotieonderzoek liepen er ook steeds andere gezamenlijke projectjes waarvan voor mij de kern is dat we elkaar in inspiratie en gedrevenheid vinden! Ook al is deze promotiereis ten einde, ik ga er van uit dat we nog veel andere 'reis activiteiten' gaan ondernemen!

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Over de auteur



Ton Satink werd op 9 september 1964 geboren in Heino. Na het behalen van het VWO-diploma in 1982, begon hij aan de opleiding tot röntgenlaborant welke hij in 1984 afrondde. Toen bleek dat Ton zich niet 'senang' voelde in het werken met patiënten vanuit het 'medisch perspectief' besloot hij de opleiding ergotherapie te gaan volgen aan de Hogeschool van Amsterdam. Na het afronden van de opleiding ergotherapie in

1991 startte zijn carrière als ergotherapeut in Indonesia in het rumah sakit Gatot Soebroto in Jakarta. Na terugkomst in Nederland, begon Ton in 1992 als ergotherapeut in revalidatiecentrum Heliomare in Wijk aan Zee. In deze periode heeft hij vooral gewerkt in de CVA-revalidatie en pijn revalidatie. Daarnaast was hij van 1995 tot 2000 afgevaardigde namens de beroepsvereniging ergotherapie voor de COTEC (Council of Occupational Therapists for the European Countries).

Gaandeweg ontstond de belangstelling voor kennisontwikkeling en kennisdeling en in 1997 trad Ton in dienst als docent aan de Hogeschool van Amsterdam bij de opleiding ergotherapie. In 2002 rondde Ton de European Master of Science in Occupational Therapy af en vanaf 2003 combineerde hij zijn baan als docent aan de bachelor opleiding ergotherapie met die van staff-member aan de European Master of Science in Occupational Therapy. Van 2003 tot 2004 participeerde hij in het lectoraat Paramedische Zorg van de Hogeschool van Amsterdam.

In 2004 stapte Ton over naar de opleiding ergotherapie van de Hogeschool van Arnhem en Nijmegen. In die eerste jaren heeft hij onderwijstaken gecombineerd met curriculum ontwikkeling. Vanaf de oprichting in 2008 is hij lid van het Netwerk Ergotherapie Onderzoekers Nijmegen (www.neonijmegen.nl). Van 2006 tot 2010 was Ton lid van het lectoraat Lokale Dienstverlening vanuit Klantperspectief om vervolgens over te stappen naar het lectoraat Neurorevalidatie in het kader van zijn promotieonderzoek.

In 2010 begon Ton aan zijn parttime promotietraject over zelfmanagement in de CVA-revalidatie. Sindsdien combineert hij zijn promotieonderzoek met de taken van hoofddocent aan de HAN en zijn taken voor de European Master of Science in Occupational Therapy. In 2013 won Ton de prijs van HAN-onderzoeker van het jaar. Van 2008 – 2013 was hij redactielid van het Wetenschappelijk Tijdschrift Ergotherapie en vanaf 2014 is Ton lid van de klankbordgroep van Hersenletsel.nl en de adviesraad Onderzoek van Ergotherapie Nederland.

About the author

Ton Satink was born on September 9, 1964, in Heino, the Netherlands. After finishing pre-university secondary education, in 1982, he started his first job as an X-ray technician. From 1987 to 1991, he worked towards a bachelor's degree in occupational therapy at the Amsterdam University of Applied Sciences. After his graduation, Ton moved to Jakarta, Indonesia, where he worked as an occupational therapist at the Gatot Soebroto Hospital. Upon returning to the Netherlands in 1992, he worked as an occupational therapist at the Heliomare Rehabilitation Centre in Wijk aan Zee. At Heliomare, he performed mainly stroke rehabilitation and pain rehabilitation. Beside his job as an occupational therapist, from 1995 to 2000, he was a delegate for the Council of Occupational Therapists for the European Countries (COTEC).

Interested in education and knowledge development, Ton started work in 1997 as a lecturer in occupational therapy at the Amsterdam University of Applied Sciences. In 2002, he received his European Master of Science in Occupational Therapy MSc degree. From 2003, he worked as a staff member of the European Masters in addition to his job as a lecturer in bachelor of occupational therapy education in Amsterdam. Furthermore, from 2003 and 2004, he conducted research work for the Allied Health Care research group at the Amsterdam University of Applied Sciences.

In 2004, Ton moved to Nijmegen to work as a lecturer in the Occupational Therapy Department at the HAN University of Applied Sciences. Initially, he combined teaching with tasks in curriculum development. Since 2008, he has participated in NEON, a network of occupational therapy researchers in Nijmegen (www.neonijmegen.nl). Between 2006 and 2010, Ton was also a researcher of the Local Services from Client Perspectives research group. In 2010, he began collaborating with the Neurorehabilitation research group as part of his PhD studies on self-management in stroke rehabilitation. In recent years, he has worked as a PhD student, a senior lecturer at the HAN University of Applied Sciences and as staff member of the European Master of Science in Occupational Therapy. In 2013, Ton was awarded the 'HAN-researcher of the year' prize. From 2008 to 2013, he was member of the editorial board of the Scientific Journal of Occupational Therapy in the Netherlands, and since 2014, he has been a member of the Hersenletsel.nl (Stroke Client Organisation) and the Ergotherapie Nederland (Dutch Association of Occupational Therapy) scientific advisory groups.

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Book chapters

1. **Satink T.** De geur en smaak van een Koerdisch recept. In: Kinébanian A, Kuiper C. Kleine wonderdjes – Verhalen over bijzondere ervaringen in de ergotherapie. Den Haag: Boom Lemma uitgevers; 2011.
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3. van Nes F, **Satink T,** Kinébanian A. Architectuur van kwalitatief wetenschappelijk onderzoek. In: Ostelo RWJG, Verhagen AP, de Vet HCW. Onderwijs in Wetenschappen – lesbrieven voor paramedici. Houten: Bohn Stafleu van Loghum; 2012.

Presentation

1. **Satink T.** De passie voor het verhaal achter occupation: het bijzondere van het alledaagse. 2013; <https://www.youtube.com/watch?v=kleKR3jN0c4>.

Schilderijen

De schilderijen op de titelpagina en tussenpagina's zijn geschilderd door Sylvia Stoop. Ik heb Syl leren kennen bij aanvang van mijn promotieonderzoek toen zij zitting nam in de klankbordgroep. Syl was getrouwd en had drie jonge kinderen toen zij op 39-jarige leeftijd een CVA kreeg. Na ruim een jaar te hebben gerevalideerd heeft zij samen met haar gezin de draad weer opgepakt en zich ingezet voor CVA-getroffenen en de naasten. Ze was een bevlogen vertegenwoordiger van de vereniging Samen Verder. Tijdens bijeenkomsten benadrukte ze regelmatig dat de gezondheidszorg verder moest kijken dan alleen de beroerte. Er zat immers een mens achter de patiënt!

Syl had het regelmatig over 'de oude' en 'de nieuwe' Syl, iets wat onder anderen tot uiting kwam in haar schilderijen. Schilderen was voor haar de manier om lekker te schilderen, mooie dingen te maken, maar ook om zichzelf te uiten. Helaas kon Syl na de beroerte een hele periode tijd niet schilderen. Ongeveer anderhalf jaar na de beroerte heeft zij het schilderen weer opgepakt, zoals ze zelf zei, door vallen en opstaan, uitproberen en veranderen van stijl. Na de beroerte kon Syl niet meer rechtshandig schilderen en besloot ze uiteindelijk linkshandig te gaan schilderen. Het kostte haar enige tijd om een nieuwe stijl te ontwikkelen. Schilderen was wat je zou kunnen noemen een betekenisvolle activiteit voor haar. Syl omschreef haar drijfveer voor het schilderen als volgt: *"Uit alle aangrijpende gebeurtenissen in mijn leven heb ik een heel sterk gevoel ontwikkeld voor loslaten, genieten van dit moment en gelaten dingen hun weg laten vinden"*.

Syl is op 15 september 2011 overleden.

De schilderijen in dit proefschrift:

Voorkant:	Doorgang, 2009
Chapter 1:	Uitdaging, 2008
Chapter 2:	Innerlijke strijd, 2008
Chapter 3:	Verbinding, 2008
Chapter 4:	Balans, 2000
Chapter 5:	Harmonie, 2009
Chapter 6:	Verheldering, 2009
Chapter 7:	Groter geheel, 2009
Chapter 8:	Verbondenheid, 2009
Chapter 9:	Rust, 2008
Nederlandse samenvatting:	Warme Liefde 2008

