Healthcare and support needs of stroke patients with mild cognitive impairments and support needs of caregiving partners three months post-stroke: an exploratory qualitative study

Naomi Larissa Rasing

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Student number	s1615793
Email	n.l.rasing@student.utwente.nl
Master	Health Psychology and Technology
Institution	University of Twente, Enschede Faculty Behavioral, Management and Social Sciences Department of Psychology, Health, and Technology Commissioned by the Medical Spectrum Twente, Enschede
Supervised by	Dr. Erik Taal *Associate Professor at the department of Psychology, Health, and Technology at the University of Twente* Dr. C.H.C. Drossaert *Associate Professor at the department of Psychology, Health, and Technology at the University of Twente.* Dr. Heleen den Hertog *Neurologist at the Medical Spectrum Twente*

Acknowledgements

You are about to read the master's thesis I wrote to complete the Master Health Psychology and Technology at the University of Twente. For the past eight months I have worked on this thesis with much joy. I found the process of qualitative research interesting and challenging. I started in January 2017 with a literature study on stroke, cognitive impairments, and healthcare and support needs. Next, interview guides were developed in close cooperation with researchers from the Medical Spectrum Twente. The recruitment of participants started slowly, so I was already anticipating that I might have to change my subject or methods. Luckily, after three weeks the first participants were found and I could finally start conducting the interviews with patients and partners. I found it very interesting to switch back and forth between a scientific perspective while writing the thesis, and an experience based perspective when listening to participants' experiences. Transcribing and analyzing the data was a very time consuming process, however, I am very satisfied with the results. Conducting the interviews and reporting the findings in a scientific report has given me great satisfaction. It made me realize that qualitative research matters, as the perspective of the patients and partners are of great value to optimize healthcare.

I would like to express my gratitude to several parties who were involved in the creation of this master's thesis. First, I am very thankful for the willingness of patients and partners to participate in this study. Their openness provided insights into the healthcare needs of patients and support needs of partners that otherwise might have gone unnoticed. Second, I would like to thank my supervisors Erik Taal and Stans Drossaert from the University of Twente, and Heleen den Hertog from the Medical Spectrum Twente. Erik, Stans and Heleen, I would like to thank you very much for all the time you have spent on giving me detailed critical feedback on my work. I learned very much from this and it kept me focused and motivated to keep improving the report. Also, I would like to thank the healthcare professionals of the Medical Spectrum Twente who were involved in this research: Moniek van Hout and Marion Podt-Dekker. Furthermore, I would like to thank Laura Pranger and Demi van Heumen, for the time they spent approaching potential participants for the interviews. My thanks also go to Mira Oberhagemann and Greetje Dikkers, who spent a lot of free time coding five of the interviews. Last but not least, I want to thank my family and friends for their support during this hectic time, especially Ayla Rasing, Anders van Riesen and Nicole Somsen.

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Abstract

Background: Cognitive impairments are a leading cause of disability in stroke patients. Cognitive impairments concern memory, visuospatial abilities, expressive and receptive language, executive function, concentration and attention, orientation, aphasia, neglect, and slowed information processing. Cognitive impairments experienced by the patient and partner may have an influence on the daily life of patients and partners. However, it is unknown what healthcare and support needs patients with mild cognitive impairments have and which support needs partners have, with respect to mild cognitive impairments, three months post-stroke. *Aim:* The aim of this study was to assess healthcare and support needs of home-dwelling stroke patients with mild cognitive impairments and the support needs of their caregiving partners three months post-stroke.

Method: Presence of mild cognitive impairments was measured six weeks post-stroke with the tests Montreal Cognitive Assessment (MoCA) and Facial Expression of Emotion: Stimuli and Tests (FEEST). Inclusion criteria of patients were a score of 24 or below on the MoCA and a score of 42 or below on the FEEST. Semi-structured interview guides were developed for both patients and partners. Interviews took place three months post-stroke in the home environment of participants. Experienced cognitive consequences of stroke, healthcare and support needs of the patient, and support needs of the partner were assessed from both the perspective of patients and partners. After data were transcribed, three coders analyzed and coded three patient interviews and two partner interviews. This resulted in a Cohen’s Kappa of 0.93, indicating a large agreement between coders.

Results: Ten patients (median age = 69.5 years) and six partners (median age = 70.5 years) participated. Patients experienced physical, cognitive, emotional, social, and behavioral consequences of stroke. Most prevalent cognitive impairments concerned memory, attention or concentration, planning or scheduling, and speed of thinking. Most prevalent change for the partner was an increase in worries about their partner. Received healthcare was evaluated minimal though sufficient, however, several unmet needs during hospital stay and after discharge were mentioned. Healthcare needs expressed by patients were that healthcare professionals should live up to their promises, show more involvement after discharge, that more and customized information is provided, more transparency about medication, and clarity about when one should be able to drive again. Some participants initiated healthcare themselves. Partners did not receive any information focused on themselves as potential caregivers. Important support needs concerned communication with healthcare professionals, information provision, involvement after discharge, and individual attention for the partner. Evaluation of existing interventions concerning information, education and training, peer contact, tools for cognitive impairments, and support in daily life, showed that both patients and partners currently – three months post-stroke – hardly feel the need for additional healthcare or support concerning mild cognitive impairments of the patient.

Discussion & conclusions: Findings of this study show that stroke patients and their partners have little need for additional healthcare and support three months post-stroke with respect to experienced mild cognitive impairments. However, it is possible that healthcare needs and support needs change over time. Therefore, it is important to be aware of the influence mild cognitive impairments after stroke can have on patients and partners on long term. A greater understanding should be developed of experienced cognitive consequences from both the patient's and the partner's perspective. This enables healthcare professionals and intervention developers to take into account the healthcare needs and support needs of home-dwelling stroke patients with mild cognitive impairments in the acute phase after stroke and on the longer term.

Samenvatting (NL)

Achtergrond: Cognitieve beperkingen zijn een vooraanstaande oorzaak van invaliditeit bij mensen met een beroerte. Cognitieve beperkingen hebben betrekking op het geheugen, visuospatiële vaardigheden, expressieve en receptieve taal, executief functioneren, concentratie en aandacht, oriëntatie, afasie, neglect, en vertraagde informatieverwerking. Cognitieve beperkingen na een beroerte ervaren kunnen het dagelijks leven van de patiënt en zijn partner beïnvloeden. Echter, er is nog niet onderzocht welke zorg- en ondersteuningsbehoeften patiënten met milde cognitieve beperkingen hebben en welke ondersteuningsbehoeften partners hebben met betrekking tot milde cognitieve gevolgen drie maanden na de beroerte.

Doelstelling: Het doel van dit onderzoek is in kaart brengen welke zorgbehoeften thuiswonende patiënten met milde cognitieve beperkingen hebben drie maanden na de beroerte en welke ondersteuningsbehoeften de partners (als mantelzorger) hebben.

Methoden: De aanwezigheid van milde cognitieve beperkingen is zes weken na de beroerte gemeten met de cognitieve testen Montreal Cognitive Assessment (MoCA) en Facial Expression of Emotion: Stimuli and Tests (FEEST). Inclusiecriteria van patiënten waren een uitkomst van 24 of lager op de MoCA en een uitkomst van 42 of lager op de FEEST. Semigestructureerde interviewschema's zijn ontwikkeld voor zowel de patiënt als voor de partner. Interviews vonden drie maanden na de beroerte plaats in de thuissituatie van de participanten. Ervaren cognitieve consequenties van de beroerte, zorg- en ondersteuningsbehoeften van de patiënt en ondersteuningsbehoeften van de partner werden in kaart gebracht. Zowel het perspectief van de patiënt als van de partner werd hierbij uitgelicht. Drie codeurs hebben drie patiënten-interviews en twee partner-interviews gecodeerd nadat de data waren getranscribeerd. Dit resulteerde in een Cohen's Kappa van 0.93, wat een grote overeenstemming tussen codeurs indiceert.

Resultaten: Tien patiënten (mediaanleeftijd = 69.5 jaar) en zes partners (mediaanleeftijd = 70.5 jaar) participeerden. Patiënten ondervonden fysieke, cognitieve, emotionele, sociale, en gedragsmatige consequenties van de beroerte. Veelgenoemde cognitieve beperkingen hadden betrekking op geheugen, aandacht en concentratie, planning en snelheid van denken. De meest ondervonden verandering voor de partner was een toename in bezorgdheid om de partner. Ontvangen zorgverlening werd geëvalueerd als minimaal doch voldoende, hoewel enkele onvoldane behoeften tijdens het ziekenhuisverblijf en na ontslag werden benoemd. Zorgbehoeften van patiënten waren: dat zorgprofessionals zich aan beloften houden, meer betrokkenheid na ontslag tonen, dat meer en gepersonaliseerde informatie wordt verschaft, meer transparantie over medicatie, en duidelijkheid over wanneer men weer mag autorijden. Enkele patiënten hebben aanvullende zorg of ondersteuning zelf geïnitieerd. Partners ontvingen geen informatie gericht op henzelf als mogelijke mantelzorgers. Belangrijke ondersteuningsbehoeften hebben betrekking op: communicatie met zorgprofessionals, informatievoorziening, betrokkenheid na ontslag en individuele aandacht voor de partner. De evaluatie van bestaande interventies omtrent informatie, educatie en training, lotgenotencontact, hulpmiddelen voor cognitieve beperkingen, en ondersteuning in het dagelijks leven, toonde aan dat zowel patiënten als partners momenteel – drie maanden na de beroerte – nauwelijks behoefte hebben aan aanvullende zorgverlening of ondersteuning wat betreft milde cognitieve beperkingen van de patiënt.

Discussie & conclusie: De bevindingen van dit onderzoek tonen aan dat patiënten en partners met het oog op de ervaren milde cognitieve beperkingen weinig behoefte hebben aan aanvullende zorgverlening of ondersteuning drie maanden na de beroerte. Het is echter mogelijk dat de behoeften aan zorg en ondersteuning in de loop van de tijd veranderen. Daarom is het belangrijk bewust te zijn van de invloed die milde cognitieve beperkingen ook langere tijd na de beroerte kunnen uitoefenen op patiënten en partners. Meer onderzoek waarbij de ervaren cognitieve consequenties vanuit zowel het perspectief van de patiënt als van de partner worden onderzocht is nodig. Hierdoor kunnen zorgprofessionals en interventie-ontwikkelaars rekening houden met de zorgbehoeften en ondersteuningsbehoeften van thuiswonende patiënten met milde cognitieve beperkingen na een beroerte, zowel in de acute fase als op langere termijn.

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1 Introduction

1.1 Stroke

Stroke is an increasingly common condition worldwide (Cooper et al., 2014; Hankey, 2016; Rigby, Gubitz, & Phillips, 2009). Presumably, this is a result of increasing life expectancy, a shift in age in the population, and worldwide population growth (Hankey, 2016). There are different types of stroke: ischemic stroke and intracerebral haemorrhage. Ischemic stroke accounts for approximately 85% of the cases (American Stroke Association, 2013; Young & Tolentino, 2009). An ischemic stroke is the temporary obstruction of the blood flow to the brain, caused by a clot. Intracerebral haemorrhage occurs when a weakened blood vessel ruptures and blood leaks into the surrounding brain tissue.

Stroke is the main cause of disability and the second cause of death in developed countries (Hankey, 2016; Scott, Phillips, Johnston, Whyte, & MacLeod, 2012). The World Health Organization (WHO) presented that each year 15 million people suffer from stroke (World Health Organization, 2004). The incidence of stroke in Europe is estimated at 1 million persons with ischaemic stroke every year (Cooper et al., 2014). In the Netherlands, cardiovascular diseases are the first cause of death among women and the second cause of death among men. Ischemic heart disease is the most prevalent cause of death for men, whereas for women stroke was the most prevalent cause of death (Van Dis, Buddeke, Vaartjes, Visseren, & Bots, 2015). The prevalence of stroke in the Netherlands is expected to increase from 186.000 patients in 2011, to 343.000 patients in 2040. This represents an estimated increase of 85% (Van Dis et al., 2015). In the Netherlands, approximately 45.000 people have a stroke every year. 75% of patients are over 65 years old. One year after admission to a hospital approximately 20% of these patients has deceased (Hersenstichting, 2017).

The amount of money spent on healthcare after stroke is large, and is likely to increase as the population is ageing (Korczyn, Brainin, & Guekht, 2015; Scott et al., 2012). In 2011 the costs of stroke in the Netherlands were approximately 2.3 billion euros (Volksgezondheidenzorg.info, 2017).

At the Medical Spectrum Twente, a large non-academic teaching hospital in Overijssel, approximately 800 stroke patients are admitted each year. Approximately 40% of patients rehabilitate at a rehabilitation center or nursing home, whereas 60% of patients is discharged home immediately after having stayed in hospital.

1.2 Cognitive impairments

In the past two decades post-stroke survival rates have increased, due to improvements in acute stroke care, such as the implementation of stroke units and the use of intravenous thrombolysis (Hankey, 2016; van Mierlo et al., 2014). As a consequence of the increasing number of stroke patients, more people have to deal with the residual symptoms of a stroke (Carod-Artal, 2012). Cognitive impairments are the leading cause of disability in stroke patients (Cooper et al., 2014; Leśniak, Bak, Czepiel, Seniów, & Członkowska, 2008; Satink, Cup, De Swart, & Nijhuis-Van Der Sanden, 2015; Schepers, Visser-Meily, Ketelaar, & Lindeman, 2006). Studies show that cognitive impairments are common in stroke patients, even with minor stroke, with prevalence ranges from approximately 50% to 78% (Leśniak et al., 2008; Renjen, Gauba, & Chaudhari, 2015; Xu, Ren, Prakash, Vijayadas, & Kumar, 2013).

Cognitive impairments can occur in several domains, including visuospatial abilities, memory, expressive and receptive language, executive function, orientation, concentration and attention, aphasia, neglect, and slowed information processing (Cumming, Marshall, & Lazar, 2013; Tatemichi et al., 1994). Visuospatial abilities concern the ability to search, draw, and construct visually. Memory concerns the recognition and recall of verbal and visual information. Executive functioning involves the ability to plan, organize, inhibit, and control thoughts. Attention refers to the ability to focus, shift, divide, or sustain attention on a task or stimulus (Cumming et al., 2013; Moran et al., 2013). Of all cognitive complaints, attention, slowed information processing, and memory are the most prominent deficits (Hochstenbach, Prigatano, & Mulder, 2005; van Heugten, Rasquin, Winkens, Beusmans, & Verhey, 2007).

Stroke patients with mild cognitive impairments may also have an impaired social cognition. Social cognition refers to information processing capabilities, whereby people perceive and understand themselves and others, and interpersonal knowledge – such as norms and procedures – necessary to adequately react in social situations (Adolphs, 2001; Beer & Ochsner, 2006; Spikman, Timmerman, Milders, Veenstra, & van der Naalt, 2012). These capabilities allow people to understand, generate, and regulate social behavior. For example, to be patient, to be aware when to listen or when to talk, or to envision someone else's perspective (Stroke Association UK, 2012). A main aspect of social cognition is emotion perception (Hoche, Guell, Sherman, Vangel, & Schmahmann, 2016; Montagne et al., 2007).

The abovementioned cognitive impairments can result in restrictions in participation in daily activities, social roles, and social, educational, and leisure activities. In fact, if these – often less visible – cognitive impairments and subsequent consequences remain untreated, they may obstruct rehabilitation outcome, reintegration in society, and stroke patients' quality of life (Hochstenbach, Anderson, Van Limbeek, & Mulder, 2001; Moran et al., 2014; Moran et al., 2013; Viscogliosi et al., 2011). Several studies have found that cognitive impairments post-stroke negatively affect stroke patients' quality of life (QoL) and participation, which is a person's involvement in social roles and activities of daily living (Astrom, Asplund, & Astrom, 1992; Mayo, Wood-Dauphinee, Carlton, Durcan, & Carlton, 2002; van Mierlo et al., 2016). Viscogliosi (2011) found that cognitive impairments led to more limitations in social roles than in daily living. For example, memory impairments caused restrictions in communication and leisure. Cognitive impairment may be a risk factor of long-term depressive symptoms and reduced quality of life (Nys et al., 2006). In turn, depressive symptoms may obstruct emotion perception (Montagne et al., 2007). Furthermore, experienced consequences of stroke, such as difficulties with concentration and attention, decreased interest in social activities, and mobility, may negatively affect patients' life satisfaction (Edwards, Hahn, Baum, & Dromerick, 2006). Though influence of cognitive impairments after stroke has been studied extensively, little research focuses on influence of mild cognitive impairments after stroke in home-dwelling patients.

1.3 Patients' coping strategies

Many studies and reviews stress the importance of coping for stroke patients. Coping strategies of the patient may influence how the patient deals with the experienced consequences of the stroke and may also affect recovery (Lazarus & Folkman, 1987). Current life satisfaction of stroke patients was found to be dependent on how they coped with their situation and in what way they created new perspectives for their lives (Pallesen, 2014). Donnellan, Hevey, Hickey, and O'Neill (2006) found that coping strategies often remain consistent over time. Therefore, the patient's coping style three months post-stroke may be an indicator for future coping strategies.

A framework that evaluates the processes of coping with a stressful event is the Transactional Model of Stress and Coping (Folkman, Lazarus, Gruen, & DeLongis, 1986). Primary appraisal is someone's evaluation of the significance of the event, for example it may be perceived as positive, challenging, irrelevant, or stressful. Secondary appraisal is someone's evaluation of the controllability of the stressor and someone's resources and options to cope with the stressor. The perception of the stressor is an ongoing appraisal of what the stressor means to a person and how to respond. As appraisal of the stressor changes over time, so do one's coping strategies (Rochette, Bravo, Desrosiers, St-Cyr Tribble, & Bourget, 2007).

Coping strategies have been defined in many ways. Functional coping occurs when a patient adapts to the consequences of stroke, whereas dysfunctional coping results in increased stress. In problem-focused coping, the patient aims to solve the experienced negative impact of the situation. In emotion-focused coping, the patient aims to change or regulate the feelings caused by the problem. Avoidant coping refers to escaping or denying the consequences of the stroke. In accommodative coping the patient changes personal goals based on the experienced consequences. Assimilative coping refers to active attempts to change undesirable circumstances and situational restrictions, based on personal preferences (Donnellan et al., 2006; Lo Buono et al., 2017; Suls & Flechter, 1985). Even though no specific coping strategies are related to a specific phase after stroke (acute or long-term), Donnellan et al. (2006) found that problem-focused coping strategies were applied more by stroke patients than emotion-focused coping strategies. Studies also show that ineffective coping strategies increase the chance of developing psychosocial problems, such as depression (Kirkevold, Bronken, Martinsen, & Kvigne, 2012; Whyte & Mulsant, 2002). Lo Buono et al. (2017) found that quality of life was higher in patients who applied active and accommodative coping strategies, in comparison to patients who preferred assimilative coping.

1.4 Patients' healthcare needs concerning cognitive impairments

Even though stroke patients' cognitive impairments and their consequences have been studied extensively, concrete healthcare and support needs of stroke patients concerning mild cognitive impairments are not yet evident. Healthcare needs relate to healthcare a stroke patient may need to recover from stroke and experienced consequences of stroke as best as possible, both in the acute phase and long-term. Examples could be information provision about potential cognitive impairments, follow up with a stroke nurse, or control consults with the general practitioner. Support needs relate to practical assistance and psychosocial or emotional assistance needed by patient or partner to cope with or adjust to potential changes in daily life after stroke. Examples could be education, training, peer contact, or respite care. To the best of our knowledge, recent studies identified many healthcare needs of patients, although often it is not made clear whether cognitive impairments play a specific role in these needs, and whether these needs occur because of cognitive impairments.

Healthcare needs may be subjective and may vary amongst stroke patients, depending on the experienced consequences of stroke, applied coping strategies, and the amount of unmet needs. Previous studies noted that the current service provision might not adequately address these differences in healthcare needs (McKevitt, Redfern, Mold, & Wolfe, 2004; Thompson & Ryan, 2009). The "*Richtlijn diagnostiek, behandeling en zorg voor patiënten met een beroerte*" found that patients need a central point of contact after discharge (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). A needs assessment amongst 209 stroke patients identified needs related to physical impairments, time for recovery, education, medical advice, therapies and services, and social and emotional needs (Moreland et al., 2009). Main facilitating factors for recovery were family and friend support, followed by therapies and medical care, and personal qualities, such as a positive attitude and determination (Moreland et al., 2009).

A clear need for patients is information provision. McKevitt et al. (2011) found that patients required more information about the cause, prevention, and recurrence of stroke. Besides, patients' need for information changes over time (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). The need for medical information shifts to the need for information about social aspects and experiences of peers after some time. Therefore, information has to be provided at the right time, as well as in the right way. Currently, information provision often does not correspond with stroke patients' information needs (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). Other important unmet needs concerned memory, fatigue, falling, concentration, emotional problems, mobility, and social participation.

1.5 Interventions concerning patient's healthcare needs for cognitive impairments

Multiple interventions or 'tools' for restoration or compensation of cognitive impairments exist. These tools aim to improve cognitive abilities, offer assistance to compensate for cognitive impairments, or adapt to cognitive impairments by applying alternative techniques (Xu et al., 2013). Examples are: prism glasses for hemi spatial neglect; an electronic paging system for stroke patients with impairments in memory and planning; and time pressure management for stroke patients with decreased information processing (Cumming et al., 2013). Interventions that may exert a positive influence on cognitive recovery are: treating hypertension, increasing physical activity, and listening to music (Cumming et al., 2013). Pharmacological agents (such as escitalopram and rivastigmine) may also improve cognitive outcomes, although currently no specific pharmacological treatment for cognitive impairments is approved (Cumming et al., 2013; Lo Coco, Lopez, & Corrao, 2016). Additional support may be given by a specialized nurse, depending on the needs of patients, by means of information, reassurance, and optionally a referral to the general practitioner. Also, education sessions and individualized informative brochures seem to be effective interventions. Furthermore, several interventions aim to improve self-management and coping strategies amongst patients (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). Although promising, efficacy of non-pharmacological interventions has not yet been sufficiently investigated (Lo Coco et al., 2016). To the best of our knowledge, little research has been done on interventions, from the perspective of the patient, that targets healthcare and support needs of stroke patients specifically focused on mild cognitive impairments of the stroke patient.

One Dutch intervention for training and education is '*Niet rennen maar plannen*', which focuses on cognitive rehabilitation for patients with brain damage and mild cognitive problems, who went home immediately after hospital discharge. In a workbook with five modules, the patient receives information and strategies on how to cope with cognitive impairments caused by the brain damage (Geusgens, Baars-Elsinga, Visser-Meily, & van Heugten, 2017). The modules assess fatigue, slowed information processing and coping with time pressure, memory problems, and planning. Furthermore, several other interventions for cognitive impairments are currently being developed and tested. One example aims to decrease problems in navigation, by educating patients on how to apply different strategies to navigation (van der Ham, Visser-Meily, Claessen, & de Rooij, 2017).

An increasingly popular medium to offer healthcare is eHealth. eHealth is the use of information and communication technologies, such as the Internet and other technologies, in healthcare (de Veer et al., 2015; Liu et al., 2015; Meier, Fitzgerald, & Smith, 2013). eHealth can increase time-efficiency and quality of healthcare delivery (Phichitchaisopa & Naenna, 2013). Furthermore, eHealth offers both patients and caregivers the opportunity to participate in an intervention in their own time, for as long as they want.

Multiple organizations provide information and support for stroke patients. For example, *Hersenletsel.nl* ("Hersenletsel.nl," 2017) is an association for patients with acquired brain injury and their significant others. This association organizes peer support and informative meetings; provides information on the website, the *Hersenletsel Magazine* and other publications; and develops supportive devices. The CVA forum ("CVA-forum," 2017) provides forums for both patients and informal caregivers. The Dutch website *verdermethersenletsel.nl* explains how to live, work, and have a life with brain damage. On the basis of themes, information on multiple topics is available, including eHealth, informal caregiving, music, working, living, volunteers, and books and films. The website also contains a special tab with numerous eHealth applications that may help with self-management. The eHealth applications contain a wide range of topics, such as housekeeping, nutrition, planning, memory, finances, energy, mood, network, health, communication, medical, goals, motor skills, self-management, and movement. Concerning cognitive impairments, applications address grocery shopping, household tasks and expenses lists, online picto agendas, alerts for medication intake, games to train memory, attention and overview, communication, pain, general practitioner advice, self-management, and exercise (Verder met Hersenletsel, 2017). Another website offers an overview of many available applications for patients with cognitive impairments, regarding daily activities, overview, memory, attention, personal energy distribution, mindfulness, shopping, communication aids, spatial reasoning skills, visual perception, and sleeping problems (“RevalidatieApps,” 2017). Evidently, many applications for cognitive impairments after stroke are available online.

The intervention ‘*Niet rennen maar plannen*’ is currently partly transposed to an eHealth intervention. Two of five modules will be offered as blended care, meaning that a part of the program is offered online and another part consists of face-to-face contact with a healthcare professional. However, this will only be the case for patients for whom a partial online intervention is suitable (Baars-Elsinga, van Heugten, & Visser-Meily, 2017). With the current diagnostic tools (neuropsychological tests) it can be difficult to diagnose cognitive problems experienced by patients while performing daily activities. Verheul et al. (2016) found that virtual reality (VR) may be a promising technique to register and train activities of daily living. A virtual supermarket situation was developed, in order to test one’s cognitive capabilities (Visser-Meily, Nijboer, Bouwknegt., Spreij, & Verheul, 2017). Another example of eHealth is the use of computer-based assistive technology (Lindqvist & Borell, 2012), which helped stroke patients create structure and increase control of their daily activities, and to resume social contacts. At the same time, responsibilities of partners decreased.

Literature reviews show existing interventions often lack theoretical foundation, while outcomes and effectiveness are often modest (Kirkevold et al., 2012). Kirkevold et al. (2012) stress interventions should: target specific goals and outcomes, adjust timing and intensity to the patient, actively involve patients and informal caregivers, and focus on coping skills relevant for the individual. Concerning the role of coping in interventions for stroke patients with cognitive impairments, it may be important to consider and build upon the patient’s own coping strategies (Donnellan et al., 2006; Kirkevold et al., 2012; Whyte & Mulsant, 2002).

Evidently, many different interventions for stroke patients, with or without cognitive impairments, have already been developed. However, the vast majority of studies targets patients with more severe consequences of stroke. Therefore, it is unknown what consequences of stroke are experienced by stroke patients with mild cognitive impairments. Furthermore, familiarity with and use of existing interventions in this target group are unknown. Hence, needs and wishes of home-dwelling stroke patients with mild cognitive impairments concerning existing interventions need to be further investigated.

1.6 Influence of cognitive impairments on the partner

Stroke does not only have an immense impact on the patient, but also on the patient's informal caregivers (Han & Haley, 1999; Hersenstichting, 2017; Mayo et al., 2002). Relatives may play an important role in the post-stroke recovery process (Satink et al., 2015). Approximately 50% of stroke patients discharged home after hospital admission lived with residual symptoms of stroke, which meant they needed some sort of help (Mayo et al., 2002). In fact, many stroke patients remain physically or cognitively impaired to some extent and therefore need long-term help from others (Han & Haley, 1999).

Caregiver burden among partners in relation to the stroke has been studied extensively. However, many studies investigated caregiver burden in an inpatient or rehabilitation setting. Furthermore, the specific influence of mild cognitive impairments has not been assessed frequently. Clark, Dunbar, Aycock, Courtney, and Wolf (2006) found that spouses experienced distress from memory and behavior changes they observed in their partner. In another study, spouses experienced feelings of stress, anxiety, loneliness, and depression while coping with behavior changes (Bulley, Shiels, Wilkie, & Salisbury, 2010). Besides, cognitive impairments may often not be recognized by partners as being a result of the stroke. Therefore, it may be difficult for spouses to accept or adapt to these changes in cognition and behavior (Bulley et al., 2010; Clark et al., 2006).

In a recent overview of qualitative systematic reviews four themes for caregiving partners were identified: loss of autonomy, uncertainty about the future, hope, and social support to be able to continue caregiving (Lou, Carstensen, Jørgensen, & Nielsen, 2017). Though, the role of mild cognitive impairments was not assessed. Uncertainty was an aspect of stroke, which could be interpreted as a positive, as well as a negative experience in caregivers (Greenwood, Mackenzie, Cloud, & Wilson, 2009). Many caregiving partners experience high burden, depressive symptoms, anxiety, and a reduction in their autonomy and independence (Greenwood, Mackenzie, Cloud, & Wilson, 2010; Han & Haley, 1999; Kruithof et al., 2016). However, caregiving may also lead to positive experiences, such as improvement of the patient's condition and a closer relationship (Mackenzie & Greenwood, 2012). Moreover, caregivers' personal characteristics, such as feelings of pride, mastery, and self-esteem, contributed to positive caregiving experiences. In a qualitative study of informal carers of stroke patients, it was found that caregivers found strategies to cope with consequences of their partner's stroke on the long term, thereby increasing the control they had on their lives (Greenwood et al., 2010). Interestingly, changes in autonomy and control were described less by older caregivers and caregivers with previous experience as a caregiver. Furthermore, severity of consequences of stroke in the patient correlates with experienced consequences for the partner, such as psychological distress, health, and caregiver burden (Draper & Brocklehurst, 2007; Lutz & Camicia, 2016).

Several studies identified difficulties stroke patients and their caregiving partners often experience as a couple. Discrepancies observed between perceptions about cognitive impairments of stroke patients and their partner is one of these difficulties. Evidently, a stroke patient and spouse can have different perceptions and levels of awareness on the presence and severity of the stroke patient's cognitive impairments (Knapp & Hewison, 1999; Visser-Keizer, Jong, Deelman, Berg, & Gerritsen, 2002). In one study, high agreement was measured between partner and patient, concerning observable and concrete stroke symptoms, such as hemiparesis, aphasia, and writing difficulties (Hochstenbach et al., 2005). Highest discrepancies were measured for cognitive, but also social and psychological functions. According to Hochstenbach et al. (2005), low agreement may indicate too little knowledge on the potential consequences of stroke. However, another explanation for low agreement may be a decreased ability of the patient to recognize their own impairments. Yet another explanation may be the use of a denying or avoiding coping style, which can occur in stroke patients, as well as in their informal caregivers (Hochstenbach et al., 2005).

1.7 Partners' coping strategies

Coping with post-stroke changes is also important for the partner. Positive experiences in caregiving may be beneficial to cope with the stress of caregiving (Mackenzie & Greenwood, 2012). For example, as a spouse begins to develop abilities and coping skills to deal with the cognitive impairments of the stroke patient (Mackenzie & Greenwood, 2012). Coping strategies may vary depending on age of the patient and partner, perception of consequences of stroke in daily life, and patients' and partners' stage of life (Buschenfeld, Morris, & Lockwood, 2009;

Periard & Ames, 1993). To illustrate, younger caregiving partners observed more changes in daily life, and greater caregiver burden (Periard & Ames, 1993). Partners of young stroke patients were mainly applying problem-focused coping strategies (Buschenfeld et al., 2009). Periard and Ames (1993) also found that younger caregivers used more specifically problem-focused strategies. Older partners appeared more accepting toward changes in daily life after stroke.

In a qualitative study, informal caregivers expressed the use of several coping strategies that were perceived as being effective for them: asking for and accepting help from others, living day by day, collecting positive experiences from caring, prioritizing and canceling scheduled activities, and arranging support from paid carers (Greenwood et al., 2010). Other commonly applied adaptive coping strategies were: seeking information and being patient and understanding, searching for own space and wellbeing, hope and optimism, and adapting to a changed role (Grant, Hunt, & Steadman, 2014; Greenwood et al., 2009; Quinn, Murray, & Malone, 2014). Also common, though less adaptive strategies, were: putting one's own needs aside and suffering in silence, (Quinn et al., 2014). Ineffective coping strategies, such as passive coping, were predictive of higher levels of depressive symptoms and/or burden (Byun & Evans, 2015). Indeed, Visser-Meily et al. (2009) found that more effective coping strategies as a caregiver, such as active coping and seeking social support, resulted in better outcomes amongst partners, such as higher QoL.

1.8 Partners' support needs associated with stroke patients' cognitive impairments

Support needs of partners of stroke patients in different settings have been studied extensively in the last decades. However, to the best of our knowledge, there is little research that specifically focuses on the partner's support needs concerning the patient's mild cognitive impairments. Greenwood et al. (2010) found that caregivers may experience less control over their lives, restrictions in choices and in planning ahead. Main support needs identified by Greenwood et al. (2009) were the need for specific information, the training of caregivers and attention for caregivers' own emotional processes with respect to the new role as a caregiver. Information provision and counseling were needs found by Visser-Meily, Van Heugten, Post, Schepers, and Lindeman (2005). These findings were confirmed by more recent studies of Quinn et al. (2014) and Lutz and Camicia (2016), who found that partners have many unmet needs, such as information provision, skills training, communication with healthcare professionals, counseling, finding and initiating resources, respite care, finances, and emotional support.

After discharge, partners experienced lack of preparation to provide care for the patient. Therefore, caregivers expressed a need to be prepared for the role as caregiver (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008; Lutz & Camicia, 2016). This was confirmed by a recent study, in which caregivers expressed that they had experienced a lack of empowering conversations with healthcare professionals and feelings of loneliness post-stroke. Hence, there was a need for more support to cope with changes in roles and in their daily life (Satink et al., 2015). Also, caregivers expressed a feeling of not having any say in how services were delivered, which was partly because they were unfamiliar with the system. Given these results, it might be beneficial to distinguish needs of experienced and new informal caregivers in order to improve support (Greenwood et al., 2010).

Support needs of caregivers were highest in the period of the patients' discharge from the hospital and during the first period at home. Furthermore, caregivers expressed the need for feedback on their caregiving abilities and practically oriented advice. Long-term support needs were mainly stressed by caregivers who take care of a partner with more severe impairments in physical, cognitive, and communicative functioning. Besides, partners of stroke patients often start talking about their experienced high burden, when they are already overworked (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). Cameron, Naglie, Silver, and Gignac (2013) found that caregivers' needs may change over time. Also, healthcare professionals should address needs of both stroke patients and caregiving partners. Partners expressed a need for more stroke-related information and caregiver training before the patient is discharged, as this would prepare them for potential caregiver tasks and help them adapt to potential consequences of stroke (Quinn et al., 2014).

1.9 Interventions concerning support needs for caregiving partners

Little research has been done on interventions that target support needs of caregiving partners, concerning mild cognitive impairments of the stroke patient. A systematic review and meta-analysis of the effectiveness of psychosocial interventions for caregivers of stroke patients found that the effect of psycho education, aiming at developing skills in problem-solving, caregiving, and coping with stress, can have a positive influence on the wellbeing of caregivers (Cheng, Chair, & Chau, 2014). Besides, it may reduce stroke patients' use of healthcare services.

Multiple associations provide information and support for informal caregivers of stroke patients. In the Netherlands, there are approximately 140 organizations for support for informal caregivers. One of them is Mezzo.nl (“Mezzo.nl,” 2017), which provides information about finances, working and living, support and advice, and peer support. “Handen in huis” (2017) is an organization that provides temporary replacement of an informal caregiver, on the basis of volunteers. Smith et al. (2008) found that interventions for partners could be more effective with an active approach, whereby information provision is combined with teaching, self-study, and individual advice and guidance.

Several eHealth interventions for informal caregivers are currently being developed and researched. For example, CARE4Carer is a project aiming to develop an eHealth intervention, which will focus on personalized psycho-education and teaching caregiving partner problem-solving skills, so that caregiving partners can deal with cognitive changes in the patient better (Cox, Schepers, Visser-Meily, & van Heugten, 2017). In a recent review on the impact of eHealth interventions for informal caregivers of stroke patients, despite a variety of study designs and small sample sizes, data suggested that eHealth usage is a promising strategy, as it offers the possibility to target caregivers in an early phase (Aldehaim, Alotaibi, Uphold, & Dang, 2016). This is essential, given the previously mentioned finding that caregivers often report high burden when it is ‘too late’ (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). According to Greenwood et al. (2009), future research should aim to gain an understanding of diversity between informal caregivers, which in turn may enhance the provision of appropriate services. eHealth may be eligible to meet this demand.

1.10 Research objective

Given the significant consequences of stroke for both patients and caregiving partners, it is essential to assess the healthcare and support needs of patients and support needs of partners concerning mild cognitive impairments of the patient. Most studies focus on patients with more severe (consequences of) stroke. Therefore, there is a need for insight into experienced consequences and needs of home-dwelling patients with minor consequences post-stroke. As previously stated, current healthcare services may not correspond to healthcare and support needs of stroke patients with mild cognitive impairments and support needs of caregiving partners. If these specific needs concerning mild cognitive impairments are known, healthcare services and interventions can specifically target these needs. It is assumed that many stroke patients and caregiving partners, to some extent, experience difficulties in the home environment in daily life after the patient has been discharged. Therefore, it is essential to assess the healthcare and support needs of stroke patients and support needs of caregiving partners from their own perspective. Hence, in-depth interviews with home-dwelling patients and their caregiving partners may provide important information on which problems they encounter, how they currently cope with these difficulties, and what healthcare and support needs they have concerning mild cognitive impairments of the patient. In case of an impaired social cognition, it is important to obtain information from both the perspective of the patient and the perspective of the partner, as their perceptions of the (consequences of the) patient's mild cognitive impairments may differ.

Therefore, the goal of this study is to (1) gain insight into the experienced consequences of mild cognitive impairments following stroke, from the perspective of both the home-dwelling stroke patient and his/her partner, (2) assess the healthcare and support needs concerning mild cognitive impairments in the stroke patient, from the patient's and partner's perspective, (3) assess support needs of informal caregiving partners, concerning mild cognitive impairments of their spouse. Furthermore, information obtained by this study may direct the development and implementation of an (online) intervention. This leads to the following research questions:

1) What consequences of mild cognitive impairments following stroke do stroke patients and their caregiving partners experience three months post-stroke?
2) What are healthcare and support needs of patients concerning mild cognitive impairments three months post-stroke, according to patients themselves and their caregiving partners?
3) What are support needs of caregiving partners concerning mild cognitive impairments three months post-stroke, according to patients and partners themselves?

2 Methods

2.1 Study design

This study is part of a larger research project, in which mild cognitive impairment after stroke and psychosocial interventions will be studied. In order to generate answers on the abovementioned research questions of this exploratory study, semi-structured interviews were developed and conducted from January until May 2017. Two semi-structured interview guides were developed for the patient and the partner. The aim was to explore healthcare and support needs of home-dwelling stroke patients with mild cognitive impairments and support needs of caregiving partners three months post-stroke. Two patient and one partner interview were conducted and transcribed, after which minor adaptations were made to the interview guides.

2.2 Participants

This study has been approved by the ethics committee of the University of Twente. Sixteen participants took part in this study. Ten patients who have had a stroke or TIA – diagnosed at the Stroke Unit at the Medical Spectrum Twente – were recruited by psychologists at the Stroke Unit of the Medical Spectrum Twente, a large non-academic teaching hospital in Overijssel, in the east of the Netherlands. Six partners also participated in this study. As the current study is part of a larger project, in which mild cognitive impairment after stroke and psychosocial interventions will be studied, potential participants, who also participated in another component of the overarching study, were invited by the researchers to participate in an interview three months post-stroke. Twenty potential participants (patients) received information by phone from two psychologists. On behalf of the researcher potential participants received information on this study and were asked by the psychologists whether the researcher could contact them for a face-to-face interview. Ten potential participants (patients) were approached by the researcher by phone, all of them decided to participate. Six partners decided to participate as well.

Inclusion criteria for patients were: (1) aged 18 years or older, (2) diagnosed with TIA or stroke on the Stroke Unit at the MST, (3) discharged home after hospital admission, and (4) mild cognitive impairments present at six weeks post-stroke. In the overarching study, mild cognitive impairments have been screened with the Montreal Cognitive Assessment (MoCA). The MoCA measures eight different cognitive domains: visuospatial and executive functions, denomination, memory, attention, mental flexibility, abstraction, language, and orientation (Nasreddine et al., 2005). A score between 26 and 30 is considered to be normal. Potential participants were selected based on a score of 24 or lower, indicating at least mild cognitive impairments six weeks post-stroke. Furthermore, potential participants were selected based on their score on the Ekman 60 Faces test. This is one of the two tests belonging to the Facial Expressions of Emotion: Stimuli and Tests (FEEST), whereby stroke patients' ability to recognize facial expressions was measured (Young, Perrett, Calder, Sprengelmeyer, & Ekman, 2002). The FEEST is a computer test in which patients have to choose which basic emotion label (happiness, anger, sadness, fear, disgust, or surprise) best describes the facial expression of a person on the picture (Young et al., 2002). The test consists of 60 pictures and investigates the patient's ability to visually perceive emotions (Cooper et al., 2014). A score between 42 and 60 is considered normal. Therefore, patients with a score of 42 or below were selected. Since the data of the MoCA and FEEST had been documented before the interviews started, these data guided recruitment of potential participants. Exclusion criteria were: (1) residing in a rehabilitation center or nursing home, (2) insufficient language and cognitive abilities to participate in a verbal interview, or (3) inability to give informed consent.

2.3 Procedures

To assess patients' healthcare and support needs and partner's support needs concerning mild cognitive impairments after stroke, in-depth interviews were conducted amongst ten patients and six partners. Stroke patients and their partners were interviewed separately, as perceptions of the patient's cognitive impairments amongst spouses may vary, so that participants do not feel constrained by the partner's presence (Dowswell et al., 2000; van Heugten et al., 2007). Purposive sampling was applied to approach patients and partners to participate in this study. Participants who met the inclusion criteria and also gave permission to be contacted by the researcher were approached by phone to set a date for the interview. Subsequently, the interview was conducted in the home environment of the participants, three months after discharge from hospital. Previous research stressed that in the first three months post-stroke, patients are still mainly focused on functional recovery and not so much on neuropsychological impairments (Hochstenbach et al., 2005; Renjen et al., 2015). The interviews were conducted between April 24th 2017 and May 26th 2017. The duration of the interviews was estimated to be 60 minutes maximum. Besides, the participants chose the time of day for the interview, whereby common consequences of stroke were taken into account, such as fatigue and short attention span. Participants were informed about the aim and nature of the study, confidentiality of personal data, and their right to refuse to participate at any time during the interview. Before the interview started, participants read the information letter (Appendix A). After reading the information letter, informed consent was signed (Appendix B). The interviews were recorded with an Olympus WS-853 voice recorder. The interviewer asked straightforward and comprehensible questions, considering potential mild cognitive impairments in the patient. Open questions were used, so that the interviewer did not direct the content of the participant's answer. Also, this enabled participants to address personally relevant issues in as much depth as they wanted.

2.4 Materials

To find an answer to the research questions, semi-structured interview guides were developed for the patient and for the partner (Appendix C and D respectively). The interview guides were based on questions of existing questionnaires for quantitative measures, questions of the neuropsychological intake of the MST, and literature on previous qualitative studies (focus groups and semi-structured individual interviews) amongst stroke patients and informal caregivers (Dowswell et al., 2000; Hochstenbach et al., 2005; Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008; Visser-Keizer et al., 2002). In an iterative process with other researchers, the interview guides were adapted.

The interviews for patients began with general questions, such as *'Welke klachten of gevolgen merkt u nog van de beroerte?'* ('Which complaints or consequences of stroke do you currently experience?'). The next two questions focused more on experienced cognitive impairments. First, a general question was asked: *'Wat merkt u van problemen in het denken?'* ('What difficulties in thinking do you notice?'). After this, the researcher asked about specific aspects of cognitive impairments, such as difficulties in memory and attention or concentration. The second question concerned experienced changes in behavior or mood after the stroke. The third part of the interview concerned coping strategies of the patients: *'Wat vindt u moeilijk of zwaar? Wat gaat juist beter dan verwacht?'* ('What do you find hard or difficult? What is going better than expected?'). The fourth part of the interview addressed potential changes for the partner and changes in spousal roles. The two following parts of the interview assessed healthcare received in hospital and healthcare received after discharge. To illustrate, patients were asked which help or guidance they received during their hospital stay and after discharge, and whether they felt the need for different or additional healthcare: *'Welke begeleiding heeft u tijdens de ziekenhuisopname gekregen?'* ('What assistance did you receive while in hospital?') and *'Wat heeft u daarin gemist? Wat had u graag anders gewild?'* ('What did you miss in it? What would you have liked to be different?'). Furthermore, patients were asked what information they received on cognitive consequences of the stroke. The final part of the interview consisted of patients expressing their thoughts about a variety of existing interventions, divided into four categories: information, training and education, peer contact, and tools (Appendix E). Informative interventions concerned a brochure or information folder, an informative meeting, and a website to retrieve information from. Interventions with a training or education function concerned the intervention '*Niet rennen maar plannen*', advice and guidance, time pressure management training, and goal management training. Peer contact concerned face-to-face contact with peers, and online contact via a forum. Tools to help patients adapt to cognitive consequences concerned apps on smartphone, electronic agenda, planning board, smartwatch, online grocery list with pictures, online goal management assistance, and online step-by-step recipes. Furthermore, patients' preferences for face-to-face or in person versus eHealth interventions were assessed. Patients were asked why this specific intervention would be useful to them, and why they would or would not use it in case they had needed it: *'Zou dit u kunnen helpen? Waarom was dit wel of niet iets voor u, als u het nodig had gehad?'* ('Could this help you? Why would or would this not be suitable for you, if you had needed it?').

Interview questions for the partner were for a large part equal to the interview questions of patients. First, general questions were asked, after which cognitive consequences were addressed. Then, the interviewer asked what these consequences meant for the partner: *'Wat betekenen de veranderingen in denken, gedrag of stemming bij uw partner voor u?'* ('What do changes in thinking, behavior, or mood of your partner mean to you?'). The third part of the interview assessed the changes for the partner and the caregiving role of the partner: *'Wat vindt u moeilijk bij het zorgen voor uw partner? Waar bent u juist tevreden over?'* ('What do you find difficult in caring for your partner? What are you satisfied with?'). As in the patient's interview guide, partners were asked about healthcare received in the hospital and healthcare received after discharge. An additional question was which information they received that was specifically aimed at the partner, as potential caregiver. The final part of the interview consisted of partners expressing their thoughts about a variety of existing interventions, divided into four categories: informative interventions, education/training, peer contact, and interventions for support in daily life (Appendix F). Same as the patients, informative interventions concerned a brochure or folder, an informative meeting, or retrieving information on a website. Education and training concerned the interventions '*Houvast, voor elkaar*' and advice and guidance. Peer contact concerned face-to-face contact with peers, and online contact via a forum. Support in daily life concerned emotional support, practical support at home, and respite care. Partners were also asked why they would or would not use a certain intervention.

2.5 Data analysis

Data analysis began after twelve of sixteen interviews were completed. The patient interviews lasted between 31 and 84 minutes. The partner interviews lasted between 15 and 62 minutes. However, in three situations the partner gave some responses during the patient's interview. First, all the recordings of the interviews were transcribed. Transcription of all recordings of the interviews resulted into 121 pages of text. To store, retrieve and organise data, transcripts were transferred to Atlas Ti 8. First, the transcripts were systematically analyzed, as the data of 10 patients and 6 partner interviews were divided into three sections, based on the three research questions. Open coding of the data was applied, as rough data were divided into experienced consequences, patients´ healthcare needs, and partners´ support needs. Second, data were assigned to categories within the research questions, using the structure of the interview guides. This resulted in four main categories: (1) experienced (cognitive) consequences of stroke for the patient, (2) experienced consequences of stroke for the partner, (3) healthcare and support needs of patients, and (4) support needs of partners. Subcategories are discussed in the results section. Appendix G includes coding trees to represent the themes, categories, and subcategories in a schematic manner.

Credibility of the data analysis was enhanced by deploying two other coders. First, the coders checked accuracy of the transcripts. Identifying data were removed to avoid recognition of participants. Consensus coding was undertaken by the researcher and two coders with three of the transcripts of patients' interviews and two of the partners' interviews, independently coding the transcripts and discussing their analysis. In case of disagreement, the three coders discussed the issue with each other until consensus was reached. Thereby, consensus was reached through an iterative process of comparison and discussion. Preliminary results were discussed with the research team, to consider alternative interpretations of the data and to increase accuracy of the coding procedure. This way, codes and categories were verified and validated. To secure reliability of the analysis of the interviews, interrater reliability was measured using Cohen's Kappa. Three randomly selected patient interviews and two partner interviews were analyzed by the researcher and two other coders. This resulted in a mean Cohen's Kappa of 0.93, indicating a large agreement between coders. After consensus was reached between three coders on three patient interviews and two partner interviews, the other interviews were coded. The results section contains tables that represent the categories and subcategories. Also, a clarifying citation was added for each subcategory.

3 Results

3.1 Research population

Ten patients were included. Demographics of participants are presented in Table 1. Median age of patients was 69.5 years (IQR = 65;73) and only one patient was female. Eight patients lived with a partner. Eight patients were retired. Median stay in hospital was one day (IQR = 1;4). Interestingly, five patients already had history of cardiovascular disease before the stroke. Seven of the patients had an ischemic stroke. Median score on Montreal Cognitive Assessment (MoCA) was 24 (IQR = 22;27) six weeks after stroke. A score of 24 or below indicated presence of mild cognitive impairments six weeks after stroke. Median score on Facial Expressions of Emotion: Stimuli and Tests (FEEST) was 40.5 (IQR = 38;44) six weeks after stroke. The FEEST measures a patient's ability to interpret the feelings or emotions of others. Patients scored lower than 42 on the FEEST, indicating mild impairment in the ability to visually recognize basic emotions.

Six partners were included. Median age of partners was 70.5 years (IQR = 56;81) and five partners were female. Four partners were retired. Four partners reported to be in good health. Two partners had history of cardiovascular disease.

Table 1. Demographics of participants

Patient	**Age**	**Sex**	**Diagnosis**	**Length hospital stay**	**Previous cardio-vascular diseases**	**Retired**	**Score MoCA**	**Score FEEST**	**Living with partner**	**Partner interviewed**	**Additional information**	**Age partner**	**Sex partner**	**Partner retired**	**Partner previous cardio-vascular diseases**
A	60	M	TIA/Minor stroke	1 day	Aneurysmic dilation arteria iliaca communis both sides	no	28	43	yes	Yes		55	F	No	No
B	68	M	Ischemic stroke	1 day	No	yes	27	57	no	No		-	-	-	-
C	65	M	TIA	1 day	Hemorrhage (2004)	yes	19	39	no	No		-	-	-	-
D	80	F	Ischemic stroke	4 days	No	yes	18	44	yes	Yes		81	M	yes	Heart infarct
E	69	M	Ischemic stroke	1 day	No	yes	23	30	yes	No		-	-	-	-
F	71	M	Ischemic stroke	4 days	No	yes	24	37	yes	No		-	-	-	-
G	64	M	TIA	2 days	No	no	22	46	yes	Yes	Multiple TIA's the weeks before	56	F	no	No
H	82	M	Ischemic stroke	5 days	Angina pectoris	yes	24	40	yes	Yes	Stroke occurred when hospitalized in cardiology for heart problems	81	F	yes	No
I	73	M	Ischemic stroke	0.5 day	Extensive cardiac history	yes	24	38	yes	Yes	Stroke occurred one month before appointment in hospital	69	F	yes	Stroke
J	70	M	Ischemic stroke	1 day	Myocard ischemie	yes	28	41	yes	Yes		72	F	yes	No

3.2 Experienced consequences of the stroke for the patient

In this section, the results of experienced consequences of stroke are given for both patient and partner. In paragraph 3.2.1, the experienced consequences of stroke from the perspective of the patient are given. Next, in paragraph 3.2.2, the consequences of stroke the partner observes in his spouse are given.

3.2.1 Patient perspective

Patients reported many different minor consequences they experienced after stroke. Experienced consequences concerned cognitive, physical, emotional, and social consequences. Besides, several coping strategies were reported.

Half of the patients stated they were uncertain about their diagnosis. Seven patients reported they had had a TIA, although only three patients had actually been diagnosed with a TIA.

> *"Ik bedoel, na die, ja ik weet niet of het een TIA is geweest hoor. Dat gokken ze gewoon."*

Patients experienced mild cognitive impairments with respect to memory, speed of thinking, attention or concentration, orientation in time or place, speech or language and planning or schedule (Table 2). Most impairments were experienced in memory, attention or concentration, planning or schedule, and speed of thinking. However, none of the patients found these consequences impeding in daily life. Interestingly, three patients were doubtful of these mild cognitive impairments being due to stroke, blaming another cause, such as old age, instead.

> *"Nou, niks eigenlijk. Neu. Ja, soms ben ik wel eens wat vergeten, maar ik bedoel, ik ben tachtig, dan heb je dat wel sowieso en dat was voor die tijd ook wel zo."*

Table 2. Experienced cognitive consequences from the perspective of the patient

Category	**Number of patients**	**Citation**
Impaired memory	5	En toen werd later ook nog wel een keer gezegd door dokter Brouwer hoe het zat. Al hoewel, die dingen die ben ik allemaal helemaal vergeten, wat er allemaal gezegd is. Wat ‘ie allemaal gezegd heeft. […] En ja, dat ben ik dan allemaal kwijt. Dat weet ik niet meer.
Decreased speed of thinking	4	Eeh… het zo snel omdenken, dat heeft een beetje met die beroerte te maken, dat het niet zo heel snel loopt. Op zich valt het wel... *Het leerproces is nog bezig.* Ja, het loopt nog, dat is nog bezig.
Decreased attention / concentration	5	Aandacht. Ja, aandacht is er wel. En concentratie. Dat valt me een beetje op zeg maar met krant lezen. Voor die tijd, wanneer ik een krant onder handen had, dan kon ik hem helemaal uitpluizen, en nou ben ik wat ongeduldig. Dan ga ik er een beetje meer in, overheen, en op een bepaald moment is het ook genoeg, en dan heb ik hem half uit en normaal dan heeft het zoveel aandacht dan weet je gewoon: dat wil ik gelezen hebben. Dus dat, een beetje een concentratiegebrek of, ik weet niet hoe je dat noemt hoor.
Impaired orientation in time / place	1	Ja, u noemt wel een punt. Ehm. Wanneer ik, hoe moet ik dat zeggen, hoe omschrijf ik dat ... wanneer het bijvoorbeeld gaat over een bepaalde plaats wordt genoemd, en of we gaan naar een bepaalde plaats, dan was het voor de tijd zo dat ik het zeg maar, m’n oriëntatie was zo in orde, dan gaan we van daar naar daar en zo. En nou, loopt dat een beetje stroever. Nou moet ik heel goed noemen, wordt er een bepaalde plaats genoemd, ja, hoe kom ik daar precies zeg maar. En dan is het… ja… de de de… dat wat vroeger vlot ging zeg maar, dat gaat nu wat lastiger.
Impaired speech / language	1	Nee, met de TIA speelde zich in de mond af. De kaak, het praten. Ik kon wat goed zeggen, sommige woorden kon ik goed zeggen en sommige woorden kon ik niet goed zeggen.
Decreased planning / scheduling skills	4	Ja, planning. Je, je, wilt af en toe wel eens wat en dan stel je het uit. Dat bedoel je dus. Zoiets. Ik sta er aarzelend tegenover zal ik zo zeggen. Geen overzicht.

An overview of experienced physical consequences from the perspective of the patient is given in Table 3. Reduced energy level and increased fatigue were important physical consequences expressed by seven patients. Physical impairments mainly led to inability to carry out activities or hobbies the way they used to.

Table 3. Experienced physical consequences from the perspective of the patient

Category	**Subcategory**	**Number of patients**	**Citation**
Physical activity	Unable to engage in hobbies	3	Ja, lezen ik mag graag lezen en puzzelen. Maar ik zeg ook wel, dat als je niet meer zo goed kunt zien dan heb je er iets meer problemen in. Ik moet het geregeld wegleggen en gewoon even de ogen rust geven en dan kan je weer even verder.
	Physical impairments due to stroke	5	Het lopen gaat nog steeds een beetje moeilijker. Dat is nog niet zo als voor de tijd.
Energy level	Less energy	5	Ik ben wel vind ik, veel moeër geworden als ik wat doe. […] Ik heb na dat herseninfarct heb ik wel het gevoel dat ik veel moe ben, dat ik niet meer de capaciteiten heb wat ik voor die tijd had.
	Adjusting to current energy level	2	Ja, ik weet het niet. Ik ben dus gewoon weer bezig gegaan en op een gegeven moment heb je je limiet, en dan ga je zitten. Maar afstanden lopen, dat eh... nee. Tien minuten, kwartier. Dat zit je zo uit te pluizen van wat gaat goed.
	Increased fatigue	5	Ja, wat ik zeg, wat ik over heb gehouden is vermoeidheid. Dat wel. Ik was zo vermoeid dat ’s morgens, als ik tandenpoetste, pff. Nou, en de schoenen dicht knuppen vind ik ook altijd zo’n, als ik de schoenen aan trek en voorover buig en dan denk ik, dan ben ik helemaal op.

Emotional consequences were expressed by patients by means of worries and feelings of loss (Table 4). Eight patients reported their worries increased after stroke, including worries about health in general, worries about second stroke, and uncertainty about skills or abilities.

Seven patients reported they experienced feelings of loss with respect to their abilities or capacities before stroke. One patient stressed that the loss of some abilities also caused a reduction in joy of living. Four patients reported positive feelings, such as relief about the prosperous recovery, and being less worried after the stroke.

Table 4. Experienced emotional consequences from the perspective of the patient

Category	Subcategory	Number of patients	Citation
Worries	About health in general	2	Ja, het realiseren dat je iets gehad hebt en dat je dus wel er wat anders tegenaan kijkt. Dat je wel heel goed moet oppassen dat je gezond blijft en dat ik daar ook naar moet leven, om het zo maar eens te zeggen. Je realiseert je heel goed van, oeh, ik heb iets gehad wat best ingrijpend is geweest.
	About second stroke	2	Nou, toen dacht ik even iets van dat is ’s morgens wat licht in het hoofd voelde. Maar toen las ik de bijsluiter van de medicatie, denk ja, dan kan het ook daarvan komen. Maar dat maakt het wel even spannend, dat je denkt, wat hoort bij wat.
	Uncertainty about skills / abilities	4	Nou, doordat ik slecht ben gaan zien, onzeker. Ja, je durft niet meer. Dus ik heb altijd van alles gedaan, maar ik durf niet meer op de trap en al dat soort dingen nee.
Feelings of loss	Abilities / capabilities	7	Je wordt een stukje teruggeworpen door dat. Dat is toch even weer terug naar af, in een keer wordt je dan geconfronteerd met de spraak en niet dat ik van slag was, maar in elk geval, hoe moet ik dat zeggen, ik heb het gevoel dat je weer overnieuw kunt beginnen.
	Reduced joy of living	1	Nee. Maar het is ook verschillend, de ene dag bij de andere dag. De ene dag heb je wel meer conditie en meer leven, hoe moet ik het zeggen, zie je het meer zitten. En soms heb je dagen dan zie je het eigenlijk niet zitten. Dan denk ik: nou, het is me allemaal even hetzelfde, ik vind het allemaal wel goed.
Positive feelings	Relief	3	Nee, ik moet zeggen, het heeft zich dan voorgedaan, het is dus een geval op zich, maar ik vind dat we er redelijk goed onder weg zijn gekomen.
	Worry less after stroke	2	Problemen in het denken... ja, ik denk eerder maakte ik me meer zorgen, ik denk wat makkelijker. Ik denk allemaal, ja, laat maar lopen. Ik maak me niet overal meer zorgen om. […] Ik wil niet meer die sores aan m’n hoofd, niks, zo weinig mogelijk.

For many patients the stroke also caused social consequences, both within the environment and within the spousal relationship (Table 5). Three patients avoided certain activities or crowds, as they felt overwhelmed with stimuli. Furthermore, because of reduced energy or not being able to be in a crowded environment, a social consequence for several patients was to prioritize and reduce social activities. Four patients reported they received social support from the environment.

Relational consequences were experienced by seven patients (Table 5). Five patients felt supported by their partner. On the other hand, two patients felt as if their partner was unable to empathize with what he or she was going through. One patient reported he received support from his partner, but also felt lack of understanding from his partner in some situations.

Table 5. Experienced social consequences from the perspective of the patient

Category	**Subcategory**	**Number of patients**	**Citation**
Environmental	Avoiding crowds / activities	3	Ik moet ook niet die drukte om me heen, moet ik ook niet. Hou ik ook niet van. Ja, gewoon drukte, als je komt in een of andere, ja wat wou ik zeggen, als er wat te doen is, een activiteit waar een hoop mensen zijn, dan voel ik me niet happy. Ja, dat is wel meer toegenomen. Eerder zocht je het meer op en nu als het kan ontloop ik het.
	Prioritizing scheduled activities	3	Ja, planning. Je, je, wilt af en toe wel eens wat en dan stel je het uit. […] Ik sta er aarzelend tegenover zal ik zo zeggen. Geen overzicht.
	Support from environment	4	Er wordt informatie ingewonnen, vanuit de vriendenkring en de bekendenkring. […] Dus, daar hou je contact mee, met je gemeenteleden en ze zijn geïnteresseerd in je, al of niet, maar ze praten met je. En dat is heel erg belangrijk.
Relational	Support from partner	5	Ahum ja, eigenlijk eh. Mijn vrouw heeft ook redelijk ervaring. Dus we hebben goed steun aan elkaar.
	Incomprehension from partner	3	Kijk, zij heeft genoeg conditie en dan houdt ze niet rekenschap mee dat ik minder heb. Dat merk ik wel.

Coping strategies, the way in which the patient coped with experienced consequences of stroke, were appointed as well (Table 6). Some patients explicitly mentioned their way of coping with minor experienced consequences, whereas others did not indicate this so clearly.

Four patients mentioned non-adaptive coping strategies, such as denial and avoidance. Three patients denied presence of potential consequences. One patient stressed he deliberately tried to ignore the fact that he had had a stroke. Two other patients tried to avoid reading information about or thinking about stroke.

Eight patients reported adaptive coping strategies, such as acceptance and adjustment. Six patients actively worked on acceptance of stroke and experienced consequences, such as having to change aspects of their lifestyle and not being able to engage in certain activities anymore. Seven patients mentioned that they try to adjust to their current situation, such as finding alternatives, taking it easy, and slowly building up one's condition.

Social comparison was mentioned by four patients, in a positive manner. These patients compared their own situation to that of others who had had more severe stroke, more sequelae after stroke, or who had other health problems. Therefore, patients felt like they were better off than others. Two patients mentioned that health deteriorates when you get older, therefore, they felt relatively positive about the minor consequences they experienced.

Table 6. Coping strategies from the perspective of the patient

Category	Subcategory	Number of patients	Citation
Non-adaptive coping	Denial	3	Nee. Piekeren doe ik helemaal niet. Ik laat alles aan mij voorbijgaan. Ik kan heel goed, tja, hoe moet je dat zeggen. Heel goed van me af zetten.
	Avoidance	2	Nee. Soms denk ik, hoe minder je weet hoe beter het is. Je kunt ook teveel. […] Ik denk je moet ook niet teveel weten, want daar wordt je helemaal ziek van.
Adaptive coping	Acceptance	6	Hoe ik ermee om ga? Wat ik kan doen dat doe ik. En wat ik nog niet kan dat moet maar achterwege blijven. Je zult het moeten accepteren, ja. De ene keer gaat dat makkelijker dan de andere keer. Je hebt geen andere keus. Je kunt wel denken van ik wil het zo, maar het moet allemaal wel kunnen.
	Adjustment	7	Je doet wat minder. En je probeert het uit. Je past je aan naar de omstandigheden. Dat kun je niet van tevoren incalculeren.
Social comparison	Positive social comparison	4	Nee maar, daar bedoel ik dus mee, dat je dus een klein stukje inlevert, ik bedoel, als ik zie, mijn vader heeft ook een beroerte gehad en ja, het kan allemaal veel slimmer.
	Comparing to old age	2	Ik weet niet of er wat beter gaat. Nee, ik denk dat het allemaal minder wordt geleidelijk aan. Dus dat heeft gewoon met leeftijd te maken.

3.2.2 Partner perspective

Partners also observed several consequences of the stroke of their partner. Observed consequences concerned minor cognitive, physical, emotional, social and behavioral consequences. Furthermore, coping strategies were identified. Five partners stated they do not observe or notice any consequences of the stroke of their partner in daily life anymore, three months post-stroke. Two partners mentioned that observed consequences after discharge in general might be characteristics of the patient’s personality that became more present or less present after stroke. On the other hand, they also mentioned they might have an increased alertness or focus on certain traits of the patient. Therefore, they stressed that these characteristics might not actually have changed, rather the partner tends to be more focussed on these characteristics after stroke. Moreover, three partners noticed that they have their doubts whether these minor consequences are due to the stroke or due to old age.

With respect to recovery of the patient after three months, five partners indicated that they were positively surprised by the speed of their partner’s recovery. Also, four partners mentioned they think their partner will not recover any more than they did so far.

> *"Ja, ik vind dat hij al enorm van hersteld is. Nou, van die TIA, ik denk dat hij daar al behoorlijk van hersteld is. Ik heb niet het gevoel dat daar nog wat verder, verder herstel mogelijk is. Ik vind in die zin dat 'ie, ja, geheugen daar zijn nog wel eens dingen."*

Several mild cognitive impairments following the stroke were observed by the interviewed partners (Table 7). Partners largely refer to the same cognitive consequences as patients. Interestingly, partners described observed minor cognitive consequences in more detail than patients. Mild impairments in memory were addressed by three partners, although they were not sure if this was caused by the stroke. Two partners observed that their partner had a reduction in speed of thinking. Impairments in attention or concentration were mentioned by three partners. Difficulties in orientation in time or place and coping with too many stimuli were indicated by two partners. Three partners associated these mild cognitive consequences with old age rather than with stroke. Just like patients, partners also found that cognitive impairments were not present to such an extent that they were obstructive in daily life.

Table 7. Observed cognitive consequences from the perspective of the partner

Category	Number of partners	Citation
Impaired memory	3	Wil nu nog wel eens gebeuren, dingen weer herhalen. En daar reageer ik dan niet op van 'oh dat heb je al verteld', want daar krijg je alleen maar irritaties van en dat moet natuurlijk niet.
Decreased speed of thinking	2	Vooral in het begin, soms nu ook wel, in de snelheid waarmee je kunt denken. Dat hij even dingen niet helemaal kon volgen of dat ik een beetje ongeduldig werd van, nou dat is toch wel logisch. En dat had dan toch net iets meer tijd nodig of iets meer stapjes nodig. […] En soms moest dat, vooral in het begin, toch wel even verduidelijkt worden.
Decreased attention / concentration	3	Dat is wel minder vind ik. Dat hij vaak in zichzelf zit. Dat hij niet bij een gesprek is helemaal. En dan vraag ik ook wel: krijg je het mee, of luister je wel? Maar dan is hij er niet altijd even bij.
Impaired orientation in place / time	2	Want op een gegeven moment, in het begin was hij helemaal de weg kwijt in de slaapkamer. Toen moest ie naar de wc, had hij ernaast geplast. Dat was echt in het begin ook.
Impaired speech / language	1	In het verwoorden van dingen, dat moet ik zeggen, daar komt hij niet zo heel goed meer uit, als hij wat moet vertellen. Dan is het allemaal een beetje zo van, ja, hoe moet ik dat ook weer doen. Dat is wel een beetje de warrigheid die erin zit. Niet zo goed dingen meer op een rij krijgen.
Decreased planning / scheduling shills	1	Planning is eh… heb ik het idee dat dat moeilijker is. Als hij wat wil, dan moet het nou af en dan kan het niet wachten tot morgen. Dus ja.
Impaired problem solving abilities	1	Ja, nogmaals of het is gemakzucht, want soms denken wij voor hem. Want het is heel gauw van dat kan niet of dat gaat niet en euh terwijl hij toen, toen was nooit wat een probleem en dat deed hij gewoon.
Decreased initiative	1	Zoals het nu is, is het een heel stuk beter, maar ik merk inderdaad dat hij geen initiatieven meer neemt, nauwelijks.
Impaired stimuli processing	2	En kort lontje is niet het goeie antwoord, maar toch kon je merken dat hij minder aankon dan daarvoor. En dan ook met prikkels en dergelijke, veel sneller zo iets had van ho stop, nou is het genoeg.

Five partners addressed physical consequences of stroke of their partner (Table 8). Most observed impairments were reduced energy level and increased fatigue, which corresponds to the experiences reported by the patients. Furthermore, half of the partners thought these physical consequences were caused not only by stroke, but partly because of old age as well.

Table 8. Observed physical consequences from the perspective of the partner

Category	Subcategory	Number of partners	Citation (age)
Physical activity	Unable to engage in activities / hobby's	1	Doordat, ze gaat slecht zien dus. En dan in een keer legt ze de boel aan de kant, want ze had nogal heel wat hobby's en ja, dat stoort me wel eens, dat vind ik zo jammer, dat dat in één keer helemaal weg is.
Energy level	Less energy	4	Ik heb niet echt het gevoel dat hij problemen ervaart. Hij heeft in het begin was wat hij wel als grootste probleem ervaarde was dat z'n energie gewoon een stuk minder was. Dat hij veel sneller moe was, dat hij veel minder aankon.
	Increased fatigue	2	Wat ik zeg, hij is alerter. […] Ik vind hem nou beter te pas als voor een tijd terug. Ja. Alleen hij is héél moe.

Emotional consequences for the patient were only mentioned by two partners. They felt like their partner was more uncertain about his abilities.

> *"Onzeker is. Dat hij denkt dat hij het niet weet, terwijl hij het misschien wel weet. Naar de bekende weg vragen. Gewoon de zekerheid dat hij het wel goed heeft."*

Five partners addressed minor social environmental consequences they observed in their partner. Two partners mentioned that their partner is less able to participate in crowded social activities, such as meetings or birthdays. Five partners stressed that they can always count on help or support from close friends and relatives when they request support.

Non-adaptive coping strategies such as avoidance and denial were mentioned by two partners (Table 9). These partners felt like the patient was denying the stroke had any consequences for their way of living. Adaptive coping was reported by five partners. Three partners observed a process of acceptance in their spouse, for example accepting fatigue and having to take medication. Furthermore, three partners felt like their partner was adjusting to current abilities. With respect to positive social comparison, one partner felt like observed consequences of stroke of her partner were very mild, in comparison to sequelae she observed in other people with stroke.

All partners observed behavioral consequences in their partner after stroke (Table 9). Five out of six partners observed minor behavior change in their partner. Interestingly, none of the patients mentioned experienced behavioral changes. Five partners mentioned that their partner became more calm, pensive, and withdrawn in their own thoughts after stroke. Four of these partners also observed that their partner participated in conversations less after stroke. Other behavior changes were: less initiative, more neglectful, and more irritable after stroke.

Table 9. Observed behavioral consequences and coping strategies from the perspective of the partner

Category	**Subcategory**	**Number of partners**	**Citation**
Non-adaptive coping	Denial	2	Hij ontkent het gewoon. Op één of andere manier of, nee hij wil helemaal niet beseffen dat het ernstig is. Of zo doet hij zichzelf voor.
	Avoidance	1	Ja, dat is weer dat temperen. Dat hij dat dat niet nodig vindt. […] Maar hij vindt ook dat je mensen niet af kunt zeggen. […] We hebben bridgeclubjes en bridgen bij mensen in huis, dat werd hem allemaal teveel. En dan ga ik dat afzeggen, maar dat vind hij dan moeilijk.
Adaptive coping	Acceptance	3	Hij heeft wel moeten leren dat je dat soort beperkingen of problemen dat dat gewoon erbij hoort, dat die moeheid, dat die concentratie, dat soort dingen, dat dat niet gek waren. Ik denk dat het soms wel even wat gefrustreerd heeft.
	Adjustment	3	Eh, nou ja, goed, hij weet dat hij dingen wel eens vergeet. En, nou, ik vind dat hij er wel redelijk goed mee omgaat. Hij vindt het wel eens lastig, maar ja, het is niet anders. […] Hij gaat er wel goed mee om.
Social comparison	Positive social comparison	1	En de beperkingen zijn ook niet zodanig dat we er elke dag bij stil moeten staan. Kijk, als je er weet ik wat voor verlamming of wat dan ook of een deel van je zelfstandigheid door kwijt raakt, dan is dat heel wat anders dan dat je alléén maar moe bent en wat moeite hebt met prikkels. Dat maakt toch dat gewone dagelijkse dingen wat sneller door kunnen gaan.
Negative change in behavior	More withdrawn (calm or silent)	5	Dat hij vaak in zichzelf zit. Dat hij niet bij een gesprek is helemaal. En dan vraag ik ook wel: krijg je het mee, of luister je wel? Maar dan is hij er niet altijd even bij. Nee, dat was voor die tijd ook al wel. Maar dat vind ik nou wel, dat is eigenlijk wel iets erger geworden.
	Less initiative	1	Ehm. Welke gevolgen. Zoals het nu is, is het een heel stuk beter, maar ik merk inderdaad dat hij geen initiatieven meer neemt, nauwelijks.
	Neglectful	1	Hij is toch wel iets anders dan vroeger zeg maar. Niet veel nadelig, maar toch wel zo van, ja makkelijker.
	Irritable	1	Wat ik vertelde, het drukke. Gauwer boos. Zich gauwer ergens over opwinden. Dat is wel veranderd, vind ik.

3.3. Experienced consequences of the stroke for the partner

As stroke does not only have an impact on patients, partners were also asked what changes they experienced personally. In this paragraph, experiences and changes for the partner are given, first from the patients’ perspective in paragraph 3.3.1, followed by the partners’ perspective in paragraph 3.3.2.

3.3.1 Patient perspective

Patients observed several changes their partner had to deal with after stroke, concerning emotional and relational consequences and consequences for support and help and household (Table 10). Four out of ten patients felt like not much had changed for their partner emotionally. Three patients felt like their partner was more worried about them after stroke. One patient felt like his partner did not understand what he was going through, but also stressed that he felt like it was difficult for her to adjust to his current capacities. No relational changes were mentioned by patients, although one patient felt like there was a bit more distance in the relationship after the stroke.

Two patients expressed there were no changes in the amount of support or help offered by the partner. Four other patients mentioned that support and help increased after stroke, for example by talking with each other or attending a doctor’s visit together. Two patients also experienced more support from the partner, as the partner was more caring with respect to healthy behavior and compliance to advice from healthcare professionals. Two patients stated there were no changes in responsibilities in the household, whereas one patient confirmed that the partner had to do more in the household right after the stroke. However, after three months, the division of tasks is almost as it was before the stroke.

Table 10. Consequences for the partner from the patient´s perspective

Category	Subcategory	Number of patients	Citation
Emotional	No changes	4	Volgens mij niet. Het enigste, hij heeft heel veel moeten doen in het begin, overal voor moeten zorgen.
	More worried	3	Dat zij bezorgder is. Ze is echt bezorgd. In alles wat ik doe: doe maar rustig aan. En ze stimuleert zelfs dat ik even ga rusten of wat dan ook. Doe maar even rustig aan en doe niet zoveel. Dat is de zorg van haar.
	Incomprehension	1	Nee, daar is verder niks in veranderd. Ik zeg alleen, dat is het enigste, dat zij moet incasseren dat ik minder kan, minder conditie heb. Ik moet op tijd even rusten en zij denkt van je kunt zo verder, en dat kan niet.
Support and help	No changes	2	Nou, we ondersteunen elkaar de hele dag, dus. Nee, maar dat, z’n normale gang.
	More support and help	4	Ja, hulp best wel. Ze is met dingen ook wel mee geweest een keer, naar de cardioloog. […] Twee weten meer dan één en dat is het voordeel dat je dan met je tweetjes bent. Weet je nog wat je toen en toen gezegd hebt en zulke dingen. Kijk, dat voordeel heb je nou.
Household	No changes	2	Nee, die is hetzelfde gebleven. Ik deed heel veel in huis, de een doet waar de een goed in is en de ander, dus in de rolverdeling is geen verandering gekomen.
	Taking more responsibility	1	Het enigste, hij heeft heel veel moeten doen in het begin, overal voor moeten zorgen. In de huishouding. […] Maar ja, nou moest hij veel meer doen.

3.3.2. Partner perspective

Partners experienced several changes they had to deal with after the stroke, concerning emotional and relational consequences, and consequences for support and help and household (Table 11). Two partners mentioned that the sequelae of stroke are so mild and invisible, they sometimes forget the stroke had happened only three months ago.

Not many changes or consequences for the partner were directly associated with mild cognitive impairments of the patient. Concerning mild cognitive impairments, one partner mentioned that the slow thinking of her husband and repeating things made her impatient sometimes. One partner expressed feelings of loss, since his partner was not able to engage with all her hobbies anymore. Another partner described how she is the one that has to cope with her partner's stroke, making sure he takes his medication, that he gets enough rest and healthy food, since he is denying everything.

Regarding emotional consequences, two partners expressed their relief about the prosperous recovery. All partners stressed that they worried more about their partner's health after stroke. Interestingly, only three patients mentioned they felt like their partner was more worried about them. Two partners experienced an increased awareness in themselves about the fact that a stroke can occur at any time.

Four partners did not experience changes in the spousal relationship (Table 11). Three partners experienced a short change of roles within the relationship. Reported reasons for this were: having a more caregiving role, less depth in the relationship, and being the only one taking initiative. With respect to changes in help and support, two partners did not feel like there was a difference between before and after stroke. Three other partners mentioned they offered more help and support right after stroke, for example driving the car, motivating their partner to resume social activities, and cancelling activities. Two partners reported there was a temporary shift in the division of household tasks, although after three months it started to go back to the way it was before stroke. Two other partners did not experience any changes in the household tasks.

Partners expressed different ways of coping with minor consequences of their partner's stroke. Non-adaptive coping was mentioned only by one partner, who openly expressed his denial. Adaptive coping was mentioned by four partners. Three partners expressed they accepted the fact that the stroke caused some changes in their partner. They mentioned they take life the way it comes, without having too many expectations. Three partners mentioned they had to adjust their own behavior to the current abilities or capacities of their partner, such as cancelling scheduled activities or taking the lead in conversations with healthcare professionals.

Table 11. Consequences experienced by the partner

Category	Subcategory	Number of partners	Citation
Emotional	Feeling relief	2	Nou waar ik heel blij mee was is dat het zo is afgelopen zoals het is afgelopen.
	More worried	6	Ik heb er zelf niks, neuh. Ik was eerst gewoon een beetje angstig natuurlijk he, als hij dan even wat langer weg was. Ooh, gaat dat wel goed daar. […] Een beetje de waakhond gevoel wat je dan.
	Adjust to partner´s abilities	3	Nee. Weet je, het gaat allemaal goed en ik kan me er heel goed of ik kan er goed mee omgaan. […] Het is alleen, soms een pas op de plaats zetten.
	Increased awareness	2	Ik denk niet dat er nu nog heel veel anders is. Anders dan er bewust van zijn dat dit is gebeurd en dat heb je niet elk moment. Soms denk je er opeens weer aan, nou ja, er is wel wat gebeurd.
	Working on acceptance	3	Van de ene kant dat ik bepaalde dingen ook gewoon moest accepteren van dat hij als hij zich anders gedroeg, dat hij minder aan kon, dat zijn belastbaarheid toch wat geringer was. Dat had toch wel direct met die CVA te maken en dat moest ik wel als een soort gegeven zien, dat is soms wel eens lastig.
Relational	No changes	3	Ja, dat heeft helemaal geen invloed. Absoluut niet. We leven gewoon ons leven door, zoals het altijd is geweest.
	Shift in roles	3	Nou, ik vind het wel eens lastig dat ik overal initiatief in moet nemen. Dat vind ik wel eens lastig. Ik denk van, ik wou dat die ander dat eens deed. Daar heb ik het meeste moeite mee. Ik ben wel constant eigenlijk bezig. […] Hij vind het wel, hij laat het zich lekker makkelijk aanleunen allemaal.
Support and help	No changes	2	Nee hoor, nee, het is ook al weer een tijdje terug. Maar nee, ik kan niet zeggen van gut, wat een problemen.
	Offering more support and help	3	Eh... dat ik een pas op de plaats moet maken, dat hij dat zelf niet doet. Dus afspraken afzeggen, als het te druk wordt. Want hij vindt het dan vervelend, maar daar ga ik dat doen. Dus dat is wel veranderd. Dat ik dus toch wel het heft in handen moet nemen om afspraken af te zeggen omdat ik weet dat het dan gewoon niet gaat. Dan is het teveel.
Household	No changes	2	Ja, we doen gewoon ons dingetje en daar is niks in veranderd. We zijn samen doen we de huishouding en dat hebben we ons hele leven gedaan.
	Taking more responsibility	2	Dat was in het begin niet, maar nou pakt mijn man ook weer alles op. Dus er is eigenlijk weinig veranderd. Dus dat is eigenlijk allemaal weer op het ouwe niveau, zoals we het altijd deden.

3.4 Healthcare and support needs of patients

In this section healthcare and support needs of patients are presented. First, evaluation of received and non-received healthcare from the patient’s perspective is given in paragraph 3.4.1, followed by evaluation of existing interventions in paragraph 3.4.2. Next, evaluation of received and non-received healthcare from the partner’s perspective is given in paragraph 3.4.3.

3.4.1 Patients’ evaluation of received and non-received healthcare

To assess healthcare and support needs of patients concerning mild cognitive impairments after stroke, both received and non-received healthcare during hospital stay and after discharge were evaluated (Table 12). Non-received healthcare refers to healthcare patients felt was missing or insufficient during their hospital stay and after discharge. When specifically asked about healthcare concerning mild cognitive impairments, all patients mentioned they did not receive any information about potential cognitive impairments after stroke. Five patients stated that information about cognitive consequences was not needed, because of the minor consequences they experienced from the stroke.

Healthcare received during hospital stay and after discharge was evaluated positively by all patients, although several themes about non-received healthcare arose. Admission to the hospital and treatment during hospital stay were perceived as positive and well-organized. Nine patients experienced minimal guidance or supervision by healthcare professionals during their hospital stay. However, they also stressed that received guidance or supervision was sufficient and no more was needed. Furthermore, these patients stressed they did receive minimal verbal or written information on stroke in general.

Several needs during hospitalization were not properly fulfilled according to patients. One patient mentioned his general practitioner did not recognize his symptoms of stroke, therefore, he only went to the hospital three weeks after the event. Another patient noticed an inconsistency in dietary advice, as the doctor told him to eat less salt, after which he was offered a salted herring and French toast. Three patients noticed information sharing about medication was not transparent or clear to them. Two patients reported that their medication had changed, but they were not informed about it themselves. For another patient the medication dosage had to be lowered due to low blood pressure. However, this was not communicated to the next shift of nurses. Inaccurate consult preparation of healthcare professionals was mentioned by two patients. To illustrate, a healthcare professional did not read the patient’s file before the consultation started and therefore was not up-to-date about the patient’s situation and received healthcare.

Table 12. Evaluation of received and non-received healthcare in hospital from the patient's perspective

Category	Subcategory	Number of patients	Citation
Information on cognitive impairments	No information on cognitive impairments received	10	Informatie over problemen in het denken. Nou, eigenlijk niet. Om te zeggen van daar moet je op een bepaalde manier mee aan de slag. […] Maar ik heb dus verder geen foldertjes of toestanden meegekregen.
General practitioner	GP did not recognize symptoms of stroke	1	We wisten wel dat er wat aan de hand was. En toen hebben ze, want de dokter zelfs, de nieuwe arts, die heeft dat op dat moment niet onderkent. *Die zei gewoon: als u weer een erge hoofdpijn krijgt dan moest 'ie bellen.* Maar die heeft toen dus niet in de gaten gehad dat het een beroerte betrof. Ja, we vissen achter het net.
Healthcare received in hospital	Received healthcare minimal though sufficient	8	Nou, dat is allemaal niet zo heel veel geweest. […] En ja, begeleiding, er was niet zoveel begeleiding. Ja, die meneer ligt daar en die moet eten en drinken en dat heb ik allemaal netjes gehad.
	Inconsistency in dietary advice	1	[…] Want ik moest zoutloos, dus op een gegeven moment, of minder zout. […] 'Wilt u soms een zoute haring meneer?'. Dat is zo lekker. Maar ik denk: hoe lang ben jij hier al op deze afdeling?
	No transparency about medication	3	[…] Dan 's morgens dat ik 's nachts door heb gegeven, dat ze toch 's morgens kwam tussen half acht en acht uur met die medicatie. Dat die persoon niet wist dat ik 's nachts al gezegd had dat de bloeddruk zo laag was, dat de medicatie moest aangepast worden. En die persoon die wist nergens van. […] Ik zeg tegen die zuster: weet je nergens wat van? Nee, weet ik niet zegt ze. Nou, dat vind ik een beetje vreemd dan. Dan moeten ze zeggen van u hebt een overleg gehad, maar u moet toch eerst nog dat of dat doorgebruiken.
	Inaccurate consult preparation of healthcare professionals	2	Alleen, en de begeleiding, er was alleen een beetje, ik was pissig op de cardioloog. […] Ik had net daarvoor had ik een kastje een week gehad vanuit het ziekenhuis van de neurologie. Ik had onderzoek gedaan, bloedonderzoek was gedaan. En ik kom bij hem en hij zegt, nou, de neurologie wil graag hebben dat u nog even met een kastje een dag loopt en dat u nog even naar het laboratorium gaat en de fietstest. Ik zeg nou, nummertje één is pas gebeurd. Dat staat in het dossier denk ik wel. Toen keek hij erin: ja klopt. Nou dan denk ik, je hebt het dossier niet doorgelezen, jongeman. En daar heb ik moeite mee. Dan denk ik, ja, blijf erbij, als je een dossier hebt lees het dan eerst even kort door wat er de laatste tijd gebeurd is.

Healthcare after discharge was perceived as minimal by half of the patients, although afterwards none of the patients felt like they had needed more healthcare (Table 13). Five patients stated they spoke to the stroke nurse, which was perceived as positive and useful. Two patients mentioned they were not contacted for a visitation with the stroke nurse, which they would have liked. Besides, the cognitive tests at the psychologist (as part of the overarching study) were also evaluated as aftercare by three patients.

Several unmet needs concerning healthcare after discharge were mentioned by patients. Insufficient guidance and involvement after discharge was noted by three patients. Two patients expressed a need for more involvement of healthcare professionals after discharge. Even though afterwards more aftercare appeared to not be necessary, these patients would have liked to receive a check-up from a healthcare professional, in order to evaluate how things are progressing after the stroke.

Three patients stressed they were supposed to receive a call from a homecare organization, where someone would take a look at their current situation and assess whether they need support in daily life. However, these patients reported they were not contacted by the organization. Even though it appeared not to be necessary, these patients stressed it would have been nice and reassuring. Two patients reported they would have liked to be contacted by the homecare organization as was promised. Three patients stated they were uncertain about when they were allowed to drive a car again. One patient mentioned it was a coincidence he even found out he could not drive a car for a few weeks. Another patient was surprised that there was not a note or remark on his driver's license, stating he was not allowed to drive until a certain date. The third patient mentioned that he could not drive for a while, but no one told him for how long he could not drive.

Finally, seven patients expressed a gap between information provision and availability, and information needs. Two patients reported lack of information sharing by healthcare professionals. For one patient it was not clear when he was allowed or able to start exercising again. Another patient had to do bike tests to measure his heart capacity, but results of these tests were not shared with him. He mentioned he would have liked to know whether his heart capacity was improving. Furthermore, one patient stated he found it difficult to retrieve the right information. Two other patients expressed a need for brochures or a personalized folder. Also, two patients stressed that they would have appreciated to receive information on cognitive impairments. Moreover, information on when one is allowed to drive a car again was an expressed need.

Also, even though patients felt they did not really need additional healthcare or support after discharge, two patients expressed it would have been nice to be informed about existing or available interventions, in case they would have felt the need for additional healthcare. One patient mentioned he would have liked to visit a consultation hour at the hospital or general practitioner in case he had questions.

Four patients initiated healthcare after discharge themselves to meet their personal needs. Two patients received job coaching after their stroke or TIA in order to integrate back into work. Three patients started physiotherapy by themselves. One patient started acupuncture and two other patients applied for assistance in household.

Table 13. Evaluation of received and non-received healthcare after discharge from the patient's perspective

Category	Subcategory	Number of patients	Citation
Healthcare received after discharge	Received healthcare after discharge minimal though sufficient	5	Ja, dat hebben we wel gehad. Dat vind ik goed. Je blijft wel onder controle. Je wordt niet aan je lot overgelaten, maar je staat gewoon onder controle.
	Visit stroke nurse positive and useful	5	Er is gebeld met over hoe het verder gaat. Nou, ik dacht, dat is toch keurige nazorg. Ik dacht een maandje. Van hoe het ging.
	No visit with stroke nurse	2	Nee er heeft niemand aan de bel getrokken zo verder, ik ben ook nergens geweest. Of ik ben het vergeten, dat zou niet best zijn.
Insufficient or non-received healthcare after discharge	Insufficient guidance or involvement after discharge	3	Begeleiding niks. 'Als je wat mankeert dan waarschuw maar even'. Maar voor de rest dus een echte begeleiding, dus van interesse en hoe is het ermee en ik kom even langs en hoe maakt u het en hoe is het nou met de gezinssituatie, nee. Hadden we ook niet nodig hoor, ten minste achteraf bekeken, laten we het zo stellen.
	Failed contact homecare organization	3	Maar ze hadden nog wel beloofd van, ik zou na die tijd nog huishoudbegeleiding krijgen van Livio. Toen ik ontslagen werd, dan zeggen ze dan: vind je dat goed dat er iemand langskomt voor begeleiding, voor in je huis kijken hoe het gaat en alles. Maar ik heb geen kip gezien.
	No clarity about driving	3	Nee. Toen ik wegging zei ik zo een beetje uit baloriheid van, moet ik mijn gedrag nu veranderen. Vroeg ik aan de verpleegster. En die zei van u mag zes weken geen autorijden. Dat had de neuroloog niet gezegd.
	Insufficient sharing of information	7	En ik weet ook niet hoe snel je weer kunt gaan sporten om maar eens wat te noemen. Ja, ik weet het niet, ik ben op die cardiofysio geweest en dan zetten ze je op zo'n apparaat en dan kan je kijken dus of je hem op 30 Watt kan houden bij wijze van spreken of dat je meer of minder kunt. Dat is het enige wat ze meten, ik weet niet wat ze met de gegevens doen, je hoort daar ook geen uitslag over van het gaat al beter dan de vorige keer of wat dan ook.
	Control consult general practitioner	1	Maar wat er dan voor de rest gezegd is, dat mis ik dan weer. […] Zo even langslopen dat gaat natuurlijk ook moeilijk want die zit ook met zijn spreekuur en z'n afspraken en z'n programma. Want de cardioloog had gezegd dat ik voorlopig wel even de boel in de gaten moet houden. Maar goed, hij zit in Enschede en ik kan niet zo even bij de huisarts binnen stappen. Van die kleine dingen, iets bekijken.

3.4.2 Patients' evaluation of existing interventions

Multiple interventions were evaluated by patients. Table 14 provides an overview of motives for and against the different interventions. Interestingly, all tools aimed to help patients adjust to mild cognitive impairments were evaluated as not needed or irrelevant by all participants (Appendix E). Therefore, these interventions have not been evaluated in depth by patients. The majority of patients was not aware of the existence of the presented education and training interventions and tools to deal with mild cognitive impairments after stroke.

Informative interventions that were evaluated concerned a folder or brochure, an informative meeting, and a website. Patients' opinions on informative interventions varied. Four patients mentioned they did not receive a brochure or information folder during their hospital stay. Only two patients mentioned they did receive information. None of the participants received verbal or printed information on cognitive impairments in general, even though some patients stressed that they would have appreciated to receive information on cognitive impairments. Half of the patients expressed a preference to use a brochure or folder to look for information about stroke. Four patients expressed a preference to search for information on a website. One patient would use both. Patients who favored a brochure felt like this offered a limited amount of information. Patients who favored a website liked the ability to search for information that is relevant for their personal, specific situation. However, half of the patients reported they had not felt the need to look for more information about (consequences of) stroke, given minor consequences they had experienced so far. The most mentioned reasons not to use the internet to retrieve information were a lack of experience with the technology and too much information available online. Concerning informative meetings, one patient went to an informative meeting once and evaluated this as useful. Three patients explicitly mentioned they did not currently feel the need to attend an informative meeting about stroke, since the experienced consequences of the stroke were not or hardly present.

Education and training was felt to be not applicable or too heavy for patients, as they experienced little to no cognitive consequences three months post-stroke. Six patients stated the intervention ‘*Niet rennen maar plannen’* might be interesting for people who experience more severe cognitive consequences post-stroke. Five patients mentioned that they currently do not need an intervention like this, as they do not experience cognitive consequences of stroke and they can perfectly manage themselves. Only one patient mentioned he might (still) be interested in an intervention like this. Two patients stressed they would not have the discipline or motivation to continue actively working on such an intervention. None of the patients felt like they needed additional advice or guidance during their process of recovery. Time pressure management training was assessed by four patients. One patient expressed interest in time pressure management training, whereas three other patients stressed that they did not experience any difficulties with time pressure management. Goal management training was not an issue for any of the patients, as they could still sufficiently conduct all tasks in daily life the way they used to.

Patients’ opinions on peer contact varied, although opinions were predominantly negative. Only two patients were moderately positive about contact with other stroke survivors, but did not currently feel the need for it. Though, one of them mentioned he might be interested in peer contact. Another patient mentioned he would not like to hear about other people’s struggles. Half of the patients were hesitant about peer contact, as they expected to feel uncomfortable being around other stroke patients with more severe sequelae. Four patients mentioned they did not feel the need for peer contact as they have their own people to turn to. They had acquaintances in their close environment who experienced health problems as well, which they evaluated as sufficient peer contact. Besides, one patient stressed she preferred to spend her time on other activities. The use of a forum was negatively evaluated by seven patients, with different motivations. Two patients did not feel the need to go on a forum, since they experienced little to no sequelae of the stroke. One patient mentioned he might consider going on a forum for peer contact, though only if he did not have a partner anymore. One patient stressed she did not want to focus attention on stroke anymore and therefore would not go on a forum. Another reason not to go on a forum, was because it required the use of computer technology. Only one patient expressed moderate interest in going on a forum. Three patients expressed a preference for in person / face-to-face contact, in case they would need additional information or support.

Most of the tools presented, aimed to assist patients with mild cognitive impairments, are delivered by eHealth, such as via a smartphone or tablet. Using apps on a smartphone was predominantly evaluated by patients as not suitable for them. Eight patients stressed they were not very much into the use of internet, smartphones, tablets, or computers in general. Eight patients did not have a smartphone at all or only used their smartphone to make calls and send texts. One patient was negative about use of smartphone applications, as he is unable to hold a smartphone in his hand due to physical impairments of a previous stroke. Two patients used their smartphone a lot in daily life. These two and one other patient also use an electronic agenda on their smartphone in daily life. Motivations for not using smartphone apps were: not having a smartphone in the first place and too little experience with technology. None of the patients felt like they needed a more structured planning board or schedule after stroke. Also, all patients stressed they did not need additional tools, such as a smartwatch or smartphone to remind them about their schedule or to take their medication. Furthermore, an app for an online grocery list with additional pictures was evaluated. None of the patients felt the need for this, as shopping with the partner still went the way it used to before the stroke. Online goal management assistance was also evaluated as not needed or irrelevant. The last online intervention aimed at cognitive impairment was an app with online step-by-step recipes. This intervention also did not match the mild or even absent cognitive impairments as experienced by the patients.

Table 14. Evaluation of existing interventions for patients

Application	Needs[a]	Motives pro	Motives con
Information			
Brochure / folder	High	• No folder or brochure received • Convenient to retrieve information • Easier to remember information from a folder • Limited amount of information	• No need for information
Informative meeting	Low	• Value information of experienced professionals	• No need
Website	Moderate	• Easy and quick accessibility • Retrieve personally relevant information	• Referrals to other sources • Too little experience with the technology • Not interested to do more than necessary online • The less you know the better • No need to retrieve information
Education/training			
'Niet rennen maar plannen'	Low	• Would use it if needed	• Not needed, due to little cognitive consequences • Too much commitment or time consuming
Advice and guidance	Low		• No need
Time pressure management training	Low	• Might be interesting to try	• No need • An entire training would be overdone
Goal management training	Low		• No need
Peer contact			
Peer contact meeting	Low	• Might be interesting to hear how other people cope	• Do not want to hear about other people's struggles • Do not want to be around people with worse sequelae • I have my own people to turn to • Would cause unnecessary worries • Waste of time
Forum	Low	• Would be convenient, as I am not much of a talker	• Not for me because it is online • Maybe if I was without partner • Preference for in person / face-to-face contact • Would not stay active on a forum • Do not want to pay attention to stroke anymore • Too impersonal compared to face-to-face contact • No need given no to little sequelae • Too much information available

(continued)

Table 14. Evaluation of existing interventions for patients (continued)

Application	Needs[a]	Motives pro	Motives con
Tools			
Apps on smartphone	Low	More positive about smartphone use than expected	Use smartphone as little as possible Unable to use smartphone due to physical impairment Do not own a smartphone
Electronic agenda	Low	Satisfied with electronic agenda on smartphone Convenient Easy accessible	No need given no to little sequelae Preference for paper agenda
Planning board	Low		No need given no to little sequelae
Smart watch	Low		No need given no to little sequelae
Online grocery list with pictures	Low		No need given no to little sequelae
Online goal management training	Low		No need given no to little sequelae
Online step-by-step recipes	Low		No need given no to little sequelae

a. Low: < 2 partners expressed need; Moderate: 2 – 4 partners expressed need; High: > 4 partners expressed need.

3.4.3 Partners' evaluation of received and non-received healthcare

Healthcare received during hospital stay and after discharge was also evaluated by partners (Table 15). Three partners shared their opinion about general practitioners with respect to stroke. One partner was very satisfied with judgment and quickly acting of their general practitioner, whereas another partner expressed her doubts about the knowledge of general practitioners on stroke. Another partner was not satisfied at all, since the general practitioner did not recognize the stroke as being a stroke, which influenced the course of healthcare.

Three partners expressed their satisfaction with healthcare they received in hospital. Furthermore, the specialized stroke unit at the Medical Spectrum Twente received much appreciation from two partners. Five partners mentioned they did not receive any information about stroke and potential cognitive impairments. With respect to information provision, one partner expressed the need to receive individual information focused on her as a partner, for example about what kind of consequences she could expect. One partner reported multiple needs that were improperly fulfilled during her partner's hospital stay, namely unsubtle communication over the phone, absence of a closing consult with a healthcare professional, and inconsistency in dietary advice. Another partner also mentioned that communication of healthcare professionals could have been clearer and delivered more carefully. To illustrate, one partner mentioned their appointment at the hospital was delayed a few hours and they were not kept informed about approximately how long they had to wait. Another partner reported that she received a blunt phone call from the hospital, informing her about her partner's stroke.

Healthcare after discharge was predominantly evaluated positively, although some comments were made by partners. In line with the evaluation by patients, two third of the partners also found that healthcare after discharge was minimal, though sufficient. All partners appreciated follow-up by a specialized stroke nurse. One partner felt like the healthcare professional was not open-minded about alternative medicine. Furthermore, two partners reported that they would have appreciated having an individual session with a social worker after a few weeks. One partner expressed the need for some more involvement or thoughtful completion at the end of the recovery process.

Table 15. Evaluation of received and non-received healthcare from the partner's perspective

Category	Subcategory	Number of partners	Citation
General practitioner	Positive about GP's guidance at time of stroke	1	En wat zij ook, de verzorging was ook prima, goed begeleid. Haar huisarts is een fantastisch mens. […] Nee, wat dat betreft heeft ze het prima begeleid.
	Doubtful about knowledge on stroke among GPs		Ik kan me situaties voorstellen dat je toch daar dan nog even tegen vragen aanloopt, die zou je dan bij de huisarts of zo kwijt moeten, maar niet alle huisartsen zijn even goed van alles op de hoogte.
	Negative about GP's recognition of stroke		Ik dacht toen, hij kwam met een erge hoofdpijn thuis, en omdat hij ook met migraine kwam, dacht ik dat kwam daarvan, verder niks. Die (huisarts) zei gewoon: als u weer een erge hoofdpijn krijgt dan moest 'ie bellen.
Healthcare received in hospital	Positive about healthcare received in hospital	3	Daar was ik gewoon wel heel tevreden over. Dat ging gewoon goed. Hij is er ook kort geweest natuurlijk. Maar ik heb dat toch echt wel als positief ervaren.
	Positive about specialized stroke unit	2	Maar dat er een aparte stroke afdeling is waar mensen ook heel specifiek op toegerust zijn, dat is gewoon heel erg prettig, omdat ze dan toch allemaal heel deskundig zijn en heel erg ingespeeld op wat patiënten dan nodig hebben, wat voor vragen ze hebben.
	No information on cognitive impairments	5	Nee want dat was niet in het denken, want dat was toen in orde, want het moest toch de tijd allemaal om te genezen. Nee, daar heb je verder niks voor gehad. […] Maar niet persoonlijk van dat of dat of dat. Dat is gewoon algemene informatie dat je hebt meegekregen.
	Unsubtle communication over telephone	1	Ja, ik werd 's morgens gebeld. Toen werd er dus heel plompverloren gezegd: uw man heeft een hersenbloeding gehad. […] Ik denk: praat toch niet zo lomp. Daar word ik een beetje kriegelig van, ik vind dat zo onzorgvuldig.
	Lack of closing / end consult	1	Nou eigenlijk hebben we dus een brief meegekregen vanuit het ziekenhuis over voeding en dat soort dingen. Maar verder hebben we ook geen eind gesprek gehad of zo. dat vond ik heel raar. In het ziekenhuis. Dat je niet een eindgesprek hebt.
	Inconsistency in dietary advice	1	Ik bedoel, hij kreeg nou een lijstje van voeding van zoutarm en noem maar op en hij ligt in het ziekenhuis: meneer wilt u een zoute haring. […] En met die tosti. […] Dat ding is zout en het is nog vet ook.
Healthcare received after discharge	Received healthcare after discharge minimal though sufficient	4	Eén keer naar de dokter geweest. Verder niet. De huisarts. Maar ja, ook niet zo dat we daar ja denken nodig te hebben eigenlijk. Want anders ja zorg ik er wel voor dat dat gebeurd. Maar daar heb ik eigenlijk niet zo'n idee van.
	Positive about visit stroke nurse	6	Dat was een goed gesprek. Ja dat valt niks over te zeggen eigenlijk. Nee. Op dat moment heb je een paar vragen en hun stellen vragen en daar kom je dan uit en dan is het goed.
	Open-mindedness of healthcare professional	1	Maar dat is van lieverlee wel weer beter gegaan en zo komen we aan de alternatieve behandeling van acupunctuur. […] Maar, daar willen de doctoren niet zo erg aan. Nee, daar heb ik echt een aanvaring gehad met een dokter. Heel jammer, dat, de manier waarop ze dan reageren, dat stoorde me het meeste. Dat je niet normaal kunt communiceren over bepaalde dingen.

3.4.4 Patients' healthcare needs three months post-stroke

In line with expectations, patients experienced little to no consequences of mild cognitive impairments in daily life three months post-stroke. Subsequently, patients expressed little to no healthcare and support needs concerning mild cognitive impairments three months after stroke. Even though several deficits became evident during evaluation of received and non-received healthcare from both the patient's and the partner's perspective, these suggestions for improvement relate to healthcare and support patients might have needed in an earlier phase of recovery. Evaluation of existing interventions gave insight into why patients would or would not use certain interventions. However, patients reported they did not need additional healthcare and support three months post-stroke concerning mild cognitive impairments.

3.5 Support needs of caregiving partners

In this paragraph support needs of partners are presented. First, evaluation of received information aimed at the partner is given in paragraph 3.5.1, followed by evaluation of existing interventions in paragraph 3.5.2. Finally, support needs expressed by partners are given in paragraph 3.5.3.

3.5.1 Evaluation of information focused on partners

Concerning information specifically for the (caregiving) partner, two partners mentioned they did not receive information or support specifically aimed at themselves as caregiving partners during hospital stay (Table 16). Moreover, two partners stressed that more attention focused on them as partner was not needed. Two other partners stressed that more information focused on the partner would have been appreciated by them. Four partners mentioned they were satisfied with the attention both patient and partner received in hospital and with the way the partner was involved during hospital stay. Three partners stressed this was useful, because the patient may not take in all the information that is given by healthcare professionals at that time. With respect to information focused on the partner after discharge, half of the partners mentioned they did not receive any information aimed at them as caregiving partner. However, they also stressed that afterwards it turned out this information was not needed. Only one partner mentioned she would have appreciated receiving more information after discharge aimed at her as partner and potential informal caregiver.

Table 16. Information focused on the (caregiving) partner

Category	Subcategory	Number of partners	Citation
Information focused on the partner during hospital stay	No specific information	2	Ik heb daar geen specifieke informatie over gekregen. Wel was het zo dat de arts wel mij bij het eindgesprek wilde hebben. […] Dus dat was wel heel bewust dat daar naar gekeken werd en dat daar op mij gewacht werd.
	No information for the partner needed	2	Meer ondersteuning zou ik ook niet nodig hebben gehad.
	Information for the partner would have been appreciated	2	Moet ik even denken. Wel samen. Maar ik heb alleen geen informatie gehad. nee. Dat was misschien wel prettig geweest. Om te weten wat je eventueel te wachten staat. Dat is, ik heb het dus wel samen, maar niet alleen. En dat is misschien wel iets wat wel goed is.
	Positive about involvement of partner during hospital stay	4	Overal ben ik bij betrokken geweest. Echt heel netjes, ja. Overal, waar hij binnen zat, zat ik ook. […] Ze hebben het me allemaal uitgelegd en wat het allemaal inhield en euh. Ja, waar ik dan rekening mee moet houden he. Met koken en dat soort dingen. Zo ben ik erbij betrokken zeg maar.
Information focused on the partner after discharge	No information for partner received after discharge, though it turned out not to be needed	3	Nou, ik heb het eigenlijk niet gemist. Nee, ik heb het niet gemist. […] Zo is het eigenlijk een beetje op een zijspoor geraakt en hebben we ons daar ook niet mee bezig gehouden zozeer. […] Dat is dus ja, nee, daar hebben we verder niks van gehad. en waarschijnlijk ook niet vanuit het ziekenhuis, omdat het eigenlijk toch ook wel weer goed ging.
	Information for the partner would have been appreciated	1	Geen, niks. Nee. we zijn samen geweest, maar als partner heb ik geen eh… maar wel in die boekjes die je krijgt over de TIA en zo, daar staat informatie in.

3.5.2 Evaluation of existing interventions for partners

In order to assess support needs of partners three months post-stroke, partners evaluated multiple interventions concerning information, education and training, peer contact, and support in daily life (Appendix F). Table 17 provides an overview of motives for and against the different interventions. Informative interventions presented were a folder or brochure, an informative meeting, and a website. Three partners mentioned they had not felt the need to retrieve information via a brochure or folder, because of little to no sequelae of stroke. However, some partners stated they would have used a brochure to retrieve information in case they felt like they needed more information. However, none of the partners felt the need to retrieve more information than the general information they had received in hospital and from the stroke nurse after discharge. Three partners expressed a preference to retrieve information via a folder or brochure. One partner said that the picture on the front of the brochure depicted a worse situation after stroke than was the case for her husband. Therefore, she expected that such information would give her more concern and worries about what could have happened than that it would give her support. Three other partners expressed a preference to searching for information online instead of reading a folder or brochure. Searching information via a website was experienced as easy accessible and more situation-specific. Two reasons for not searching information online were that the internet might show worse cases of stroke and that not all information is accurate or true. Moreover, some partners experienced the internet as overwhelming, with too much information about too many people. Two partners responded positively to the idea of an informative meeting, although they did not feel the need to attend one.

With respect to education and training, three partners stressed that additional advice and guidance was not necessary for them. The visit to the stroke nurse was sufficient for them. However, two partners reported that, if their partner's stroke had been worse and if the consequences had been more present, they might have liked the possibility to have another meeting with a healthcare professional a few weeks or months post-stroke. One partner responded rather negatively to advice and guidance, as he felt like conversations only make you more insecure. Three partners were moderately interested in the eHealth intervention '*Houvast, voor elkaar'*, even though they currently did not feel the need to use it. One of these partners expressed a preference for an online program and not a face-to-face program, as you can attend at your own time, at your own pace. The other partners stressed they would not use eHealth interventions. The main reason given was that consequences of their partner's stroke were not that severe. Three partners stressed they would first approach a healthcare professional if they needed additional support or information. Two partners would not use eHealth interventions because it is less personal than in person or face-to-face interventions.

None of the partners responded positively to peer contact with other partners of stroke patients. Half of the partners mentioned peer contact was not their thing in general. Four partners mentioned they would not attend such meetings, because they have friends and colleagues to turn to about stroke-related aspects. Also, they preferably deal with their issues themselves, in their own home environment and with close friends. Three partners would not look for peer contact with other partners of stroke patients, because they do not want to hear stories about other people's struggles. Furthermore, none of the patients felt the need to find support of peers or ask questions to peers on a forum. Four patients stressed that the idea of a forum was not appealing to them at all. One partner said she would use a forum to look for information of other people, but not to ask questions herself as this would be too much of an effort. Another partner would first approach her general practitioner or doctor, before turning to a forum. Four partners expressed a negative attitude towards eHealth interventions in general. Two of these partners mentioned they found online interventions too impersonal. They would prefer to look for support by means of face-to-face contact with a professional.

Support in daily life was found irrelevant three months post-stroke by all partners. None of the partners needed additional emotional support, as they have their own resources to get support. Practical support at home was also not necessary according to four partners, given minor experienced consequences of stroke of their partner. However, if practical support would turn out to be needed in the future, they would know where to get it. Interestingly, one partner mentioned she and her partner had already anticipated on impairments associated with ageing, as they had moved the bedroom and bathroom to the ground floor several years ago. Respite care was also not required in any of the cases, given minor sequelae of the patients' stroke. Nevertheless, four partners appreciated the existence of such organizations.

Table 17. Evaluation of existing interventions for (caregiving) partners

Application	Needs[a]	Motives pro	Motives con
Information			
Brochure / folder	Moderate	• Limited amount of information	• Folder depictures worse situation • Folder is too general, not situation-specific • May cause unnecessary worries • No need for additional information
Informative meeting	Low	• Reliable information	• No need for additional information
Website	Moderate	• Easy and quick accessibility • Search for personally relevant and specific information	• Too much information available • Unreliable information • May cause unnecessary worries • Not needed, due to little cognitive consequences • No need for additional information • Impersonal information
Education/training			
'Houvast, voor elkaar'	Low	• Easy accessibility • Participate in your own time • Might be interesting • Online provides more flexibility	• No need, given little to no sequelae • Online is too impersonal • Preference for face-to-face contact with specialized professional •
Advice and guidance	Low	• Optional visit after x months would be appreciated	• No need • Visit stroke nurse was sufficient
Peer contact			
Peer contact meeting	Low		• Preference for contact with family or friends • No need to talk or hear about other people's struggles • Enough acquaintances with health issues to talk with • Waste of time • Not my thing in general
Forum	Low	• Easy accessibility • Participate in your own time	• To retrieve information, not to participate or ask questions • Too much effort • Unreliable information online • Too impersonal

(continued)

Table 17. Evaluation of existing interventions for (caregiving) partners (continued)

Application	Needs[a]	Motives pro	Motives con
Support in daily life			
Emotional support	Low		• No need given no to little sequelae • May cause unnecessary worries • Have friends to turn to for support
Practical support at home	Low		• No need given no to little sequelae
Respite care	Low		• No need given no to little sequelae

a. Low: < 2 partners expressed need; Moderate: 2 – 4 partners expressed need; High: > 4 partners expressed need.

3.5.3 Partners' support needs three months after stroke

Partners reported little to no support needs three months after stroke concerning consequences of mild cognitive impairments in their partner. This is in line with healthcare needs of patients, who also reported little to no needs three months after stroke. An agreement between patients and partners is also observed in the evaluation of received and non-received healthcare during hospital stay and after discharge. Partners identified several improperly fulfilled needs during hospital stay and after discharge, although these partly unmet needs do not reflect their needs three months post-stroke. Evaluation of existing interventions gave insight into why partners would or would not use or need certain interventions. In accordance with patients' experiences, partners also expressed that they do not feel a pressing need for additional support to cope with mild cognitive impairments of their partner. In fact, partners mentioned that they experienced little to no cognitive consequences in their partner three months post-stroke. These potential cognitive impairments are found to be so little, that it hardly has any influence in daily life three months after stroke.

4 Discussion

The aim of this study was to gain insight into experienced consequences of mild cognitive impairments and healthcare and support needs, three months post-stroke, of stroke patients and their partners. Both patients and partners experienced little to no consequences of cognitive impairments three months post-stroke. Mild cognitive impairments concerning memory, speed of thinking, attention or concentration, and planning or scheduling were reported. However, these mild cognitive impairments did not have a significant influence on participants' daily life. Most frequently reported consequences of stroke concerned reduced physical capacities and reduced energy level in patients and increased worries in partners. As a result of minimal impact of mild cognitive impairments, patients had little to no healthcare and support needs three months post-stroke, whereas partners reported little to no support needs. The main healthcare need expressed by patients and partners concerned availability of information and information provision. Concerning existing interventions, both patients and partners reported a need for information, whether or not through eHealth. Interventions for patients concerning training and education, peer contact, and tools to help adjust to cognitive impairments were considered unnecessary, due to minimal experienced cognitive impairments. Interventions for partners concerning education and training, peer contact, and support in daily life were also evaluated as unnecessary.

Results show that most prominent cognitive impairments concerned memory, speed of thinking, and attention or concentration, which is in line with findings of previous studies (Hochstenbach et al., 2005; van Heugten et al., 2007). Cognitive impairments did not impede patients and partners in daily life three months post-stroke, which is in line with expectations, as patients were discharged after only a few days in hospital and measured cognitive impairments were quite mild. In accordance with patients, partners also found that cognitive impairments were minimal, hence, not obstructing daily life. Indeed, Viscogliosi et al. (2011) found that the degree of difficulties in daily life is related to severity of cognitive impairments. Interestingly, partners repeatedly expressed their doubts about whether cognitive impairments were due to stroke or had another cause such as old age. Indeed, Bulley et al. (2010) and Clark et al. (2006) also found that cognitive impairments may often not be recognized by partners as being a result of stroke. Therefore, an implication for practice is to provide both patients and partners with practical information about which stroke-related cognitive impairments they might encounter.

It appeared that patients did not experience many consequences of stroke in general. Possibly, patients had a reduced disease insight and were therefore were unable to assess what exact cognitive consequences they experienced. However, this is not likely, as partners' observed consequences of stroke are in accordance with patients' experienced consequences. Hochstenbach et al. (2005) found that patients are more focused on functional recovery in the early stage of stroke recovery. Perhaps, three months post-stroke is too soon after stroke occurred to identify lasting difficulties, both from the perspective of patients and partners. It seems plausible that three months post-stroke, patients and partners are relieved with the prosperous stroke-recovery, are glad to be home, and are focused on getting back to the way their life was before stroke. Indeed, previous studies found that (coping with) remaining disabilities, such as persistent cognitive impairments, became more prominent in the chronic phase (van den Bos, Visser-Meily, & van Exel, 2007; Anne Visser-Meily et al., 2009). Consequently, future research may assess the influence of mild cognitive impairments in daily life of stroke patients and their partners on long term.

Patients and partners were not aware of potential cognitive impairments post-stroke, nor did they receive information on this subject in hospital and after discharge. Therefore, information provision and availability was found to be a prominent need of patients and partners. Additional information, healthcare and support turned out not to be necessary for most participants. However, multiple participants mentioned they would have liked to be aware of existing possibilities for additional healthcare and support. Previous studies also found that information provision in stroke-related healthcare is not yet optimal (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008; McKevitt et al., 2011). Information provision during hospital stay and after discharge on potential cognitive impairments after stroke was minimal. Possibly, healthcare professionals do not pay attention to this, or they are not certain what to offer patients. However, it is possible that because of the stress and worries, participants do not accurately remember what information they received. This was also reported by one patient and two partners. Naturally, cognitive impairments might also play a role in recalling what information was provided during hospitalization and after discharge. Information transfer during hospital stay was found to be either minimal or not remembered by patients. Therefore, it is recommended to provide customized instead of general information on stroke and potential cognitive consequences. For example, an information folder with general information might be supplemented with customized information, such as links to relevant websites, information about potentially interesting interventions, or information about possible cognitive impairments and what impact they may have. Also, a summary with important issues addressed during consultation might be added. This way both patient and partner can reread the information that was given during consultation.

Cognitive impairments after stroke also affected partners, although partners in this study felt they could cope well with the mild cognitive consequences of stroke. Partners experienced some distress and increased worries about their partner after stroke. In contrast to other studies, partners did not mention an increase in anxiety, loneliness, or depression (Bulley et al., 2010; Clark et al., 2006). However, this is in line with expectations, as consequences of stroke were assumed to be moderate, since patients were discharged home after short hospitalization. Furthermore, patients with more severe cognitive impairments and other sequelae of stroke would have to rehabilitate in a rehabilitation center or nursing home, which would probably have much more impact on the partner. Many patients reported that stroke did not have a large impact on their partner in general and on the spousal relationship. Interestingly, partners themselves reported more changes for themselves with respect to their partner´s stroke. To illustrate, all partners experienced an increase in worries about their partner, whereas only three out of eight patients thought their partner was more worried about them after stroke. Perhaps this indicates an impaired social cognition, given low scores on the FEEST, as patients may be unable to empathize with how the partner experienced consequences of stroke. Another possible explanation could be that, when the interviewer asked '*Wat is er door de beroerte veranderd voor uw partner?'* ('What has changed for your partner because of stroke?'), patients thought about more practical changes and not that much about emotional changes for the partner. A recommendation for future research is to take into account the finding that caregiver burden or experienced consequences for the partner might be more prohibitive after a longer period after stroke. Therefore, it would be interesting to conduct research in a later stage of recovery, for example after six months or a year. Healthcare needs and support needs may change during the recovery process. A prospective quantitative study might provide insight into changing support needs of partners.

Half of the patients and one third of the partners had previous experience with cardiovascular diseases. This might have influenced their evaluation and appreciation of the consequences of the stroke (Buschenfeld et al., 2009). A previous study found that older caregivers and partners with previous caregiver experiences may experience less changes after stroke than younger caregivers or partners without caregiver experiences (Greenwood et al., 2010). This may have influenced the way participants experienced the consequences of the stroke. Furthermore, participants expressed they had a certain frame of reference, as most participants have acquaintances who have experienced a stroke and who had more severe and more visible consequences. Therefore, many patients and partners feel lucky with the minor consequences of the stroke, as it could have been much worse. Besides, previous studies found that experienced consequences for the partner correlated with severity of consequences of stroke in the patient (Draper & Brocklehurst, 2007; Lutz & Camicia, 2016). Low caregiver burden in this study may be explained by this finding, as cognitive consequences of patients in this study were found to be considerably mild three months post-stroke.

Patients' healthcare needs during hospital stay concerned more transparency or clarity about medication, and more accurate consult preparation of healthcare professionals. Healthcare needs after discharge concerned improvement of information provision and sharing of information, receiving promised contact by homecare organization, and more clarity about driving. This variety of healthcare needs complements findings of previous studies, which also indicated that needs varied among patients and that needs varied over time (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008; McKevitt et al., 2004; Moreland et al., 2009; Thompson & Ryan, 2009). An important deficiency was the promised contact by the homecare organization. Even though most participants did not need additional support in their homes in daily life, it is recommended to improve communication between the hospital and such organizations. Several participants were expecting to be contacted and eventually initiated this homecare themselves, as they never heard from the homecare organization. Multiple participants were unsure who to contact in case they experienced consequences of stroke and needed help. A recommendation for practice is to designate a stroke nurse or a social worker who could be the central person of contact. This way, patients and partners have one person they can turn to. Finally, as none of the partners received information focused on them as caregivers, more individual attention and information for the partner is recommended.

Support needs of partners were not pressing three months after stroke, although several unmet needs were reported. Additional support to meet partners' needs during hospital stay should target information provision focused on the partner as potential caregiver, and communication of healthcare professionals. This was also found by Camak (2015), who stated that healthcare professionals often solely focus on the patient's needs. Additional support to meet partners' needs after discharge should target involvement after discharge, and the possibility of social work contact for the caregiving partner individually. Previous studies also reported that partners may need more information and support to prepare for a potential role as caregiver

(Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008; Lutz & Camicia, 2016; Satink et al., 2015). Three months post-stroke, partners did not feel the need for additional support. However, it is important to keep in mind that partners' support needs as well as patients' healthcare needs may change over time (Cameron et al., 2013).

Many interventions have been developed for stroke patients, with or without cognitive impairments, and their caregiving partners. Interestingly, neither patients nor partners were aware of the existence of the majority of presented interventions. Unmet needs reported by patients and partners concerned awareness of interventions, availability of information, and information provision. Hence, patients and partners reported a relatively high need for informative interventions. As participants were unaware of existing interventions, information should be provided about who to contact in case of arising difficulties, or what possibilities there are for patients or partners to fulfil their healthcare or support needs. Future research may assess how informative interventions can target needs for information and how these needs can best be fulfilled. Besides, future research might also look into the effect of general and customized information and interventions. The amount and content of provided information might influence whether stroke patients and partners actively seek support after stroke. Perhaps patients and partners will look for additional support in an earlier phase if they are aware of existing interventions. Findings of this study indicate that patients did not feel the need for interventions concerning education and training. None of the patients and hardly any partners felt the need for additional support three months post-stroke. For most of them the visit with the stroke nurse approximately six weeks post-stroke was sufficient. Possibly, the current sample consisted of participants who actually do not have that many sequelae and therefore do not have pressing needs for healthcare or support. Another possible explanation is that after three months patients and partners do not yet feel the need for additional healthcare or support. This is consistent with the finding that interest in supporting interventions often arises in the chronic phase after stroke (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). A third explanation is that patients lack disease awareness and therefore do not experience their consequences as problems. None of the patients and partners could imagine themselves engaging in peer contact, which is contradictory to two recent studies, where stroke patients and their caregivers reported interest in and appreciation of peer contact (Davoody, Koch, Krakau, & Hägglund, 2016; Tielemans et al., 2016). Multiple partners stressed that if they needed additional support, they would preferably contact a healthcare professional, such as the stroke nurse or the general practitioner. Also, partners preferred to first try to find support in their own close environment, such as family, neighbours, and friends. Multiple patients and partners indicated they did not want to think about the stroke and its consequences too much, and just resume life as it was before the stroke. Tools to offer assistance to compensate for cognitive impairments, to adjust to cognitive impairments, or to improve cognitive functioning were evaluated as not needed by all patients, which can be explained by the minimal experienced cognitive impairments. Tools delivered by eHealth, such as apps on a smartphone, were not popular among patients. This might be explained by the age of patients, as they did not have much experience with technology use in general. Partners did not need additional support in daily life, such as practical or emotional support or respite care, as the experienced consequences of stroke were moderate.

4.1 Limitations and strengths

Strong aspects of the research design were the semi-structured interviews with open questions, addressing multiple topics across the healthcare trajectory. These enabled participants to address issues that were important to them. Furthermore, a broad age group of patients was interviewed. Finally, interviewing both patients and partners resulted in an overall broad picture of healthcare and support needs three months post-stroke.

This study has several limitations. First, sampling bias may have occurred, as the patients who agreed to participate might have experienced less cognitive consequences of stroke and therefore felt more able to participate. Furthermore, only one female stroke patient participated. However, this is in line with the expectation that stroke occurs more amongst men than women in the age range of 60 to 80 (Van Dis et al., 2015). Second, the sample size of the partners was rather small. Only six partners participated, and saturation was not yet reached. Even though patients and partners addressed similar issues, a larger sample size of partners might have given more insight into what issues are more pressing than other issues. Possibly, quantitative research could provide more insight into needs for information of both patients and partners three months post-stroke. Also, quantitative research may assess experienced cognitive impairments more specifically. Another potential limitation was the general question in the interview: ‘*Wat merkt u van problemen in het denken?’* (‘What difficulties in thinking do you notice?’). Possibly, patients did not know what this question meant. Because, when the questions about difficulties in thinking were formulated more specific, patients did mention some minor impairments.

Participants with a score on the cognitive tests MoCA (<24) and FEEST (<42) were approached by psychologists of the Medical Spectrum Twente. However, two participants had a higher score on both of the cognitive tests (28;43 and 27;57). One patient had a higher score on the MoCA (28) and one patient had a higher score on the FEEST (46). Nevertheless, transcripts of these patients were included anyway, since the information they provided with respect to the research questions was found to be relevant. The scores of the MoCA and FEEST indicated a presence of at least mild cognitive impairments six weeks after the stroke. However, three months post-stroke, participants reported experiencing little to no cognitive impairments. At least not to such an extent that it was found to be obstructive in daily life. Remarkably, previous research suggests that neuropsychological tests in the acute phase post-stroke may not be useful, as the process of recovery is still in full swing (Kwaliteitsinstituut voor de Gezondheidszorg CBO, 2008). This might explain why cognitive impairments were milder three months post-stroke than the researcher expected. Furthermore, FEEST scores indicated that mild impairments in emotion recognition were present six weeks post-stroke. However, during interviews, this aspect of cognitive impairment was not specifically targeted.

For the evaluation of existing interventions, several pictures of interventions for information, education and training, peer contact, tools, and support in daily life were found by the researcher. However, it is possible that this was not an accurate representation of interventions the target group might have needed. The researcher's expectation was for stroke patients to have more visible or more severe cognitive impairments. Therefore, some of the interventions shown during the interview were more appropriate for patients that experienced worse cognitive impairments. Same goes for the partners, who did not feel like actual caregivers for their partner.

4.2 Conclusion

In conclusion, stroke patients with mild cognitive impairments had little to no need for additional healthcare and support three months post-stroke. Partners of stroke patients had little to no support needs three months post-stroke. Healthcare in hospital and after discharge was, aside from several partially unfulfilled needs, evaluated positively. Information provision was experienced as minimal, with respect to information on stroke in general, information on cognitive impairments, and information for the partner as caregiver. Even though more information was not needed, according to the participants, it would have been appreciated to know where to look for information or who to turn to in case they needed additional healthcare or support. The need for interventions concerning education and training, peer contact, tools, and support in daily life was minimal for both patients and partners. In conclusion, stroke patients with mild cognitive impairments and their partners did not experience substantial difficulties in daily life three months post-stroke. Hence, they do not have pressing healthcare and support needs that have to be fulfilled three months post-stroke.

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Appendices

Appendix A. Information letter

UNIVERSITEIT TWENTE.

MST

Onderzoek naar de hulpbehoefte bij patiënten met een CVA en hun partner.

Informatie voor deelnemers

Enschede, mei 2017

Geachte meneer en/of mevrouw,

Bij deze vragen wij u vriendelijk of u mee wilt doen aan een interview over de behoefte aan zorg en hulp van patiënten die een CVA hebben gehad en hun partners. Dit onderzoek wordt uitgevoerd door onderzoekers van de afdelingen Medische Psychologie en Neurologie van het Medisch Spectrum Twente in samenwerking met de Universiteit Twente.

U beslist zelf of u mee wilt doen en deelname is vrijwillig. Voordat u een beslissing neemt, kunt u deze informatiebrief rustig doorlezen, om meer te weten te komen over het onderzoek. U kunt de inhoud bespreken met uw partner of met familie of vrienden.

Heeft u na het lezen van deze informatiebrief nog vragen over het interview? Dan kunt u contact opnemen met de onderzoeker Naomi Rasing. Onderaan deze brief vindt u haar contactgegevens.

Als u besluit dat u niet mee wilt doen, hoeft u verder niets te doen. Als u wel meedoet, kunt u zich tijdens het interview altijd bedenken en alsnog stoppen. Hiervoor hoeft u dan geen reden op te geven. De Ethische Commissie van de Universiteit Twente heeft een positief oordeel uitgebracht over dit onderzoek.

Doel van het onderzoek

Veel patiënten die een CVA hebben gehad, hebben na ontslag uit het ziekenhuis moeite om het dagelijks leven thuis weer op te pakken, bijvoorbeeld door problemen in het denken. Het doel van dit onderzoek is om in kaart te brengen welke behoefte aan zorg en hulp mensen hebben die na een CVA-problemen in het denken hebben en wat men vindt van de zorg en hulp die men al ontvangen heeft in het ziekenhuis en na ontslag uit het ziekenhuis.

Voor veel partners zijn er ook veranderingen in het dagelijks leven na de beroerte van de partner, bijvoorbeeld doordat de taakverdeling in huis veranderd is. Het doel van het onderzoek is ook om in kaart te brengen óf en welke behoefte aan ondersteuning of hulp partners hebben.

Wie voert het onderzoek uit?

Het onderzoek wordt uitgevoerd door Naomi Rasing. Zij studeert Gezondheidspsychologie en Technologie aan de Universiteit Twente. Begeleiders van het onderzoek zijn dr. H.M. den Hertog, dr. Erik Taal en dr. C.H.C. Drossaert.

Wie kunnen deelnemen aan het interview?

Het onderzoek is bedoeld voor mensen die een CVA hebben gehad en die na een aantal dagen in het ziekenhuis weer naar huis mochten.

Het onderzoek is ook bedoeld voor partners van mensen die een CVA hebben gehad. U hoeft niet allebei aan het onderzoek mee te doen. U of uw partner mag ook alleen mee doen.

Hoe lang duurt het interview?

Het interview duurt maximaal een uur per persoon. De onderzoeker interviewt één iemand tegelijk. Als u en uw partner allebei deelnemen, wordt u na elkaar geïnterviewd.

Waar vindt het interview plaats?

Het interview vindt plaats op een locatie van uw voorkeur. Dit mag bij u thuis zijn, maar ook in het ziekenhuis (Medisch Spectrum Twente) of op de Universiteit Twente. Als u een andere rustige plek weet waar u graag komt, is dat ook mogelijk.

Het interview

In het interview van de patiënt en van de partner komt een aantal onderwerpen bod:

- Wat is er voor u veranderd sinds de beroerte?
- In hoeverre heeft u last van problemen in het denken?
- Welke informatie of hulp heeft u gekregen in verschillende fases van het traject (in het ziekenhuis, bij ontslag, nazorg thuis)?
- Welke informatie of hulp had u graag willen hebben?
- Voorbeelden van interventies: waarom zou dit wel of niet wat voor u zijn?

Aanmelden voor het interview

U heeft tijdens uw bezoek aan het MST deze informatiebrief ontvangen van uw zorgverlener. Tijdens het consult heeft uw zorgverlener gevraagd of Naomi Rasing u (telefonisch) mag benaderen voor het onderzoek. U kunt eerst thuis rustig deze informatiebrief doorlezen. U kunt altijd nog afzien van deelname wanneer Naomi Rasing contact met u opneemt.

Voordat het interview begint, dient u toestemming te geven voor deelname aan het interview. Door het tekenen van de toestemmingsverklaring, gaat u akkoord met de voorwaarden voor deelname.

Wat wordt er van u verwacht?

Het is belangrijk dat u en eventueel uw partner voor het interview allebei één uur de tijd hebben. Daarnaast mag u zelf kiezen waar u het interview wilt doen, maar dit moet wel een rustige, stille ruimte zijn. De interviews worden afgenomen in april - juni 2017.

Privacy

Uw persoonlijke gegevens en antwoorden tijdens het interview worden vertrouwelijk behandeld. Van het interview wordt een opname gemaakt. Deze wordt alleen door Naomi en eventueel haar begeleiders beluisterd. Alle gegevens worden strikt vertrouwelijk en anoniem verwerkt en zijn niet te herleiden naar personen. Uw behandelend arts heeft er geen toegang toe; hij/zij wordt uitsluitend op de hoogte gesteld van de algemene gegevens van het onderzoek.

Vragen of aanmelden

Heeft u na het lezen van deze informatiebrief nog vragen?
Wilt u en/of uw partner zich aanmelden voor het interview?

Neem gerust contact op met de uitvoerder van het onderzoek:

Naomi Rasing

Appendix B. Informed consent

UNIVERSITEIT TWENTE.

MST

Toestemmingsverklaring

Geachte heer/mevrouw,

U wordt verzocht onderstaande tekst door te lezen. Wanneer u medewerking wilt verlenen aan het interview over de behoefte aan zorg en hulp bij mensen die een CVA hebben gehad en hun partner, dient u onderaan uw handtekening te zetten. Dit formulier is alleen te zien door de onderzoeker en haar begeleiders van de Universiteit Twente en het Medisch Spectrum Twente.

1. Ik heb de informatiebrief over het onderzoek gelezen. Ik kreeg de mogelijkheid vragen te stellen over het onderzoek en mijn vragen zijn voldoende beantwoord.
2. Ik ben ervan op de hoogte dat deelname aan het onderzoek geheel vrijwillig is. Ik weet dat er geen vergoeding wordt gegeven voor de deelname. Ik kan op ieder tijdspunt van deelname afzien of daarmee stoppen, zonder opgave van redenen. Mijn behandelende arts zal daarover niet worden geïnformeerd. Afzien van deelname heeft geen enkel gevolg voor mijn behandeling.
3. Als ik me om de een of andere reden onprettig zou voelen gedurende het interview heb ik het recht geen antwoord op een vraag te geven of het interview te beëindigen.
4. Ik geef toestemming om de gegevens uit het interview te gebruiken voor doeleinden die in de informatiebrief zijn beschreven.
5. Ik ben bereid deel te nemen en me te laten interviewen door Naomi Rasing en geef toestemming voor een geluidsopname van het interview. Het interview zal ongeveer een uur duren. Er kunnen tijdens het interview aantekeningen worden gemaakt door de onderzoeker.
6. Ik begrijp dat de onderzoeker mijn naam niet gaat vermelden in rapporten waarin informatie uit het interview gebruikt wordt. Alle gegevens worden strikt vertrouwelijk en anoniem verwerkt en zijn niet te herleiden naar personen.
7. De opnames worden alleen door de betrokken onderzoekers beluisterd. Andere medewerkers van de universiteit of het ziekenhuis hebben geen toegang tot de opnames en de ruwe aantekeningen. Ook mijn behandelend arts wordt uitsluitend op de hoogte gesteld van de algemene gegevens van het onderzoek.
8. Ik heb een kopie van deze verklaring ontvangen.

Mijn handtekening   Datum

Handtekening onderzoeker

Appendix C. Interview guide patient

Interview zorgbehoefte patiënt

Preambule

- Doel van het onderzoek/interview;
- Opnemen van interview & vertrouwelijkheid van gegevens;
- Het recht om op ieder moment te stoppen met het interview en vragen niet te beantwoorden als dat niet gewenst is;
- Tekenen toestemmingsverklaringsformulier.

A. Algemene vragen

- Wat is uw leeftijd?
- Wat is/was uw beroep?
- Wat voor soort beroerte heeft u gehad?
- Wanneer heeft u een beroerte gehad?
- Hoe is uw gezondheid verder? Heeft u chronische aandoeningen?
- Welke klachten/gevolgen merkt u nog van de beroerte?
- Wat zijn de voornaamste problemen die u nu ervaart?
- Wat is de verwachting van in hoeverre u zult herstellen van de beroerte?

Voorbeelden cognitieve problemen:
Geheugen:
inprenten, opdiepen, opslaan / herkennen
Aandacht & Concentratie:
tempo van informatieverwerking, afleiding, twee dingen tegelijk doen, aandacht vasthouden
Oriëntatie:
in tijd/plaats/persoon, in de ruimte, zoals de weg vinden
Taal & Spraak:
tempo, articulatie, woordvindproblemen, begrip
Planning & Probleem oplossen:
koken, knutselen, klussen

B. Cognitieve stoornissen

- Wat merkt u van problemen in het denken?
  Doorvragen: In het bijzonder met bijvoorbeeld in het geheugen (vergeetachtigheid) aandacht en concentratie; oriëntatie; taal en spraak; planning en probleem oplossen? Dat wordt met een 'duur' woord 'cognitieve problemen' genoemd.
- Hoe voelt u zich veranderd in gedrag of stemming sinds de beroerte?
  Bijvoorbeeld slecht gehumeurd, vrolijk, onrustig, angstig, somber, hoopvol, energiek.

C. Coping

1. Hoe gaat u met gevolgen van uw beroerte om? Wat helpt voor u wel of juist niet? *Bijvoorbeeld: geloofsovertuiging, steun van vrienden of familie, lotgenoten, partner, hobby's.*
2. Wat vindt u moeilijk of zwaar? Wat gaat juist beter dan verwacht?
3. Wat helpt u met problemen in het denken om te gaan? Wat helpt voor u juist niet?
   Voorbeelden wat kan helpen: gebruiken van hulpmiddelen, geheugensteuntjes, post-its, stappenplan.

D. Rol van de partner

- Wat is er door de beroerte veranderd voor uw partner?
- Waarbij krijgt u hulp en steun van uw partner?
- Hoe is de relatie met uw partner? Wat is daar na de beroerte eventueel in veranderd?

Bijvoorbeeld andere taak/rolverdeling in huis, huishoudelijke taken, afspraken nakomen, communicatie met elkaar.

E. Begeleiding tijdens ziekenhuisopname

1. Welke begeleiding/hulp heeft u tijdens de ziekenhuisopname gekregen?
   Doorvragen: De standaardbegeleiding omvat: informatiemap, begeleiding van de ergotherapeut, fysiotherapeut, logopedist, revalidatiearts.
2. Wat vond u van deze informatie/hulp? Hoe tevreden was u erover?
3. Wat heeft u daarin gemist? Wat had u graag meer of anders gewild?
4. Wat voor begeleiding of informatie heeft u over mogelijke problemen in het denken gekregen? Hoe tevreden was u hierover?
   Bijvoorbeeld folders, een website, of mondelinge informatie van een zorgverlener.

F. Begeleiding nazorg thuis

1. Welke begeleiding/hulp heeft u na ontslag uit het ziekenhuis gekregen?
   Doorvragen: De standaardbegeleiding omvat: informatiemap, begeleiding van de nazorgverpleegkundige of huisarts, maatschappelijk werk, psycholoog, activiteitentherapie, controle CVA-verpleegkundige na zes weken.
2. Wat vond u van deze informatie/hulp? Hoe tevreden was u erover?
3. Wat heeft u daarin gemist? Wat had u graag meer of anders gewild?
4. Wat voor begeleiding of informatie heeft u bij de nazorg over mogelijke problemen in het denken gekregen?
   Bijvoorbeeld via folders, een website, of mondelinge informatie van een zorgverlener.

G. Mogelijke interventies

Er bestaan verschillende programma's om mensen met problemen in het denken na een beroerte te ondersteunen.

1. Zou dit **afbeeldingen tonen ter illustratie** u kunnen helpen? Waarom wel of niet? Wat voor interventie zou wel wat voor u zijn?

Appendix D. Interview guide partner

Interview ondersteuningsbehoeften partner

Preambule

- Doel van het onderzoek/interview;
- Opnemen van interview & vertrouwelijkheid van gegevens;
- Het recht om op ieder moment te stoppen met het interview en vragen niet te beantwoorden als dat niet gewenst is;
- Tekenen toestemmingsverklaringsformulier.

A. Algemene vragen

1. Wat is uw leeftijd?
2. Wat is/was uw beroep?
3. Hoe is uw gezondheid? Heeft u chronische aandoeningen?
4. Welke gevolgen merkt u van de beroerte bij uw partner?
5. Wat zijn de voornaamste problemen die uw partner nu ervaart?
6. Wat is de verwachting van in hoeverre uw partner zal herstellen van de beroerte?

B. Cognitieve stoornissen

1. Wat merkt u van problemen in het denken bij uw partner?
   Doorvragen: In het bijzonder met bijvoorbeeld in het geheugen, aandacht en concentratie, oriëntatie, taal en spraak, planning en problemen oplossen? Dat wordt met een 'duur' woord 'cognitieve problemen' genoemd.
2. Hoe gaat uw partner om met eventuele problemen in het denken?
   Bijvoorbeeld gebruiken van hulpmiddelen, geheugensteuntjes, post-its, stappenplan.
3. Op welke manier is uw partner in gedrag of stemming veranderd na de beroerte?
   Bijvoorbeeld slecht gehumeurd, vrolijk, onrustig, angstig, somber, hoopvol, engergiek.
4. Wat betekenen de veranderingen in denken, gedrag of stemming bij uw partner voor u?

<u>Voorbeelden cognitieve problemen:</u>
Geheugen:
inprenten, opdiepen, opslaan / herkennen
Aandacht & Concentratie:
tempo van informatieverwerking, afleiding, twee dingen tegelijk doen, aandacht vasthouden
Oriëntatie:
in tijd/plaats/persoon, in de ruimte, zoals de weg vinden
Taal & Spraak:
tempo, articulatie, woordvinding problemen, begrip
Planning & Probleem oplossen:
koken, knutselen, klussen

C. Rol als mantelzorger

1. Wat is er door de beroerte voor u veranderd?
2. Welke problemen ervaart u door de beroerte van uw partner?
3. Zorgt u voor uw partner? Waarbij?
4. Wat vindt u moeilijk bij het zorgen voor uw partner? Waar bent u juist tevreden over?
5. Wat voor hulp en steun krijgt u bij het zorgen voor uw partner uit uw sociale omgeving (familie, vrienden, buren) of van professionele zorgverleners?
6. Hoe is de relatie met uw partner? Wat is daar na de beroerte eventueel in veranderd?

Bijvoorbeeld andere taak/rolverdeling in huis, huishoudelijke taken, afspraken nakomen, communicatie met elkaar.

D. Begeleiding tijdens ziekenhuisopname

1. Welke begeleiding/hulp hebben u en uw partner tijdens de ziekenhuisopname gekregen?
   Doorvragen: De standaardbegeleiding omvat: informatiemap, begeleiding van de ergotherapeut, fysiotherapeut, logopedist, revalidatiearts.
2. Wat vond u van deze informatie/hulp? Hoe tevreden was u erover?
3. Wat heeft u daarin gemist? Wat had u graag meer of anders gewild?
4. Wat voor begeleiding of informatie heeft u over mogelijke problemen in het denken gekregen?
5. Wat voor informatie heeft u tijdens de ziekenhuisopname gekregen gericht op u als partner en/of als mantelzorger? Hoe tevreden was u hierover?
   Bijvoorbeeld folders, een website, of mondelinge informatie van een zorgverlener.
6. Wat heeft u daarin gemist? Wat had u graag meer of anders gewild?

E. Begeleiding nazorg thuis

1. Welke begeleiding/hulp hebben u en uw partner na ontslag uit het ziekenhuis gekregen?
   Doorvragen: De standaardbegeleiding omvat: informatiemap, begeleiding van de nazorgverpleegkundige of huisarts, maatschappelijk werk, psycholoog, activiteitentherapie, controle CVA-verpleegkundige na zes weken.
2. Wat vond u van deze informatie/hulp? Hoe tevreden was u erover?
3. Wat heeft u daarin gemist? Wat had u graag meer of anders gewild?
4. Wat voor begeleiding of informatie heeft u bij de nazorg over (omgaan met) mogelijke problemen in het denken gekregen?
   Bijvoorbeeld via folders, een website, of mondelinge informatie van een zorgverlener.
5. Wat voor begeleiding heeft u na uw partners ontslag gekregen gericht op u als partner en/of als mantelzorger? Hoe tevreden was u hierover?
6. Wat heeft u daarin gemist? Wat had u graag meer of anders gewild?
   Bijvoorbeeld meer informatie, ondersteuning, hulp bij het uitvoeren van dagelijkse activiteiten, structuur aanbrengen, aanpassingen in huis, rust nemen.

F. Mogelijke interventies

Er bestaan verschillende programma's om partners van mensen met problemen in het denken na een beroerte te ondersteunen.

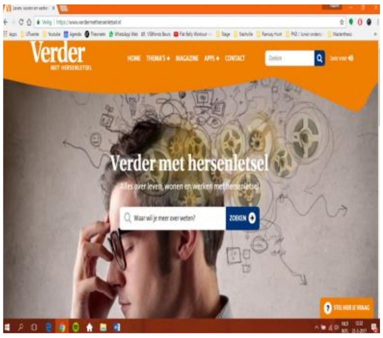
Zou dit *afbeeldingen tonen ter illustratie* u kunnen helpen? Waarom wel of niet? Wat voor interventie zou wel iets voor u zijn?

Appendix E. Interventions for patients

Informative interventions

- Brochure / folder
- Informative meeting

Informative interventions



- Website

Education/training

- 'Niet rennen maar plannen'

Education/training

- Advice and guidance

Education/training

- Time pressure management training

Education/training

- Goal management training

Peer contact

- Peer contact meeting

Peer contact

Lotgenotencontact

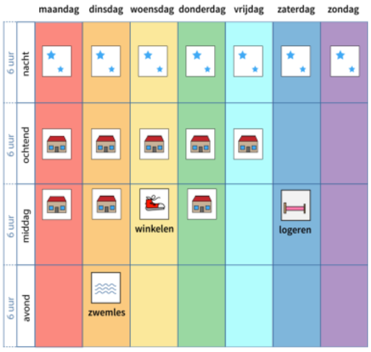
	Lotgenotencontact - Algemeen en Landelijk Uw CVA ervaringen delen met anderen. Gebruik deze rubriek voor algemene en landelijke CVA onderwerpen. Voor discussies per regio verwijzen wij u naar betreffend Regio forum. Er is ook een aparte rubriek speciaal voor partners van .... Gewoon gezellig babbelen kunt u in het Babbelcaf�.	773	8,519
	Stel je voor! De meeste mensen op het forum willen graag weten met wie zij te maken hebben. Daarom deze rubriek 'Stel je voor!'. Plaats hier geen persoonlijke gegevens als adres, telefoonnummer en emailadres. Wil je iemand een persoonlijk bericht sturen dan kan dat via de mailbox. Dit is volkomen veilig en alleen de ontvanger kan je bericht lezen. Realiseer je dat alle informatie die je hier 'schrijft' door iedereen gelezen kan worden. Probeer de onderwerpen zoveel mogelijk in andere rubrieken op te starten of onder te brengen en niet hier de discussie te starten. Natuurlijk mag er een reactie gegeven worden op het voorstellen maar probeer te voorkomen dat hier lange discussies ontstaan.	283	2,281
	Partners en relaties van CVA getroffenen Hier kunnen partners en relaties van een CVA-getroffene hun vragen, opmerkingen, suggesties en verhalen kwijt.	113	1,164
	Babbelcaf� In dit forum kunt u gewoon gezellig babbelen over alles en nog wat. Maak desgewenst uw eigen Babbelonderwerp aan. Stel hier geen vragen over CVA gerelateerde onderwerpen.	500	6,283
	Europese Dag van de Beroerte De Europese Dag van de Beroerte (CVA), afgekort als EDvdB, wordt in 2014 voor de 10e maal in Nederland gehouden. Op de tweede dinsdag in mei (13 mei 2014) worden op meer dan 100 locaties (ziekenhuizen, revalidatiecentra, etc.) activiteiten georganiseerd met als thema "Voorkom en Herken een CVA (beroerte).	1	1
	Lotgenotencontact - Voor CVA op kinderleeftijd Op het landelijk secretariaat van de Nederlandse CVA vereniging komen met regelmaat vragen binnen over kinderen die een CVA hebben gehad. Ook zijn er verzoeken voor contact met Lotgenoten. Dit forum is daarom speciaal voor de groep "Lotgenoten voor CVA op kinderleeftijd".	4	6

- Forum

Tools

- Apps on smartphone
- Electronic agenda

Tools



- Planning board

Tools

- Smart watch

Tools

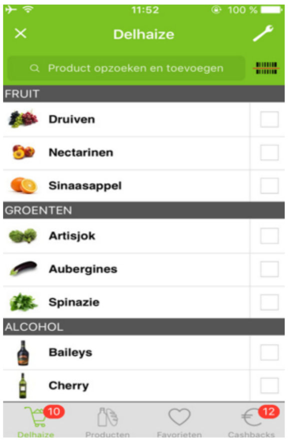
Thee drinken

Genoeg water drinken!

1. Water koken
2. Water in theekopje doen
3. Thee in kopje doen
4. 2 min wachten en roeren
5. Zakje uit kopje halen

- Online goal management assistance

Tools



11:52 100 %

Delhaize

Product opzoeken en toevoegen

FRUIT
- Druiven ☐
- Nectarinen ☐
- Sinaasappel ☐

GROENTEN
- Artisjok ☐
- Aubergines ☐
- Spinazie ☐

ALCOHOL
- Baileys ☐
- Cherry ☐

- Online grocery list with pictures

Tools

- Online step-by-step recipes with pictures

Appendix F. Interventions for partners

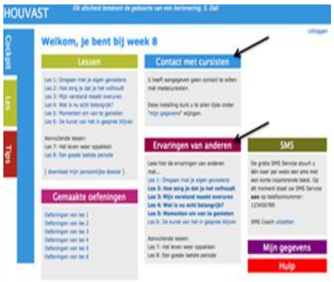
Informative interventions

- Brochure / folder
- Informative meeting

Informative interventions

- Website

Education/training



- 'Houvast, voor elkaar'

Education/training

- Advice and guidance

Support

- Peer contact meeting

Support

- Forum

Support

'Je stelde me vragen die mij aan het denken hebben gezet. Over mijn aandeel in de situatie. Niet leuk maar wel goed.'

Dag en nacht een luisterend oor

- Emotional support

Support

- Practical support at home

Support

handen in huis

MANTELZORGVERVANGING NEDERLAND

- Respite care

Appendix G. Coding trees representing (sub)categories

Figure 1. Coding tree of experienced consequences of stroke

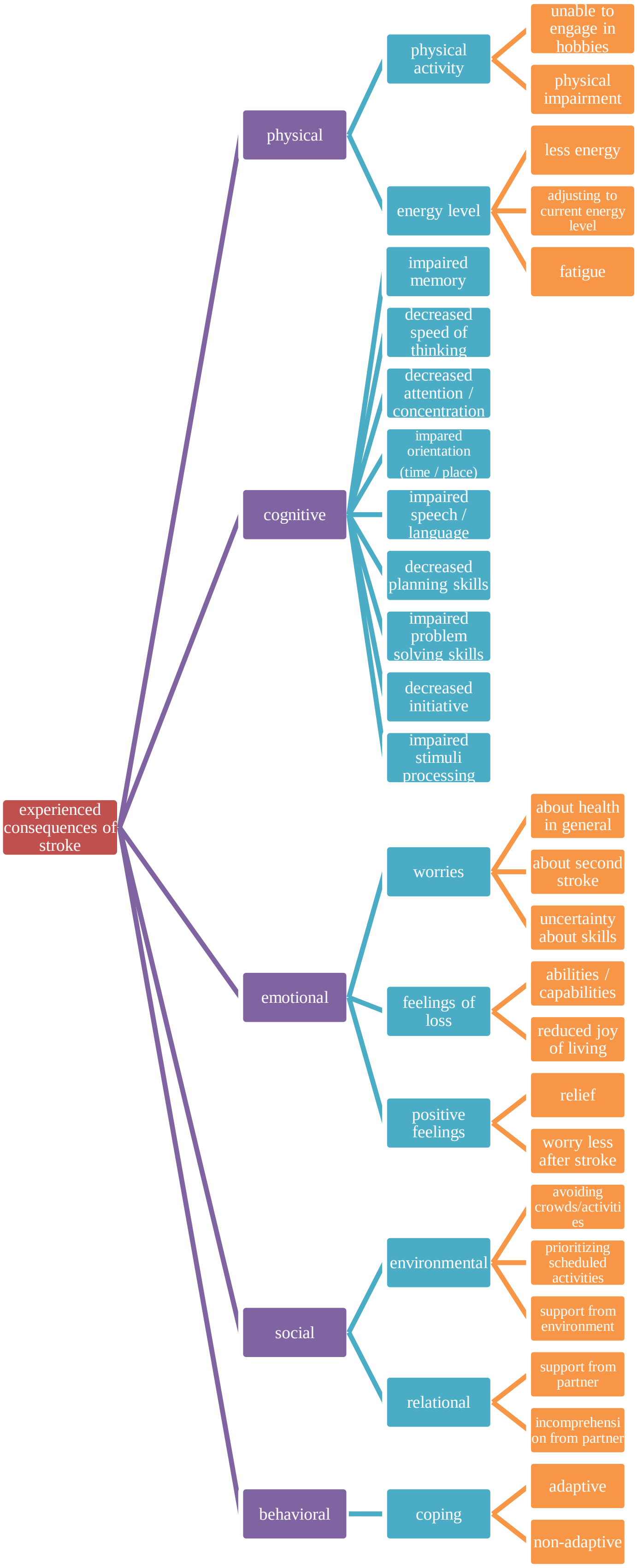


Figure 2. Coding tree of patients' healthcare needs

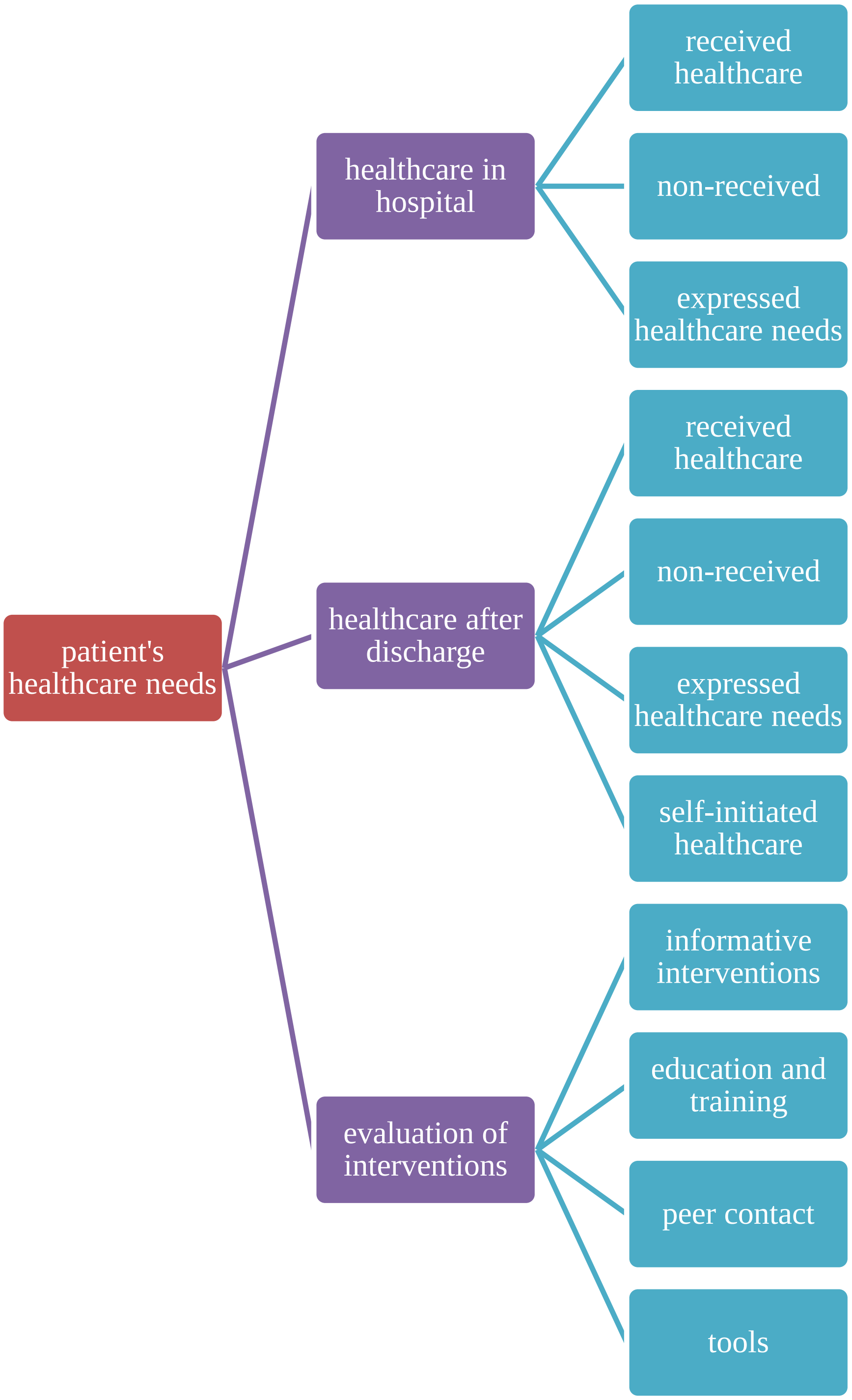


Figure 3. Coding tree of partners’ support needs