

CVA-ECOACH

Assessing the Needs and Stressors of Informal
Caregivers of Young Stroke and Stroke Patients. Can the
CVA eCoach App Provide Effective Support?

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Foreword/Acknowledgements

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Abstract

Background: Cerebrovascular accidents (CVAs), commonly known as strokes, affect millions of people annually, significantly impacting patients and their caregivers. Informal caregivers often face substantial stress and have unmet informational, emotional, and practical needs, particularly during the transition from hospital to home care.

Research Question & Aim: This study aims to explore the stress factors and needs of informal caregivers of stroke patients at the ISALA hospital in Zwolle. The main research question is: "How do relatives/partners of stroke patients experience the stress factors associated with their role as caregivers, and what specific needs (including informational, emotional, and practical) do they have, and can the CVA eCoach app contribute to supporting these needs?" Additionally, the sub-question "What is the difference between Young Stroke (YS) participants and Stroke (S) participants?" was explored to identify specific needs and stressors unique to caregivers of younger stroke patients compared to older stroke patients.

Methods: This qualitative study involved semi-structured interviews with 11 informal caregivers of stroke patients. The interviews were thematically analysed using deductive and inductive coding to identify key themes, main codes, and sub-codes related to perceived stressors, coping mechanisms, and needs.

Results: The study identified informational, emotional, and practical needs among caregivers. Informational needs included personalised information about the type of stroke and continuous updates post-discharge. Emotional needs involved feeling heard and supported, particularly in the initial weeks post-stroke. Practical needs centred on assistance with daily tasks such as cooking and household chores. Differences (e.g. primary concerns and the support they required) were observed between caregivers of young stroke (YS) patients and older stroke (S) patients. All participants recognised the potential benefits of a tailored app like the CVA eCoach, suggesting features such as personalised information, emotional support channels, and practical advice sections would be useful.

Discussion & Conclusion: The findings highlight a substantial gap in support for informal caregivers, underscoring the need for interventions like the CVA eCoach app, which is also available for informal caregivers. The app can provide timely and tailored support, reducing caregiver burden and potentially

improving patient outcomes. Future research should focus on developing and implementing such an app, incorporating caregiver feedback to ensure it effectively meets their needs.

Introduction

CVA

Every year, millions of lives are forever altered by a sudden and often devastating event- a Cerebrovascular Accident (CVA), more commonly known as a stroke. In the Netherlands, approximately 42,000 people suffer a stroke annually, and 20,000 experience a transient ischemic attack (TIA), with around 48,500 hospital admissions and an average stay of 6.2 days (Zorg voor beter, 2023; Volksgezondheid en Zorg, 2022). Mooij et al. (2021) noted that approximately 60% of patients return home after their hospital stay rather than going directly to a rehabilitation centre.

A stroke is an interruption in the flow of blood to cells in the brain. When the cells in the brain are deprived of oxygen, they die. A stroke occurs when a blockage in an artery prevents blood from reaching cells in the brain or when an artery ruptures inside/outside the brain; this causes a haemorrhage (The George Washington University Hospital, n.d.). Symptoms of a stroke are sudden numbness or weakness of the face, arm or leg (most of the time on one side of the body), trouble speaking or understanding others, vision problems in one or both eyes, loss of balance or coordination, severe headache with no known cause. There are two types of strokes: ischemic (80%) and haemorrhagic (20%). An ischemic stroke is caused when blood vessels become clogged. Some are preceded by stroke-like symptoms called transient ischemic attacks (TIAs) that can occur months before the stroke. A haemorrhagic stroke occurs when weakened blood vessels inside the brain rupture (The George Washington University Hospital, n.d.). The limitations in the acute and chronic phase are important due to varied biopsychosocial changes in the short and long term of the stroke survivors. These statistics show the big impact of strokes, not just on patients but also on their families and caregivers.

Impact of Stroke on Patients

For patients, stroke highly affects their daily lives by affecting themselves and their environment. Consequences of stroke include both disability and impairment (Bartlova et al., 2022). Stroke Association (n.d.) adds that damage to the brain can affect how the body works and can also change how a person thinks and feels. Stroke creates a major impairment of the nervous system and other organic systems. Due to these impairments, disabilities in various capabilities (e.g., language,

behaviour, intellectual function, sensory perception, motor skills, and balance) may arise. People can vary in their ability to perform daily activities and social roles depending on the extent of the disability (Vincent et al., 2007). Bartlova et al. (2022) adds that stroke is one of the main causes of disability and it doubles the risk of dementia. Stroke also is associated with QoL (Quality of Life) impairment. Variables that are closely associated with a lower QoL of post-stroke patients include depression and lower functional status. Even patients who have regained their functional independence continue to suffer considerable deficits, limitations and changes in their cognitive functions and behaviour (Bartlova et al., 2022). Frustration, anxiety and despair occur in reaction to physical, cognitive and psychosocial changes resulting from stroke (Wang et al., 2018).

After a stroke, social participation can be affected by social and physical environmental factors. Social environmental factors include support from family and utilisation of health and social services; physical environmental factors include natural or technological elements (e.g., climate). These factors can help or hinder the performance of daily activities and social roles (Vincent et al., 2007).

Post-stroke can be divided into the acute phase (transition from hospital to home until six months post-stroke) and the chronic phase (from six months post-stroke and lasting over time) (Da Silva et al., 2020). In The Netherlands, 60% of patients with a stroke go home after 48 hours or after a short revalidation process (Mooij et al., 2021). Da Silva et al. (2020) add that the majority of stroke survivors have cognitive, psychological, and motor impairments that limit their ability to perform basic daily activities and social participation, making them dependent on their families to provide care during community rehabilitation.

CVA-eCoach app for patients

The ISALA hospital in Zwolle developed and uses the CVA-eCoach app to improve these patients' transition to the home situation. This app stimulates patients to maintain self-management of the unseen consequences and also aims to stimulate healthy behaviour. This app allows healthcare professionals to monitor patients and coordinate care in the first three months after discharge from the hospital. At the same time, patients are stimulated to maintain control over their recovery. The app contains three modules: Information, Measurements, and Self-management. The first part,

Information, shows different subjects related to stroke, such as what a stroke is, the causes of the stroke, a healthy lifestyle, and medication. Patients can click on these items to receive information about the subject and tips. The second part of the app is *measurements*. Patients receive a pop-up in the app to complete a questionnaire about certain topics like anxiety, fatigue, activity, and mood every two weeks. The patients have a week to complete this questionnaire, and answers will be saved in the app. The questionnaire scores will be based on points; for example, when scoring fatigue, the patient can give a score from 0 (I do not suffer from fatigue) to 10 (highly fatigued). When the score in this example is high, the patient will receive a notification from the app with “The score of the questionnaire “Fatigue” indicates that you are fatigued; we advise you to read the information about unseen consequences of fatigue. When you stay fatigued for a longer period, you can read the information “how to handle fatigue parts 1 and 2”. The patient will also receive a pop-up the next week to fill out the questionnaire again. When a high score appears multiple times, a nurse from the hospital will contact them to see why this is the case and how to support the patient. Lastly, *self-management* indicates when the patient fills in the questionnaires and works with the information given. The patient needs to monitor their condition themselves, and they can use the app to read information and ask questions. Patients can contact a nurse practitioner via the app if they have questions. After four to ten weeks, they will also receive a pop-up message asking if they want to contact a nurse practitioner; they need to react to this message in the app.

Patients who have been admitted to the brain care unit of the ISALA hospital in Zwolle and potentially can return home after 48 hours or have a short stay at the neurology department have the option to use the CVA-eCoach app or get information in a binder (or sometimes both). When a patient wants to use the CVA-eCoach app, a nurse will explain what this means and, if needed, help the patient install the app on his/her phone. After this, the patient gets the credentials via email. This app aims to improve recovery and support lifestyle changes after a stroke at home. The program lasts 24 weeks and is meant for patients discharged after 48 hours at the brain care unit or patients who needed a short revalidation period and were discharged afterwards. At the ISALA hospital in Zwolle, the app differs for two groups of stroke patients: Young Stokes (YS), patients 50 years old and younger, and stroke patients (S) older than 50. The majority of authors consider young stroke patients 45 years old

and younger (Griffiths, 2011). Bukhari (2023) describes Young Strokes as patients 50 years and younger and adds that young strokes account for 10% of all strokes. YS get more information based on returning to work, etcetera, and S patients don't get this information.

Informal Caregivers

To improve the app, focus groups were held by the ISALA hospital to explore the experiences of patients and informal caregivers with the CVA eCoach. During these focus groups, it became apparent that informal caregivers felt less involved in the process, as healthcare workers' information and attention were focused on the patient. Informal caregivers wanted to be more involved in the patient's process after the hospital stay. Secondly, from the bachelor thesis on this subject, the conclusion was that informal caregivers wanted information about how to handle certain behaviours and how to help as informal caregivers (Bilen, 2023).

The results of the bachelor thesis are not surprising since it is known that stroke affects not only the patient but also the informal caregiver of this patient (Ogunlana et al., 2014; Beunder et al., 2015; Jírů-Hillmann et al., 2022). Informal caregivers provide unpaid care to family, close relatives, friends, and neighbours (Li, 2019). Due to cognitive, psychological, and motor deficits that reduce their ability to perform basic daily activities and social participation, patients sometimes need support from others, such as family caregivers. A study in Spain found that the average daily hours required for informal care were 8.7 hours three months post-stroke and 7.2 hours 12 months post-stroke. This study included patients who received extensive care and those who received less care (Wang et al., 2021). Consequently, these caregivers experience the burden of care, meaning the deterioration of physical and mental health, which affects their Quality of Life (QoL) (Da Silva et al., 2020). The research of Watanabe et al. (2015) concluded that regardless of the degree of independence of a patient's Activities of Daily Living (ADL), the caregiver burden was severe. Because of this, it is important to investigate informal caregivers' perceived stress and needs in the transition from hospital to home and the period after. The study by Bendova (2024) showed that informal caregivers felt like they lacked information about stroke and available services, and the hospital did not provide this. Also, some caregivers felt separated and ignored by healthcare professionals and felt like these professionals could not meet their need for information. The need for information was mostly about

more information about strokes, the likelihood of reoccurrence, information related to specific individual symptoms and their needs for financial or social services, and care-related topics and finding time for themselves (Bendova, 2024).

The information mentioned above mostly focuses on patients with many residual symptoms who cannot function properly because of these symptoms. Because of this, it is important to study these burdens of care based on the physical and mental health of informal caregivers of patients with less care needs. Also, all data about informal caregivers are not focused on informal caregivers of young stroke patients. Caregivers in this group (under 50 years old) can have younger children and, therefore, have different needs and perceived stress. Because of this, it is important to analyse this group of informal caregivers. To conclude, the target group of this research is informal caregivers of patients who have had short hospital stays and can revalidate at home or via a revalidation centre but for a short time.

The Stress and Coping model of Lazarus & Folkman can help understand the challenges faced by caregivers. This model focuses on how caregivers perceive and respond to the stress of caregiving. This may include their need for information to manage and cope with their situation effectively. This model contains the following determinants: stressors (influencing factors), primary appraisal, secondary appraisal, coping strategies (problem-focused and emotion-focused) and outcomes (Lazarus and Folkman, 1984). However, this model does not contain all the elements that this study wants to research. The bachelor thesis of Bilen (2023) concluded that informal caregivers wanted to be more involved in the patient's process after the hospital stay. However, this thesis did not ask about informal caregivers' specific needs and stressors. Secondly, during the focus groups held by the ISALA hospital, it became clear that informal caregivers felt like they were kept on a sideline. Therefore, this study introduces the Perceived Stress and Needs model, which is built upon Lazarus and Folkman's Stress and Coping model. While their model focuses on how individuals manage stress, the Perceived Stress and Needs model specifically addresses the unique challenges faced by informal caregivers after a stroke. Informal caregivers experience not only emotional stress but also require practical support and relevant information (Rigby et al., 2009). This model contains only the elements 'Influencing Factors' and 'Coping' of the Stress and Coping model and adds 'Perceived Stress' and the 'Needs'

(informational, emotional, and practical) (see Figure 2). Arrows are added to the model, but this does not mean this is the only way the model can go. For example, perceived stress can influence the needs of an informal caregiver. But the needs an informal has can also influence the perceived stress. Therefore, the arrows are only added to make it more structured.

Figure 1:

The Stress and Coping Model of Lazarus & Folkman.

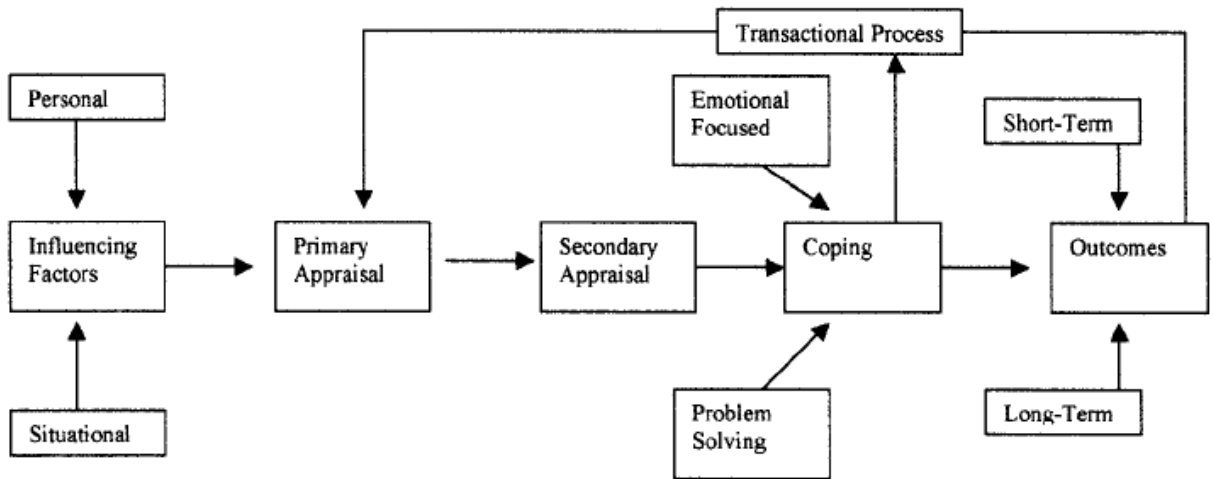
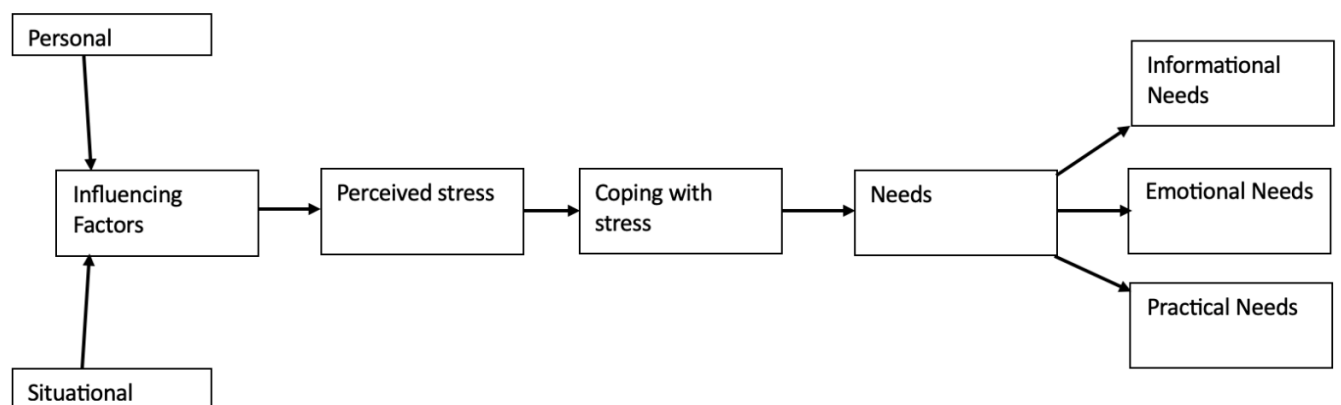


Figure 2:

Model of Perceived Stress and Needs



Aim and research question

This study aims to research the specific stressors and unmet needs of informal caregivers of stroke patients at the ISALA hospital in Zwolle post-discharge, utilizing the Perceived Stress and Needs model. This model integrates caregivers' emotional, informational, and practical needs, to identify tailored interventions, such as the CVA eCoach app, to address these challenges. Therefore,

the research question of this study is: *“How do relatives/partners of stroke patients experience the stress factors associated with their role as caregivers, and what specific needs (including informational, emotional, and practical) do they have and can the CVA eCoach app contribute to supporting these needs?”*, because of the lack of data and information collected during the interviews, the sub-question: *“What is the difference between YS participants and S participants?”* was created and also explored. Understanding informal caregivers' perceived stress and needs is essential for developing effective interventions that reduce caregiver burden and improve patient and caregiver outcomes.

Methods

Study design

This qualitative study used a combination of a Phenomenological Approach and a Needs Assessment Approach to explore the needs of informal caregivers of patients who had a stroke and went home after 48 hours or after a short revalidation process. Combining these two approaches, this study will capture both the deep, subjective experiences of caregivers (phenomenological aspect) and also identify and categorise their specific needs (needs assessment aspect) (Dovetail's Editorial Team, 2023; Gillam et al., 1996). This approach ensures an in-depth analysis of both the subjective experiences of stress and the concrete needs of informal caregivers. Data was collected by conducting semi-structured interviews with informal caregivers. This study is approved by the ethical commission of the BMS at the University of Twente (dossier number: 231434).

Participants

The participants in this study were Informal caregivers of patients who had a stroke with little revalidation needs (going home after 48 hours or a short revalidation period). The patients needed to be qualified to use the CVA eCoach app. The participants in this study were recruited via convenience sampling. Listed in this group:

- Informal caregiver of stroke survivors who qualify for the CVA eCoach app
- Patients of the ISALA hospital in Zwolle
- Dutch or English-speaking

Exclusion criteria:

- Minor informal caregivers (under 18 years old)
- Informal caregivers were contacted for another research involving the CVA eCoach.
- Caregivers with dementia or other mental problems and/or anxiety problems. These were excluded due to the possible effects on their own mental health. This was pre-checked by the hospital itself.

The participants were recruited from a list of patients at ISALA Hospital. Following these steps, including ethical approval, participant screening and informed consent, helped build a solid foundation for the research. The data collection in this research was between January 29 2024, and April 30 2024. Sixty-five informal caregivers were contacted via the list of telephone numbers provided by the ISALA hospital for patients who have used the CVA eCoach. Every informal caregiver was called once and was contacted via mail or app with reminders 2 more times. 54 informal caregivers of this group didn't participate in this study. Of the group who didn't participate, more than 50% didn't respond (30 informal caregivers). Of the 25% (12 informal caregivers) who said they didn't want to participate, 15% (8 informal caregivers) said it was because of a bad experience with the hospital, and the other 10% (4 informal caregivers) couldn't because of their personal situation. Other informal caregivers didn't give a reason. Eventually, 11 informal caregivers participated in the study.

Demographics of these informal caregivers can be found in Table 2.

Intervention

The intervention used for patients followed after the stroke is called CVA eCoach (described in the introduction). This app is currently only used for patients and not for informal caregivers. Information and other options in the app cannot be used or seen by informal caregivers. Screenshots of the app can be found in Appendix C.

Materials

Interview

A semi-structured interview with open-ended questions was conducted with the participants, covering the following two areas:

- Perceived stressors associated with the caregiving role
- Specific needs: Informational, Emotional, Practical

The interview questions were developed based on the Perceived Stress and Needs model, which focuses on understanding the connection between caregivers' stress and unmet needs in these three key areas. Follow-up questions were asked to enrich and fully understand the participants' answers.

Concrete interview questions are in Appendix B.

Procedure

At first, the researcher contacted informal caregivers of patients via the patient's dossier at the ISALA hospital in Zwolle. When someone was interested, the researcher provided information about the study. Also, information about the study was explained to the possible participants. Before participating, the researcher sent them the informed consent form with more information, which the participant needed to sign (see Appendix A). After giving informed consent, participants were asked to set a date for explaining the eCoach app at a location and a date for the interview.

Data were collected between January 29 and April 30. The participant was asked to set a date and time with the researcher. When a date was set, the participant could decide which location he/she would prefer. Half of the participants wanted to do the interview at the ISALA hospital in Zwolle, and the other half preferred to do it at their home. When the interview was at the hospital, the hospital's research nurses booked a room.

The participant was reminded via mail or a message on the interview day. When the interview started, the participant was asked if he/she consented to using a voice recorder to record the interview. After this, the CVA eCoach app was explained to all the participants, which took around 30 minutes, and the participants could see what functions the app provided. Most participants had seen the app before but didn't see all the functions. The functions were shown so the participants had an idea of the app's functions when some questions were asked about it during the interview. When the participants felt like they knew the use of the app and had seen enough, the interview started. The interview took about 1 hour. This resulted in a total time of 1.5 hours for all participants. During the interview, the participants were open to stopping anytime they wanted when they would get emotional or if they wanted to take a break. At the end of the interview, the participants were asked if they had any

questions or suggestions for the CVA eCoach and the interview. Lastly, they were asked if they wanted a summary of the study's results.

Eventually, the participants were thanked for their participation in the research and were asked if they could be contacted again for questions if they occurred.

Data-analysis

The researcher transcribed the interviews verbatim using recordings captured with a voice recorder. These transcriptions were then imported into ATLAS.ti, a qualitative data analysis software, to facilitate the coding and thematic analysis process.

The data were analyzed using thematic analysis, following the six-phase approach outlined by Clarke and Braun (2006). Thematic analysis was chosen to systematically identify and interpret patterns within the qualitative data. The analysis combined both deductive and inductive coding strategies. Deductive coding was applied first, guided by the Perceived Stress and Needs model. This framework provided the basis for identifying six pre-defined themes: "Perceived Stressors," "Coping with Stressors," "Informational Needs," "Emotional Needs," "Practical Needs," and "CVA eCoach." These themes served as a foundation for coding the data, ensuring that the analysis was aligned with the theoretical framework.

Secondly, inductive coding was used to develop specific codes and sub-codes within the pre-defined themes, based on the participants' responses. For example, within the theme of "Informational Needs," the code "Information Already Given" was created to capture participants' references to the information provided by the hospital. Further sub-codes, such as "Information Provided by the Hospital", were developed to categorize specific aspects of participants' experiences with the information they received. These codes allowed for a more detailed analysis of the data, while still fitting within the original thematic structure.

Once the coding process was completed, the data were divided into two groups based on the age of the stroke patients: under 50 years and over 50 years. This division facilitated a comparative analysis to explore potential differences in the experiences and needs of caregivers based on the age group of stroke patients. By examining these two distinct groups, the analysis aimed to identify

whether the age of the stroke patient influenced the stressors faced by caregivers or the support they required.

The thematic analysis, using both deductive and inductive coding approaches, offered a detailed understanding of the informal caregivers' experiences. This process emphasized the caregivers' perceived stressors, coping strategies, and specific needs across the two age groups. The insights gained from this analysis are important for answering the research questions and shaping the development of targeted interventions, such as the CVA eCoach, to better address the varying needs of caregivers.

Table 1

Themes of the Interviews (deductive codes) with Main- and Sub-codes (Inductive)

Theme	Definition	Main Code	Subcode
Perceived Stressors	Things or situations after the stroke of their partner/family that are seen by the participant as stressful and overwhelming	Fear of re-occurrence	
Coping with Stressors	How the participant handles the stress related to the stroke of their partner/family.	Emotional support	
Informational Needs	Information the participant required after the stroke	Information already given	Information provided by the hospital
Emotional Needs	This means the things the participant needed based on their emotional or mental stressors after the stroke	Feeling heard	
Practical Needs	This means the things the participant needed that relate to the daily tasks and responsibilities as an informal caregiver of a stroke patient	Daily responsibilities	

Ethical considerations

This research was approved by the ethical comity of the BMS at the University of Twente (dossier number: 231434). Before participating, all informal caregivers must sign the informed consent form at the end of the information form. Their participation was voluntary, and their anonymity will always be preserved. This will be achieved by anonymising their names or any personally identifiable information.

To protect the mental health and well-being of participants, caregivers with dementia, other mental health issues, and/or anxiety problems were excluded from the study. This exclusion criterion was implemented to prevent any potential adverse effects on their mental health, ensuring that participation in the study would not exacerbate an existing condition

Results

Participant characteristics

In this study, most participants were female, and almost all were patient partners. Only one was the patient's mother. All patients in this study have had a cerebral infarction. This study also made a distinction between young stroke and stroke. Most of the informal caregivers in this study had a partner/family member who was seen as an S patient. More than one-third of the partners/family members of the participants were YS patients. All the details about the demographic variables of the participants can be seen in Table 2.

Table 2*Participants Demographic Characteristics*

Participant	Gender participant	Age participant	Gender patient	Age patient	Relation	Form of Stroke	<50 (Young Stroke) / >50 (Stroke)
1.	Male	69 years old	Female	69 years old	Partner	CI	S
2.	Female	55 years old	Male	62 years old	Partner	CI	S
3.	Female	63 years old	Male	70 years old	Partner	CI	S
4.	Male	41 years old	Female	40 years old	Partner	CI	YS
5.	Female	58 years old	Male	62 years old	Partner	CI	S
6.	Female	51 years old	Male	44 years old	Partner	CI	YS
7.	Female	46 years old	Male	49 years old	Partner	CI	YS
8.	Female	69 years old	Female	33 years old	Mother	CI	YS
9.	Female	51 years old	Male	60 years old	Partner	CI	S
10.	Male	68 years old	Female	61 years old	Partner	CI	S
11.	Male	59 years old	Female	58 years old	Partner	CI	S

Note: CI=Cerebral infarction

Results Interviews

Tables 3 and 4 contain the two main themes with codes based on the first part of the research question (perceived stressors and coping with stressors). Tables 5, 6 and 7 contain the main themes with codes based on the participants' informal, emotional and practical needs (the second part of the research question). Table 8 contains information based on the possibilities of the CVA eCoach based on the three needs. The results will be explained per theme and main codes, and in some themes, sub-codes were created to make the main code clearer. Also, the results of stroke and young stroke informal caregivers will be compared.

PERCEIVED STRESSORS

Table 3

Code Scheme Interviews Theme Perceived Stressors

Code	Definition	Quotes
<ul style="list-style-type: none"> □ Fear of re-occurrence (4,5) 	<ul style="list-style-type: none"> - How many residual symptoms the patients had after the stroke and the stress that came with this because these symptoms could be seem as similar 	<ul style="list-style-type: none"> □ “I needed to provide a bit more care. He was more tired than usual but he wouldn’t do anything different than before. I was more alert to symptoms, there was some fear afterwards.” (P9) □ “I felt stressed and anxious when my husband looked crossed eyed again and I thought that it happened for a second time.” (P6)
<ul style="list-style-type: none"> □ Household (3,3) 	<ul style="list-style-type: none"> - How other family members experienced the stroke and differences in household after stroke 	<ul style="list-style-type: none"> □ “My family and my son have seen when the stroke happened. My son has developed anger issues after the incident. Oldest daughter could handle the situation better.” (P4) □ “Because my husband was home more often this resulted in having more arguments also not related to the stroke ” (P10)

Code	Definition	Quotes
<ul style="list-style-type: none"> □ Activities (3,3) 	<ul style="list-style-type: none"> - How they experienced doing activities after the CVA 	<ul style="list-style-type: none"> □ “I do feel stressed when we go out with the car and my husband is driving. I want to stop every hour because I do feel anxiety when he drives for too many hours.” (P7) □ “I can’t always take my husband to all the activities because of all the stimulus, it is more than he can handle” (P3)
<ul style="list-style-type: none"> □ Giving support to the patient (2,3) 	<ul style="list-style-type: none"> - Extra support giving after the CVA and the stress related to this. 	<ul style="list-style-type: none"> □ “I am his source of information, his taxi driver, mostly everything. In the beginning this was a lot worse, he couldn’t do anything alone.” (P5)

Note: the first number after the subcode is the number of participants where this code occurred. The second number is the number of times this code appeared in total in all 11 interviews.

Perceived stressors

As seen in Table 3, the perceived stress is based on the severity of the stroke and the 'Fear of re-occurrence'. All the participants mentioned they were very happy that their partner or family/friend didn't have much or no residual symptoms. This resulted in them "going with the flow." and "taking things as they came". The most significant stressors were perceived in the beginning after being discharged from the hospital. During the interviews, three participants said it was nice that their husbands were home more often (code 'Household'). For one participant, it felt like going 15 years back in time in a positive way. For two of these participants, it also gave some stress because other things like housekeeping were more difficult with their husbands at home. This also resulted in them having direct conflict with their husbands. Two participants said that their own health was also a stressor, and they felt like their health was on hold because of the stroke. One participant (P10) had appendix surgery at the same moment as his wife had the stroke. Because of this, the beginning period was more difficult because he couldn't mobilise much after the surgery. The biggest stressor for a YS participant (P4) was his kids. He has children who are four and seven years old. The 7-year-old child had seen the symptoms his mother had (which resulted in her laying on the floor) and had seen that his dad called someone, and because of this action, his mom was taken away (in the ambulance). When the mom returned home, the 7-year-old didn't want his dad around his mother because he was scared his father would take his mother away again. The 7-year-old developed anger management issues after the stroke, and the YS participant said that it was a lot to handle after the stroke. Other participants said it was harder to undertake activities after the stroke, especially in the beginning. They were scared that it may reoccur or their partner didn't want to be left alone. Most participants said they ensured that their partner/family member wasn't left alone in the beginning. A few participants said that they felt they were psychologists for their partners. Their partner was very passive after the stroke, or they acted like the stroke didn't happen, and this resulted in a lot of stress for the informal caregivers.

Positive stressors

Some answers that were seen as negative stressors by participants also made some positive situations after the stroke. For example, some participants said that it was more difficult when their husbands were at home, while others explained that having their husbands at home was a blessing. One

participant said it felt like they were 16 years old again because of their time together. Another participant said that it was nice to have her husband at home because he spends more time with the kids.

COPING WITH STRESSORS

Table 4

Code Scheme Interviews Theme: Coping with Stressors

Code	Definition	Quotes
□ Social Support (4,7)	□ Social support after the stroke provided by professionals or family members	□ “I have shared with my brother and in the church that my daughter had a stroke. I had a lot of support from this community when I needed it. I feel a lot of support within my faith.” (P8)
□ Emotional support (3,5)	□ Emotional support after the stroke provided by professionals or family members	□ “Before the hospital stay, I had already contacted a nurse practitioner. Because of the nurse practitioner, I could handle my emotions after the stroke. These appointments are without my wife. When I feel stuck within my feelings, I talk with the nurse practitioner.” (P10)

Note: the first number after the subcode is the number of participants where this code occurred. The second number is the number of times this code appeared in total in all 11 interviews.

Coping with stressors

All participants had asked for support after their partner's stroke. This support was mostly asked of close family and friends and contained social and emotional support. One participant already had a nurse practitioner in primary care before the stroke, which he consulted afterwards for mental support. Two participants had close family members who worked in healthcare and could be asked questions about medications, etc. Two participants also asked for help from their families because they had young children. Three participants said they didn't need help but could go to their families or friends for social and emotional support. When asked how they coped with challenges, one participant replied, *"I think very practical, and I am sober-minded. Being sober-minded helped me tell my story to people I knew. Especially during the first few days, it felt good that I had good communication with my wife. My wife doesn't have symptoms related to the stroke anymore. The possible cause of the stroke was her heart. We have less stress because we found the cause of the stroke."*

Tables 5, 6, and 7 show the needs based on the three main themes: Informational Needs, Emotional Needs, and Practical Needs.

INFORMATIONAL NEEDS

Table 5:

Code Scheme Interviews Theme: Informational needs

Code	Definition	Subcode	Quotes
<ul style="list-style-type: none"> □ Information already given (9, 12) 	<ul style="list-style-type: none"> □ The information that is already provided by the hospital after the stroke. This can be either positive or negative. 	<ul style="list-style-type: none"> □ Information provided by the hospital (4,5) 	<ul style="list-style-type: none"> □ “The hospital only provided a small folder with some information. I didn’t receive any other information besides that. I would have liked more information about how to handle and what to do when something happens.” (P11) □ “I feel like we have had enough information about the stroke provided by the hospital. They were very

Code	Definition	Subcode	Quotes
			helpful and understanding” (P4)
		□ Information before going home (5,7)	□ “What is would have liked is knowlegde about how to act around my partner. What can he do and what do we need to avoid. I also would have liked to know if I needed to let him try everything or when I needed to correct him in his behaviour.” (P6)
□ Additional information (5,8)	□ Additional information the participant missed but would have liked to have.	□ Availability to ask questions (3,3)	□ “I didn’t feel like I could go anywhere with my questions. My husband could ask questions via the

Code	Definition	Subcode	Quotes
			app but I didn't know where I could go with mine." (P5)

Note: the first number after the subcode is the number of participants where this code occurred. The second number is the number of times this code appeared in total in all 11 interviews.

Informational needs

All participants agreed that they needed additional information to the information given at the hospital. The difference between YS and S participants is that all the YS participants thought the information given at the hospital was almost complete. They felt they could rely on the hospital for additional information and were very positive. Almost all S participants didn't feel heard and said they didn't get enough information from the hospital. They felt like their loved one was sent home and that they needed to find out how to deal with it. One participant said, "We didn't get any information. We did get some folders, and after that, they said: *"If you need anything, just call"*. When the participants were asked about their informational needs, almost all said they wanted to receive the same information their partner had been given. Participants also wanted more information about lifestyle, what was expected after their partner went home, and the possible consequences. A young stroke informal caregiver wanted information about how to tell children about the stroke.

EMOTIONAL NEEDS

Table 6:

Code Scheme Interviews Theme: Emotional needs

Code	Definition	Quotes
<ul style="list-style-type: none"> <input type="checkbox"/> Feeling heard (2,2) 	<ul style="list-style-type: none"> <input type="checkbox"/> This is the feeling that the informal caregiver of a stroke patients feels like they were listened to as well as by the hospital and their environment 	<ul style="list-style-type: none"> <input type="checkbox"/> “I would have liked it if someone would have listened to my fears and concern (by the hospital). Now it felt like I didn’t matter.” (P6) <input type="checkbox"/> “I could go to my family and friends when I needed to talk about the situation.” (P3)
<ul style="list-style-type: none"> <input type="checkbox"/> Time (3,4) 	<ul style="list-style-type: none"> <input type="checkbox"/> The timespan in which they wanted to receive this help 	<ul style="list-style-type: none"> <input type="checkbox"/> “I think it would been nice to have a small line between us and professional help if you need it. (P10)
<ul style="list-style-type: none"> <input type="checkbox"/> Emotional Support (5,7) 	<ul style="list-style-type: none"> <input type="checkbox"/> The possibility of emotional support they got from professionals or family and friends after the stroke 	<ul style="list-style-type: none"> <input type="checkbox"/> “I have sought help. I talk with my friends about the situation. Professional help would have been nice but not necessary.” (P6)

Code	Definition	Quotes
□ Fear of re-occurrence (5,6)	□ The emotions felt with symptoms similar to the stroke.	□ “It was very scary when she showed signs of a new stroke, in the end I was very happy that it was false alarm” (P4)

Note: the first number after the subcode is the number of participants where this code occurred. The second number is the number of times this code appeared in total in all 11 interviews.

Emotional needs

When asked if the situation had influenced them emotionally, the first three participants and the sixth participant said that it hadn't influenced them emotionally because they were too down to earth or the situation afterwards hadn't changed that much. They said they were adjusting to the circumstances or had already sought help from close family members (Emotional Support). A few participants said they felt the most stressed when their partner/family member again showed symptoms of a stroke (code: Symptoms). One participant said, *"I felt very stressed when her leg went numb again; I thought, "Oh no, not again?"*. When asked if they received emotional support, one participant (code: Feeling Heard) said, *"Looking back, I don't think there was any form of emotional support provided by the hospital. It would have been better if I had received it. Then, I would have known what to expect or how to experience the symptoms related to the stroke. I just wanted to feel heard. It wouldn't have mattered who it was, but I wanted someone to answer my questions and listen to my concerns."* When asked when emotional help would be the best, all participants said it was very personal for everyone and that they couldn't pinpoint a time for that (Time). Most participants said as soon as possible, but two said emotional help would be more helpful after multiple weeks so you could settle down first and process what had happened.

Researcher's observations related to emotional needs

The participants who said that the situation hadn't influenced them emotionally had some mixed answers, and their body language signalled at least ambivalent experiences, although reporting no impact. One participant said she wanted to be heard because informal caregivers weren't giving enough attention at the hospital. The other participants also showed frustration and sadness but said the situation was mostly the same as before the stroke.

PRACTICAL NEEDS

Table 7:

Code Scheme Interviews Theme: Practical needs

Code	Definition	Quotes
□ Daily tasks (5,5)	□ These are the tasks the informal caregiver needed to do around the house, for example cleaning, cooking and being a taxi for their partner/family member	□ “My partner is more at home right now which makes doing the household chores more difficult.” (P7) □ “In the beginning I had my daughter that cooked for us but that was just the first few days” (P1)
□ Daily responsibilities (7,8)	□ These are the responsibilities of the informal caregiver outside their household, for example work and doing activities.	□ “It made a big difference that I only had 10 hours on paper at work. I could plan my own time at work how I wanted, and I could arrange a lot with my clients.” (P7)

Note: the first number after the subcode is the number of participants where this code occurred. The second number is the number of times this code appeared in total in all 11 interviews.

Practical needs

Some participants had received practical support like a maid or family and friends that supported them (Daily tasks). This was mostly in the beginning. Almost all S informal caregivers said they didn't need practical help; if needed, it was mostly in the beginning, directly after discharge. A few of them were retired, or they were stay-at-home moms. One informal caregiver said, "*I could work it out because my work was very flexible (Daily responsibilities). It would have been nice if the hospital or health insurance provided a possibility to use a taxi to drive my partner to his appointments*". The YS informal caregivers had more practical needs, mostly because of the younger children and to get their daily lives back on track.

CVA ECOACH

Table 8

CVA eCoach

Code	Subcodes	Informational needs	Emotional needs	Practical needs
CVA eCoach		<ul style="list-style-type: none"> <li data-bbox="712 687 1088 855">□ “Information about eating habits, medication, sports and driving the car.” (P7) <li data-bbox="712 895 1088 1062">□ “Tips to change your lifestyle and to decrease the risk at a new stroke.” (P7) <li data-bbox="712 1102 1088 1262">□ “I want to receive the same information as given to the patient” (P11) 	<ul style="list-style-type: none"> <li data-bbox="1178 687 1565 1062">□ “Measuring the stress of the partner in the app. It would be nice if the partner can ask specific questions, for example with a smart chat (AI).” (P11) <li data-bbox="1178 1102 1565 1262">□ “In the app, emotional needs can also be supported by given the right information. 	<ul style="list-style-type: none"> <li data-bbox="1641 687 2029 1126">□ “Practically seeing, it would be nice to know which possibilities we would have and how to get help etc. Also, it would be handy to know how it is handled financially.” (P1) <li data-bbox="1641 1166 2029 1334">□ “I would like a chat-function. If I can ask any question and I can get my

Subcodes	Informational needs	Emotional needs	Practical needs
Code		The app can provide this	answer immediately or soon
		information” (P1)	that would be nice. I can
			than ask this chat
			information about home care
			or how to get it if needed”
			(P2)

As seen in Table 8, the last main code, CVA eCoach App, will be explained based on the three needs: informational, Emotional, and Practical. The participants were asked what needed to be added to the app based on the need and how this could be done.

CVA eCoach App

All participants said an app like the CVA eCoach would be useful for informal caregivers. This app mostly needs to include information that is personalised to their situation. One participant added (P10) that it would be best that besides having two different apps for YS and S patients, it would be a good idea to split up these groups and have a separate app for Cerebral Infarction, Cerebral Haemorrhages and TIA. He said this would be very helpful because you didn't have to look for the right information based on the stroke. The app is needed when going home and about 12 weeks after the partner's stroke; all participants saw these as critical weeks. A few participants said that informal caregivers should always be able to use the app. One participant said that the app needed a place where they could find help if they needed it. Also, she wanted to feel heard. Another participant was asked whether they needed emotional help, and she responded, "*Maybe I would have needed it, but I didn't know where I could have gone for professional help*" (P7). Later, when she answered whether the CVA eCoach would have helped, she said it would have been very helpful for informal caregivers to have this app. One condition was that the app would need to provide the right information about how to seek the help needed (as well as practical help). One YS informal caregiver said a child part was an additional important app function for YS patients. Their children had seen the situation at home before their mom was taken to the hospital. They thought explaining what happened to their younger children was very difficult. A given solution was that maybe the hospital could make animated videos.

Additional perceived information

Most participants said that the need for the CVA eCoach resulted from the need for more information provided by the hospital. All the S participants said they felt like they needed to figure out how to handle the situation after the stroke of their partner/family after they were sent home. Some said it would be nice if the hospital asked them if they felt okay or needed emotional or practical help. One participant was sent home with their partner and hadn't spoken to any medical professionals (P9). Her partner had received the app, but he had been kicked out before the 12 weeks. Because of this, she

had a larger need to receive the CVA eCoach app. This problem was probably based on technical difficulties.

Discussion

Main Results

The primary aim of this study was to investigate the stress factors and specific needs (informational, emotional, and practical) of informal caregivers of stroke patients and assess how the CVA eCoach app could support these needs. The study interviewed 11 informal caregivers, revealing significant informational, emotional, and practical needs. A notable difference was observed between Young Stroke (YS) participants and Stroke (S) participants. Informational needs were seen among all participants, with a desire for more personalised information based on the type of stroke (cerebral infarction, cerebral haemorrhages, and TIA) and the age group (YS or S) (4 participants specifically requested this). Participants expressed the need for continuous information from hospital discharge through the 12-week post-stroke period. Emotional needs were centred around feeling heard and receiving support, particularly during the initial weeks following the stroke. Practical needs involved assistance with daily tasks and responsibilities, which became more present based on the patient's condition. All participants acknowledged the potential benefits of an app like the CVA eCoach tailored for informal caregivers. They suggested features such as personalised information, emotional support channels if needed, and practical advice sections. These findings indicate a substantial gap in the support system for informal caregivers, highlighting the need for interventions like the CVA eCoach app.

Interpretation of findings

The theoretical models used in this study, primarily the adapted model of Perceived Stress and Needs based on the Stress and Coping Model of Lazarus & Folkman, provided a robust framework for understanding the experiences of informal caregivers. The findings show that caregivers face emotional, informational, and practical challenges that are closely connected, as described by the Perceived Stress and Needs model. For example, when the needs of informal caregivers were not met—such as when they did not receive the necessary information—this often resulted in increased

emotional stress. This demonstrates the non-linear nature of the model, where stress and unmet needs influence each other in a cycle rather than a straight line.

Interestingly, the study also revealed that Young Stroke caregivers face unique challenges compared to older stroke caregivers. Younger caregivers often balance multiple roles, such as managing careers and caring for young children, which compounds the stress of caregiving. This contrasts with older caregivers, who, most of the time, have older children who don't live at home anymore. This differentiation suggests that the model could be expanded to consider the specific needs of younger caregivers, particularly regarding support with managing multiple roles and long-term planning. The model was particularly effective in highlighting how caregivers perceive and respond to the stress of caregiving, underscoring the importance of informational and emotional support in managing stress. However, additional layers of complexity, such as age-related differences, could enrich the model further and provide more targeted support.

One of the most significant stressors identified was the period immediately following the patient's discharge from the hospital. This critical time highlights the urgent need for immediate support for caregivers to manage the sudden influx of responsibilities and emotional strain. This finding underscores the necessity of having an app like the CVA eCoach to provide timely support and resources right from the beginning of the caregiving journey.

Comparing earlier studies

The results based on the needs of the informal caregivers were expected, comparing existing data and previous bachelor thesis about this topic. Our findings are consistent with previous studies showing that caregivers often feel unprepared and unsupported after the patient is discharged from the hospital. For instance, Bendova (2024) highlighted the lack of information and support provided to caregivers, leading to isolation and frustration. Similarly, as seen in the study of Lütcher et al. (2022), informal caregivers of cancer patients also had a high need to discuss their concerns with doctors or healthcare professionals (feeling heard). However, this study also mentioned a high need for coping with fears about the physical or mental problems of the patient. Compared to this study, participants didn't have a high need for coping with fear about the physical or mental problems of the patient. In

this study, participants wanted to be heard and feel more involved in the care. Also, they wanted to know where to go when they could go if they had questions about the care for their loved one.

Comparison ecoach

The participants said the CVA eCoach app has many features that should also be available for informal caregivers. They added that the app's functions could be similar to those for patients. In addition, two participants said AI as a chatbot could help with any questions they had when trained by the hospital. Chatbot technologies can be used to increase daily needs, including social and emotional support and information-seeking (Ruggiano et al., 2024). AI interventions are mostly used for the elderly with cognitive impairment and for monitoring these elderly (Milella, 2023). Therefore, little is known about the use of AI in healthcare apps such as the CVA eCoach app. On the other hand, AI can be used in the decision-making process, and outside healthcare is used a lot to answer questions (McChrystal Group, 2024).

Secondly, the study by Fuller et al. (2020) states that a mood bar can show improvements in stress, depression and anxiety in informal caregivers and can give an improvement in their mental health. A mood bar is a tool or feature often found in apps or digital platforms that allow users to record and track their emotional states over time quickly. It usually presents a simple interface where users can select their current mood from various options (e.g., happy, sad, anxious, calm) and sometimes provide additional context or notes. The data collected from these entries can be visualised in charts or graphs, giving users insight into their emotional patterns (Cherry, 2023).

Theoretical Implications:

The results of this study suggest that the model of Perceived Stress and Needs, based on the Stress and Coping Model of Lazarus and Folkman, applies to understanding the challenges faced by caregivers. This model helps explain the caregivers' need for information, emotional support, and practical assistance to manage and cope effectively with stressful situations. To better understand the strengths and limitations of this model, it is helpful to compare it with other models that have been developed based on different diseases, such as cancer. By comparing these models, we can see how the model created for this study fits within the broader research on caregiving and whether it addresses the specific needs of caregivers as effectively as other approaches.

Firstly, as applied to cancer caregiving, the Resource Model of Stress highlights the significance of psychological resources such as resilience, self-efficacy, and social support in mitigating the effects of caregiving stress. According to Cassidy (2015), caregivers with greater perceived resources tend to experience less psychological distress, even when caregiving demands are high. While this model offers valuable insights into how external support systems can buffer stress, it diverges from the approach of this study by focusing more on external supports rather than the immediate need for information and practical assistance that were central in this study. Incorporating aspects of the Resource Model could enhance understanding of how external supports can increase stress but might divert attention from the specific and immediate needs of caregivers that are critical in stroke recovery (Cassidy, 2015).

The Stress-Appraisal-Coping Model, frequently used in the context of cancer caregiving, closely aligns with this study's approach. This model focuses on how caregivers perceive stressors and the coping mechanisms they employ, particularly within the cognitive and emotional domains (Lazarus & Folkman, 1984). By emphasising perceived stress and needs across different caregiving situations, the model in this study provides broader applicability, potentially offering valuable insights into a wider range of caregiving scenarios (Lazarus & Folkman, 1984; Pearlin et al., 1990).

The Caregiving Stress Process Model, commonly used in dementia and cancer caregiving research, offers a comprehensive structure that outlines the interaction of various stressors over time, leading to caregiver outcomes such as burnout and health decline (Pearlin et al., 1990). This model includes primary stressors directly related to caregiving tasks and secondary stressors arising from the caregiving role. While effective in explaining long-term stress and coping processes, this model may not fully address the caregivers' immediate and specific needs. Consequently, the model in this study offers a more focused approach to understanding and addressing caregivers' immediate practical and emotional needs, particularly in the early stages of their caregiving journey (Pearlin et al., 1990; Nolan et al., 1996).

The adapted model focuses on perceived stress and needs and is well-suited to capturing the specific and immediate challenges of informal caregivers of stroke patients. While other models, such as the Resource Model of Stress and the Caregiving Stress Process Model, provide broader or longer-

term perspectives, they may not address the acute needs critical in the early stages of caregiving. By concentrating on these immediate needs, the adapted model provides actionable insights that can be directly applied to improve support for caregivers, making it a valuable tool in both research and practical applications.

Practical Implications

These findings can be applied in developing the CVA eCoach app to provide immediate and tailored support to informal caregivers. The app should include features such as stress measurement, an intelligent chat function for specific queries, and resources for practical support like transportation to medical appointments. To effectively develop the CVA eCoach app, several critical areas of expertise and technological implementation must be considered. The process begins with *User Experience (UX) Design and Prototyping*. As Garrett (2011) outlined, a user-centred design approach is essential for creating an intuitive and effective interface that meets the specific needs of informal caregivers. Therefore, close contact between informal caregivers and the app makers must exist. Also, the findings in this study can be used to shape the app.

For integrating *Artificial Intelligence (AI) and Machine Learning*, Heaton et al. (2016) explored the techniques needed to develop intelligent chat functions and personalised content delivery systems. The application of AI in this context will allow the CVA eCoach app to respond dynamically to caregivers' queries, significantly enhancing user interaction.

Following development, *Pilot Testing and Iteration* are essential to validate the app's effectiveness in real-world settings. Nielsen (1993) provides a framework for conducting pilot tests, gathering feedback, and making necessary iterations to refine the app before it is fully used.

Finally, *deployment and maintenance* are key to the app's long-term success. Kavis (2014) emphasises the importance of planning for ongoing maintenance and updates to ensure the app remains effective and responsive to user needs over time. The hospital also needs to check regularly if the app still satisfies the needs of informal caregivers and improve the app if needed.

Feasibility of the App

It is also worth exploring whether an app can offer the necessary support in specific cases. While it might be challenging to address all possible scenarios, an app can provide solutions to

common problems and offer exercises and advice to support caregivers. For instance, one caregiver of a 7-year-old with anger issues due to the situation suggested that the app could include animated videos to help explain the situation to younger children. This indicates that the app could be a valuable tool for providing practical information and emotional support tailored to the family's needs.

Strengths

The first strength of this research is the use of qualitative data. Because of the open interview questions, additional information was collected, which can only be done by asking open questions. Also, qualitative data enabled the collection, analysis, and interpretation of rich, non-numerical data, which explored the behaviours of individuals. The data consisted of subjective experiences and perceptions of participants, which gave insights that might be overlooked in quantitative research. The interviews provided deep insights into the 'lived realities' and needs of informal caregivers (Anderson, 2010).

This research has a good variety of participants regarding the differences in characteristics between male and female participants and young stroke and stroke participants. Therefore, the data showed a difference between YS and S participants. This gave the answers a bigger diversity and perspective (Mack et al., 2005).

Thirdly, using a thematic analysis framework, combining deductive and inductive coding, allowed for a comprehensive understanding of the data.

Furthermore, this study's strength is its combination of a phenomenological approach with a needs assessment. This combination allowed the study to capture caregivers' deep, subjective experiences and comprehensively identify and categorise their needs. This methodological strength ensures a holistic understanding of the caregivers' experiences and needs, providing a foundation for developing targeted interventions like the CVA eCoach app.

Additionally, the study's focus on both YS and S participants provided a nuanced view of the differences in needs between these groups, which is crucial for developing targeted interventions.

Limitations

Several limitations must be acknowledged in this research. In addition, the participants in this study all had a cerebral infarction, were from the same hospital, and were mainly partners of the stroke

patient. On the other hand, this research ensured a variety of recruited participants. The participants were of different age and gender.

Secondly, the sample size was relatively small, with only 11 participants, which may limit the generalizability of the findings. This study aimed to recruit 15 participants. However, this was not achieved due to the informal caregiver's lack of responses. When more time was given, 15 participants could have been achieved.

Finally, the study was conducted in a single hospital, which may limit the applicability of the findings to other settings or regions. Recruiting was done via a list provided by the ISALA hospital, and all the participants were from the same hospital. Because of this, the results of this study will be less generalisable to all stroke participants. When, for further research, the CVA eCoach is used in different hospitals, there can be a wider variety of informal caregivers.

Conclusion

The study highlights the informational, emotional, and practical needs of informal caregivers of stroke patients, particularly during the transition period from hospital to home. The findings show the potential benefits of an app like the CVA eCoach, tailored to support informal caregivers by providing personalised information, emotional support, and practical advice. Addressing these needs can enhance the caregiving experience, reduce caregiver burden, and improve patient outcomes. Future research should explore developing and implementing such an app, incorporating feedback from caregivers to ensure it meets their needs effectively.

Recommendations

Based on the study findings, several recommendations can be made:

Firstly, the development of an informal caregiver CVA eCoach App. An app designed specifically for informal caregivers should be developed, incorporating features such as personalised information based on the type of CVA and age group, emotional support resources, and practical advice sections.

Secondly, informal caregivers are becoming more involved in-patient care. Healthcare professionals should actively involve informal caregivers in the care process, providing them with the necessary information and support from discharge.

Thirdly, tailored support for YS and S caregivers is needed. Recognising the different needs of YS and S caregivers, interventions should be tailored accordingly, with specific resources and support mechanisms for each group. Future research with larger and more diverse samples (for example, all forms of stroke) is needed to validate the findings and explore the effectiveness of caregiver-specific interventions like the CVA eCoach app in different settings. As seen in the study of Su et al. (2000), patients with cerebral haemorrhage are more impaired in tasks of executive functioning than patients with cerebral infarction. This means that informal caregivers can have different needs based on possible impairments of cerebral haemorrhage patients

Lastly, while the Perceived Stress and Needs model has proven useful for understanding caregiver stress, its applicability may be limited by the small and homogenous sample used in this study. To enhance the model's generalizability, future research should include more diverse caregiver populations, such as those caring for patients with different types of strokes or chronic illnesses. Furthermore, it would be valuable to explore the model's relevance in other caregiving contexts, as well as across different cultural and socioeconomic backgrounds

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Appendix A: Information form

INFORMATIE OVER DEELNAME AAN EEN WETENSCHAPPELIJK ONDERZOEK

Titel: *Hoe ervaren naasten van CVA-patiënten de stressfactoren die samenhangen met hun rol, en welke specifieke behoeften (inclusief informatieve, emotionele en praktische) hebben zij en kan de CVA-eCoach bijdragen aan het ondersteunen van deze behoeften?"*

Onderzoekers: Charlotte Moes, dr. C. Bode, dr. A van Dongen, dr. H. den Hertog

Centrum: University of Twente & Isala ziekenhuis Zwolle

Inleiding

Geachte meneer en /of mevrouw,

Uw naaste heeft de CVA eCauch app gebruikt, hierdoor krijgt u een uitnodiging om deel te nemen aan dit onderzoek. In dit onderzoek worden de behoeftes van naasten, waarvan patiënt de CVA eCoach heeft gebruikt, en de mogelijke bijdrage van de *CVA-eCoach app* aan deze behoeftes onderzocht.

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 doel van het onderzoek. Dit onderzoek zal voor u niet direct of op korte termijn iets verbeteren, maar andere naasten/partners, van een persoon die een CVA heeft gehad, kunnen mogelijk in de toekomst voordeel hebben uit de informatie die in dit onderzoek wordt verzameld. Hebt u na het lezen van deze informatie nog vragen? Dan kunt u terecht bij de hoofdonderzoeker. In de bijlage vindt u de contactgegevens.

Doel van het onderzoek

Het doel van dit onderzoek is erachter te komen wat de stressfactoren zijn en welke behoeften naasten/partners hebben, van een persoon die een CVA heeft gehad, en hierbij de mogelijke ondersteuning van de *CVA-eCoach app* aan deze behoeften. Deze persoon moet in aanmerking gekomen zijn voor het gebruik van de *CVA-eCoach app* of hebben deze al gebruikt hebben na het ontslag uit het ziekenhuis. Deze app is gemaakt voor het verbeteren van de overgang van het ziekenhuis naar de thuissituatie van de patiënt. Daarnaast kunnen behandelaren de patiënten monitoren en gecoördineerde zorg leveren in de eerste drie maanden na het ontslag uit het ziekenhuis. Tegelijkertijd worden patiënten gestimuleerd om de regie over hun herstel te houden. Op dit moment is de app voornamelijk gericht op de behoeftes van de patiënten na een CVA. Een doel

van dit onderzoek is de stressfactoren en behoeftes van de naaste/partner te achterhalen als de patiënt weer thuis is en hierbij de mogelijke bijdrage van de *CVA-eCoach app*. Mocht u meer informatie willen over de huidige e-coach app dan wordt in het volgende filmpje aan u uitgelegd hoe de e-coach werkt; <https://luscii.com/nl/hoe-werkt-het?hsLang=nl>



Hoe wordt het onderzoek uitgevoerd?

Als u deelneemt aan dit wetenschappelijk onderzoek, wordt u uitgenodigd om deel te nemen aan een interview. Voordat dit interview plaatsvindt, wordt de werking en het gebruik van de *CVA-eCoach app* aan u uitgelegd, zodat u de mogelijkheid heeft om vragen te stellen over de app. Het interview kan zowel online als op locatie (nader te bepalen) afgenomen worden. Het zal vragen omvatten over de stressfactoren en behoeftes van naasten/partners, van een persoon die een cerebrovasculair accident (CVA) heeft gehad. Daarnaast zullen er vragen gesteld worden over de mogelijkheden van de *CVA-eCoach app* met betrekking tot deze behoeftes. De uitleg van de *CVA-eCoach app* zal naar verwachting maximaal 30 minuten duren. Het interview zal naar verwachting hooguit een uur duren. In totaal zou de deelname ongeveer 1,5 uur duren.

Wat wordt er van u verwacht?

Wanneer u meedoet aan dit onderzoek wordt u benaderd voor het inplannen van een afspraak voor het uitleggen van de *CVA-eCoach app* en een interview. De afspraak voor het uitleggen van de *CVA-eCoach app* wordt op het ziekenhuis uitgelegd (of op locatie, mocht het ziekenhuis niet mogelijk zijn voor u). Het interview kan direct na deze uitleg worden afgenomen maar zou mogelijk ook online op een later tijdstip plaats kunnen vinden. Het interview bevat vragen over de stressfactoren en behoeftes van naasten/partners van een persoon die een CVA heeft gehad. Daarnaast worden er vragen gesteld over de inzet van de *CVA-eCoach app* met betrekking tot deze behoeftes.

Wat gebeurt er als u niet wenst deel te nemen aan dit onderzoek?

U beslist zelf of u meedoet aan het onderzoek. Deelname is geheel vrijwillig. Als u besluit niet mee te doen, hoeft u verder niets te doen. U hoeft geen reden te geven waarom u niet wilt meedoen.

Als u wel meedoet, kunt u zich altijd bedenken en toch stoppen, ook tijdens het onderzoek. U hoeft geen reden te geven waarom u wilt stoppen.

Wat gebeurt er met uw gegevens?

Voor dit onderzoek worden geen persoonsgegevens gebruikt die terug kunnen leiden naar u als persoon. Het gaat om gegevens zoals uw leeftijd, geboortedatum, de relatie met de patiënt met CVA en de antwoorden van de interviewvragen. Het verzamelen, gebruiken en bewaren van uw gegevens is nodig om de vragen van dit onderzoek te kunnen beantwoorden en de resultaten te kunnen publiceren. Wij vragen voor het gebruik van uw gegevens uw toestemming.

Privacy van uw gegevens

Om uw privacy en identiteit te beschermen krijgen uw gegevens een anonieme code. Uw naam en andere gegevens die u direct kunnen identificeren worden daarbij weggelaten. Alleen de hoofdonderzoeker heeft toegang tot deze codelijst. Uw data wordt opgeslagen met een sleutel en code. De sleutel van de code blijft veilig opgeborgen in een beschermde database van de Universiteit Twente. De gegevens in rapporten en publicaties over het onderzoek zijn eveneens niet naar u te herleiden.

Toegang tot uw gegevens voor controle

Om te kunnen controleren of het onderzoek goed en betrouwbaar is uitgevoerd, krijgen sommige personen toegang tot de gegevens die worden opgeslagen voor het onderzoek. Ook tot de gegevens met een code. Personen die ter controle inzage krijgen in uw gegevens zijn de onderzoekers (zie bovenaan) en bevoegde medewerkers die betrokken zijn bij dit onderzoek. Zij zullen voorzichtig met u gegevens omgaan en zullen u privacy beschermen. Wij vragen u voor deze inzage toestemming te geven.

Bewaartermijn gegevens

Uw data wordt bewaard zo lang als dit nodig is voor het onderzoek die gedaan wordt voor de CVA eCoach. Wanneer uw data niet meer nodig is, wordt deze vernietigd.

Intrekken toestemming

U kunt uw toestemming voor gebruik van uw gegevens altijd weer intrekken. De onderzoeksgegevens die zijn verzameld tot het moment dat u uw toestemming intrekt worden nog wel gebruikt in het onderzoek.

Meer informatie over uw rechten bij verwerking van gegevens

Voor algemene informatie over uw rechten bij verwerking van uw persoonsgegevens kunt u de website van de Autoriteit Persoonsgegevens raadplegen.

Kosten

Er zijn geen extra kosten voor dit onderzoek

Ethische goedkeuring

Een ethische goedkeuring is afgegeven door de Faculteit BMS van de Universiteit Twente

Heeft u verder nog vragen?

Wanneer u na het lezen van deze informatie of tijdens deelname aan dit onderzoek vragen heeft kunt u contact opnemen met:

Indien u na zorgvuldige overweging besluit deel te nemen aan dit onderzoek, dan vragen we u om het toestemmingsformulier te ondertekenen en van een datum te voorzien.

Met vriendelijke groet,

Charlotte Moes

Master Thesis student Psychologie, richting Gezondheidspsychologie & Technologie

Bijlage A: Contactgegevens

Bijlage B: Toestemmingsformulier

Bijlage A: Contactgegevens voor onderzoek

- Mw. C. Moes, student Master Health Psychology and Technology (**hoofdonderzoeker**)
Bazaar 19
7552 KP Hengelo
Beschikbaar maandag-vrijdag (8:00-17:00) via e-mail: c.s.moes@student.utwente.nl
telefoonnummer: +31637375356
- Dr. C. Bode (**eerste begeleider**)
Universitair Hoofddocent en directeur van Self-management & Health Assessment Lab bij de afdeling Psychologie, Gezondheid en Technologie aan de Universiteit van Twente.
c.bode@utwente.nl

- Dr. A. van Dongen (**tweede begeleider**)
Universitair docent aan de Universiteit Twente
a.vandongen@utwente.nl
- Dr. M.H. den Hertog (**externe begeleider**)
Neuroloog ISALA ziekenhuis in Zwolle
m.h.den.hertog@isala.nl

Bijlage B: Toestemmingsformulier

- Ik heb de informatiebrief gelezen. Ook kon ik vragen stellen. Mijn vragen zijn voldoende beantwoord. Ik had genoeg tijd om te beslissen of ik meedoe.
- Ik weet dat meedoen vrijwillig is. Ook weet ik dat ik op ieder moment kan beslissen om toch niet mee te doen of te stoppen met het onderzoek. Daarvoor hoef ik geen reden te geven.
- Ik geef toestemming voor het verzamelen en gebruiken van mijn gegevens op de manier en voor de doelen die in de informatiebrief staan
- Ik geef toestemming om mijn medische gegevens nog 15 jaar na dit onderzoek te bewaren. Mogelijk kan dit later nog voor meer onderzoek worden gebruikt, zoals in de informatiebrief staat.
- Ik weet dat voor de controle van het onderzoek sommige mensen toegang tot al mijn gegevens kunnen krijgen. Die mensen staan vermeld in deze informatiebrief. Ik geef toestemming voor die inzage door deze personen

Naam deelnemer:

Handtekening:

Datum : __ / __ / __

Ik verklaar dat ik deze deelnemer volledig heb geïnformeerd over het genoemde onderzoek.

Als er tijdens het onderzoek informatie bekend wordt die de toestemming van de deelnemer zou kunnen beïnvloeden, dan breng ik hem/haar daarvan tijdig op de hoogte.

Naam onderzoeker:

Handtekening:

Datum: __ / __ / __

* Doorhalen wat niet van toepassing is.

De deelnemer krijgt een volledige informatiebrief mee, samen met een kopie van het getekende toestemmingsformulier.

Appendix B: Interview Questions

<i>Soort vraag</i>	<i>Vraag</i>
Persoonlijke gegevens	<ul style="list-style-type: none"> - Wat is uw leeftijd en geslacht? - Wat is de leeftijd en geslacht van uw naaste? - Wat is relatie met de persoon voor wie u zorgt? - Welke vorm van een CVA heeft deze persoon gehad? Dit kan een herseninfarct of hersenbloeding zijn geweest (misschien weet u dit) - Wanneer was de opname? - Hoelang was de ziekenhuisopname? - Wat voor werk doet u en wat is uw hoogst genoten opleiding? - Wat voor werk doet uw naaste/partner en wat is zijn/haar hoogst genoten opleiding?
Sociale consequenties van mantelzorg	
<i>Warm-up vragen</i>	<ul style="list-style-type: none"> - Hoe ziet uw rol als naaste/partner van een persoon die een CVA heeft gehad, eruit? - Kunt u beschrijven hoe een typische dag voor u als naaste/partner eruitziet?
<i>Vragen voor beantwoorde stressfactoren</i>	<ul style="list-style-type: none"> - Hoe veranderde uw rol als naaste/partner sinds uw partner/naaste een CVA heeft gehad? - Is de invulling van uw dag/dagelijkse activiteiten veranderd sinds de opname? Zo ja, wat is er veranderd? <ul style="list-style-type: none"> o Heeft u hiervoor hulp gezocht? - Wat zijn uw dagelijkse uitdagingen waar u als naaste/partner mee te maken krijgt? <ul style="list-style-type: none"> o Mensen in uw situatie gaan verschillend om met deze uitdagingen. Hoe gaat u hiermee om? o Deelt u deze met anderen? - Heeft u door uw verantwoordelijkheden als naaste/partner gezondheidsproblemen ervaren? (Fysieke of mentale) - Is de relatie tussen u en uw naaste/partner veranderd sinds hij/zij een CVA heeft gehad? Zo ja hoe? <ul style="list-style-type: none"> o Heeft dit invloed op uw stemming? - Hoe vindt u balans tussen naaste/partner zijn, en uw eigen leven?

Eind vragen voor dit gedeelte

- Is er iets veranderd in uw sociale activiteiten sinds de opname van uw naaste/partner? Denk hierbij aan het op bezoek gaan bij vrienden/familie, het uitoefenen van hobby's etc.?
 - o Zo ja hoe? Zo nee, hoe heeft u dit kunnen plannen?
 - Heeft het zijn van naaste/partner uw persoonlijke relaties beïnvloed?
 - o Zo ja, hoe?
 - o Zo nee, hoe heeft u dit kunnen regelen?
- Terugkijkend op uw ervaring, welk advies zou u geven aan iemand die op het punt staat om naaste/partner te worden voor een persoon die een CVA heeft gehad?

Specifieke behoeften: Informatief

Warm-up vragen

- Vindt u dat u voldoende informatie en training heeft gehad om effectief te kunnen zorgen voor uw naaste/partner?
 - o Welke aanvullende vaardigheden of kennis zou u nuttig vinden?
 - o Wat had u graag willen weten voordat uw partner/naaste een CVA kreeg.
 - o Wat had u graag willen weten voordat uw partner/naaste naar huis ging?

Uw naaste/partner heeft een app meegekregen in de ondersteuning van de nazorg van het ISALA ziekenhuis

- Weet u dat uw naaste deze app heeft gekregen?
- Weet u waar de app over gaat?
- Bent u betrokken bij deze app, bijvoorbeeld bij het invullen van de vragenlijsten of het lezen van de informatie die beschikbaar is?

Vragen voor beantwoorden specifieke behoeften

- Zou u behoefte hebben aan een vergelijkbare app voor ondersteuning?
- Welke informatie zou u in deze app belangrijk zijn?
- Hoe zou dit in de app eruitzien? (Informatieve gedeelte)

Specifieke behoeften: Emotioneel

Informatieve vragen (warm-up vragen)

- Hoe heeft het zijn van een naaste/partner u emotioneel beïnvloed?
 - o Kunt u specifieke voorbeelden delen waarin u zich gestrest voelde?
 - o Kunt u specifieke voorbeelden delen waarin u zich juist gelukkig en trots voelde?
 - o Hoe ging u hiermee om?
- Wat zijn uw belangrijkste bronnen van stress als naaste/partner, en hoe gaat u daarmee om?
- Hoe zorgt u voor uw eigen emotioneel welzijn terwijl u voor iemand anders zorgt? (denk hierbij aan verdrietige boze momenten)
- Wat zijn specifieke emotionele uitdagingen waar u mee te maken kreeg na de opname?
- Welke activiteiten of bezigheden waren/zijn prettig voor emotioneel welzijn?

Vragen voor beantwoorden specifieke behoeften

- Had u emotionele ondersteuning nodig na de opname van uw naaste/partner?
- Hoe zou deze ondersteuning eruit kunnen zien?
- Op welk moment van het traject na de opname zou deze ondersteuning het beste zijn?
- Hoe zou een app zoals de CVA eCoach u emotioneel kunnen ondersteunen?
- Hoe zou dit gedeelte er in de app uit kunnen zien?

Specifieke behoeften: Praktisch

Informatieve vragen (warm-up vragen)

- Welke dagelijkse taken of situaties vindt u bijzonder lastig of tijdrovend als naaste/partner?
- Hoe balanceert u de verantwoordelijkheden van naaste/partner met andere verplichtingen zoals werk of gezin?
- Welke veranderingen of aanpassingen heeft u in uw leven moeten maken?

*Vragen voor beantwoorden specifieke
behoeften*

**CVA eCoach vragen (kunnen ook
eerder gevraagd zijn)**

Einde interview

- Welke soort praktische ondersteuning ontvangt u (of zou u willen ontvangen) in uw rol als naaste/partner?
- Welk soort hulp of verlichting zou op dit moment het grootste verschil maken in uw leven?
- Welke behoeften had u voornamelijk in de overgang van ziekenhuis naar huis?
- Zijn deze behoeften veranderd?
- Hoe zou een app zoals de CVA eCoach u kunnen ondersteuning in dit aspect?
- Hoe zou deze ondersteuning eruit kunnen zien in de app?

- Uit welke onderdelen zou deze app moeten bestaan?
- *Zou u behoefte hebben aan een vergelijkbare app voor ondersteuning? (Informatief)*
- *Hoe zou dit er voor het informatieve gedeelte uitzien? (Informatief)*
- *Hoe zou een app zoals de CVA eCoach u emotioneel kunnen ondersteunen? (Emotioneel)*
- *Hoe zou dit gedeelte er in de app uit kunnen zien? (Emotioneel)*
- *Hoe zou een app zoals de CVA eCoach u kunnen ondersteuning in dit aspect? (Praktisch)*
- Wat zou er in deze app niet mogen ontbreken?
- Denkt u dat zo'n app nuttig zou zijn voor naasten/partners? En waarom?
- Wanneer zou deze app niet meer nodig zijn denkt u?
- Heeft u nog toevoegingen of vragen die van waarde kunnen zijn voor dit interview of de CVA-eCoach?

Appendix C: Screenshots CVA eCoachapp

