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Challenges and needs in cerebrovascular disease pathway: A qualitative descriptive study from the patients' and healthcare professionals' perspectives

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Abstract

Aim(s): To understand patients' and healthcare professionals' experiences to improve care in and across different domains of the cerebrovascular disease pathway.

Design: A qualitative descriptive study.

Methods: Semi-structured in-person interviews were conducted among 22 patients diagnosed with acute cerebrovascular disease and 26 healthcare professionals taking care of them in a single tertiary-level hospital from August 2021 to March 2022. Data were analysed using deductive and inductive content analysis. The consolidated criteria for reporting qualitative research was used to ensure reliable reporting.

Results: Overall, 19 generic and 79 sub-categories describing perceived challenges with 17 generic and 62 sub-categories describing perceived needs were identified related to primary prevention, organization of stroke services, management of acute stroke, secondary prevention, rehabilitation, evaluation of stroke outcome and quality assessment, and life after stroke.

Conclusion: Several challenges and needs were identified in and across the different domains of the cerebrovascular disease pathway. There is a requirement for adequate resources, early initiation of treatment, early diagnostics and recanalization, dedicated rehabilitation services, long-term counselling and support, and impact evaluation of services to improve cerebrovascular disease care. Future research on caregivers', and clinical leadership experiences in and across the cerebrovascular disease pathway is needed to explore the provision of services.

Implications for the Profession and/or Patient Care: The results of this study can be applied by organizations, managers and research for developing and improving services in the cerebrovascular disease pathway.

Impact: This study identified several patient-related, organizational and logistical needs and challenges, with suggestions for required actions, that can benefit the provision of effective, high-quality cerebrovascular disease care.

1 | INTRODUCTION

Cerebrovascular diseases include different neurological dysfunctions, such as transient ischemic attack and stroke, that can be caused by infarction (i.e. ischemic stroke) or haemorrhage (Sacco et al., 2013). Globally, cerebrovascular diseases cause a major burden to public health. The average lifetime cost of stroke, depending on the cause, is around 63,900–71,200 euros (Strilciuc et al., 2021). In Europe alone, the socioeconomic costs of cerebrovascular diseases have been around 45 billion euros in 2015 (Wilkins et al., 2017), with expectations of growth as the number of patients with cerebrovascular diseases are estimated to increase by 27% by the year 2047 due to the aging population and increased survival rates (Wafa et al., 2020). Globally, stroke is also one of the leading causes of death and long-term disability (Feigin et al., 2022), inflicting deficits in movement, cognitive and functional disturbances, along with emotional and behavioural challenges (Virani et al., 2020) with patients requiring health services for possibly long periods of time.

2 | BACKGROUND

During the last decades, the organization of acute cerebrovascular disease services has evolved and improved significantly from the prevention of secondary injury to management of acute stroke. Strokes are largely preventable by a healthy lifestyle, as about 90% of strokes are attributed to modifiable and manageable risk factors (e.g. environmental, socioeconomic, and educational) (Hankey, 2020). Although they are also highly recurrent, with 25% of stroke patients suffering a second stroke within 5 years, this recurrence is amenable by risk-factor modification (Singh et al., 2018). Therefore, along with the management of acute stroke, there is a need to improve primary and secondary prevention and rehabilitation and long-term support in life after stroke (Norrving et al., 2018). The 2–5 years after the initial stroke is a critical period for the patients both for health recovery and potential stroke recurrence as, depending on the severity of the stroke and individual attributes, daily functioning can still improve (Gil-Salcedo et al., 2022).

However, the care continuum from primary prevention to life after stroke at home currently varies in quality due to the lack of comprehensive primary prevention (Owolabi et al., 2022) and long-term post-stroke care programs (Boehme et al., 2021), individualized

secondary prevention, education to support cerebrovascular disease awareness (Tulek et al., 2017) and a siloed organization of stroke services in and across primary and secondary care (Aquino et al., 2020) and rehabilitation (Chen et al., 2016). In addition, patients and their caregivers have unmet needs related to secondary prevention, rehabilitation and life after stroke (Chen et al., 2016; Pindus et al., 2018; Zawawi et al., 2020).

Clinical pathways have been used to perceive the steps in a course of care with a criteria-based progression of actions and timeframes to address clinical problems, procedures or a domain in care of a population group (Lawal et al., 2016). Patient journey mapping (Davies et al., 2023) can be used to further understand how the different health systems are navigated through, identifying challenges and unmet needs, evaluating continuity of care, understanding the comprehensiveness of care, and comparing patient experiences to clinical practice guidelines or standards of care (Jansson et al., 2020). Healthcare professionals usually see only the part of the domain of care they are responsible for (Busetto et al., 2022), while patients go through the whole pathway and can therefore identify problems in and across their entire journey (Jansson et al., 2022). In that sense, a pathway can include many patient journeys, with both viewpoints complementing each other in the assessment and development of a care continuum.

Previous studies have mainly focused on individual and separate domains of cerebrovascular diseases care such as acute stroke care (Busetto et al., 2022; Lachkhem et al., 2018), discharge (Chen et al., 2021) and post-discharge primary care (Pindus et al., 2018). The perceived challenges and needs in and across the entire cerebrovascular disease pathway, however, are unknown. For that reason, more qualitative research is needed to understand the context, healthcare system, and clinical pathway to improve the various domains of cerebrovascular disease care from the perspectives of the patient and the healthcare professional.

3 | THE STUDY

3.1 | Aim(s), objective(s) and research question

The aim of the study was to understand patients' and healthcare professionals' experiences to improve care in and across the cerebrovascular disease pathway. The research question was: *What kind of perceived challenges and needs do patients and healthcare professionals have in the cerebrovascular disease pathway?*

4 | METHODS

4.1 | Design and theoretical framework

A qualitative descriptive phenomenological approach was employed using semi-structured interviews and deductive and inductive analysis techniques to explore the experiences of patients with acute cerebrovascular disease and the healthcare professionals providing care for them (Polit & Beck, 2018).

4.2 | Study setting and recruitment

This study was conducted at a single tertiary-level hospital in Finland. Convenience sampling was used to recruit patients and healthcare professionals by a study nurse (RL). Patients over 18 years with diagnosed ischemic stroke and transient ischemic attack (I63.0-63.9, G45.0-G45.9, I60, I61.-61.9) and able to give their informed consent were included. Healthcare professionals directly involved in cerebrovascular disease care were included, excluding supportive services.

Finland is a high-income country having the required three stroke units per million inhabitants, with a need for one more comprehensive stroke centre (Aguiar de Sousa et al., 2019). In Finland, the case fatality of cerebrovascular disease has declined over the past years due to advancements made in the public health and the organization of stroke services (Puumalainen et al., 2016). In addition, there are clinical practice guidelines nationally available for the management of ischemic stroke and transient ischemic attack (Ischemic Stroke and TIA. Current Care Guidelines, 2016). Finland also has a Patient Data Repository of the Kanta Services, which is a national information system service for archiving electronic patient data (What Are Kanta Services?—Professionals—Kanta. Fi, 2023).

The hospital is in the geographically largest hospital district area for specialized medical care in Finland, with long travelling distances and five healthcare districts with a varying population, disease prevalence and service structures (Finnish Institute of Health and Welfare (THL), 2020). This area also has one of the highest prevalence of cerebrovascular disease in Finland (Map—Sotkanet.Fi Statistics and Indicator Bank, 2019).

4.3 | Data collection

The data was collected between September 2021 and March 2022. Semi-structured interviews were conducted in Finnish using separate topic guides designed for both healthcare professionals and patients and based on a previous study (Jansson et al., 2020). All the participants were interviewed once individually in a private room at the hospital by an experienced study nurse (RL). The interviews were recorded and transcribed verbatim by a professional transcription service. Additional field notes were not made, as the study focused on thought patterns and sentences describing perceived challenges or needs. The patient interviews lasted between 19 and 72 min, and the healthcare professional interviews were 11–89 min long. Participants were recruited until data saturation (Polit & Beck, 2018), which was ensured by the second author (KM).

4.4 | Data analysis

The content of the interview transcripts was coded and categorized using NVivo qualitative data analysis software (QRR International Pty Ltd., Version 1.6.1). A combination of deductive and inductive content analysis was applied. The analysis was conducted by the corresponding author (HH, Doctoral Researcher, MSc) with verification of the process by the second (KM, Doctoral Researcher, MSc) and last author (MJ, PhD) and through discussion with the research team. The data was classified into open codes basing the unit of analysis to a thought pattern (Kyngäs, 2019). The different domains of cerebrovascular disease care were categorized into seven main categories (incl. primary prevention, organization of stroke services, management of acute stroke, secondary prevention, rehabilitation, evaluation of stroke outcome and quality assessment, and life after stroke) according to the European Stroke Action Plan (Norrving et al., 2018), which acted as a deductive analysis matrix (Kyngäs & Kaakinen, 2020). The identified challenges and needs (generic categories) were then further defined inductively using content-specific words. An example of the categorization is presented in Table 1.

4.5 | Rigour and reflexivity

Evaluative frameworks were used to ensure the trustworthiness of the study in terms of credibility, dependability, confirmability, authenticity, and transferability (Lincoln & Guba, 1985 and Guba & Lincoln 1994, as cited in Polit & Beck, 2018). To provide appropriate informants and sample size, the participants were selected purposefully and recruited until data saturation, ensuring credibility. Dependability was ensured by verification and discussion of the analysis and resulting findings among the research team. The corresponding author had no prior connection to the participants and access to only ID-numbered transcriptions, reducing bias. Transcripts were examined several times to confirm that the findings accurately represented the participants' views, establishing confirmability. Authenticity was ensured using several quotations from different participants presenting the connection of results to the data. The results may be applicable to similar contexts with similar patients and healthcare professionals. For the assessment of transferability, the demographic characteristics are provided (Table 2). For more information, please contact the corresponding author. To ensure reliable reporting, the consolidated criteria (Tong et al., 2007) for reporting qualitative research (COREQ) have been used.

TABLE 1 Example of the categorization and quotations in the organization of stroke services.

Matrix category	Generic category	Subcategory	Examples of quotations
Organization of stroke services	Symptom-to-hospital delay	Identification of signs and symptoms	"Maybe if it is not a weakness on either side, then it is not noticed. With dizziness or nausea, one may not necessarily know to seek help so easily." (H8) "In terms of the education of the population, there is the problem that people do not identify the symptoms of cerebrovascular disease…" (H2)
		Urgency of the situation	"People are still saying home and not leaving early enough to like be in the timeframes for these acute treatments of ours." (H10) "So, it should be something that a caregiver knows what they are… for example. Like if they do not know what the signs are… many times they have not been guided (interviewees' acquaintances) to treatment fast enough if they have had, for instance, a cerebrovascular disturbance." (P11)
		Help-seeking	"…the challenges are kind of like personal… like that I have not always gone (to seek help)." (P13) "…maybe the patients are considering too long to seek help and are afraid to call the emergency number and seek help, meaning that, yes, they hang on at home as long as they can." (H4)
		Inability to call for help	"The person who gets sick, then you don't always know that they maybe cannot call for help if the stroke is very severe." (H5) "It was quite scary because I woke up…at small hours, yes, and I live alone. So, I woke up to the world spinning and my legs are not working. I cannot walk…. So, with determination, I crawled to the phone and dialled the emergency number." (P9)

4.6 | Ethical considerations

Good ethical conduct based on national guidelines was ensured throughout the study process (*Finnish National Board on Research Integrity TENK*, 2019). This study was reviewed and approved on the 15th of March 2021 by the Ethics Committee of Northern Ostrobothnia Hospital District (Decision No: 46/2021) and on the 17th of May by the Northern Ostrobothnia Hospital District Board (Decision No: 30/2021). Participants were informed of the study and their voluntary participation with the possibility to withdraw at any time for no reason and with no impact on their care (patients) or employment (healthcare professionals). Participants gave a written consent before the interviews. All research data, including interview recordings and transcripts, were stored in digital password-protected files accessible only by the research team. The anonymity of the participants was protected by not stating or recording names in the interviews and using participant- specific ID numbers for the transcription and analysis phases.

5 | FINDINGS

5.1 | Characteristics of participants

The participants of this study included 22 patients and 26 healthcare professionals (Table 2). Most of the patients had recently experienced their first cerebrovascular disease (transient ischemic attack or ischemic stroke), whereas six of them had been treated for previous cerebrovascular signs. The healthcare professionals were physicians or psychologists specialized in neurology or neuropsychology, registered nurses, practical care nurses, and physiotherapists or speech therapists actively working in cerebrovascular disease care.

5.2 | Primary prevention

The identified challenges related to the primary prevention of cerebrovascular disease were inductively formed into three generic categories: insufficient preventive care, lack of competence, and lack of engagement. Insufficient preventive care was due to a lack of organization of primary prevention services (e.g. risk screening, services to support life-style change), and inadequate resources (e.g. diagnostic imaging and laboratory services, healthcare staffing shortages). Patients expressed the difficult access and availability of primary care services, which could lead to withdrawal from follow-up, as described by one patient interviewee:

> …this frustrates people, so they may not then care to try go anywhere.
>
> (P15, patient)

Delayed initiation of treatment and withdrawal from a follow-up would then result in a negative impact on modifiable risk factors for stroke (Data S1). The lack of patients' self-management (e.g. blood pressure control, medication adherence) and monitoring data (e.g. blood

TABLE 2 Demographic characteristics of the interviewees.

Characteristic, n (%)	Patients (n = 22)	Healthcare professionals (n = 26)
Gender		
Female	7 (32%)	21 (81%)
Male	15 (68%)	5 (19%)
Age		
20–39	2 (9%)	14 (54%)
40–59	8 (36%)	12 (46%)
60–79	7 (32%)	0
≥80	5 (23%)	0
Highest academic degree		
Primary education	8 (36%)	0
Vocational training	9 (41%	3 (12%)
Undergraduate degree	5 (23%)	10 (38%)
Graduate degree	0	13 (50%)
Working status		
Student	1 (5%)	N/A
Employee or entrepreneur	9 (41%)	N/A
Retired	12 (55%)	N/A
Profession		
Practical care nurses	N/A	4 (15%)
Registered nurses	N/A	9 (35%)
Physiotherapists or speech therapists	N/A	3 (12%)
Physician or psychologists	N/A	10 (38%)
Prior cerebrovascular symptoms		
Yes	6 (27%)	N/A
No	16 (73%)	N/A

Abbreviations: N/A, Not applicable/available; Undergraduate, bachelor's degree; Graduate degree, master's degree, licentiate, doctoral degree.

pressure) also hindered preventive care, as demonstrated by one interviewee:

> Even if the risks were identified, do they (patients) then adhere to care, such as blood pressure (control)? Do they take the medications? Do they monitor it (blood pressure)?
>
> (H5, physician)

According to interviewees, patients do not engage in self-management (e.g. risk-factor modification) due to a lack of self-management competence (e.g. knowledge, skills, attitudes) and low self-confidence. In addition, patients do not understand the risk factors of cerebrovascular disease and the long-term consequences of hypertension.

The identified needs related to primary prevention were inductively formed in two generic categories: multichannel public health education and service structure for primary prevention. According to interviewees, there is a need to deliver reliable health information (e.g. risk factors, cerebrovascular disease signs and symptoms, self-monitoring, brain health and ergonomics, lifestyle) using public health messaging (e.g. television, Web-based materials, social media, and educational campaigns). In addition, there is a need for a service structure involving opportunistic screening (e.g. interviews, surveys and laboratory tests) of those at increased risk on a national level, and further systematic screening for risk factors on an individual level to improve primary prevention in primary, occupational and school healthcare (Data S2). The service structure should also promote early access to care, regular follow-ups, and support self-management using a skilled workforce (e.g. specialists, nurses, public health nurses, psychologists) along with strategies for their retention.

5.3 | Organization of stroke services

The identified challenges related to the organization of stroke services were inductively formed in five generic categories: symptom-to-hospital delay, lack of competence, inadequate resources, lack of decision support and insufficient data management. The symptom-to-hospital delay was due to the non-identification of signs and symptoms of acute cerebrovascular disease as well as misunderstanding the urgency of the acute cerebrovascular disease, which was especially described by several patient interviewees. This could result to patients not seeking help in time or being unable to call for help due to severity of the situation, as demonstrated by one patient-interviewee:

> Maybe at home one could be faster in calling for an ambulance or something. I think that is where the greatest mistake happens, at least with older people.
>
> (P3, patient)

According to interviewees, pre-hospital identification and early initiation of treatment were delayed due to healthcare professionals' lack of knowledge of urgent care criteria, skills to perform neurological assessment, and challenges to identify atypical signs, postoperative complications, and other conditions (e.g. disorders of vital functions, diseases, intoxication and delirium) from acute cerebrovascular disease, as described by two interviewees:

> And then there is that, how many of our patients have called the emergency number with slurring speech and were told that you are just drunk?
>
> (H7, registered nurse)

I was interviewed for probably 15-20 minutes and then said that the symptoms are not the type that you can go by an ambulance... and then it was confirmed by the doctor like two times by asking it somehow and then we left for the hospital.

(P11, patient)

In addition, the healthcare professionals lacked competence to provide comprehensive rehabilitation after acute cerebrovascular disease with attention paid to patients' cognitive and functional challenges along with challenges in assessing the patient's discharge condition.

The lack of resources was related to equipment (e.g. telemetry, audio-visual counselling materials), facilities for patient counselling, and bed capacity due to COVID and telemetry monitoring. In addition, the lack of decision-support tools (e.g. clinical care guidelines, information systems and validated tools and scales) hindered neurological and status assessment, as described by one interviewee:

If the patient has aphasia and cannot talk or anything, then according to the Glasgow Coma Scale, it would be kind of weak—the delivery of speech, even though in the end, they cannot do anything about it. You cannot put the situation back to the beginning and compare because the NEWS follow-up marker is red all the time that the patient is in terrible condition, even though in the end, the patient has been stable and the same for several weeks.

(H18, registered nurse)

According to interviewees, data management was insufficient due to the lack of health data (e.g. allergies, medication, living conditions and severity of disabilities), interorganizational health information exchange, and access to the Patient Data Repository of Kanta Services prior to patient admission. For patients, this was shown as patient transfer delays. In addition, the low quality of documentation (e.g. inconsistent, inadequate, and duplicate documentation and manual data entry) and a poor user interface design (e.g. complex layout, hierarchy) hinder information retrieval, which was demonstrated by one interviewee:

It is so that I am surfing through all the pages from Kanta, and I am trying to listen to the patient, where they have been and if that type of page can be found and what is documented there. And there is the same thing with these medical imaging systems and laboratory systems and all of those... so it takes quite a lot of time...

(H11, physician)

The identified needs related to the organization of stroke services were inductively formed in five generic categories: reducing

symptom-to-hospital delay, competence development, care coordination, increasing data accessibility, and creating data management tools. According to especially patient interviewees, there is a need for digital first aid kits (e.g. decision-support tools and prediction recurrence risk) and automated alert systems for early detection to reduce symptom-to-hospital delay. In addition, continuous interprofessional education (e.g. on cerebrovascular disease care, early rehabilitation and discharge criteria), organizational visits and online learning platforms should be utilized to develop competencies. New service models are also needed for caregivers (e.g. remote hospital visits) and transient ischemic attack patients (e.g. fast-track protocols, remote telemetry monitoring) to improve care coordination, as described by one interviewee:

For high-risk atrial fibrillation patients, if you wanted a little longer telemetry monitoring, it could be done so that the patient did not have to stay in the hospital. Sometimes we have those with suspected atrial fibrillation, but it is not caught in the first 24 hours, so you can continue for two, three days...

(H13, physician)

Increasing data accessibility was related to health data (e.g. MyData, personal health tracking), quality of data (e.g. structured documentation), and seamless health information exchange especially in interorganizational care transitions (e.g. vital recordings via wireless data transfer). According to interviewees, communication and service platforms (e.g. EHR programs, applications, digital care pathways) could be utilized to support patient-caregiver-provider communication and constructive collaboration between primary and secondary care. In addition, data management tools (e.g. protocols, checklists, scoring systems, data visualizations, alarms and reminders) could be created to support triaging and clinical decision-making, as described by one interviewee:

There would be a list like this, that these need to be checked by the end of the shift. Or the need for medication administration or similar would come up on the display. Now it is really like, if you do not remember to go and check something, then it will or might be forgotten.

(H24, practical care nurse)

5.4 | Management of acute stroke

The identified challenges related to the management of acute stroke were inductively formed in two generic categories: delayed stroke assessment and insufficient recanalization therapy. Delays in stroke assessment were due to the lack of human resources as well as laboratory and diagnostic imaging. Insufficient recanalization therapy was due to delays in onset-to-needle times (e.g. long distances in

rural areas) and lack of reliable health data (e.g. anamnestic data) for re-perfusion assessment. The cerebrovascular disease care system was seen as inefficient due to the lack of accelerated assessments, transportation plans, and earlier initiation time-dependent recanalization therapies in the acute cerebrovascular disease pathway, as demonstrated by one interviewee:

> Sometimes it can take quite long for an ambulance to arrive in those rural areas... It can take like an hour before you get to the hospital
>
> (P13, patient)

The identified needs for the management of acute stroke were inductively formed to one generic category of providing diagnostic support. According to interviewees, there is a need for mobile and diagnostic solutions for early detection and differential diagnosis of cerebrovascular disease for early initiation of recanalization therapy.

5.5 | Secondary prevention

The identified challenges related to secondary prevention were inductively formed in two generic categories: inadequate patient counselling and insufficient prevention care. The inadequate patient counselling was due lack of time because the reduced length of the hospital stay does not leave much time for patients to adjust to their acute situations, causing an information overload, as demonstrated by one interviewee:

> And then when a patient comes with all kinds of symptoms, it can the first time in a hospital. Then there are many issues that come at the same time. Then it is kind of useless to give all kinds of counseling because the patient does not remember them all.
>
> (H22, practical care nurse)

Insufficient prevention care was due to the lack of organization of secondary prevention services, structured follow-up, resources (e.g. staff, time), access to secondary prevention, and prevention measures. This was demonstrated by one patient-interviewee:

> If there is nothing like an actual agreed follow-up, then you are a kind of left on your own, or you are in the hands of the health center's emergency room.
>
> (P1, patient)

The identified needs for secondary prevention were inductively formed in two generic categories: service structure for secondary prevention and self-management support. There is a need to monitor patients' engagement in self-management (e.g. lifestyle changes, medication adherence) and health data to support secondary prevention. In addition, there is a need for cerebrovascular disease coordinators and clinics to assess, coordinate, and support integrated post-discharge care during rehabilitation and secondary prevention, respectively, as described by one interviewee:

> I would set up these cerebrovascular disease patients' own clinics with multi-professional collaboration in a way that a physical therapist, an occupational therapist, and if needed a speech therapist would assess the situation beforehand and hand over the feedback to the caring physician, who would decide on further rehabilitation and, at the same time, on secondary prevention care. And these would be physicians with an orientation in this area and with one day a week dedicated to this function.
>
> (H2, physician)

According to interviewees, the patients' self-management competencies could be supported with various methods, such as home-based counselling or communicating via telephone and technological solutions (e.g. digital care pathways). Supportive content for self-management should also be easily available to cerebrovascular disease patients early on and throughout the patient journey.

5.6 | Rehabilitation

The identified challenges related to rehabilitation were inductively formed in two generic categories: Inadequate evaluation of rehabilitation needs and inadequate provision of rehabilitation. Inadequate evaluation and provision of rehabilitation were related to cognition, speech (early phase of recovery), and long-term assessments as well as access to specialized (e.g. medical, neuro-psychological), public and private rehabilitation services and recovery care due to lack of resources. Patients were concerned for having enough time recuperate before discharge. According to the interviewees, especially working-aged patients with mild or unclear cognitive symptoms have lacked or even dropped out of follow-up, guidance and targeted rehabilitation, as demonstrated by one interviewee:

> Rehabilitation programs are, of course, directed to those with clear noticeable cognitive problems... Like many times, the patients in like this examination seem that everything is moderately okay and the patient themselves do not experience anything as they have not yet returned to work, then maybe that is already a challenge as they can truly appear later. So where, who would follow up on them, or how would they get to rehabilitation if they need it.
>
> (H17, psychologist)

The identified needs for rehabilitation were inductively formed in two generic categories: service structure for rehabilitation and

utilization of rehabilitation options. There was a need for a service structure that provides early and easy access to a seamless and segmented rehabilitation process. In addition, there is a need for multidisciplinary rehabilitation (e.g. neuropsychology, therapists), dedicated rehabilitation units and comprehensive therapy protocols (e.g. speech therapy, physiotherapy, occupational therapy and extended assessment). In addition, different rehabilitation options should be utilized such as music therapy, interprofessional home visits, and remote home rehabilitation via videoconferencing and applications with multimedia content.

5.7 | Evaluation of stroke outcome and quality assessment

The identified challenges related to evaluation of stroke outcome and quality assessment were inductively formed in two generic categories: lack of quality measures and patient-reported undesirable events. There was lack of quality measures due to legal restrictions hindering data collection, lack of follow-up data on rehabilitation outcomes, and joint registries to follow up on the rehabilitation process. In addition, according to interviewees, the quality of services varied extensively between regions.

Lack of patient satisfaction was related to patient expectations and physical needs, length of hospital stays and lack of emotional support (e.g. fear, anxiety, insecurity, neglect, ignorance), with distrust towards of healthcare professionals' abilities. In addition, patients experienced that they did not receive information about their condition, treatment and post-discharge care, as demonstrated by the patient interviewees:

> There was no information on where you are going and when, and it was only said that at some point to somewhere, and then there was nobody seen, heard in an hour and a half... many times, the same people walked by and nobody paid any attention, so you did not know that you were brought to the right place.
>
> (P19, patient)

The identified needs for stroke outcome and quality assessment were inductively formed in three generic categories: creating a national cerebrovascular disease care pathway, creating a national database, and benchmarking. According to interviewees, there is a need for a national cerebrovascular disease care pathway with unified regional care pathways and protocols. In addition, a national database was needed for sharing information about existing tools for rehabilitation and psychoeducation. The interviewees identified different types of quality (e.g. access to primary prevention, treatment adherence, impact of risk-factor modification to cerebrovascular disease incidents, door-to-needle time, patient experiences) and patient-centred outcome measures (e.g. long-term cognitive, physical and social disability, quality of life, working ability related factors, self-determination capability and lifestyle changes) to be collected for benchmarking. In addition, there

is a need to integrate EHR into the cerebrovascular disease registry to collect evaluation data from follow-up visits in both primary and secondary care. The need for quality measures was highlighted by one interviewee:

> More prolific in this healthcare is to study and aim at the care being effective, not how many patients have been treated or visits or treatment episodes... to remove everything that has no distinct effect, and from there, get the resource for let's say to prevention and rehabilitation that clearly have been studied to show effect.
>
> (H12, physician)

5.8 | Life after stroke care

The identified challenges related to life after stroke were inductively formed in three generic categories: lack of health data, difficulties in functionality assessment and inadequate support for self-management. Lack of health data was due to a lack of reliable health data (e.g. blood pressure, blood glucose, pulse, weight, height) because patients do not understand the value of self-gathered data. Difficulties in functionality assessment were related to patients' self-determination capacity, self-management competence, and driving capability due to cerebrovascular disease-related disabilities (including aphasia, cognitive and physical impairments), respectively.

According to interviewees, there is a lack of self-management support for emotional needs, administrative matters, health literacy, and adherence to treatment. Discharged patients are confused and scared, not fully knowing what has happened and how to proceed having to cope in life and manage their symptoms alone and lacking the ability or guidance to seek information and handle administrative matters (e.g. filing forms, using digital services) due to age or cerebrovascular disease-related cognitive challenges. The consequences of a lack of support for adherence was demonstrated by one interviewee:

> We have these transient ischemic attack patients and those with mild cerebrovascular disease... some come back again, that something has gone wrong with patient counseling, or they have not adhered to their treatment, not taken medication, and because of that have a new acute cerebrovascular disease.
>
> (H1, nurse)

The identified needs for life after stroke were inductively formed in two categories: long-term support and caregiver support. Different solutions are needed to support self-management (e.g. risk factors and conditions, self-measuring, healthy lifestyle, medications, laboratory and imaging, decision-support) long-termly. In addition, adjustment support is needed on how to adapt and cope with cerebrovascular disease-related changes in functionality, life situation, and permanent

challenges in everyday life and where to receive help and support services. Also, there is a need for driving assessment methods, patient education and peer-support by using remote services, as described by one interviewee:

> And there was individual (content) and then some teamwork and I think that was good.
>
> (P10, patient)

The need for caregiver support was expressed by many interviewees. Coaching, peer support, and long-term guidance with communication with healthcare professionals are needed for caregivers by utilizing different solutions (e.g. digital platforms and pathways). Long-term guidance should focus on cerebrovascular disease-related changes to patients' personality, cognition, mental state, available support and services, secondary prevention and caregivers' own well-being. This was demonstrated by one interviewee:

> Or how you can support the one who has fallen ill or how to take... it is important for a caregiver how you take care of your own resources... suddenly the disease may get the entire family sick. It would be a pathway like, with information told but also with a link to which expert to contact, but also how to further prevent these...
>
> (H25, physiotherapist)

6 | DISCUSSION

This descriptive study identified 19 generic and 79 sub-categories related to perceived challenges along with 17 generic and 62 sub-categories related to perceived needs encompassing the entire cerebrovascular disease pathway from both patients' and healthcare professionals' perspectives, highlighting the understudied acute cerebrovascular disease patient's perspective on care. Based on these perspectives, suggestions for actions to improve care in and across the different domains of cerebrovascular disease pathway were formed (Figure 1).

Actions are required to support primary prevention. In accordance with the previous literature (Norrving et al., 2018; Owolabi et al., 2022), the need for population-based opportunistic screening and systematic screening of individuals from childhood to late adulthood were identified to initiate early preventive services and engage individuals in self-management to decrease the risk of cerebrovascular disease. Patient especially valued self-management of risk factors, with access and availability of primary services. In addition, novel educational methods are needed to increase public awareness of the risk-factor modification but also of the warning signs of cerebrovascular disease. Investing in primary prevention is crucial to improve outcomes (e.g. morbidity, mortality, disability) and reduce the economic burden (Owolabi et al., 2022) by decreasing the incidence and reoccurrence of acute cerebrovascular disease (Hankey, 2020; Singh et al., 2018).
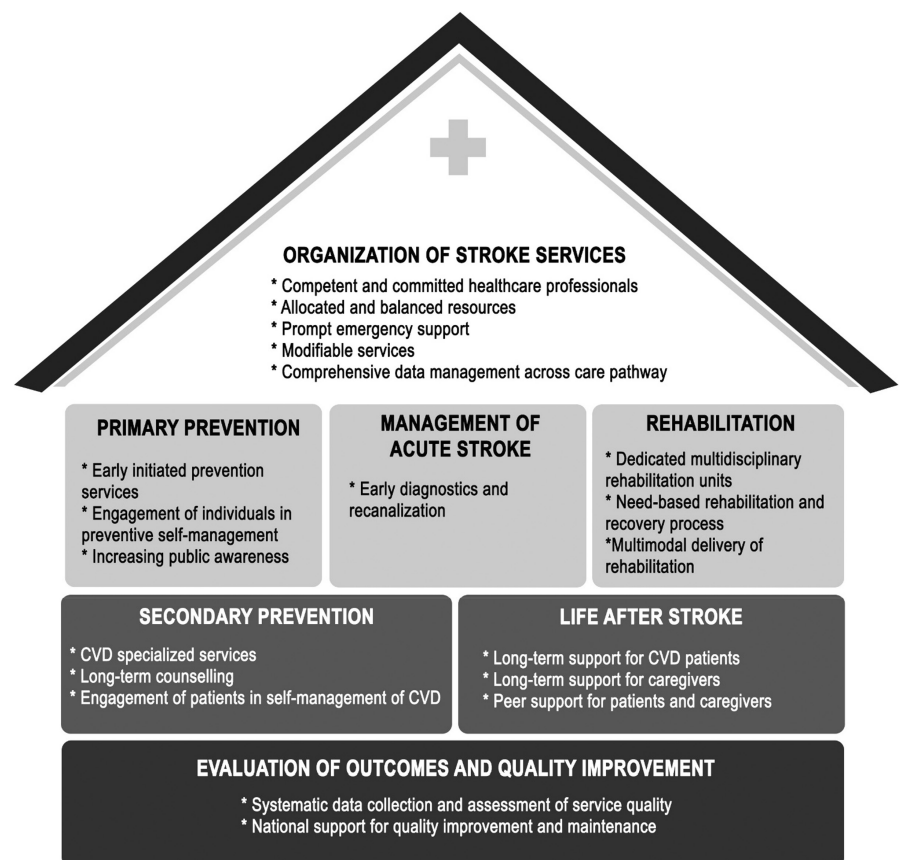

FIGURE 1 Actions to improve care in and across the cerebrovascular disease pathway.

The organization of stroke services requires competent and committed healthcare professionals working in multidisciplinary teams (Herpich & Rincon, 2020; Norrving et al., 2018). However, lack of knowledge and skills related to the core competence areas of cerebrovascular disease care were identified, which is in line with previous research (Jarva et al., 2021; Tulek et al., 2017). This highlights the requirement of continuous education along with decision-support tools (e.g. guidelines, scales, electronic health record integrations) for the planning, provision and monitoring of the care of cerebrovascular disease patients, as they can increase the quality and safety of care (Cervero & Gaines, 2015; Dunn Lopez et al., 2017; Hassan et al., 2021) and increase trust in patients.

This study identified symptom-to-treatment delays due to patient factors (e.g. lack of knowledge and skills in cerebrovascular disease identification, digital first aid kits), organizational factors (e.g. human resources, education, diagnostics capabilities) and logistical factors (e.g. acute pathways in care systems) (Lachkhem et al., 2018). In the previous literature (Herpich & Rincon, 2020), workflows and organized systems of acute care with telemedicine and mobile stroke units have reduced delays, but it also highlights the importance of early recognition of cerebrovascular disease in the community by individuals and professionals. In this study, especially the patients described a lack of knowledge to seek help. The provision of emergency support in the form of validated tools for patients, caregivers and healthcare professionals for early recognition was identified. This supports early diagnosis and early recanalization therapy in the management of acute stroke in a dedicated stroke centre, which significantly reduces morbidity and mortality (Herpich & Rincon, 2020).

In line with (Jansson et al., 2022), poor user interface design and lack of health data hindered information retrieval. In addition, insufficient health information exchange, poor quality of documentation, usability, and functionality issues were identified, which are concerning, as they can amplify human errors and risk patient safety (Hyvämäki et al., 2022, 2023). Therefore, comprehensive data management is required by addressing the needs for data collection, interoperability, and communication in healthcare systems and thus secure coordination and patient safety across the care continuum (Kierkegaard et al., 2014; Menachemi et al., 2018).

Providing access to equal and high-quality health services is a global challenge in cerebrovascular disease care with the rising costs and decreasing resources in healthcare (Dieleman et al., 2017). In Finland, the service structures for the management of acute cerebrovascular disease are nationally advisable (Ischemic Stroke and TIA. Current Care Guidelines., 2016). Albeit this study identified challenges and needs in the provision of equal access and high-quality health services in rural areas with long distances, as in the study by (Seabury et al., 2017). The lack of resources (e.g. staff, facilities, equipment, bed capacity) was seen as hindering this in several domains of acute cerebrovascular disease care. Implementing modifiable services with the inclusion of digital opportunities could provide utility and cost reductions (Antonenko et al., 2021). The implementation of methods to evaluate care (e.g. patient and process-related outcomes) and national governance (e.g. cerebrovascular disease registries, databases, and national care pathways and protocols) could improve the quality of care and comparability of regional service provision. By including costing benchmarks for the nationally similar service pathways, the efficient allocation and balancing of resources could also be promoted (Strilciuc et al., 2021).

Previous studies have shown that transitioning from specialized tertiary level services to secondary care is challenging in the cerebrovascular disease pathway due to a lack of communication, discontinuity of post-discharge services, and a lack of long-term follow-up (Aquino et al., 2020; Boehme et al., 2021; Kable et al., 2018). In accordance with the study by (Chen et al., 2016), there was a lack of comprehensive assessment and continuity of rehabilitation. For instance, patients with mild cognitive symptoms might easily fall from follow-up and rehabilitation, with patients concerned of too early discharge. Actions are needed to develop a need-based rehabilitation and recovery process, with multimodal rehabilitation in dedicated multidisciplinary units, as they can reduce stroke-related disability (Platz, 2019).

Patients and healthcare professionals both identified the lack of emotional support, timely availability of relevant health information, and knowledge during post-discharge care and rehabilitation services in patients, as highlighted in the studies by Pindus et al. (2018) and Zawawi et al. (2020). Due to varying individual cognitive and functional challenges in recovery, patients and their caregivers require long-term support with possibilities for peer support throughout the patient journey, highlighting both the secondary prevention and life after stroke domains. In line with Boehme et al. (2021) and Lip et al. (2022), this study identified that interprofessional collaboration is required in the form of cerebrovascular disease clinics and coordinators to provide equal, highly specialized care to engage patients in self-management to improve recovery, reduce the recurrence of cerebrovascular disease, and increase quality of life. With different service models and interventions available, it is important to research and establish models best suited for long-term care and support of cerebrovascular disease patients and their caregivers (Norrving et al., 2018).

6.1 | Strengths and limitations of the work

This study has limitations that should be considered in the interpretation of results. As the cerebrovascular disease patients in this study were ischemic stroke and transient ischemic attack patients, and healthcare professionals worked mainly in the acute, tertiary hospital care of these types of cerebrovascular disease patients, the results of this study may not be transferrable to all cerebrovascular disease patients' care. Also, the patients were interviewed in the acute phase of their care, limit their perceptions, in addition to first-time cerebrovascular disease patients having not experienced the pathway subjectively before. The experiences of patients and healthcare professionals were still quite similar regardless of this. The strength of this study is indeed the complementing combination

of patient and healthcare professional experiences to gain a wider perspective of needs and challenges in the cerebrovascular disease pathway with results similar to studies specific to singular domains. The European Stroke Action Plan also provided a valid deductive framework for the analysis process, as it provides an assessment of the current state of services and a roadmap for future cerebrovascular disease care in Europe.

6.2 | Recommendations for further research

This study explored experiences of patients and healthcare professionals to improve care in and across different domains of the cerebrovascular disease pathway. In future, perceived challenges and needs across the cerebrovascular disease pathway should be investigated also from caregivers and clinical leadership perspectives. In line with previous literature (Boehme et al., 2021; Norrving et al., 2018), the support for patients' secondary prevention and life after stroke should be further explored with special attention paid to the long-term experiences and needs of cerebrovascular disease patients in different parts of their lifespan. Further studies could elaborate the challenges highlighted in the different domains of the pathway and identify systems and solutions to solve these challenges such as data management issues, needs for knowledge, support and guidance.

7 | CONCLUSION

Several challenges and needs were identified in and across the different domains of the cerebrovascular disease pathway. There is a requirement for adequate resources, early initiation of treatment, early diagnostics and recanalization, dedicated rehabilitation services, long-term counselling and support, and impact evaluation services. Continuity and quality of care can be assured with comprehensive data management and systematic national evaluation and support for developing of services. Primary and secondary prevention and long-term support services are especially needed to increase awareness, engage patients in self-management and support caregivers to prevent the occurrence and recurrence of acute cerebrovascular disease and promote health and well-being.

CONFLICT OF INTEREST STATEMENT
The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT
Research data are not shared.

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