

Barriers to and facilitators for making emergency calls – a qualitative interview study of stroke patients and witnesses

Ida Bakke, MD,^{a,b} Christian Georg Lund, MD, PhD,^c Maria Carlsson, MD, PhD,^{b,d}
Rolf Salvesen, MD, PhD, Professor emeritus,^d and Britt Normann, PT, PhD, Professor^{e,f}

Background and objectives: Early access to hospital for diagnosis and treatment is strongly recommended for patients with acute stroke. Unfortunately, prehospital delay frequently occurs. The aim of the current study was to gain in-depth insight into patient experience and behavior in the prehospital phase of a stroke. *Methods:* We conducted qualitative interviews with a purposive sample of 11 patients and six witnesses within four weeks post stroke. The interviews were audio recorded, transcribed, and analyzed utilizing Systematic Text Condensation. *Results:* The material was classified according to two main categories each containing three subgroups. The first category contained the diversity of sudden changes that all participants noticed. The subgroups were confusing functional changes, distinct bodily changes and witnesses' observations of abnormal behavior or signs. The second category was delaying and facilitating factors. To trivialize or deny stroke symptoms, or having a high threshold for contacting emergency services, led to time delay. Factors facilitating early contact were severe stroke symptoms, awareness of the consequences of stroke or a witness standing by when the stroke occurred. *Conclusions:* Prehospital delays involved interrelated elements: (1) Difficulties in recognition of a stroke when symptoms were mild, odd and/or puzzling; (2) Recognition of a stroke or need for medical assistance were facilitated by interaction/communication; (3) High threshold for calling emergency medical services, except when symptoms were severe. The findings may be helpful in planning future public stroke campaigns and in education and training programs for health personnel.

Key Words: Acute stroke—Prehospital delay—Qualitative research—Emergency call

© 2022 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>)

Abbreviations: IS, Ischemic Stroke; IVT, Intravenous Thrombolysis; EMS, Emergency Medical Services; EMCC, Emergency Medical Communication Centre; EMD, Emergency Medical Dispatch; FAST, Face Arm Speech Time; COREQ, Consolidated Criteria for Reporting Qualitative Research; MRI, Magnetic Resonance Imaging; NIHSS, National Institutes of Health Stroke Scale; ED, Emergency Department; GP, General Practitioner; OOH-service, Out-of-hours service; STC, Systematic Text Condensation; CPSS, Cincinnati Pre-Hospital Stroke Scale

From the ^aPatient Safety Unit, Nordland Hospital Trust, Bodø, Norway; ^bDepartment of Clinical Medicine, UiT The Arctic University of Norway, Tromsø, Norway; ^cDepartment of Neurology, Oslo University Hospital, Oslo, Norway; ^dDepartment of Neurology, Nordland Hospital Trust, Bodø, Norway; ^eFaculty of Nursing and Health Science, Nord University, Bodø, Norway; and ^fDepartment of Physiotherapy, Nordland Hospital Trust, Bodø, Norway.

Received July 11, 2022; accepted August 14, 2022.

Grant support: The study was funded by the Northern Norway Regional Health Authority.

Corresponding author: Patient Safety Unit, Mailbox 1480, Nordland Hospital Trust, 8092 Bodø, Norway E-mail: ida.bakke@uit.no.
1052-3057/\$ - see front matter

© 2022 The Author(s). Published by Elsevier Inc. This is an open access article under the CC BY license

(<http://creativecommons.org/licenses/by/4.0/>)

<https://doi.org/10.1016/j.jstrokecerebrovasdis.2022.106734>

Introduction

Stroke is a leading cause of death and disability worldwide.¹ Ischemic stroke (IS) accounts for 85 % of all stroke cases.² Reperfusion therapy with intravenous thrombolysis (IVT)^{3,4} and endovascular thrombectomy are effective treatments of IS.⁵ However, treatment results are highly time dependent.^{6,7}

Reduction of prehospital delay is an important measure in reducing time to treatment in stroke patients. Previous studies of prehospital delay have shown several factors influencing time to hospital arrival, e.g. lack of awareness of stroke symptoms, seeing a family doctor first, and not involving emergency medical services (EMS).⁸ An interview study found that factors such as fear, denial and reluctance to burden others caused delay in admission of acute stroke patients. Many had the perception that the proper and first action was to contact the General Practitioner (GP).⁹

This is in line with earlier findings that failure to recognize, or denial regarding, symptoms, and the decision to first contact primary care rather than EMS resulted in delay. Witness advice was associated with more rapid recognition and care.¹⁰

Early contact with the EMS and severe stroke symptoms have been associated with early hospital arrival.¹¹ Having a witness when the stroke occurs, knowledge of symptoms and understanding that stroke is a serious condition are reported to be associated with help-seeking and shorter prehospital delay.¹² The use of ambulance transport as compared to self-transport reduces time from onset of symptoms to hospital arrival, as well as intra-hospital door-to-needle time (DNT).¹³

In a Norwegian study, delay of the decision to seek medical assistance in acute stroke accounted for more than half of the prehospital delay.¹⁴ Stroke campaigns aim to enable people to recognize a stroke and raise awareness that a stroke is a medical emergency where prompt treatment is crucial. A systematic review showed that such campaigns may improve recognition of signs of stroke, but have limited impact on awareness of the need for EMS.¹⁵ Witnesses and family members are typically those contacting the EMS.¹⁶ A qualitative interview study of witnesses to stroke reported multiple influences on their response being to call EMS: acting instinctively, environmental context and resources, social influences and beliefs about consequences.¹⁷ Knowledge of interactions between witnesses and acute stroke patients is scarce.¹²

The aim of the current study was to gain in-depth insight into the prehospital phase from the perspective of patients' and witnesses', and to identify aspects influencing time to contact the EMS. Knowledge of these factors may contribute to further development of the health services involved, and in planning public information campaigns.

We posed the following research question: How do patients surviving acute ischemic stroke, and their

witnesses, experience the situation when the stroke occurs, and what are their considerations regarding contacting help and the EMS?

Methods

Design

We chose a qualitative approach using individual in-depth interviews, because this is an adequate method for deriving scientific knowledge from people's reflections and experiences.¹⁸

Context of the study

The participants were recruited from a stroke ward located in Northern Norway. In Norway, the public are advised to call the EMS number 113, in the case of needing acute medical assistance. This connects to the nearest emergency medical communication center (EMCC), and trained emergency medical dispatch (EMD) answer the call, and can dispatch an ambulance when appropriate.

Participants

A purposive sample of 17 individuals,¹⁹ 11 patients with an acute IS, and six witnesses (spouses or adult children) were included. All participants gave written, informed consent. The inclusion criteria for patients were: IS diagnosis confirmed by magnetic resonance imaging (MRI) and age ≥ 18 years. Individuals with aphasia, significant cognitive impairment, or inability to give informed consent were not included. To ensure variation and depth in the material we included patients or witnesses to stroke patients of both sexes, varying in age, time to hospital admission, and with a spectrum of National Institutes of Health Stroke Scale (NIHSS) scores (**Table 1**). The age, time to admission and NIHSS of the patients were representative for a Norwegian stroke population.²⁰ When no new themes emerged in the interviews, we decided that our sample had reached saturation.¹⁹ Patient characteristics are presented in **Table 1**.

Data collection

The interviews were conducted by the first author (IB) between April 2020 and January 2021. Due to the COVID-19 pandemic they were performed on telephone (14 interviews) or as video conference on a secure platform (3 interviews). The interviews were audio-recorded, lasted from 37 to 69 min with a total of 877 min, mean time 52 min, and were performed as early as possible after stroke onset (range five to 27 days). We developed theme-based interview guides (Appendices 1, 2), with contributions from a user representative. They contained the following topics: (1) background of the participants (2) description of the acute situation and experiences and reflections from contacting EMS, (3) experiences and

Table 1. *Participants characteristics.*

Participants Characteristics	
Participants	
Total number stroke cases included, n	17
Patients interviewed, n	11
Witnesses interviewed, n	6
Sex, stroke cases (male/female), n	9/8
Age stroke patients, median (range)	76 (53-90)
NIHSS ¹ score stroke cases	
At admission, median (range)	3 (0-19)
At discharge, median (range)	1 (0-6)
Patients and witnesses contacting EMS ¹ , GP ¹ or OOH ¹ and admission time from symptom onset	
Contact ≤30 min, admission ≤4 h, n	7
Contact > 30 min, admission ≤ 4 h, n	3
Contact > 30 min, admission > 4 h, n	4
Wake up stroke or unknown time of onset, n	3

(1) NIHSS, National Institutes of Health Stroke Scale; EMS, Emergency Medical Services; GP, General Practitioner; OOH-services, Out-of-hours services.

reflections from the timeline from onset to arrival hospital and, (4) experiences from and reflections on hospital admission and stroke campaigns. The interviewer (IB) asked open-ended questions and follow-up questions, and when appropriate, rephrased the participants' answer from time to time to make sure that it was correctly understood.²¹

Analysis

The interviews were transcribed, anonymized and systematized using NVivo12.0 software (QSR International). We analyzed the material using Malterud's Systematic Text Condensation (STC),¹⁸ a process of de- and re-contextualization, through the following four steps; (1) Two of the authors (IB, BN) read all the interviews and the other authors read several of the interviews. Guided by the research question, preliminary themes were identified independently by IB and BN, discussed and agreed on within the research group. (2) IB identified meaning units, or text fragments containing information about the research question and labeled (coded) these. (3) The coded meaning units were organized into groups (decontextualization) based on their content by IB, then discussed within the authors group. Subsequently, IB organized the coded text into sub-groups and created a shortened text in the first person (condensate), complemented with illustrative quotes. (4) The first-person condensates were then transformed into analytic texts in third-person format, and verified against the original transcripts (recontextualized) by IB. The coding, labeling of sub-groups and categories emerged through a dynamic process. Two of the authors (IB, BN) discussed the interpretations at every step in the process, and all the authors verified the main steps from preliminary themes to the analytic text. The final organization of categories and subgroups was agreed on by all the authors. Examples from the analytic process are presented in [Table 2](#).

Research team and reflexivity

The first author (IB) is a neurologist with clinical experience from five years in a neurological department with a stroke unit. IB did not work as a clinician in the department recruiting the participants and had no clinical or personal relationship with the participants. The last author is a neurological physiotherapist and is experienced in qualitative methods. The other authors are experienced senior consultants in neurology and researchers in neurology and stroke. The varied backgrounds within the research team contributed to different questions to the material and enriched the interpretations.²¹ The researchers discussed the interpretations critically, questioning and reflecting on the coherence of the analysis and how the researchers' pre-understandings influenced it. The Consolidated Criteria for Reporting Qualitative Research (COREQ) was used to conduct and report this study.²²

Results

The results are presented as two categories, each with three subgroups of condensates supplemented with quotations ([Table 3](#)). The quotations are marked by identification number (ID), patient (P) or witnesses (W), early call within 30 min from symptom onset (EC) or late call 30 min or more after symptom onset (LC). In cases of early contact with health services, type of contact such as EMS, general practitioner (GP) or out-of-hours services (OOH-services) was specified. In six of the 17 stroke cases calling the EMS was the first choice of contact, in nine cases the patients or witnesses contacted the GP or the OOH-service and in two cases they met directly at the OOH-service without calling. The transportation methods to hospital varied from directly from home with ambulance (six patients) to different transport with private car, taxi or

Table 2. Description and two examples of the analytic process.

STEPS	Description of steps	Example 1	Example 2
STEP 1	Preliminary themes and overview	Sudden changes Change in behavior Noticed the onset of symptoms The decision to call	Don't want to bother anyone Respect for authorities Self esteem / self-confidence
STEP 2	Meaningful unit (shortened examples)	<i>"My mother sat in her chair. Her face was scared and stiff. Her eyes looked different. She made noises like 'uuuhhh, uuuhhh', only noises, but not any words, not any letters indeed."</i>	<i>I think you can call 113 if someone is shot or attacked with a knife. Or a car crash.</i>
STEP 3	Code group Subgroups (meaningful units classified into subgroups) Condensates (each subgroup is reformulated to a condensate to summarize and retell the relevant subgroup)	Onset of symptoms and changes Witnesses' observation of abnormal behavior The witnesses spoke about changes they could see and that something abnormal happened. One witness described that her husband spoke completely understandably, and another witness that his wife suddenly could not complete sentences. One daughter said that her mother made loud noises and was roaring.	Preconceptions regarding calling emergency phone High threshold The participants had a huge respect for calling emergency phone. It must be acute, such as situations where your life is threatened. They would not bother others. They did not like to take the doctor's time if someone else would have to wait.
STEP 4	Category (main themes)	Diversity of sudden bodily changes	Delaying and facilitating factors in action

Table 3. *Categories and subgroups.*

Categories	Subgroups
Diversity of sudden bodily changes	Confusing functional changes Distinct bodily changes
Delaying and facilitating factors in action	Witnesses' observation - abnormal behavior Trivialization and denial High threshold Visibility, communication and awareness

ambulance from GP to OOH-services (10 patients). One patient walked from the OOH-services to the hospital.

Diversity of sudden bodily changes

This part of the material is characterized by a diversity of perceived and observed changes regarding the body and functional activities.

Confusing functional challenges

"I have taken it every night. I did not understand how to get the spray (i.e., asthma medication) out. I tried several times. I messed around with it and felt so strange. I think I understood something very odd happened to me, but I did not understand it at the same time." (ID 5, P, EC, contacted 113).

Half of the patients described a normal day or situation until they suddenly noticed something unusual while performing ordinary activities. Daily activities unexpectedly caught their attention and felt difficult to conduct. Examples of challenges were difficulties in reading text on TV, difficulties putting a book in a purse, and even forgetting to take off their trousers while visiting the toilet. These situations were reported as confusing, odd and/or puzzling. One participant told that when she lost a stitch while knitting, she struggled enormously to pick it up again. Normally, this was an easy thing to fix. The challenges were confusing and unclear, and one patient put it like this:

"It's hard to explain, but I felt something pop in my head. It felt like a 'brainfreeze' and it suddenly was very, very difficult to speak." (ID 3, P, LC)

The perceived functional changes were not associated with pain except in two patients experiencing headache at symptom onset. A key feature of the stories was that all the patients immediately became aware and reflected upon the abnormalities in their behavior, but did not associate them with a stroke. Some waited for hours and up to more than a day to speak about their perceptions or call for medical help.

Distinct bodily changes

"Then, I lay down to sleep and the arm was just crazy. It was not my arm! "Take this arm away, it is not my arm," I said to my husband. He said: "Stop kidding, it's your arm." (ID 4, P, LC)

Approximately of the patients perceived bodily changes that they could not ignore. Whereas some described either the initial puzzling changes as persistent or worsening, others described new severe and visible deviations from the normal which demanded their attention. They noticed more clear and severe bodily dysfunctions, or inability to perform daily activities. One of the patients noticed a sudden visible change to his arm:

"I was about to turn off the power plug. When I tried, I noticed that my right arm felt so strange. I noticed at once that I could not use it. My arm. It wouldn't obey my orders. And I do not know if I could feel my arm. It was certainly a huge surprise to me." (ID 10, P, EC, contacted the OOH-services).

The bodily changes described by the patients involved both "loss of sensation," and numbness in fingers, arms or feet, weakness, skewed mouth and functional problems. Examples of functional problems were disturbed balance when walking and speech challenges. They recognized these changes in daily situations, such as losing control of their arm and the words suddenly stopped or became slurred while speaking. Features common to all these more manifest deviations were that they were exigent, visible to themselves and others, and caused actions in terms of telling others or contacting medical assistance.

Witnesses' observations – abnormal behavior

"I called her name from the kitchen, the breakfast was ready. She did not answer. I first thought she was very tired. I went back to the bedroom, and then I realized something was very wrong. She looked deadly drunken." (ID 8, W, EC, contacted 113)

A common experience from the witnesses' perspective was changes regarding bodily functions or behavior of the stroke individual. They described abnormal, or lack of, verbal responses or expressions in the face such as stiffness, that the eyes looked different, and that their husband or wife looked scared, upset or shaky. Another example of loss of function, was changes in handwriting. Speech difficulties varied from completely incomprehensible speech to more discrete changes where sentences were not completed. One daughter said that her mother made loud noises and was roaring:

"My mother sat in her chair. Her face was scared and stiff. Her eyes looked different. She made noises like "uuuhhh, uuuhhh", only noises, but not any words, not any letters indeed." (ID 17, W, EC, contacted 113)

Delaying and facilitating factors for action

The participants made different choices regarding their first contact with health services; six of 17 chose to call 113 while the others contacted the GP or the OOH-service.

Trivialization and denial

"I was only weak and numb in my leg, my arm was fine. I sat in the chair and felt my leg go numb. I thought it could be because of my sitting position, that I had been sitting with my leg squeezed." (ID 14, P, EC, contacted OOH-services).

The patients with initially puzzling and vague functional changes associated these deviations with previously experienced illness or disease. Typical examples were relating the felt deviations to prior musculoskeletal or orthopedic problems. The perceived balance problems in the actual situation were related to a previous knee surgery, and that balance had been worse ever since. Likewise, numbness in the fingers and dizziness, were associated with past neck pain and an nerve entrapment.

Several informants assumed that the changes were not dangerous. They described that trouble in getting dressed and feeling a bit strange were nothing to pay attention to. Difficulties in knitting were explained by the black colored yarn being more difficult to see than light colors. Both patients and witnesses said that they tried to suppress the fear that this was the worst case and the reality of the situation. Even if they noticed something abnormal happened, they thought that they were not suffering a stroke. One of them said:

"It's how humans think – Let us wait and see if this goes over. It's nature's way, nature is the best medicine." (ID 2, W, EC, contacted GP)

Many of the informants explained that they were dealing with uncertainty, particularly if they perceived a change in only one body part or function. Some patients denied the symptoms; one massaged their lip to make the "unhappy look" disappear, while another thought it could not be a serious illness since he could lift both hands over his head. Consequently, they concluded that the perceived changes did not amount to an emergency.

High threshold

"I think you can call 113 if someone gets shot or attacked with a knife." (ID 11, P, LC).

A common attitude among the patients and witnesses was a huge respect for dialing 113 as calling this number was associated with life threatening situations. Several of the participants said they did not call 113 because they did not want to disturb the medical services. Some of them related this to previous episodes when they visited the doctor with a problem they were worried about, and it ended up being nothing to be afraid of. Three participants described previous negative experiences where they felt rejected when calling the EMS or visiting the doctor's surgery. These episodes made them feel ashamed of spending time on it. Some also spoke about a fear of being considered a hypochondriac. They considered that these experiences might have led to uncertainty next time they considered contacting 113 or the GP. One participant shared an episode she had with her child:

"I've been to the doctor once with my child. I was very worried because he looked so sick. They yelled at me because I turned up there without an appointment." (ID 15, P, LC)

The participants, except for one, said that the COVID-19 pandemic did not influence their choice of contact. This patient was driven to the OOH service by a witness. He described how they considered driving to the hospital when the symptoms occurred. They chose OOH because they thought the hospital was busy, and that the restrictions would be a barrier to getting inside.

Visibility, communication and awareness

"Something wrong has happened here. My face is crooked. I think I'm having a stroke. I do not think I understood myself how to call. But I said to my husband – you have to call 113." (ID 1, P, LC, contacted 113).

In the cases where the EMS were contacted directly, the phone call was made by the husband, wife or daughter/

son. Consequently, a witness, and not the person suffering the stroke, made the emergency call. Factors facilitating calling EMS were marked visible changes and severe stroke symptoms. Two patients underwent a severe stroke (NIHSS > 10), and this was followed by immediate calls by the witnesses. The two witnesses in these situations said it was clear to them that this was the right choice.

A common feature in the material is that it was important to tell a trusted person about the changes taking place. These discussions resulted in contacting the GP, the OOH service or calling 113. Some of patients said that it, in starting the conversation, was important that their son or daughter worked in health care. One of the patients spoke to a daughter two days after the facial palsy appeared and described this:

"My daughter got angry. I got the message to call the doctor at once. And she would call me back in 10 min to check if I'd done it." (ID 11, P, LC)

The participants' knowledge and considerations regarding the consequences of a stroke had a positive impact on an early admission and contacting the GP, but not necessarily on calling the EMS. When talking about the consequences of a stroke, some of them described that thinking of this influenced their choice on calling help in the acute situation.

Several participants thought that the national stroke campaigns could have had an effect and strengthened their knowledge about stroke. However, at the time, only two recalled the recent national campaign "Speech, Smile, Lift". Some experienced their attention being on heart attack rather than stroke, while others referred to knowledge regarding stroke resulting in early contact with the GP:

"We have learned about stroke on a course, so I was thinking of a stroke. But we have learned that a stroke affects one half, both the arm and the leg." (ID 14, P, EC, contacted GP)

Most of the participants considered knowledge of stroke to be of great importance in the acute situation. The participants said it was meaningful for them to share their stories if others could learn from them, especially as they regretted their 'wait and see' attitude.

Discussion

The main findings of the study were: (1) A diversity of perceived sudden bodily changes when the stroke occurred, ranging from vague uncommunicated deviations to persistent unignorable changes, and witnesses' descriptions of abnormal behavior. (2) Trivialization and denial of the perceived changes, doubts regarding

severity and reluctance to call the EMS were barriers to seeking medical help. (3) Severe deviations, a witness at the occurrence of the stroke, informing a family member about the perceived bodily change, and, to some extent, knowledge about the consequences of a stroke were facilitators for seeking medical help, however not necessarily the EMS.

The variation in and vagueness of symptoms at the onset of the stroke described in our study are in line with Edlow et al.²³ who highlight the need to be aware that some patients will present uncommon and atypical stroke symptoms.²³ A study investigating EMS calls found that classical stroke symptoms were mentioned more frequently by the callers in stroke calls; speech problems (15%), limb weakness (15%) and facial weakness (4%).²⁴ However, many calls relating to stroke patients did not mention any of these keywords.²⁴ Data from the Norwegian Stroke Register in 2020 showed that 69% of patients presented one or several of the most common stroke symptoms on admission: facial palsy, limb paresis and/or speech disturbances.²⁰ Interestingly, 68% scored NIHSS 0-5 defined as a mild stroke and 45% with the low score NIHSS 0-2.²⁰ These register data do not make clear the exact symptoms in every stroke case but give us the information that many of the stroke patients have few and milder symptoms when examined at the hospital. This implies that a considerable proportion of the stroke population will present with mild and/or less clear symptoms, e.g. troubles with knitting or difficulties with reading text as found in our study.

Interestingly, we found that the initial bodily changes were clearly noticed by the stroke survivors, but not, however, in several cases recognized as a stroke. The denial and trivialization of perceived bodily changes, also reported in a previous study,²⁵ are perhaps not surprising because a stroke survivor interprets the various changes from a first-person and lay perspective. Thus, these deviations are related to what they feel, the context/situation, prior experiences of transient illnesses, and general knowledge. Stroke campaigns are a measure for increasing knowledge about stroke symptoms. The presence of (one or more of) facial palsy, arm weakness and speech abnormality has good validity for identifying, especially, those with anterior circulation stroke.²⁵ Many stroke awareness campaigns, including a recent Norwegian one, therefore focus on Face, Arm, Speech, Time (FAST) as an easily remembered, simplified message.²⁶ Vague, different or minor symptoms may hinder the person from associating these deviations with the FAST symptoms. Moreover, with minor perceived bodily changes, the stroke survivors are still able to perform the activities of daily living by using alternative strategies, such as spending more time or performing them in another way. Thus, the person's autonomy, feeling of control and ownership of ones' body and functional movements, which is known to be important in how one views oneself,²⁷ are changed/

compromised but not seriously threatened. From this perspective it is reasonable that the patients related the perceived changes to prior transient illness and not an emergency situation.

The key change, in our study, in terms of taking action to seek medical help, occurred when the patients informed and discussed the perceived changes with someone they trusted. Asking for a second opinion allows for viewing the signs and symptoms from 'outside' or an observer position. The patients' stories about these conversations indicate that the severity of the symptoms then became evaluated in another way, better related to the signs and symptoms of a stroke and/or the need of seeking help. Similarly, the witnesses' descriptions and considerations seemed to match knowledge of the signs and symptoms of a stroke. The importance of immediately informing another person about sudden perceived puzzling bodily- or behavioral changes may be advantageous to consider when developing future public information campaigns.

The high threshold for calling the EMS revealed in our study appears as an essential aspect of the prehospital delay. Only six chose to call EMS, while eleven contacted the GP or the OOH service.

In line with a previous review¹¹ and another qualitative study,¹⁰ severe symptoms resulted in rapid contact with EMS. Viewing only life-threatening situations as a reason for calling EMS is supported by Li et al.²⁸ The surveys in their study reported that laymen only consider the two stroke symptoms "no recognition of one side of the body" and "arm or leg paralysis" as an emergency situation. Other symptoms associated with acute cerebrovascular accidents (abnormal skin sensation, abnormal gait, speech disturbance, problems swallowing, and coordination loss) were not deemed emergency conditions.²⁸ Similarly, a population-based questionnaire investigating knowledge and presenting hypothetical stroke-related scenarios found that intention to call the EMS was low, even among those with knowledge of stroke signs.²⁹ Our results indicate that delays are exaggerated by fears that the situation is not serious enough for calling the EMS, or even the GP, a finding in agreement with a previous interview study.⁹ Prior experiences with medical services, e.g. being rejected when meeting at the OOH service, experiencing these services as being very busy and dealing with the 'serious' cases, seem to cause delay. Moreover, fears of being misinterpreted as hypochondriac or being wrong both seem to prevent calling for medical help, which we consider to be related to the fear of 'losing face'. These findings may be culturally related regarding what qualifies for calling the GP and, particularly, the EMS. The informants' regret about not making the call immediately supports the need for lowering the threshold for calling EMS. In order to minimize prehospital delay, individuals perceiving signs of a stroke or

witnesses/bystanders should be encouraged to call the EMS immediately.

Strengths and limitations

The major strength of our study is a strategic sample consisting of both patients and their witnesses. This sample allowed for exploration of experiences regarding the acute situation from both perspectives which provided insights regarding the interaction between the patients and the witnesses as well as differences in their considerations. The timing of the interviews within four weeks after the acute situation, we also consider to be a strength. Moreover, the sample covered a variation regarding severity of the stroke symptoms, early or late arrival to hospital, distance between home and hospital as well as gender and age and sex. The saturation of the material followed the principles for qualitative research.¹⁹

Inclusion bias may be a limitation in our study. We only reached those who were admitted to hospital within 4 weeks from the stroke onset, and patients with persistent aphasia were not included. They might have different experiences. The participants were from one region, which is rather rural. Informants from other geographical regions may have extended the material. Due to the pandemic the interviews were performed digitally. Performing qualitative interviews on video or telephone, however, are valid alternatives to face-to-face interviews.³⁰ In the interviews, the researcher's profession and preconceptions impact their way of asking questions and also the participant's answer to a person who is a health professional, i.e. a neurologist.³¹ At the same time, such professional knowledge is a strength, providing 'positioned insights', for developing and conducting a study.³²

Conclusions

Prehospital delays occurred due to complex interrelated elements: (1) Difficulties in recognition of a stroke when symptoms were mild: a variety of sudden behavioral- or bodily changes were noticed as the stroke occurred. Mild, odd, puzzling changes were trivialized or denied and not communicated to anyone in the acute situation. (2) Recognition of a stroke or need for medical assistance were facilitated through interaction/communication: informing a family member about the perceived bodily changes or having a bystander when the stroke occurred promoted use of knowledge regarding signs and symptoms of a stroke. Such discussions facilitated medical help seeking. (3) High threshold for calling EMS, except when symptoms were severe: delays were exaggerated by calling the GP or the OOH services, and by fear of calling EMS. The EMS' competence in terms of guiding patients regarding their symptoms seems to be a less known resource for the public. The findings may be helpful in planning future

public stroke campaigns and in education and training programs for health personnel.

Ethics

The study was approved by the Regional Committee for Medical and Health Research Ethics in Norway (REK-ref 2016/1729) and performed in compliance with the Declaration of Helsinki. The study is registered in ClinicalTrials.gov Identifier: NCT04373993.

Declaration of Competing Interest

The authors declare no conflict of interest.

Acknowledgments: We would like to thank all the participants and the user representative for their contributions to this study. The study was funded by the Northern Norway Regional Health Authority.

Supplementary materials

Supplementary material associated with this article can be found in the online version at doi:10.1016/j.jstrokecerebrovasdis.2022.106734.

References

1. Feigin VL, Stark BA, CO J, et al. Global, regional, and national burden of stroke and its risk factors, 1990–2019: a systematic analysis for the Global Burden of Disease Study 2019. *Lancet Neurol* 2021;20:795-820.
2. Musuka TD, Wilton SB, Traboulsi M, et al. Diagnosis and management of acute ischemic stroke: speed is critical. *Can Med Assoc J* 2015;187:887-893.
3. group. I-C. The benefits and harms of intravenous thrombolysis with recombinant tissue plasminogen activator within 6 h of acute ischaemic stroke (the third international stroke trial [IST-3]): a randomised controlled trial. *Lancet N Am Ed* 2012;379:2352-2363.
4. Lees KR, Bluhmki E, von Kummer R, et al. Time to treatment with intravenous alteplase and outcome in stroke: an updated pooled analysis of ECASS, ATLANTIS, NINDS, and EPITHET trials. *Lancet N Am Ed* 2010;375:1695-1703.
5. Goyal M, Menon BK, van Zwam WH, et al. Endovascular thrombectomy after large-vessel ischaemic stroke: a meta-analysis of individual patient data from five randomised trials. *Lancet* 2016;387:1723-1731.
6. Bourcier R, Goyal M, Liebeskind DS, et al. Association of time from stroke onset to groin puncture with quality of reperfusion after mechanical thrombectomy: a meta-analysis of individual patient data from 7 randomized clinical trials. *JAMA Neurol* 2019;76:405-411.
7. Meretoja A, Keshtkaran M, Tatlisumak T, et al. Endovascular therapy for ischemic stroke: save a minute—save a week. *Neurology* 2017;88:2123-2127.
8. Fladt J, Meier N, Thilemann S, et al. Reasons for prehospital delay in acute ischemic stroke. *J Am Heart Assoc* 2019;8:e013101.
9. Mackintosh JE, Murtagh MJ, Rodgers H, et al. Why people do, or do not, immediately contact emergency medical services following the onset of acute stroke: qualitative interview study. *PLoS One* 2012;7(10):e46124. <https://doi.org/10.1371/journal.pone.0046124>. Epub 2012 Oct 4. PMID: 23056247; PMCID: PMC3464281.
10. Mellor RM, Bailey S, Sheppard J, et al. Decisions and delays within stroke patients' route to the hospital: a qualitative study. *Ann Emerg Med* 2015;65:279-287.e273.
11. Pulvers JN, Watson JDG. If time is brain where is the improvement in prehospital time after stroke? *Front Neurol* 2017;8. (Mini Review).
12. Iversen AB, Blauenfeldt RA, Johnsen SP, et al. Understanding the seriousness of a stroke is essential for appropriate help-seeking and early arrival at a stroke centre: a cross-sectional study of stroke patients and their bystanders. *Eur Stroke J* 2020;5:351-361.
13. Evenson KR, Foraker R, Morris DL, et al. A comprehensive review of prehospital and in-hospital delay times in acute stroke care. *Int J Stroke* 2009;4:187-199.
14. Faiz KW, Sundseth A, Thommessen B, et al. Factors related to decision delay in acute stroke. *J Stroke Cerebrovascular Dis* 2014;23:534-539.
15. Lecouturier J, Rodgers H, Murtagh MJ, et al. Systematic review of mass media interventions designed to improve public recognition of stroke symptoms, emergency response and early treatment. *BMC Public Health* 2010;10:1-10.
16. Jones SP, Carter B, Ford GA, et al. The identification of acute stroke: an analysis of emergency calls. *Int J Stroke* 2013;8:408-412.
17. Dombrowski SU, Sniehotta FF, Mackintosh J, et al. Witness response at acute onset of stroke: a qualitative theory-guided study. *PLoS One* 2012;7:e39852.
18. Malterud K. Systematic text condensation: a strategy for qualitative analysis. *Scand J Public Health* 2012;40:795-805.
19. Malterud K, Siersma VD, Guassora AD. Sample size in qualitative interview studies: guided by information power. *Qual Health Res* 2016;26:1753-1760.
20. Fjortoft H., Indredavik B., Mørch, B. et al. Årsrapport 2020. Norsk Hjerneregister 2020. 2021.
21. Kvale S, Brinkmann SIV. Learning the Craft of Qualitative Research Interviewing 2018:272-294.
22. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349-357.
23. Edlow J, Selim M. Atypical presentations of acute cerebrovascular syndromes. *Lancet Neurol* 2011;10:550-560.
24. Leathley MJ, Jones SP, Gibson JM, et al. Can you send an ambulance please?": a comparison of callers' requests for emergency medical dispatch in non-stroke and stroke calls. *Emerg Med J* 2014;31:e25-e28.
25. Kothari RU, Pancioli A, Liu T, et al. Cincinnati prehospital stroke scale: reproducibility and validity. *Ann Emerg Med* 1999;33:373-378.
26. Advani R, Naess H, Kurz M. Mass media intervention in Western Norway aimed at improving public recognition of stroke, emergency response, and acute treatment. *J Stroke Cerebrovasc Dis* 2016;25:1467-1472.
27. Gallagher S. A pattern theory of self. *Front Hum Neurosci* 2013;7. (Original Research).
28. Li J, Galvin HK, Johnson SC. The "prudent layperson" definition of an emergency medical condition. *Am J Emerg Med* 2002;20:10-13.
29. Fussman C, Rafferty AP, Lyon-Callo S, et al. Lack of association between stroke symptom knowledge and intent to

- call 911: a population-based survey. *Stroke* 2010;41:1501-1507.
30. Saarijärvi M, Bratt EL. When Face-to-Face Interviews are Not Possible: Tips and Tricks for Video, Telephone, Online Chat, and Email Interviews in Qualitative Research. Oxford University Press; 2021.
 31. Maxwell JA. *Qualitative Research Design: An Interactive Approach*. Los Angeles: Sage publications; 2012.
 32. Paulgaard G. *Feltarbeid i egen kultur-innenfra, utenfra eller begge deler* (Field work in your own culture. From the inside, the outside or both ways). Oslo: Universitetsforslaget, 1997.