


## ORIGINAL RESEARCH

# Decision-Making in Seeking Emergency Care for Stroke Symptoms

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**BACKGROUND:** Previous studies have shown that rapid treatment for stroke, especially ischemic stroke, reduces mortality and disability. The focus has mainly been on reducing time from arrival at hospital to start of treatment. However, the main reason for delay is often time from symptom onset to arrival at hospital. This study therefore aimed to explore decision-making processes after the onset of stroke symptoms in patients experiencing a first-time stroke.

**METHODS:** We included 36 patients aged 18 and older, all of whom were hospitalized with a first-time stroke between October 2018 and April 2020. All patients were interviewed once within 4 weeks of symptom onset and before hospital discharge. Eligible patients were identified retrospectively through a targeted review of medical records. The data were collected and analyzed according to the grounded theory methodology.

**RESULTS:** In total, 43 potential patients were identified and asked to participate. Overall, 36 patients were included in the study: 17 women (median age 77.0 years, interquartile range 17.5) and 19 men (median age 65.7 years, interquartile range 17.2). All interviewees felt fear, and this affected their decision to seek emergency care. The decision-making processes were described by the core category of “Acting on fear.” The reason for feeling frightened determined the actions taken. The reasons were sorted into 3 main categories: (1) “seeking care”—recognized stroke symptoms and acted immediately; (2) “pending and reluctance”—suspected stroke but awaited to seek care; and (3) “seeking an explanation”—confused by symptoms.

**CONCLUSION:** We found that decision-making when experiencing stroke symptoms was complex. All patients felt fear, which determined their actions. Some patients knew about stroke symptoms and acted immediately. Others suspected stroke but still chose to wait, whereas others were confused and tried to find answers. These results could contribute to form future awareness campaigns.

**Key Words:** decision-making ■ grounded theory ■ prehospital delay ■ qualitative methodology ■ stroke symptoms

Stroke is a common cause of mortality and morbidity worldwide and associated with devastating consequences for both daily life and work ability.<sup>1</sup> To reduce brain damage, rapid reperfusion treatment within the therapeutic window is imperative. The focus has primarily been on reducing door-to-needle time<sup>2</sup> but the main reason for delayed treatment is, in most cases, time from symptom onset to

hospital arrival (onset-to-door).<sup>2,3</sup> Despite campaigns about stroke awareness and the importance of fast emergency care, people often still delay calling for help.<sup>4,5</sup>

Several studies have focused on factors that influence prehospital delay in people with stroke. These include being alone, not contacting anyone, or the first contact with nonemergency services delaying arrival

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at hospital.<sup>6,7</sup> Other factors included difficulties among both those affected and caregivers in recognizing symptoms as related to stroke and not managing them immediately.<sup>7,8</sup> Factors associated with faster arrival at hospital were the presence of bystanders and perceived seriousness of symptoms.<sup>7</sup> Symptoms occurring during daytime and outside the home decreased the prehospital delay.<sup>9</sup>

Seeking help after acute stroke is a complex process<sup>10</sup> associated with feelings such as fear of illness, hospitalization and denial.<sup>11</sup> These are related to later arrival at hospital.<sup>12</sup> Previous qualitative studies have mainly focused on factors and feelings that affect the prehospital delay in stroke. To our knowledge, few studies have investigated how the decision to seek emergency care is taken and underpinned. The aim of this study was therefore to explore the decision-making processes after the onset of stroke symptoms in people experiencing a first-time stroke.

## METHODS

### Design

This interview study used a classic grounded theory methodology and adapted the Standards for Reporting Qualitative Research checklist.<sup>13</sup> This design enabled us to discover the main concern of participants and the common actions they initiated to resolve that concern. The grounded theory developed within this study aims to explain the main behaviors among patients with a first-time stroke.<sup>14</sup> The data that support the findings of this study are available from the corresponding author upon reasonable request.

### Data Collection

We included patients aged 18 years and older hospitalized with a first-time stroke during October 2018 to April 2020. The study was conducted at 3 stroke units in western Sweden, 2 at a university hospital, and 1 at a local hospital. Eligible patients were identified retrospectively through a targeted review of medical records. Exclusion criteria were inability to make independent decisions or inability to express or understand the Swedish language. Stroke was defined according to *International Classification of Diseases, Tenth Revision (ICD-10)* codes I61, I63, and I64. Transient ischemic attacks, traumatic events to the head, subdural hematoma, and subarachnoid hemorrhage were excluded but no distinction was made between ischemic or hemorrhagic stroke.

In total 43 potential patients were identified and asked to participate, of whom 1 patient declined to participate and 6 patients were excluded because of cogni-

## CLINICAL PERSPECTIVE

- Decision-making when experiencing stroke symptoms is complex and leads to various actions.
- Even if symptoms of stroke cause fear, some cope and postpone the decision to seek medical care.
- Awareness that not typical symptoms or symptoms perceived as less serious could be stroke is needed.

tive difficulties or extensive neurological sequelae associated with stroke. After these exclusions 36 patients were included in the study. All patients were interviewed once within 4 weeks of symptom onset, and before hospital discharge. In total, 30 interviews were recorded and 6 were transcribed by hand during the interview. Every interview started with an open-ended question, “*Can you please tell me what happened when you experienced the stroke symptoms?*” The mean length of the interviews was 29 minutes (range 13–56 minutes). The interviews were supplemented with questions about demography through a questionnaire to describe the sociodemographic characteristics of the study group (Table).

### Ethical Considerations

All patients received oral and written information before inclusion in the study. They were informed that participation was voluntary and that they could withdraw from the study at any time without consequences and further explanations. They were free to choose the time and location of the interview. Statements from interviews were handled confidentially. The interviewer was a clinical nurse specialist with clinical experience in stroke care. If the interview caused emotions of any kind, the patients were free to contact the interviewer or the hospital counselor. The study was approved by the Regional Ethical Review Board in Gothenburg, Sweden (Dnr: 487-18). The study conforms to the principles outlined in the Declaration of Helsinki.

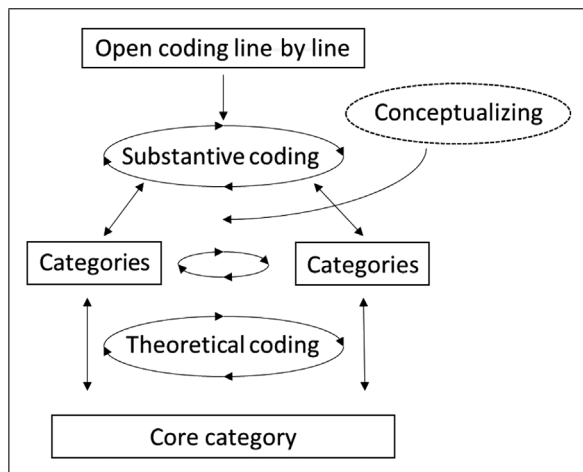
### Analysis

A grounded theory approach following methods outlined by Glaser was used to analyze the interview data.<sup>14</sup> Memos were written during and after the interviews to support the analysis process. Initially each interview was transcribed verbatim and then coded line by line into substantive codes that were grouped

**Table. Patients' Sociodemographic Characteristics**

	Total n = 36	Men n = 19	Women n = 17
Age range (y)	34–95	34–92	38–95
Median age (y) (IQR)	71.7 (18.0)	65.7 (17.2)	77.0 (17.5)
Mean age (y) (SD)	69.8 (14.7)	67.9 (13.0)	71.9 (16.1)
Married/cohabitating, n (%)	21 (58.3)	13 (68.4)	8 (47.0)
Living alone, n (%)	15 (41.7)	6 (31.6)	9 (52.9)
Atrial fibrillation, n (%)	3 (8.3)	–	3 (8.3)
Ischemic heart disease, n (%)	3 (8.3)	1 (2.8)	2 (5.6)
Hypertension, n (%)	19 (52.8)	12 (33.3)	7 (19.4)
Diabetes, n (%)	8 (22.2)	5 (13.9)	3 (8.3)

IQR indicates interquartile range.



**Figure 1. Analysis process according to classic grounded theory.**

based on similarities and differences. Codes were compared on an ongoing basis to identify similarities and differences and enable categories to be developed. The analysis and data collection were carried out in parallel, so that the analysis could be used to direct further data collection. The researchers reexamined the data to ensure that the categories were represented in the transcripts. Interchangeability indicated that saturation had been achieved. The analysis proceeded from a descriptive to a conceptual level to allow a core category to emerge. Memos were used to help in selective coding of the most relevant categories related to the core category. Theoretical coding enabled the conceptual integration of a core category and its relation to the categories (Figure 1). The material was analyzed repeatedly through structured discussions between the authors. When consensus had been reached for each part of the analysis, the researchers proceeded to the next stage of the analysis process. Memos facilitated the identification of gaps in existing data and helped to develop ideas on the emerging categories. This was tested by going back to the transcripts to trace

the categories toward the emerging core category. Citations from the transcripts are shown in the results to illustrate the categorization.

## RESULTS

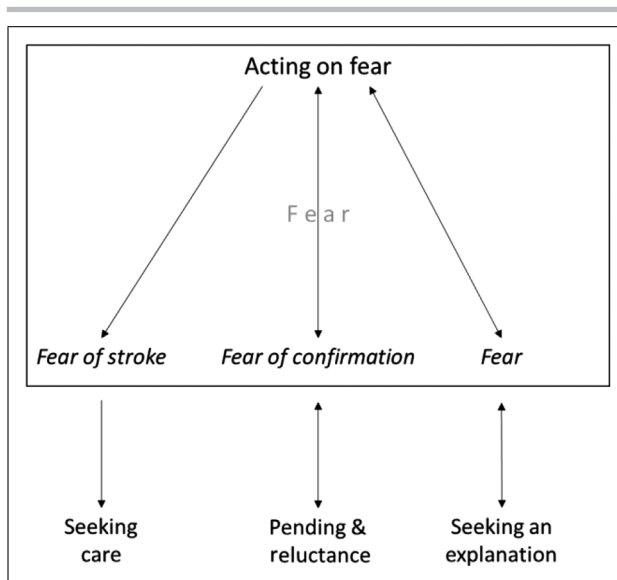
In total, 43 potential patients were identified and asked to participate. Overall, 36 patients were interviewed, of whom 17 were women (median age 77.0 years, interquartile range 17.5) and 19 men (median age 65.7 years, interquartile range 17.2). Nine women and 6 men were living alone (Table). The study revealed a complex pattern of decision-making among those experiencing stroke symptoms. Everyone was feeling frightened. Their interpretation of the symptoms and knowledge of stroke, as well as their fear, affected the decision to seek emergency care in different ways. The decision-making processes were described by the core category of “acting on fear.” Fear was decisive for the actions taken, which fell into 3 main categories: (1) seeking care, (2) pending and reluctance, and (3) seeking an explanation (Figure 2).

### Acting on Fear

The emerging main categories were related to the different causes of fear that underpinned the decision-making processes in the core category “acting on fear.” Individuals’ stroke symptoms varied, but they all knew that this was something they had never previously experienced. Regardless of the type of symptoms, those affected were preoccupied by mastering the fear caused by the symptoms.

### Seeking Care

Knowledge of stroke and the consequences of brain injury motivated the decision among some of the interviewees. When these patients realized that they were having a stroke, they were afraid that they would not receive emergency care in time. Their interpretation of



**Figure 2.** Model shows the core category “Acting on fear,” which underpins the decision-making processes.

the symptoms was based on their knowledge of stroke, and these patients immediately recognized the symptoms as stroke. They understood the importance of immediate medical treatment. Several gave directions to someone nearby to call for emergency help; others were determined to call an ambulance, including “crawling to the phone.” A majority planned how to proceed despite difficulties of dysfunction. Altogether, this knowledge facilitated the decision to seek emergency care immediately.

“So I just opened the door, shouted at him”. I told him: “Call the ambulance, I think I’ve had a stroke. Do not be afraid. Do as I say. Tell them I’m breathing well, but I’m just paralyzed!”

“To call 112 as fast as possible, because I know... it’s minutes when it’s a stroke. That it is important to get in as quickly as possible.”

### **Pending and Reluctance**

Some interviewees were reluctant to acknowledge their symptoms because they feared that their suspicion of stroke would be confirmed. Even though they suspected stroke, they decided to wait before seeking emergency care. They could not accept being someone who suffered a stroke and hoped their suspicion would be wrong. These patients knew about stroke symptoms but chose to wait instead of seeking emergency care. Their suspicion that they had experienced a stroke was based on previous knowledge of stroke symptoms, but they still found it unbelievable. While evaluating their symptoms, they hoped that their suspicions

were incorrect. They therefore evaluated their symptoms as not being signs of anything severe. They hoped that the symptoms would disappear, tried to cope with the situation, and adjusted to it. Some described testing their ability to function and comparing their symptoms with known stroke symptoms. They tried to continue their normal activities and adjusted to the loss of function. Some adjusted or adapted their home to facilitate accessibility, such as removing carpets so that they would not trip. Others chose to wear slippers instead of shoes or supported themselves against the walls to enable them to walk around. Someone ordered take-away food via the internet to avoid having to talk to anyone. A few talked to others about their situation but waited to act on the advice to seek care. Being unwilling to acknowledge the symptoms extended the time before they sought emergency care.

“Well, I ordered pizza online. Then I did not have to talk to anyone.”

“I could not use a fork but I was fine with a spoon!”

### **Seeking an Explanation**

A majority of interviewees reported that experiencing symptoms led to fear and confusion. They never thought of stroke; instead, they wondered what was going on. They consulted others to help them understand but did not always think of asking anyone in health care. They had their ability to function evaluated by others, called others to discuss their symptoms or debated what to do. Patients tried to alleviate the symptoms but were dependent on others to reach a conclusion of the cause. Some called a primary health care center, but assessment by health care professionals did not lead to suspicions of a stroke. They ended up taking painkillers or having a rest, a massage, or a shower to try to relieve their symptoms. All of them were afraid of what was going on and tried to find an explanation. Wanting to understand what was happening was crucial but misjudging symptoms was an obstacle, and the need for emergency care was not obvious. Instead, the symptoms were considered as odd and hard to interpret and caused confusion. Consulting relatives, family, friends, or health care professionals was crucial in the eventual decision to seek emergency care. The confusion therefore delayed the decision for these interviewees.

“No, I couldn’t understand why I was vomiting when I ate so it came up immediately. Then I had to go and rest.”

“I said, you must call dad ... for this ... because I do not know what this is. I do not recognize this ... it hurts in the arm. It hurt so I just screamed!”



## DISCUSSION

This study showed that the process for deciding to seek emergency care when experiencing stroke symptoms is complex. Acting on fear emerged as the core category. The onset of stroke symptoms triggered fear, which was crucial in driving the action. Some interviewees chose to seek emergency care immediately, based on their knowledge of stroke and fear of the consequences. Others chose to wait, even though they knew about stroke, because they were frightened that their suspicion of stroke would be confirmed. Others waited to seek emergency care because of both confusion and fear. All patients had eventually sought emergency care, despite various actions that delayed contact.

The results showed that the majority of patients were confused and feared their symptoms, but the decision to consult others, including health care professionals, did not necessarily lead to seeking help sooner. Instead, their uncertainty led to a delay. Indecision has previously been shown to be a cause for delay,<sup>15</sup> as has contact with relatives or others.<sup>16</sup> Contact with nonemergency care or ambulance transport that did not interpret the symptoms as signs of stroke can also cause prehospital delay.<sup>8,17,18</sup> Interpretations by primary care of acute stroke symptoms could vary; Mackintosh et al<sup>12</sup> and Hansson et al<sup>19</sup> showed that health care professionals in prehospital settings find it hard to interpret stroke symptoms.

When the symptoms were diffuse, and not typical of stroke, it was difficult for some patients to interpret their symptoms as signs of stroke. The symptoms were varying and did not necessarily include clear motor dysfunction. Many were unsure of what was going on and did not know what to do. Instead, they were confused by their symptoms and felt fear. Delays in seeking emergency care can be affected by lack of knowledge about stroke symptom.<sup>12,20</sup> Ability to recognize stroke is associated with different factors as facial impairment or a history of stroke or transient ischemic attack. Another factor independently associated with rapid health care contact is speech problems,<sup>21</sup> but having no pronounced motor dysfunction is often a cause of delay in seeking care.<sup>22,23</sup> Nontypical symptoms are common among both men and women but more so in women, which could explain the confusion for some interviewees.<sup>24</sup> As a previous study has pointed out, there is a need to raise awareness that stroke may be expressed as multifaceted neurological symptoms.<sup>25</sup>

The importance of rapid treatment to improve the outcome of a stroke is well proven, and not receiving timely care can lead to extensive damage.<sup>26</sup> However, knowledge about treatment for stroke may be

low.<sup>27</sup> People need a better understanding of how early treatment of neurological symptoms can improve control over life after a stroke.<sup>28</sup> To increase awareness of stroke symptoms and the importance of rapid treatment, governments have carried out public stroke awareness campaigns, for example, to publicize the Face Arm Speech Test.<sup>29</sup> However, evaluations of campaigns to raise awareness of stroke signs have been fragmented.<sup>5</sup> Our findings suggest that campaigns also need to be adapted to match the diversity in society, and it is important to increase accessibility of information. They should also make clear that symptoms can be varying, diffuse, and transient. Information designed in collaboration with patient associations could be helpful to develop campaigns based on the experience of previous stroke victims.

We found that patients who immediately sought emergency care knew about the importance of rapid treatment. The ability to provide adequate treatment is time limited.<sup>30</sup> However, stroke can have devastating consequences for individuals, with complications to varying degrees that may have a major impact on daily life and ability to work.<sup>31</sup> Patients drew parallels between their symptoms and what they knew from stroke campaigns. Most of those in this group had pronounced stroke symptoms. They understood that they were suffering from a stroke and feared the consequences of not receiving treatment in time, and sought emergency care immediately. Some could not contact emergency care themselves and asked others to call for the ambulance. This is consistent with earlier studies, which showed that asking for help immediately after symptom onset and perceiving symptoms as unmanageable were associated with a shorter delay.<sup>9</sup>

Delays in seeking emergency care can partly be the result of lack of knowledge about stroke symptoms,<sup>12,20</sup> but help-seeking behavior is not governed by symptom awareness alone.<sup>32</sup> Good theoretical knowledge about stroke in the general population does not always mean that individuals take the appropriate actions in an emergency.<sup>10,32,33</sup> People appear to respond differently independent of the overall severity of stroke symptoms,<sup>34</sup> which is consistent with our findings. The perceived severity of the symptoms did not necessarily lead to a decision to seek emergency care. Many chose to wait despite believing that they were experiencing a stroke. This is in line with previous studies that have shown that people have a tendency to wait and see if the symptoms disappear spontaneously.<sup>12</sup> If the diagnosis was not established, these patients often thought that there was another explanation of their symptoms. They could not accept that they had suffered a stroke and hoped that their suspicion would be wrong. This led to delay in contacting medical care. This is consistent

with a previous study that showed that not seeing oneself as someone who could suffer a stroke, and thinking that the symptoms were related to a minor condition, caused delay.<sup>25</sup> Seeking help after acute stroke is therefore a complex process.<sup>10,12</sup> The action may depend on perceptions of the severity of the symptoms and the emotional response, rather than the ability to correctly identify symptoms.<sup>35</sup>

This study revealed a complex decision-making process when experiencing stroke symptoms. "Acting on fear" was the core category, which was decisive for the actions taken. Some patients immediately understood the importance of medical care and acting swiftly, but others waited. The most worrying group is those who suspected they were experiencing a stroke but decided that this was not possible because they were not at risk of stroke or who tried to explain away the symptoms and wait for a while. Stroke awareness campaigns should emphasize the importance of seeking medical care at the slightest suspicion of stroke, even if the symptoms are not typical or perceived as less serious. Other patients were confused by their symptoms and did not suspect stroke at all. Instead of seeking emergency help, they tried to find an explanation. Some of this group contacted primary care instead of emergency care. It is therefore important that care providers at all levels have knowledge of stroke and the importance of rapid treatment.

### Strengths and Limitations

This qualitative grounded theory interview study has several strengths. First, it involved a relatively large number of patients, including 36 men and women with a wide age range and different experiences. Another strength is that we included people who had attended both university hospitals and a local hospital, ensuring that the sample was representative of the population experiencing strokes. The result could therefore be transferable to others who suffered a stroke. The concurrent data collection and analysis, in line with the grounded theory methodology, enabled the development of a theory grounded in data. However, this study also had limitations. The study did not include anyone who had suffered severe stroke or were not able to express themselves. Nor were patients included where a surrogate decision-maker was involved. These groups could have other experiences that were not captured in this study. Information of the type of symptoms that the patients' experienced is not provided, which could be a limitation because the type of symptoms could influence the interpretation. Hence, categorization of symptoms was beyond the scope of this article.

## CONCLUSIONS

Decision-making when experiencing stroke symptoms is complex. All patients felt fear, which determined their actions. Those patients who had knowledge about stroke symptoms acted immediately, while others were confused and contacted primary care instead of seeking emergency care. Others suspected stroke but still chose to wait. Stroke awareness campaigns should emphasize the importance of seeking medical care at the slightest suspicion of stroke, even if the symptoms are not typical or perceived as less serious. Awareness of the importance of rapid stroke treatment needs to increase among caregivers and in the community. These results could contribute to form future awareness campaigns and the understanding of how people with stroke underpin the decision to seek medical contact.

### ARTICLE INFORMATION

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#### Disclosures

None.

#### Supplemental Materials

Questionnaire Demographic Data

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