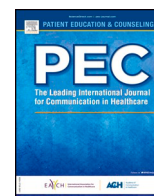




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## Experiences with information provision and preferences for decision making of patients with acute stroke



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### ABSTRACT

**Objective:** The aim of this study was to gain insight into experiences of patients with acute stroke regarding information provision and their preferred involvement in decision-making processes during the initial period of hospitalisation.

**Methods:** A sequential explanatory design was used in two independent cohorts of patients with stroke, starting with a survey after discharge from hospital (cohort 1) followed by observations and structured interviews during hospitalisation (cohort 2). Quantitative data were analysed descriptively.

**Results:** In total, 72 patients participated in this study (52 in cohort 1 and 20 in cohort 2). During hospitalisation, the majority of the patients were educated about acute stroke and their treatment. Approximately half of the patients preferred to have an active role in the decision-making process, whereas only 21% reported to be actively involved. In cohort 2, 60% of the patients considered themselves capable to carefully consider treatment options.

**Conclusions:** Active involvement in the acute decision-making process is preferred by approximately half of the patients with acute stroke and most of them consider themselves capable of doing so. However, they experience a limited degree of actual involvement.

**Practice implications:** Physicians can facilitate patient engagement by explicitly emphasising when a decision has to be made in which the patient's opinion is important.

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## 1. Introduction

Every minute that the treatment of a patient with acute ischaemic stroke is delayed, 1.9 million neurons are lost [1]. To

improve functional outcome and reduce long-term disability in patients with acute ischaemic stroke, early recognition of symptoms and presentation at the emergency department (ED) [2,3] are essential to apply efficient diagnostic approaches [4–6] and initiate reperfusion therapy [7–9]. Due to the recently extended treatment window for intravenous thrombolysis [10–12] and endovascular thrombectomy [13,14], reperfusion therapy is feasible in an increasing number of patients. Nonetheless, each individual treatment related decision-making process is complex because the extreme time dependent context at the ED, in which patients should be informed about patient-relevant outcome information (e.g., important

*Abbreviations:* CPS, control preference scale; ED, emergency department; SD, standard deviation; SDM, shared decision making

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risks and benefits of reperfusion therapy) [7]. Because of these time constraints, health care professionals might feel tempted to refrain from involving patients and relatives in acute treatment decisions [15]. From a patient perspective, patient engagement in such critical health-related decisions is desirable.

Patients can be empowered to participate in health-related decision-making processes through education about the diagnosis, explanation of treatment options, and clarification of individual values and preferences [16,17]. By combining the best available evidence and the patient’s values and preferences, well-informed decisions could be collaboratively made by physicians, patients and/or relatives in the process of shared decision making (SDM) [18–21]. Several studies have shown the benefits of SDM, and it is considered to be a key component of high-quality care [17,22–24]. Also in emergency medicine, it has been shown that patients prefer to be involved in acute medical decisions whenever possible, and that they feel sufficiently capable of participating in decisions about their health [25]. Although several clinical frameworks have been established on how to approach SDM in emergency medicine [26,27], emergency physicians that endorse SDM still experience patient-related barriers to deploy it [28].

In acute stroke care, several studies investigated patients’ preferences for decision making at the ED, but their results are divergent. One study found that most patients would like to receive clear information about therapy with intravenous thrombolysis to enable active involvement in the decision-making process [29]. Another study found that there was a large variation in patients’ risk perception of therapy with intravenous thrombolysis [30], and to optimally support the decision-making process, a tailored communication method has been developed [31]. However, a recent study concluded that both patients and physicians desired only a limited level of patient involvement in acute treatment decisions, which would make decision support and SDM for reperfusion therapy trivial [32]. In view of this conflicting evidence, the aim of this study was to gain insight into experiences of patients with acute stroke with information provision and into their preferences regarding involvement in decision-making processes during the initial period of hospitalisation.

## 2. Methods

### 2.1. Design and setting

A mixed-method approach with a sequential explanatory design was used in two independent cohorts (Fig. 1), starting with a survey after discharge from the hospital (cohort 1). In order to gain more insight into the data gathered in the surveys and to thoroughly assess the initial period of hospitalisation, observations were

performed at the ED followed by structured interviews on the neurology ward (cohort 2).

The study was conducted at three high-volume stroke centres in different regions of the Netherlands from July 2019 until March 2020. All participating hospitals are member of Santeon, a group of seven Dutch teaching hospitals that use the value-based healthcare framework as their guiding principle to measure and compare outcomes and costs in a structured, standardised manner in order to improve care.

### 2.2. Participants and recruitment

Two independent cohorts of patients with stroke were studied. In the first cohort, consecutive patients with stroke were informed about the study in all participating hospitals during their admission at the neurology ward if they were above 18 years of age, and able to complete a structured digital survey. When interested, they were contacted by telephone within three months after being discharged, and invited to participate in the study. The second cohort consisted of an independent sample of consecutive patients with acute ischaemic stroke who were eligible for reperfusion therapy. In order to gain more in-depth information that might explain the outcomes of the survey collected in the first cohort, this independent group of patients were observed at the ED of one of the participating hospitals (OLVG). Subsequently, they were asked to participate in a structured interview.

Patients were excluded from study participation if they had insufficient Dutch language proficiency or were unable to complete the survey or interview due to cognitive impairments, global aphasia or altered consciousness. Written informed consent was obtained from all participating patients.

### 2.3. Data collection

In the first cohort, retrospective data were collected by means of a cross-sectional survey in consecutive patients who had suffered a stroke within the past year in order to explore patients’ experiences with the acute decision-making process. The quantitative survey comprised 24 items, including questions regarding socio-demographic characteristics (e.g., age and education level), self-constructed questions about the patients’ perceptions of information provision, and two validated questions to assess each patient’s preferred and actual role in the decision-making process, by using a modified version of the Control Preference Scale (CPS) [33]. The CPS consists of a single question with five response categories (A-E) about the (preferred and actual) role of patients and health care professionals in a decision-making process.

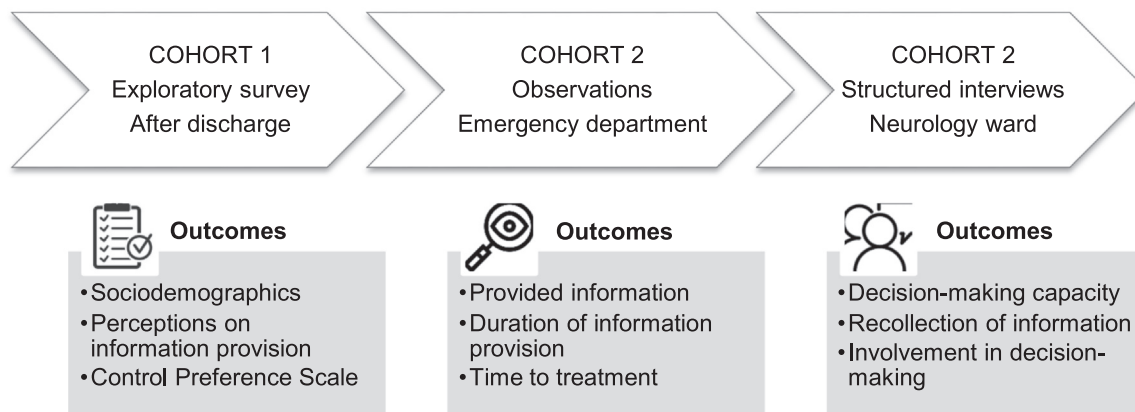


Fig. 1. Schematic overview of the two investigated independent cohorts and outcomes per cohort.

**Table 1**  
Roles in the decision-making process based on the modified Control Preference Scale [33].

Role	Description	Response options
Active	Patient-controlled role	Response A: "I made the decision" Response B: "I made the decision after seriously considering the health care professionals' opinions"
Collaborative	Jointly controlled role	Response C: "The health care professionals and I shared the responsibility for the decision making"
Passive	Health care provider-controlled role	Response D: "The health care professionals made the decision after seriously considering my opinion" Response E: "The health care professionals made the decision"

In the second cohort, consecutive patients who presented during day shifts were observed at the ED in order to further assess patients' involvement in decision-making in the acute setting of stroke care. The researcher (VZ) was a passive observant, and had an acute stroke emergency pager which provided a warning when a patient with acute stroke was to arrive. Treating physicians were not informed of the precise goal of the observation to exert as little influence on the procedure as possible. Information provision by the clinician was noted by the researcher, using a checklist to document whether or not information was provided concerning diagnosis, treatment options, and patient-relevant outcome information, such as important risks and benefits of reperfusion therapy. Furthermore, the duration of information provision and time to treatment were recorded. Subsequently, during a structured interview within 24–48 h of reperfusion therapy, each patient's decision-making capacity was evaluated using the criteria of Appelbaum et al.: understanding of information, reasoning about treatment options, understanding of consequences of the situation, and ability to communicate treatment choice [34]. These aspects were assessed by means of self-reported competence on the mentioned criteria, using a 4-point Likert scale without a neutral option. Furthermore, the recollection of information, experiences and involvement in the decision-making process at the ED were evaluated by means of closed and open-ended questions about the procedure. Data were registered, coded and managed in the password-protected, cloud-based electronic data capture platform Castor EDC [35].

2.4. Data analysis

An overview of the demographic and clinical characteristics of patients in the study population was provided using descriptive statistics. Continuous data were expressed as a mean with the standard deviation (+/-SD), or as the median (interquartile range) where appropriate. Categorical data were expressed as frequencies (%) unless stated otherwise. The four-point Likert scale measures for decision-making capacity were dichotomised into "sufficient ability" and "insufficient ability" by grouping the two response options for adequate ability and the other two response options for inadequate ability. If patients reported that they felt insufficiently capable in one of the aspects of decision-making capacity, we judged the decision-making capacity to be impaired. The quality of information transmission was assessed using a 1–7 Likert scale, with a score of ≥4 points indicating complete and comprehensible information. Quantitative data were analysed with IBM SPSS (version 22).

The outcomes of the modified CPS (Table 1) were clustered into three (actual and preferred) roles of patients and health care professionals in the decision-making process [33].

**Table 2**  
Four-step shared decision making model as described by Stiggelbout et al. [36].

Step	Description
Choice	The health care professional informs the patient that a decision is to be made and that the patient's opinion is important
Options	The health care professional explains options and the pros and cons of each relevant option
Preferences	The health care professional and the patient discuss the patient's preferences and the professional supports the patient in deliberation
Decision	The health care professional and the patient discuss the patient's decisional role preference, make or defer the decision, and discuss possible follow-up

Questions from the structured interviews were categorised into a four-step SDM model as described by Stiggelbout et al. [36] and expressed as frequencies (%) unless stated otherwise. Table 2 shows the steps that can be distinguished in the four-step SDM model, which is an extended version of the three-step SDM-model by Elwyn et al. [18].

Patients' answers to open-ended questions in the structured interviews were directly transcribed by the interviewer (VZ). These transcriptions were open coded and categorised in a code tree with transcending themes by two independent, trained researchers (JP& VZ). Coding was performed using MAX Qualitative Data Analysis (QDA) version 2007.

2.5. Ethical approval

Ethical and research governance approval was obtained from the Medical Research Ethics Committees United and the local medical ethics committees of the participating hospitals. This study was conducted in accordance with the Declaration of Helsinki [37].

3. Results

3.1. Patients

In the first cohort, 112 patients were invited to participate in the study. Of them, 65 agreed to participate, and 52 patients with stroke shared their experiences with the acute decision-making process (response rate 80%). The mean age of the participants in this cohort was 70 years, 54% were male and 42% had a low education level. In the second cohort, 20 patients with stroke were observed at the ED and interviewed immediately afterwards on the neurology ward. The mean age of these participants was 72 years, 45% were male and 13% had a low education level. Other baseline characteristics were similar in the two cohorts (Table 3).

3.2. Patients' experiences with information provision (cohort 1)

The vast majority of the patients (90%) in cohort 1 were informed about their diagnosis and treatment during hospitalisation. Forty-six percent self-reported that they were informed at the ED and 44% at the neurology ward. One patient reported that the diagnosis "stroke" was not mentioned at all during hospitalisation. The majority of the patients (87%) were accompanied by a relative at the ED, of whom 69% were informed about the patient's diagnosis (Supplementary A). Information was provided by a physician (85%) and/or a nurse (39%). Verbal information provision was the most commonly used communication method at the ED (90%). Other communication methods

**Table 3**  
Baseline characteristics of the patients.

Characteristic	Cohort 1 (n = 52)	Cohort 2 (n = 20)
Age, years – mean (SD)	70.4 (12.8)	72.0 (11.9)
Male sex	28 (53.8)	9 (45)
Education level		
– high	11 (21.2)	6 (40)
– middle	18 (34.6)	7 (46.7)
– low	22 (42.3)	2 (13.3)
– unknown	1 (1.9)	0 (0)
Diagnosis		
– ischaemic stroke	48 (92.3)	20 (100)
– haemorrhagic stroke	2 (3.8)	0 (0)
– TIA	2 (3.8)	0 (0)
Location of ischaemic stroke		
– middle cerebral artery	32 (61.5)	8 (40)
– anterior cerebral artery	0 (0)	2 (10)
– posterior cerebral artery	4 (7.7)	0 (0)
– vertebrobasilar	11 (21.2)	9 (45)
– missing	1 (1.9)	1 (5)
NIHSS – median (IQR)	3 (1–5)	2 (1–4)
Treatment at ED <sup>a</sup>		
– intravenous thrombolysis	18 (34.6)	20 (100)
– endovascular thrombectomy	2 (3.8)	1 (5)
– none	32 (61.5)	0 (0)
Period since stroke, months		
– 0–3 months	17 (32.7)	20 (100)
– 3–12 months	33 (63.5)	N/A
– > 12 months	1 (1.9)	N/A
– unknown	1 (1.9)	0 (0)

All data are presented as n (%) unless otherwise specified.

Abbreviations: ED emergency department; IQR: interquartile range; NIHSS: National Institutes of Health Stroke Scale; SD: standard deviation; TIA: transient ischaemic attack; N/A not applicable.

<sup>a</sup> Treatment modalities were not mutually exclusive.

were barely used; one patient received written information and none of the patients received digital information.

Approximately one-third of the patients reported that the provided information about their diagnosis was incomplete (35%) or difficult to understand (33%). Similarly, approximately one-third of the patients reported that the provided information about their treatment was incomplete (33%) or difficult to understand (37%). Patients suggested that additional outcome information, specifically on risks and prognosis would be desirable. A majority of the patients (83%) was generally satisfied with the information provision at the ED (Supplementary A).

### 3.3. Patients' preferences regarding involvement in acute decisions (cohort 1)

Approximately half of the patients (48%) in cohort 1 preferred an active or collaborative role in the acute decision-making process (Table 4), whereas 21% of the patients experienced this role. Most patients (71%) experienced a passive, provider-controlled role in the acute decision-making process at the ED. Of the patients that preferred an active or collaborative role, the minority actually experienced their preferred role. In the subgroup of patients that preferred a passive role in the acute decision-making process, the preferred role was predominantly equal to the actual role.

**Table 4**  
Patients' preferred and actual role in the acute decision-making process.

	Preferred role	Actual role	Preferred role equals actual role (ratio per role)
Cohort 1 (n = 52)			
Active: patient-controlled	5 (9.6)	3 (5.8)	2 (40.0)
Collaborative: jointly controlled	20 (38.5)	8 (15.4)	5 (25.0)
Passive: provider-controlled	23 (44.2)	37 (71.1)	21 (91.3)
Missing	4 (7.7)	4 (7.7)	N/A

Data are presented as n (%) unless otherwise specified.

**Table 5**  
Patients' reported involvement in the acute decision-making process following the four steps of shared decision making.

Step	Topic	n (%)
Choice	I was informed ...	
	... about my diagnosis	12 (60)
Options	... that a decision had to be made	10 (50)
	I was informed about ...	
	... the treatment options	15 (75)
	... the potential complications	10 (50)
Preferences	... the benefits of treatment	3 (15)
	... the consequences of treatment	4 (20)
	I understood all information	4 (20)
	I prefer to ...	
	... make the treatment decision myself	0 (0)
	... make the treatment decision myself after seriously considering my health care professional's opinions	1 (5)
	... make the treatment decision together with my health care professional	5 (25)
Decision	... let the health care provider to make the treatment decision after seriously considering my opinion	7 (35)
	... let the health care professional make the treatment decision	5 (25)
	Missing	2 (10)
	My consent for treatment was asked	8 (40)
	It was not possible to refuse treatment	5 (25)

### 3.4. Observations of information provision at the ED (cohort 2)

From the observations of the patients in cohort 2 at the ED, it appeared that all patients were informed about their diagnosis and about intravenous thrombolysis. The majority of patients were consistently informed about the treatment mechanism of action (85%) or potential complications (95%). Treatment benefits were discussed with 45% of the patients. In 80% of the observations, patients were asked for permission to start treatment. None of the patients' relatives were involved in the acute decision-making process (Supplementary B). The median time since patients' arrival at the ED until receiving intravenous thrombolysis, the 'door-to-needle time', was 23 min (interquartile range: 16–26). On average, 1.3 min (range: 0.2–4) were spent on providing patients with information and obtaining consent for treatment.

### 3.5. Patients' involvement in the acute decision-making process (cohort 2)

Patients in cohort 2 were interviewed on their involvement in the acute decision-making process according to the following four steps of SDM (Table 5). When categorising patients' preferences following Degner and colleagues [33], 1 patient preferred an active role, 5 patients a collaborative role, and 12 patients a passive role.

### 3.6. Patients' view on the acute decision making-process (cohort 2)

#### 3.6.1. Emotions & information

When asked about their experiences at the ED, some patients mentioned that they were frightened, which resulted in no complete

understanding of what was happening at the ED. Others mentioned that they were calm, and experienced the procedure as pleasant. Many patients reported that a large number of people were present at the ED. For some of the patients this was intimidating, while others thought it was great that such a large number of health care professionals were there to help them. Some patients stated that it was helpful that they were informed by the ambulance paramedic prior to their arrival, about what they could expect at the ED. Others had earlier similar experiences at the ED (e.g., acute myocardial infarction), which made them more prepared of what was about to happen.

### 3.6.2. Capacity & trust

Patients reported that stress of the acute situation and their level of consciousness were important considerations in their desire to be involved in the decision-making process. Trust in their doctor's (medical) expertise, and lack of their own expertise were important reasons for patients to not desire involvement in their treatment decision. Many patients reported that they felt involved in the decision-making process, because information was provided by doctor. Some patients reported that they preferred more involvement of family. One patient was not satisfied with her involvement as no information about treatment benefits was provided, and no consent for treatment was asked.

### 3.6.3. Information provision

When asked about the required information in order to be able to make a treatment decision, patients' responses varied, although the majority required at least some kind of information about the condition and treatment options. Some stated that information about the (risks and benefits related to) treatment options is most important. Others mentioned that information about their diagnosis and prognosis is important to be able to make a treatment decision. Some wanted complete information, including information on the consequences of not starting treatment. A minority of the patients preferred no information at all, because their only concern was rapid treatment initiation.

## 3.7. Patients' decision-making capacities (cohort 2)

Most patients (n = 12) in cohort 2 considered themselves capable to carefully consider treatment options in the acute setting (Table 6). The majority of patients reported that they were capable of communicating a choice. For two patients no data on their decision-making capacity was available. Around one-third of the patients fulfilled all the criteria for adequate decision-making capacity. Five patients could not remember being treated at the ED.

## 4. Discussion and conclusion

### 4.1. Discussion

In this multicentre study, the experiences and preferences of patients with acute stroke were investigated concerning information

**Table 6**  
Self-reported capacity of patients in cohort 2 on the four criteria of decision-making capacity described by Appelbaum et al. [34].

Criterion	Sufficient
All criteria fulfilled	7 (35.0)
– Understanding of information	13 (65.0)
– Reasoning about treatment options	12 (60.0)
– Understanding of consequences of the situation	10 (50.0)
– Ability to communicate treatment choice	17 (85.0)
No data available	2 (10.0)

All data are presented as n (%).

provision and involvement in the acute decision-making process during the initial period of hospitalisation. Approximately half of the patients preferred to be actively involved in the decision-making process. However, the majority experienced a passive role at the ED. In the second cohort, we discovered considerable discrepancies between the provided and recalled information on the diagnosis, therapeutic options, and potential complications. For example, while the majority of the patients were informed about their diagnosis and therapeutic options, only half of the patients remembered being informed at the ED. Moreover, in patients who were eligible for reperfusion therapy, potential complications were consistently discussed in 95% of the cases, whereas only half of the patients remembered that these complications were discussed. In addition, the information that was provided appeared to be incomplete or difficult to understand in more than one-third of the cases. Interestingly, the vast majority of the patients were generally satisfied with the information provision at the ED. Patients reported that emotions, information, capacity and trust played an important role in their experience of the decision-making process at the ED.

These results lead us to make three main observations. Firstly, although the vast majority of the patients in this study were educated about acute stroke and its treatment, a considerable number of patients could not recall this information later on. Patient education, for example through providing patient-relevant outcome information, has been described as an important component of patient-centred care at ED [38]. It empowers patients to play an active role in decision-making processes [16]. Our findings are in line with results from previous studies that show that patients with stroke often cannot recollect information that was provided at the ED [39,40]. This might negatively affect patient empowerment and patient-centred care.

Secondly, only one-third of the patients in cohort 2 reported to fulfil the criteria for adequate decision-making capacity in the acute setting. Receiving and understanding information in order to participate in health-related decision-making processes can be challenging for patients with stroke, especially in a highly time-pressured situation [40]. Recent studies found that it was neither possible nor desirable for patients with stroke to be actively involved in acute decision-making, because of the emotional impact of the diagnosis [39] and patients' wish to leave the decision to their physician in order not to delay treatment with reperfusion therapy [32]. The differences between our findings and these previous studies might be related to the low stroke severity or the relatively high education level of the patients in cohort 2, which might have improved their decision-making capacity or their self-efficacy [41].

Thirdly, our findings support the assumptions that a considerable number of patients with stroke prefer to be actively involved in acute decisions [25,29,42,43], and that consistent information provision, including patient-relevant outcome information, can contribute to patient engagement at the ED [27,44–46]. Interestingly, desires for a passive role in the acute decision-making process at the ED were far more often fulfilled than desires for an active and collaborative role (91% versus 40% and 25% respectively). This is also in line with earlier findings that patients still experience a limited degree of actual involvement in acute decisions at the ED [47], which also might be attributable to patients' limited recollection of the acute decision-making process or the way that the information was provided. This indicates the need to explicitly discuss that an acute treatment decision has to be made, or to combine verbal communication with written or visual information, which could improve patients' recollection of provided information [48].

A strength of this study was that the perspectives of patients after as well as during hospitalisation were taken into account, resulting in a complete view of patients' perceptions on decision-making processes in acute stroke care. In addition, by combining a quantitative and qualitative approach with observations, valuable

insights were gained into patients' preferences for decision-making in acute stroke care. However, a larger study population with a wider range of stroke severity could have enhanced the generalisability of our results. Also, it would have been useful to register the number of patients that were presented to the ED during night shifts and to evaluate their experiences. Furthermore, semi-structured interviews could have provided more insight into (social or emotional) factors affecting acute decision-making processes than the currently used open-ended questions. Future research that combines robust quantitative and qualitative approaches can provide additional data on patient empowerment and SDM in acute stroke care. Another limitation of this study was that no data were obtained about the treatment preferences of patients in cohort 2 (who were all eligible for reperfusion therapy). In clinical practice, treatment options for acute stroke might not be framed as a preference-sensitive choice, which means that a choice is dependent on patients' preferences after considering two or more valid treatment options (including taking no action) of which the outcomes are equally desirable [49]. In acute ischaemic stroke care, however, starting and withholding reperfusion therapy might not be equally desirable, as there is convincing evidence for treatment efficacy [7–9]. Further research is required to reach consensus on whether patient involvement, as an important element of high-quality care, outweighs rapid treatment initiation, which might reduce neuronal loss and improve functional outcome. To do so, future studies should evaluate the perspective of both patients and health care professionals on this dilemma. Also, it is likely that the physicians were (unintentionally) influenced during the observations at the ED, as they knew they were being observed. This bias cannot be completely prevented, but by being a passive observant, the researcher tried to exert as little influence on the physicians as possible. Another limitation was that the level of involvement of the relatives in the decision-making process at the ED varied considerably between the two independent cohorts. Therefore, no conclusions could be drawn about the optimal role of relatives in acute decision-making, while a previous study showed that relatives can be helpful to make informed decisions [50]. Future research should therefore investigate the optimal role of relatives of patients with stroke in decision-making processes. Lastly, one can argue that a collaborative approach in decision-making is already reached when a health care professional seriously considers a patient's opinion (response D of the CPS). Within the traditional categories of role responses of the CPS (i.e., active, collaborative, passive), this response is associated with a passive role. Future studies could further investigate this.

#### 4.2. Conclusion

Active involvement in the acute decision-making process is preferred by approximately half of the patients with acute stroke and most of them consider themselves capable of doing so. However, they experience a limited degree of actual involvement. Although physicians provide consistent information to patients about their diagnosis and therapeutic options, approximately one-third of the patients consider this information to be either incomplete or difficult to understand. It is important to highlight that patients are not always able to recall the provided information, resulting in a discrepancy between the actual provided information and the experienced information provision.

#### 4.3. Practice implications

Our results provide valuable knowledge for both physicians and patients that could contribute to patient engagement at the ED, which is considered a key element of high-quality care. We determined three aspects of decision-making that could support patients with acute stroke and their physicians to make collaborative,

well-informed treatment choices at the ED. Firstly, knowledge among patients with stroke should be enhanced, by providing precise and tailored information about the diagnosis, risks, and benefits of reperfusion therapy at different moments of hospitalisation. As there was a discrepancy between the provided information and patients' experienced or recalled information provision, the role of relatives in sustainable knowledge transmission could be pivotal and should be better studied. In addition, verbal communication could be combined with written or visual information in order to improve patients' recollection of the provided information. Secondly, patients' decision-making capacity should be clinically assessed, by verifying whether patients understood the information about the diagnosis, therapeutic options and consequences of their condition. Thirdly, although acute stroke care might be an inappropriate setting for deploying preference-sensitive care, explicitly emphasising the first step of the SDM model ("a decision is to be made and the patient's opinion is important") might structure the decision-making process and may contribute to patient engagement and effective information transmission.

#### Author agreement

The authors declare that they have seen and approved the final version of the manuscript being submitted. The article is the authors' original work, hasn't received prior publication and isn't under consideration for publication elsewhere.

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#### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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#### Appendix A. Supporting information

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## References

- [1] Saver JL. Time is brain—quantified. *Stroke* 2006;37(1):263–6. <https://doi.org/10.1161/01.STR.0000196957.55928.ab>
- [2] Kobayashi A, Czlonkowska A, Ford GA, Fonseca AC, Luijckx GJ, Korv J, et al. European Academy of Neurology and European Stroke Organization consensus statement and practical guidance for pre-hospital management of stroke. *Eur J Neurol* 2018;25(3):425–33. <https://doi.org/10.1111/ene.13539>
- [3] Lin CB, Peterson ED, Smith EE, Saver JL, Liang L, Xian Y, et al. Emergency medical service hospital prenotification is associated with improved evaluation and treatment of acute ischemic stroke. *Circ Cardiovasc Qual Outcomes* 2012;5(4):514–22. <https://doi.org/10.1161/CIRCOUTCOMES.112.965210>
- [4] Ekundayo OJ, Saver JL, Fonarow GC, Schwamm LH, Xian Y, Zhao X, et al. Patterns of emergency medical services use and its association with timely stroke treatment: findings from Get With the Guidelines-Stroke. *Circ Cardiovasc Qual Outcomes* 2013;6(3):262–9. <https://doi.org/10.1161/CIRCOUTCOMES.113.000089>
- [5] Adeoye O, Nystrom KV, Yavagal DR, Luciano J, Nogueira RG, Zorowitz RD, et al. Recommendations for the establishment of stroke systems of care: a 2019 update. *Stroke* 2019;50(7):e187–210. <https://doi.org/10.1161/STR.0000000000000173>
- [6] Powers WJ, Rabinstein AA, Ackerson T, Adeoye OM, Bambakidis NC, Becker K, et al. Guidelines for the early management of patients with acute ischemic stroke: 2019 update to the 2018 guidelines for the early management of acute ischemic stroke: a guideline for healthcare professionals from the American Heart Association/American Stroke Association. *Stroke* 2019;50(12):e344–418. <https://doi.org/10.1161/STR.0000000000000211>
- [7] Lees KR, Bluhmki E, von Kummer R, Brodt TG, Toni D, Grotta JC, et al. Time to treatment with intravenous alteplase and outcome in stroke: an updated pooled analysis of ECASS, ATLANTIS, NINDS, and EPITHET trials. *Lancet* 2010;375(9727):1695–703. [https://doi.org/10.1016/S0140-6736\(10\)60491-6](https://doi.org/10.1016/S0140-6736(10)60491-6)
- [8] Fonarow GC, Zhao X, Smith EE, Saver JL, Reeves MJ, Bhatt DL, et al. Door-to-needle times for tissue plasminogen activator administration and clinical outcomes in acute ischemic stroke before and after a quality improvement initiative. *JAMA* 2014;311(16):1632–40. <https://doi.org/10.1001/jama.2014.3203>
- [9] Goyal M, Menon BK, van Zwam WH, Dippel DWJ, Mitchell PJ, Demchuk AM, et al. Endovascular thrombectomy after large-vessel ischaemic stroke: a meta-analysis of individual patient data from five randomised trials. *Lancet* 2016;387(10029):1723–31. [https://doi.org/10.1016/S0140-6736\(16\)01613-x](https://doi.org/10.1016/S0140-6736(16)01613-x)
- [10] Thomalla G, Simonsen CZ, Boutitie F, Andersen G, Berthezene Y, Cheng B, et al. MRI-guided thrombolysis for stroke with unknown time of onset. *N Engl J Med* 2018;379(7):611–22. <https://doi.org/10.1056/NEJMoa1804355>
- [11] Ma H, Campbell BCV, Parsons MW, Churilov L, Levi CR, Hsu C, et al. Thrombolysis guided by perfusion imaging up to 9 h after onset of stroke. *N Engl J Med* 2019;380(19):1795–803. <https://doi.org/10.1056/NEJMoa1813046>
- [12] Thomalla G, Boutitie F, Ma H, Koga M, Ringleb P, Schwamm LH, et al. Intravenous alteplase for stroke with unknown time of onset guided by advanced imaging: systematic review and meta-analysis of individual patient data. *Lancet* 2020;396(10262):1574–84. [https://doi.org/10.1016/S0140-6736\(20\)32163-2](https://doi.org/10.1016/S0140-6736(20)32163-2)
- [13] Albers GW, Marks MP, Kemp S, Christensen S, Tsai JP, Ortega-Gutierrez S, et al. Thrombectomy for stroke at 6 to 16 h with selection by perfusion imaging. *N Engl J Med* 2018;378(8):708–18. <https://doi.org/10.1056/NEJMoa1713973>
- [14] Nogueira RG, Jadhav AP, Haussen DC, Bonafe A, Budzik RF, Bhuva P, et al. Thrombectomy 6 to 24 h after stroke with a mismatch between deficit and infarct. *N Engl J Med* 2018;378(1):11–21. <https://doi.org/10.1056/NEJMoa1706442>
- [15] Mendelson SJ, Courtney DM, Gordon EJ, Thomas LF, Holl JL, Prabhakaran S. National practice patterns of obtaining informed consent for stroke thrombolysis. *Stroke* 2018;49(3):765–7. <https://doi.org/10.1161/STROKEAHA.117.020474>
- [16] Castro EM, Van Regenmortel T, Vanhaecht K, Sermeus W, Van Hecke A. Patient empowerment, patient participation and patient-centeredness in hospital care: a concept analysis based on a literature review. *Patient Educ Couns* 2016;99(12):1923–39. <https://doi.org/10.1016/j.pec.2016.07.026>
- [17] Barry MJ, Edgman-Levitan S. Shared decision making—pinnacle of patient-centered care. *N Engl J Med* 2012;366(9):780–1. <https://doi.org/10.1056/NEJMp1109283>
- [18] Elwyn G, Frosch D, Thomson R, Joseph-Williams N, Lloyd A, Kinnersley P, et al. Shared decision making: a model for clinical practice. *J Gen Intern Med* 2012;27(10):1361–7. <https://doi.org/10.1007/s11606-012-2077-6>
- [19] Hargraves I, LeBlanc A, Shah ND, Montori VM. Shared decision making: the need for patient-clinician conversation, not just information. *Health Aff* 2016;35(4):627–9. <https://doi.org/10.1377/hlthaff.2015.1354>
- [20] Stiggebout AM, Van der Weijden T, De Wit MP, Frosch D, Legare F, Montori VM, et al. Shared decision making: really putting patients at the centre of healthcare. *BMJ* 2012;344:e256. <https://doi.org/10.1136/bmj.e256>
- [21] Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 1997;44(5):681–92. [https://doi.org/10.1016/S0277-9536\(96\)00221-3](https://doi.org/10.1016/S0277-9536(96)00221-3)
- [22] Shay LA, Lafata JE. Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Mak* 2015;35(1):114–31. <https://doi.org/10.1177/0272989X14551638>
- [23] Stacey D, Legare F, Lewis K, Barry MJ, Bennett CL, Eden KB, et al. Decision aids for people facing health treatment or screening decisions. *Cochrane Database Syst Rev* 2017;4:001431. <https://doi.org/10.1002/14651858.CD001431.pub5>. [CD001431].
- [24] Crossing the quality chasm: a new health system for the 21st century. Washington (DC). 2001. (<https://doi.org/10.17226/10027>).
- [25] Schoenfeld EM, Kanzaria HK, Quigley DD, Marie PS, Nayyar N, Sabbagh SH, et al. Patient preferences regarding shared decision making in the emergency department: findings from a multisite survey. *Acad Emerg Med* 2018;25(10):1118–28. <https://doi.org/10.1111/acem.13499>
- [26] Probst MA, Noseworthy PA, Brito JP, Hess EP. Shared decision-making as the future of emergency cardiology. *Can J Cardiol* 2018;34(2):117–24. <https://doi.org/10.1016/j.cjca.2017.09.014>
- [27] Probst MA, Kanzaria HK, Schoenfeld EM, Menchine MD, Breslin M, Walsh C, et al. Shared decisionmaking in the emergency department: a guiding framework for clinicians. *Ann Emerg Med* 2017;70(5):688–95. <https://doi.org/10.1016/j.annemergmed.2017.03.063>
- [28] Kanzaria HK, Brook RH, Probst MA, Harris D, Berry SH, Hoffman JR. Emergency physician perceptions of shared decision-making. *Acad Emerg Med* 2015;22(4):399–405. <https://doi.org/10.1111/acem.12627>
- [29] Slot KB, Berge E. Thrombolytic treatment for stroke: patient preferences for treatment, information, and involvement. *J Stroke Cerebrovasc Dis* 2009;18(1):17–22. <https://doi.org/10.1016/j.jstrokecerebrovasdis.2008.06.009>
- [30] Mangset M, Berge E, Forde R, Nessa J, Wyller TB. “Two per cent isn’t a lot, but when it comes to death it seems quite a lot anyway”: patients’ perception of risk and willingness to accept risks associated with thrombolytic drug treatment for acute stroke. *J Med Ethics* 2009;35(1):42–6. <https://doi.org/10.1136/jme.2007.023192>
- [31] Murtagh MJ, Burges Watson DL, Jenkins KN, Lie ML, Mackintosh JE, Ford GA, et al. Situationally-sensitive knowledge translation and relational decision making in hyperacute stroke: a qualitative study. *PLoS One* 2012;7(6):37066. <https://doi.org/10.1371/journal.pone.0037066>
- [32] Busetto L, Stang C, Hoffmann J, Amiri H, Seker F, Purrucker J, et al. Patient-centredness in acute stroke care – a qualitative study from the perspectives of patients, relatives and staff. *Eur J Neurol* 2020;27:1638–46. <https://doi.org/10.1111/ene.14283>
- [33] Degner LF, Sloan JA, Venkatesh P. The control preferences scale. *Can J Nurs Res* 1997;29(3):21–43.
- [34] Appelbaum PS. Clinical practice. Assessment of patients’ competence to consent to treatment. *N Engl J Med* 2007;357(18):1834–40. <https://doi.org/10.1056/NEJMc074045>
- [35] Castor EDC. Castor electronic data capture, 2019. (<https://castoredc.com>). [Accessed 28 August 2019].
- [36] Stiggebout AM, Pieterse AH, Haes JCDe. Shared decision making: concepts, evidence, and practice. *Patient Educ Couns* 2015;98(10):1172–9. <https://doi.org/10.1016/j.pec.2015.06.022>
- [37] A. World Medical. World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA* 2013;310(20):2191–4. <https://doi.org/10.1001/jama.2013.281053>
- [38] Pham JC, Trueger NS, Hilton J, Khare RK, Smith JP, Bernstein SL. Interventions to improve patient-centered care during times of emergency department crowding. *Acad Emerg Med* 2011;18(12):1289–94. <https://doi.org/10.1111/j.1553-2712.2011.01224.x>
- [39] Visvanathan A, Mead G, Dennis M, Whiteley W, Doubal F, Lawton J. Maintaining hope after a disabling stroke: a longitudinal qualitative study of patients’ experiences, views, information needs and approaches towards making treatment decisions. *PLoS One* 2019;14(9):0222500. <https://doi.org/10.1371/journal.pone.0222500>
- [40] Decker C, Chhatiwalla E, Gialde E, Garavalia B, Summers D, Quinlan ME, et al. Patient-centered decision support in acute ischemic stroke: qualitative study of patients’ and providers’ perspectives. *Circ Cardiovasc Qual Outcomes* 2015;8(6 Suppl. 3):S109–16. <https://doi.org/10.1161/CIRCOUTCOMES.115.002003>
- [41] Barstow C, Shahab B, Roberts M. Evaluating medical decision-making capacity in practice. *Am Fam Physician* 2018;98(1):40–6.
- [42] Davis MA, Hoffman JR, Hsu J. Impact of patient acuity on preference for information and autonomy in decision making. *Acad Emerg Med* 1999;6(8):781–5. <https://doi.org/10.1111/j.1553-2712.1999.tb01206.x>
- [43] Schoenfeld EM, Goff SL, Downs G, Wenger RJ, Lindenauer PK, Mazor KM. A qualitative analysis of patients’ perceptions of shared decision making in the emergency department: “let me know i have a choice”. *Acad Emerg Med* 2018;25(7):716–27. <https://doi.org/10.1111/acem.13416>
- [44] Flynn D, Knodler MA, Hess EP, Murad MH, Erwin PJ, Montori VM, et al. Engaging patients in health care decisions in the emergency department through shared decision-making: a systematic review. *Acad Emerg Med* 2012;19(8):959–67. <https://doi.org/10.1111/j.1553-2712.2012.01414.x>
- [45] Armstrong MJ. Shared decision-making in stroke: an evolving approach to improved patient care. *Stroke Vasc Neurol* 2017;2(2):84–7. <https://doi.org/10.1136/svn-2017-000081>
- [46] Damman OC, Jani A, de Jong BA, Becker A, Metz MJ, de Bruijne MC, et al. The use of PROMs and shared decision-making in medical encounters with patients: An opportunity to deliver value-based health care to patients. *J Eval Clin Pract* 2020;26(2):524–40. <https://doi.org/10.1111/jep.13321>
- [47] Schoenfeld EM, Probst MA, Quigley DD, St Marie P, Nayyar N, Sabbagh SH, et al. Does shared decision making actually occur in the emergency department? Looking at it from the patients’ perspective. *Acad Emerg Med* 2019;26(12):1369–78. <https://doi.org/10.1111/acem.13850>
- [48] Sherlock A, Brownie S. Patients’ recollection and understanding of informed consent: a literature review. *ANZ J Surg* 2014;84(4):207–10. <https://doi.org/10.1111/ans.12555>
- [49] Elwyn G, Frosch D, Rollnick S. Dual equipoise shared decision making: definitions for decision and behaviour support interventions. *Implement Sci* 2009;4:75. <https://doi.org/10.1186/1748-5908-4-75>
- [50] Visvanathan A, Dennis M, Mead G, Whiteley WN, Lawton J, Doubal FN. Shared decision making after severe stroke – how can we improve patient and family involvement in treatment decisions? *Int J Stroke* 2017;12(9):920–2. <https://doi.org/10.1177/1747493017730746>