

Experience of Information Provision at the Stroke Unit From the Perspective of Relatives to Stroke Survivors

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ABSTRACT:

INTRODUCTION: Stroke not only affects the stroke survivor, it also significantly affects their families. Given the important supportive role that relatives of stroke survivor have, they should receive information that helps them plan and cope with the new situation. The objective of the study was to explore how relatives to stroke survivors perceived the information provided by the stroke unit.

METHODS: This qualitative study was based on extensive semi-structured interviews with an inductive approach. A heterogeneous convenience sample of relatives to stroke survivor (n=14) was selected. Qualitative content analysis served to analyze the transcribed interview texts.

RESULTS: The content analysis yielded four categories, each with 2–3 subcategories. The overall theme was “to be acknowledged or not”: it encompassed the underlying meaning and the relationships between the categories. The four categories were as follows: shifting information needs; striving for information; lacking of continuity and structure; and taking part and being acknowledged.

CONCLUSIONS: The study highlighted that the relatives of stroke survivors have a strong need for information and showed that the relatives experienced that they did not always feel satisfactorily informed and supported by the healthcare professionals in the stroke unit. A challenge for the healthcare professionals was to be able to give the right information at the right time and in the appropriate way. The study also showed that when the relatives were acknowledged and invited to participate in the rehabilitation process, they were less anxious of the discharge.

KEYWORDS: Stroke rehabilitation, access to information, time factors, patient participation

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Introduction

Stroke not only affects the stroke survivor but it also considerably affects their families, and therefore, it is important that they are closely involved in the rehabilitation process. As people with a brain injury after stroke often have difficulties with communication and motivation, the relatives must often play a very important supportive role. For example, the relatives may have to take responsibility for the contacts of the stroke survivor with health care and other support systems.¹ Consequently, it is important that relatives are given sufficient information about what to expect, thus enabling them to plan.² However, at present, rehabilitation programs often only focus on the stroke survivor. To better support the relatives in their new role, it is important to be aware of their information needs. It is also important to meet these needs in a family-centered care setting: stroke rehabilitation with a family-centered focus during all phases of the rehabilitation process is likely to yield better outcomes than solely patient-oriented approaches.³

According to the National Board of Health and Welfare in Sweden, the best outcomes of stroke survivors are achieved when they are cared for in a stroke unit. Stroke units are staffed

by teams of various professionals that have expertise in stroke and rehabilitation and thus can provide the necessary medical, nursing, and rehabilitation skills. The team is responsible for the information and training that are given to the stroke survivor and their relatives during the hospital stay.⁴ The National Board of Health and Welfare states that the information needs of the relatives regarding stroke information should already be identified during the acute care phase in a stroke unit. The worries and concerns of the relatives should also be addressed during this period.⁵ The relatives may need information about the diagnosis, health, care, and treatment of the stroke survivor.⁶

In the stroke unit, the focus of the information needs to be on the person with stroke at this point but also broaden the approach to a more family-centered one that clearly addresses the problems and questions of the relatives as well.⁷ This is supported by Creasy et al⁸ who showed recently that health care workers should find out the needs of relatives from the perspective of the relatives; this will allow the health care workers to understand the problems of the relatives and therefore be able to help manage and solve these problems. In particular, the relatives often want to be actively involved in the rehabilitation of



the stroke survivor so that they feel more prepared for discharge. A key question of relatives is, "who can we ask for help when we have problems or questions?" However, as shown by the Swedish Stroke register, up to 39% of respondent relatives of stroke survivors stated that they did not know who in the health care system they should contact for advice or support after discharge. Moreover, only half of the respondent relatives felt that they had enough information and knowledge in general: the other half felt that they needed more information in a variety of areas.¹ The study by Wallengren et al⁶ also showed that the information needs of the relatives vary among individuals. This means that health care workers must identify the specific information needs of the relatives rather than following standard information-providing procedures. Cameron and Gignac⁹ also showed that the support needs of the relatives can change during the various phases of rehabilitation. Thus, giving situation-specific information should be a key objective of health care workers. However, this advice is clearly still not resonating in the stroke care milieu because relatives continue to feel that they are inadequately informed about stroke and the available support.^{10,11} The National Board of Health and Welfare found that, while relatives initially do not have expectations regarding their own achievements, they do expect that the health care system should be the information provider.¹²

It is difficult to communicate medical information because people tend to remember such information poorly and inaccurately, especially when they are older and/or anxious: as much as 40% to 80% of medical information that is provided by health care practitioners is forgotten immediately.¹³ Moreover, almost half of the information that is remembered is incorrect.¹⁴ Inadequate information provision may also be due to system problems,¹⁵ such as health care professionals providing information in an unstructured manner.¹⁶

These observations indicate that, to get access to the right support when needed, relatives must be provided with relevant information and counseling.¹⁷ Various types of interventions have been found to be effective for informing relatives, including counseling, training, and problem-solving education.¹⁸ However, while many studies have explored the information needs of relatives,^{1,5-8,10,11,17-20} little is known about their information needs while the stroke survivor is in the stroke unit and how the relatives experience the information they receive in the stroke unit. The information that is provided by the stroke unit is very important because it should help the relatives to prepare for the future and become armed with tools that will help them to cope with the new situation. To address this issue, this qualitative study with a heterogeneous group of relatives of stroke survivors was performed. The relatives were asked how they perceived the information they received while the stroke survivor was in the stroke unit, and their responses were subjected to qualitative content analysis.

Aim

The objective of the study was to explore how relatives to stroke survivors perceived the information provided by the stroke unit.

Materials and Methods

Design

To be able to capture the experiences of the stroke survivor relatives, a qualitative approach consisting of extensive semistructured interviews with an inductive approach was used.²¹ The content was then analyzed by qualitative content analysis, as described by Graneheim and Lundman.²² Content analysis is a method for analyzing data such as transcribed text from interviews. It can be used with different levels of abstraction: either it can be used to identify the manifest content (*i.e.* what is directly expressed in the text) or it can be used to analyze the latent content (*i.e.* the researcher interprets the meaning of the text). In this study, the text was analyzed for latent content.²²

Participants and setting

The participants in this study were 14 relatives of people who sustained a stroke and were admitted to any of the three stroke units at Sahlgrenska University Hospital (SU) in Gothenburg, Sweden. The three stroke units follow the criteria from the National Board of Health and Welfare and are organized in-hospital facilities that are entirely (or next to entirely) devoted to care for patients with stroke. Several different definitions of a stroke unit have been used. The definition used in the Swedish national stroke guidelines published by the National Board of Health and Welfare⁴ is based on definitions agreed upon by the Stroke Unit Trialists' Collaboration^{23,24} and the European Stroke Initiative.²⁵ It is staffed by a multidisciplinary team with special knowledge in stroke care that meets at least once a week.⁴ In Sweden, there are educational programs leading to a stroke competence certification.²⁶ The team consists of physician(s), nurse(s), assistant nurse(s), physiotherapists(s), occupational therapist(s), social worker(s), and speech therapist and has access to a dietician and a psychologist, preferably with a neuropsychological profile. It provides detailed information and educates patients and next-of-kin during the hospital stay. It is concerned with immediate mobilization and early rehabilitation after stroke. On average, stroke survivors undergo inpatient care in a stroke unit at SU for 12 days.

Relatives of people being cared for in the stroke units at SU receive information in various ways. First, the stroke unit team strives to invite the relatives to a structured meeting at the stroke unit, thus helping the relatives to meet with the whole team. However, these meetings sometimes do not occur because of lack of time, lack of communication in the team, or sudden discharge. Second, the relatives often have informal meetings with various professionals in the team when they visit the stroke unit. Third, the stroke unit provides a variety of written material. Fourth, after discharge, it is possible to participate in a patient and family education program that is conducted at the stroke unit several weeks to months after discharge.

Relatives were invited to participate in the study if they were partners, children, grandchildren, or people who had a close relationship to the person who had a stroke and were aged above 18 years. A prerequisite for participating in the study was being able to understand and speak the Swedish language. Participants were also excluded if the researcher had been the occupational therapist in charge of patient treatment during their time at the stroke unit.

The relatives were approached by either an occupational therapist or the researcher at the stroke unit, or by the researcher at the patient and family education program that is provided by SU after discharge. The relatives received verbal and written information about the study. Once the relatives had given their informed consent to participate, the researcher called them and arranged the time and place for the interview. The interviews took place in the participant's home, at the stroke unit, or at another location chosen by the participant. The aim was to obtain a heterogeneous sample that could provide variance in the data.^{22,27} Strategic selection with convenience sampling was used, and recruitment was ended after the 14th person agreed to participate in the study.

Data collection

The data were collected by semistructured interviews that were conducted by the researcher using an interview guide.²⁸ A pilot interview that was not included in the study was conducted to validate the interview guide. The questions in the interview explored the information needs of the relatives and how they perceived the information provided by the stroke unit. The interview began with an open question. The interview guide included support questions relating to the open question. Probing questions such as "Can you tell me more?" and "Can you elaborate on that?" were asked to search for more in-depth answers.²⁸ Field notes were used to contextualize the response. Demographic data were collected after the interviews. The data collection was completed when it was deemed to be satisfying, meaning that the interview was no longer producing new information.²⁹ Each interview lasted about 45–90 minutes and was recorded and transcribed afterward.²³ All the content was transcribed except for sounds such as ahh and mmm. The transcriptions resulted in 69 pages, written with single space and Times New Roman in 12 pt size. The data were collected between March 2015 and September 2015.

Table 1. Overview of the analytical process with two related examples.

MEANING UNIT	CONDENSATION	CODE	SUBCATEGORY	CATEGORY
The only bit of information I got was when I happened to be with my wife and heard the doctor tell her	I happened to be there	Coincidence	By chance	Lack of continuity and structure
When you have been signed in, to get some sort of general information, what is this disease and what happens now?	When the stroke survivor was signed in, we needed information about stroke and what had happened	Signed-in	Experience in the acute phase	Shifting information needs

Data analysis

The qualitative content analysis described by Graneheim and Lundman²² was used to analyze the transcribed interview text. The text was analyzed for latent content because this approach yields a higher level of abstraction and a deeper understanding.²² The method followed the description by Graneheim and Lundman.²² First, all interviews were read several times to obtain an overall understanding. Second, meaningful units that related to the research questions were identified and marked: meaningful units consist of words, sentences, or pieces of text. The meaningful units were then extracted, condensed, and labeled with codes. The interviews were read once more to ensure that the meaningful units and codes were coherent and corresponded to the original text. Third, similar codes were further abstracted, grouped together, and sorted into categories and subcategories. An example of the analysis process is presented in Table 1. Samples of the interviews were analyzed in parallel by the researcher and the supervisor, and the various stages of the analysis process were continuously discussed. The analytical process involved back-and-forth movements between the different qualitative content analysis steps.²²

Ethical considerations

This study was approved by the Regional Ethics Board in Gothenburg (2015-03-26, registration number 194-4). The study was conducted according to the tenets of the Declaration of Helsinki 1975, revised in Hong Kong 1989. The participants were informed verbally and in writing that participation in the study was voluntary and that they could withdraw at any time. Informed consent was obtained before all interviews. All participants could also choose the time and place for the interviews.

Results

In total, 14 relatives participated in the study. The average age was 65 (range, 31–78) years. There were 12 women and 2 men. Most (12/14) were born in Scandinavia. Half were spouses, 6 were children of the stroke survivor, and 1 was a close relative. Half were working and half were senior citizens. In this study, the inpatient care of the stroke survivors varied from several days to several weeks. The time from discharge to the interview ranged from 1 week to 1 year.

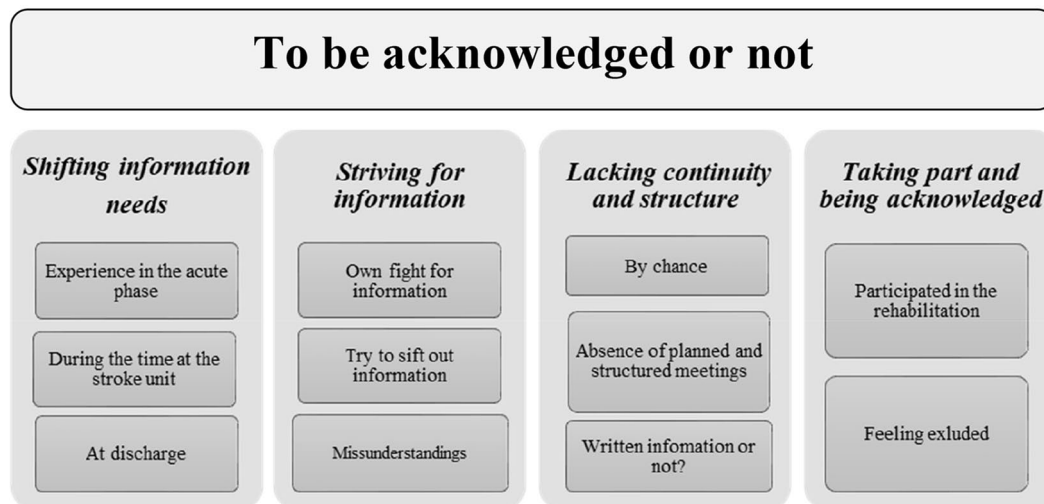


Figure 1. Overview of the theme, categories, and subcategories that emerged from the interview analyses (n=14).

The content analysis of the interviews resulted in four categories, each of which had 2 to 3 subcategories (Figure 1). An overall theme emerged, namely, “To be acknowledged or not.” This theme encompasses the underlying meaning of the categories as well as the relationships between the categories.

In the following article text, a number of quotes from the relatives that illustrate the meaning of each category are cited. Each quote is followed by a number in brackets (1-14) that indicates which participant is being quoted. Double slashes (//) in the quotes indicate omitted words or sentences.

Shifting information needs

The relatives perceived that their information needs altered during the time the stroke survivor was in the stroke unit.

Experience in the acute phase. The relatives stated that immediately after admission of the stroke survivor to the stroke unit, they had a general need to understand what had happened and what it meant to have a stroke. Some recounted how they had had to search for information to obtain a better understanding of the situation. However, others reported that the health care personnel at the stroke unit were able to satisfy their information needs.

We got very good information the first night when we came in, but then I was of course so shocked myself that maybe I didn't understand it really. [8]

During the time at the stroke unit. The relatives found that, over time, they needed more information and feedback in relation to the rehabilitation of their relative and future planning. Most of the relatives felt that these information needs were not met by the stroke unit team.

He was put on the right treatment, but we had no information about it, or what would happen then, or risks or anything. [3]

However, some relatives felt that they had received appropriate feedback and information from the health care team at the right time.

Then they became very nice and explained what they had come up with. [12]

At discharge. Many of the relatives recalled feeling uncertain about what would happen after discharge due to lack of information from the health care team. Many relatives said that they were unsure where to get support and information after discharge.

But then she would be discharged, but then there was no information. Or the letter would be written to the care center, she received a letter that she would leave at the rehabilitation center and that's it. No information about how will life be after the stroke? How will your life be affected? No such information was given. [13]

However, again, other relatives described a different experience at discharge: they said the discharge had been very well prepared and they felt well informed by the health care team. They felt they had received the information they needed to feel secure after discharge.

I don't feel that I am missing any information. [2]

Striving for information

The relatives said that during the stay of the stroke survivor in the stroke unit and after discharge, they had expected that the health care team would take the initiative to inform them about what to expect and where to find further information and support. However, many relatives felt that they themselves had had to look for the information they needed, a task that was made doubly difficult given that it was a shocking time for them. Several reported having had to use the Internet to answer their information needs. Others also stated that the lack of information had led to misunderstandings.

Own fight for information. Several relatives expressed disappointment that they were not approached by the health care team and given the information they needed and that instead they had had to fight by themselves to obtain that information. There was a general feeling that they had had to actively search and ask for information.

We, as relatives, had to go to the healthcare team; it was not that they reached out to us. [6]

Try to sift out information. When the relatives did not receive the information, they needed from the health care team, they turned to the Internet, as this was their most readily accessible information source. Several relatives stated that they found the information on the Internet to be frightening and overwhelming. In particular, several relatives expressed frustration about the fact that they had had to try to sift out information that was not relevant to them among the mass of information that was available on the Internet; they felt that proper support from the health care team would have helped them to obtain the right information more easily.

Sure, I began to read online; of course, there are all kinds of things but everything is not true. What you read in the healthcare service guide, it's quite overwhelming, and one becomes quite frightened. [13]

Misunderstandings. Some relatives said that the fact that they had had to find the relevant information by themselves sometimes led them to overlook important information because they did not realize that this information was relevant for them. This in turn sometimes led to misunderstandings and later feelings of guilt about the possibility that the relative may have acted incorrectly in terms of addressing the stroke survivor's needs.

Had I known it on day one, I would not have made her sad. I asked her to forgive me, I said: "I have to apologize and you have to forgive me for this, I didn't realize it was your stroke, I've been downright mean to you // I never understood what this means for you, no one said anything." [7]

Lacking continuity and structure

The relatives felt there was a lack of continuity and structure in terms of how and when the necessary information was given to them at the stroke unit. They felt that knowing when and where they could be informed was important and the health care team had not managed to give that to them. Several expressed the feeling that they only obtained the information because they happened to be there at the time the health care team came by, and thus they may have missed some information when they were not there.

By chance. A few relatives said that they felt there was no continuity in terms of the health care staff at the stroke unit, and

that this hindered information transfer and communication. They also frequently said that they obtained information from the health care staff by chance when they met them in the corridor or when they were in the patient's room.

Then, in came a doctor, who told me something when I was there but it could just as easily have been the case that I wouldn't have been there. Nah, it was probably just that I happened to be there. [4]

Most relatives said that they had the feeling that they got the information by chance, that if they had not been visiting at that time they would not have received the information.

The only bit of information I got was when I happened to be with my wife and heard the doctor talk to her. [1]

Absence of planned and structured meetings. Almost all relatives complained about the lack of planned and structured information meetings at the stroke unit. They had expected that at some point, they would be able to sit down with representatives from the health care team to obtain the answers to their questions. Many were surprised and disappointed by the lack of such meetings and expressed feeling the absence of a place where information could be exchanged or received.

So, one would think that they would, after all, call us for an informational meeting. // we needed someone to sit down and say, yes I am the responsible physician, head nurse, and so forth //, that would have been great to hear. [5]

Written information or not? Some of the relatives mentioned receiving written information in the stroke unit but not everyone receives it in a structured way. There was great variation in the type of written material they received: it included brochures, information sheets, diaries, and mental fatigue brochures. The participants who received written information felt more informed and secure and said that it was a good thing that they could bring the information home to read and thereby get a better understanding about stroke, mental fatigue, and medications.

I found the brochures right away, but I met a nurse in the ward and she gave us even more brochures. [14]

Most participants complained about the lack of written information and said that they would have appreciated receiving such information.

Nothing. No paper, no brochures, no nothing. And that's probably what I'm most disappointed about. [3]

Taking part and being acknowledged

Some participants felt that they were not given enough information about how to engage in the rehabilitation of the stroke survivor and that they were very disappointed about that

because they felt that they could have contributed more. However, other participants said that they felt they had received sufficient information about how to participate and that they felt sufficiently informed and secure when it was time for discharge.

Participated in the rehabilitation. Some relatives said that it had been possible for them to be involved in the rehabilitation and at the same time receive information about the training/rehabilitation that was performed. They felt welcomed and informed by the health care team, which invited them and informed them about how to participate in the care and rehabilitation of the stroke survivor. They felt that they had been able to participate in the rehabilitation of the stroke survivor to the extent that they and the stroke survivor wanted. They found that the opportunity to get information during the rehabilitation training gave them a sense of security and confidence in how to support the stroke survivor. Thus, taking part in rehabilitation was experienced as a positive experience for those participants who wished to become involved and learn from the professionals.

It was very convenient that you got the information during training. Then we talked about it afterwards// It felt good when I came home. [10]

Feeling excluded. Some relatives expressed feeling disappointed that they were not getting enough information about how to be more involved in the training/rehabilitation process. They felt that they had more to offer and felt lost and excluded when they were not given the information and support they needed to know what to do during the stroke unit stay. They felt that their need to help and be involved was not seen by the health care team as being an important part of the rehabilitation process.

No, we had to do a lot but it was not as if it was someone, someone who sat down and talked about Mom's situation. Do you want to be involved in this, you can take these walks, or you can do these things. But we were there 9 hours a day, so it is clear that we could have done a lot more. [9]

Discussion

This qualitative study explored how the relatives of stroke survivors experienced the information that was provided while the stroke survivor was in the stroke unit.

The most important finding of the study was that the relatives felt that their information needs were met when the health care staff acknowledged that their personal knowledge of the stroke survivor would help in the training/rehabilitation process and they were invited to participate in the process. The satisfaction of the participants with the information given by the stroke unit clearly depended on whether they had been acknowledged and welcomed by the health care staff. The participants who felt acknowledged and welcome also felt that it

had been easier to ask questions and communicate openly; therefore, they had a more positive experience regarding the provision of information by the stroke unit. By contrast, the relatives who felt that they were not acknowledged described how they found it hard to get the information they needed. Some said that they felt they were bothering the health care staff when they tried to ask for information. Some also said that, instead of staying and taking part in the talks and rehabilitation program, they left when the representatives of the stroke unit staff came because they felt unwelcome or ignored. In these cases, the participants inevitably reported that they felt that the stroke unit had not met their information needs. The importance of being included as relative is also described in other studies, such as a systematic review by Luker et al.³⁰ Luker highlights that efforts are needed to provide more inclusive systems that can enable relatives to easily access support, information, and training for their new roles, based on their individual needs and preferences.

The information needs of the relatives changed over time. They reported that, in the acute phase, they felt shocked and had a strong need for information that was sometimes not readily available, which also have been described in other studies.^{30,31} By the time of discharge, while some felt adequately informed, others felt unprepared and anxious because of insufficient communication from the health care staff. This is in line with the findings of Wallgren et al.⁶ and Cameron et al.² It is essential that the health care system has a strategy that will support the relatives of stroke survivors during all the care phases in the stroke unit. To achieve this, it may be useful to institute a framework called "Timing it right." This framework highlights the fact that the support and information needs of the relatives change during the various care phases (*i.e.* the acute phase, during the time at the stroke unit, and at discharge). Such awareness may help health care professionals to provide the right information and support at the right time.^{2,9}

Many of the relatives in this study stated that they had a strong need for information that would improve their understanding of the situation. They often strove hard to find such information. Such efforts have also been described by Brereton and Nolan³² in an article about seeking information as a relative of a stroke survivor. They, like us, found that it is often not easy to access the needed information and that the searching process often leads to frustration. The need for information is also described by Camicia et al.,³³ who found that "consistency" was a key to eventually being able to hear and understand what was being said. Relatives in this study stated that they felt disappointed that the health care professionals did not take more responsibility in terms of involving and informing them; they said that, had these information needs been met, they would have felt less anxious and more confident. It is essential for health care professionals to be aware of the strength of the information needs of relatives of stroke survivors because an awareness may promote a better support.

The relatives in this study also expressed frustration about the lack of organization on the stroke unit; they had expected more structure and clearness in the communications not only between the health care staff and themselves but also between the health care professionals. Such lack of continuity and structure clearly acted as a barrier that prevented the relatives from obtaining the information they needed, thus forcing them to strive to meet those needs at a time when they felt shocked and vulnerable. These observations have also been reported by others. For example, Eames et al¹¹ described the prevalence of limited communication between health care professionals. Notably, a study exploring the information needs of stroke survivors and their relatives suggested that this situation may be improved by giving written information as well as face-to-face information.³⁴ Indeed, Wachters-Kaufmann et al³⁵ recommend that stroke units should systematically give out written information. Similarly, the relatives in this study stated that they welcomed receiving both face to face and written information. The study by Roy et al³¹ identified a gap between health professionals' theoretical understanding of best practice in information provision and their actual practice. In this study, the health professionals were not interviewed, but from the respondent's statements, one may conclude that the guidelines for information and meetings at the unit were not always followed. A major reason may have been time constraints and the unawareness of the importance of the information in a structured way.

The study highlighted the experience of the relatives and how they expressed their need to be invited and involved in the rehabilitation process. A study by Creasy et al⁸ also described how relatives feel the need for hands-on practice during the time in the stroke unit, as this helps them to prepare themselves before taking the stroke survivor home. Moreover, several studies show that, when relatives are given appropriate education and training in terms of how to support the stroke survivor, they feel less anxious and have a better quality of life.^{36,37} This was also observed in this study: the relatives who had participated in the training said they felt less anxiety at discharge and afterward. However, some relatives said that their desire to participate was ignored and they were not told what to do during rehabilitation; as a result, they felt anxious and unprepared at discharge and later at home.

Methodological considerations

Qualitative content analysis was considered to be the appropriate methodological approach in this study because our objective was to collect as wide a range of participant experiences as possible.^{22,38} We chose to use the method described by Graneheim and Lundman²² because they explained the method in detail.

This study had several limitations. First, there was a gender imbalance: the relatives were nearly all female. However, this may simply reflect the composition of the larger population: most relatives of stroke survivors are female.¹ Second, the

interviews differed in some ways, as the interviews could take place in the informant's home or some other place and in the length of the interview. However, this did not seem to have any negative impact on the result. Third, a limitation to the study was the exclusion of relatives who did not understand and speak the Swedish language. However, to compensate for this loss, we specifically tried to include respondents originated from other countries than Sweden that could express them self in Swedish language.

However, several features of the study support the credibility of its results.²² First, the possibility that we accurately described the various experiences of relatives of stroke survivors is supported by the demographic heterogeneity of the study population. Second, the same interview guide was used for all the participants. Third, the analytical process involved back-and-forth movements between the different steps of the qualitative content analysis.²² Finally, the results of the study are consistent with the findings of other studies.

Transferability is of great interest in qualitative research. It can be defined as the applicability of the results in other similar settings and samples. The stroke unit care in Sweden is well defined and followed by the Swedish stroke registry, Riksstroke, which ensure conformity in the organization of the care at the units and how information should be given. This together with the heterogenous sample and thorough qualitative analyzes make it possible to believe in a good transferability, of the perception of information delivery of relatives found in the study, to the other stroke units in Sweden.

Conclusions and Clinical Implications

This study showed that the relatives experienced that they did not always feel satisfactorily informed and supported by the health care professionals in the stroke unit. Their needs of information varied over time, a challenge for the health care professionals to be able to give the right information at the right time and in the appropriate way. The study further highlighted that the relatives of stroke survivors have a strong need for information.

Finally, the study showed that when the relatives were acknowledged and invited to participate in the rehabilitation process, they were more satisfied with information and less anxious of the discharge. Information provision through participation in training were an effective way to give relatives an understanding

Clinical Messages

- For a more satisfying information provision to relatives of stroke survivors, the health care professionals need to consider the change in information needs over time at the stroke unit and invite the relatives to be a part in the rehabilitation process.
- It is essential for a good and structured information provision that guidelines on information organization and meetings are implemented and may be followed.

Author Contributions

LK and AB were responsible for the study conception and design and the drafting of the manuscript. L.K. performed the data collection. LK and AB performed the data analysis. LK obtained funding and AB provided administrative support. AB supervised the study.

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