Original Article

Communication, the Key in Creating Dignified Encounters in Unexpected Sudden Death – With Stroke as Example

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Abstract

Aim: The aim of this study was to illuminate the communication and its meaning in unexpected sudden death with stroke as example, as experienced by stroke team members and next of kin. **Subject and Methods:** The study has a qualitative design. Secondary analysis of data from four previous interview studies with stroke team members; physicians, registered nurses, and enrolled nurses from the stroke units (SU) and next of kin of patients who had died due to acute stroke during hospital stay were utilized. **Results:** Communication is revealed as the foundation for care and caring with the overarching theme foundation for dignified encounters in care built-up by six themes illuminating the meaning of communication in unexpected sudden death by stroke. **Conclusion:** Communication shown as the foundation for dignified encounters in care as experienced by stroke team members and next of kin enables the patient to come forth as a unique person and uphold absolute dignity in care. Acknowledging the next of kin's familiarity with the severely ill patient will contribute to personalizing the patient and in this way be the ground for a person centeredness in care despite the patients' inability to defend their own interests. Through knowledge about the patient as a person, the foundation for dignified care is given, expressed through respect for the patient's will and desires and derived through conversations between carers and next of kin.

Keywords: Communication, next of kin, person-centered care, stroke team members, supplementary secondary analysis

INTRODUCTION

It is hard to imagine care and caring taking place without communication in some form. Communication is present in all encounters independent of context and how communication takes places is of importance to create a caring relationship. A good relationship between patients, next of kin, and health-care professionals is crucial, not least in times of rapid changes in health and when high-value questions such as questions about life and death are at stake. The aim of this study was to illuminate the communication and its meaning in unexpected sudden death with stroke as example, as experienced by stroke team members and next of kin.

BACKGROUND

Stroke is an illness with immediate onset having the potential to totally change a person's life and it is a leading cause of death globally.[1] The majority of the patients afflicted by stroke survive but a substantial number die in the acute phase. Mortality from the acute incident, that is, death within 1 week from stroke is approximately 8% in Sweden and equivalent numbers have been reported from Germany too.[2] This implies that a substantial number of patients die acutely from stroke globally. Research shows that the next of kin accordingly might be shocked by the unexpected sudden onset.[3,4] This will also affect the communication, implying that the issue of communication is highly relevant in this context.

Communication is an activity to convey meaning through a shared system of signs and rules.[5] The word "communication" comes from Latin commūnicāre, meaning "to share." Often communication means to transfer information from one person to another, and this does not have to be in spoken words. Communication as a subject has been extensively studied within many areas of care; both inpatient and outpatient care, acute,

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rehabilitative, and palliative care and with different age groups and perspectives; from the perspective of patients, next of kin, and carers. Yet still, the communication is complex and demanding.

There are several problems related to verbal communication such as misinterpretations, misunderstandings, and other obstacles to understanding the message[5] not least in health-care contexts. Communication is also described as influenced by many factors such as age, gender, and educational level. The individual's capacity to communicate is also affected by several factors such as language skills, cognitive function, and level of consciousness. Every context in care and caring also has its own problems and specific barriers to handle, related to the patients being cared for. In stroke care, there are many such problems as stroke may affect the patients' ability to understand and use spoken language due to aphasia as well as other cognitive functions. It is also a well-known fact that a majority of the patients who die in the acute phase of stroke are unconscious from the onset of stroke,[6,7] and in such cases, normal communication is impeded. In the Swedish Health and Medical Services Act[8] and the Patient Act,[9] the patients right to information and participation in decisions about care is stressed. This is, however, hard to accomplish when the patient is unconscious. In these situations, next of kin will often function as surrogates and be the patient's spokesperson.[4]

Research on sudden unexpected death, excluding death by epilepsy and sudden infant death, is scarce. When focusing on experiences of carers or next of kin, it is even rarer. Research on unexpected sudden death by stroke has identified ethical concerns to be of importance, not least because of the uncertainty in the course of the disease[4,10-14] and found the situation of the next of kin to be troublesome.[3] Uncertainty about prognosis and during the time before death has also been found to be a major concern in patients dying from cancer in situations not described as acute.[15] Research on the needs of families of patients with life-threatening diseases, though not described as sudden or unexpected, tested an intervention in the form of a support program.[16] The study indicates that the way health professionals invite and interact with family members is of importance, thus implying the importance of communication.

When patients affected by acute illness such as the incidence of stroke, their next of kin, and health-care professionals meet in the acute situation, skill in communication is needed as a basis for care. The next of kin might feel lonely and vulnerable in this situation and that their knowledge about the patient is not acknowledged by carers.[3] Knowledge about the meaning of communication in existentially threatening situations in care is limited. Such knowledge may possibly give insights to carers useful for attending to and thoughtfully communicating with shocked next of kin.

Subject and Methods

Design

In the present study, a secondary analysis utilizing data originally obtained for a project about ethical concerns in unexpected sudden death by stroke[4] has been performed. Secondary analysis of data is applied to illuminate the meaning of communication in unexpected sudden death in stroke, utilizing data from four studies [Table 1, Study A-D]. Secondary analysis allows researchers to apply a new research question to data already collected for other research purposes.[17,18] The kind of secondary analysis chosen for this study aligns with supplementary analysis as described by Heaton.[18] This method means that all previously collected data are subjected to a more in-depth analysis of an emergent issue from the previous studies, focusing on a topic not specifically addressed in the primary analysis. In hindsight, communication could be seen in the interviews for several studies performed for the project, although it had not been the focus. From the results of the four studies, it became evident that communication seemed to be of importance. The present study was performed to focus on and further illuminate the meaning of communication in unexpected sudden death.

Setting

The studies were carried out in a part of Western Sweden, serviced by collaborating county hospitals which provided both acute and rehabilitative stroke care following national and international guidelines.[19,20] The collaboration as such had been in place for several years and concerned both clinical and practical issues and the SU had developed a common local care program. All patients afflicted by stroke within the catchment area were cared for on these SUs. No selection of patients admitted to the SUs was made according to factors such as age, stroke severity, comorbidity, or previous vitality. As a consequence of this nonselective admission, the SUs regularly cared for patients dying from acute stroke. The SUs differed in size and had 8–18 beds. The teams caring for the dying patients on the SUs consisted of physicians, registered nurses (RNs) and enrolled nurses (ENs), and represented one way of working together, as the teams were loosely assembled from staff on duty that particular day and shift. Hence, the staff that constituted the teams changed from day to day and shift to shift. The SUs had a positive attitude to next-of-kin participation in everyday care around the clock, for patients in acute, rehabilitative, as well as palliative phases. For patients in palliative care, next of kin were offered the possibility to stay with the dying person around the clock and be involved in the care if they wished. Even though health care in Sweden is publicly funded, care and treatments are given based on health-care providers assessments, not by the patients demand for certain care.

Participants

The participants in Study A–C consisted of stroke team members [Table 1]. In total, 27 stroke team members participated; 4 physicians, 17 RNs, and 6 ENs. They were of mixed age and gender, had varying lengths of work experience, and specialist education in stroke care. All participants in Study C had participated in Study B and two of them had also participated in Study A. In Study D, 12 next of kin of patients who had died due to acute stroke during hospital stay

Table 1: Overview of the included studies with participants, number and gender, data collection, research focus, and setting

Study	Participants	Number and gender male/female	Data collection (*n*)	Research focus	Setting
A[13]	Registered nurses	10 registered nurses (10 females)	Interviews (10)	Nurses experiences of end of life for patients afflicted by acute stroke	3 acute and rehabilitative stroke care units
B[4]	Stroke team members	19 participants (4 males/15 females) 4 physicians, (3 males/1 female) 9 registered nurses (1 male/8 females) 6 enrolled nurses (6 females)	Focus group interviews (4)	Stroke team experiences of ethical problems and how the teams manage the situation in sudden and unexpected death from stroke	4 acute and rehabilitative stroke care units
C[12]	Stroke team members	15 participants (4 males/11 females) 4 physicians (3 males/1 female) 7 registered nurses (1 male/6 females) 4 enrolled nurses (4 females)	Interviews (15)	Stroke team members' preferences and usage of ways to handle ethical problems and perceived hindrances in the care	2 acute and rehabilitative stroke care units
D[37]	Next of kin of patients who died due to acute stroke during hospital stay	12 participants (4 males/8 females) of 8 patients	Interviews (12)	Next-of-kin experiences of a relatives sudden and unexpected death from acute stroke	2 acute and rehabilitative stroke care units

participated [Table 1]. The participants were spouses, children, and grandchildren of mixed age and gender.

Material

The four datasets included in the secondary analysis, one from each Study A–D, consisted of individual interviews (Study A, C, and D) and focus group interviews (Study B). All interviews were conducted by the first author in the form of open conversations, that is, conversations of daily life.[21] The interviews and focus group interviews with the stroke team members (Study A–C) focused on end-of-life care due to stroke and ethical problems experienced in connection with this. The interviews with the next of kin (Study D) focused on the next of kin's narratives about their relative's unexpected sudden death by stroke.

Analysis

The methodology underpinning the secondary analysis was qualitative content analysis as described by Krippendorff[22] and Baxter.[23] The focus was on the meaning of communication in care of patients dying from unexpected sudden death by stroke. The analysis aimed at finding the underlying message in the text, the latent content, and to interpret this. All the interviews were read through and text addressing the issue of communication in its widest definition was marked. Initially, the authors read the same interviews, one from each dataset and marked text concerning communication. Both authors' markings of the text were then compared and a considerable pattern of agreement between the two was found. For text marked by only one of the authors, discussions were undertaken to decide what to count as and include as "communication." Two further interviews were handled in the same way and the markings now showed a distinct pattern of agreement. In this way, a sort of calibration, that is, an interrater reliability of what to consider as relevant for the issue of communication was achieved. The rest of the interviews were accordingly divided between the authors so that each author read half of the interviews from each dataset and marked text concerning communication assigned for analysis. The marked parts of the texts were gathered and read again with focus on its meaning. The text was divided into meaning units, interpreted, condensed, and coded. The codes were sorted according to differences and similarities in the meaning of communication and arranged in preliminary themes. They were tested and modified, and finally, six themes with an overarching theme emerged.

Ethical considerations

Approval for the project was obtained from the University Research Ethics Committee (DNR Ö 700–03) and from the Regional Ethics Review Board, Gothenburg, Sweden (DNR 615–08). The permission was also obtained from the director of each SU. The present study as well as the project have complied with ethical principles in research in accordance with the Declaration of Helsinki[24] which safeguards the anonymity and integrity of participants and patients. The identity of participants is protected by the confidential handling of data.

Results

Communication is through the analysis revealed as the foundation for care and caring. The overarching theme foundation for dignified encounters in care built-up by six themes illuminates the meaning of communication in unexpected sudden death by stroke. [Table 2] Under these circumstances, creating a relationship is crucial for communication between next of kin and the team members. The relationship is of importance for next of kin and carers to trust each other. Information enabling understanding of what has happened to the patient as well as all parties having the will to communicate and share information with each other are essential. The sharing of information is also giving ground for unanimity about care. The carers need to get to know the dying patients, who in this situation, are often unconscious. Through information from the next of kin, given by communication, it is possible for the carers to personalize the patient being preconditioned for decisions about care. Next

Table 2: Overarching theme and themes

Overarching theme	Themes
Foundation for dignified encounters in care	Creating relationship Information enabling understanding Giving ground for unanimity Personalizing the patient Preconditioning for decisions Giving and experiencing support

of kin are often shocked by the unexpected and sudden event, the stroke constitutes and what has happened, and this affects the possibilities of giving and experiencing support.

Creating a relationship

Communication, when death is an unexpected sudden death, is through the analysis shown to be of great importance to establish a relationship between carers and next of kin. According to the carers, it is essential that a relationship is rapidly established to promote trust and for next of kin to be satisfied with the care. In this way, much was considered to be won. They further stated that the first meeting is invaluable, as a bad start is hard to recover from.

It's really hard to regain trust, it's really hard to turn it around when it's gone wrong. Then it's really easy for the relations to get hung up on the small stuff which perhaps is not actually relevant in the end (Study C, participant X, RN).

Communication also matters for the carers to be able to recognize how the next of kin experience the situation. It is stressed that the carers need to really listen to what next of kin says for a relationship to be established. In this, an honest and sincere communication is vital.

So yeah, I believe that honesty … we have. try to have as direct communication as possible, we tell them what we know and they can ask if there's anything they are wondering about so that they feel there is a platform where we can talk even if it's difficult stuff (Study C, participant VII, RN).

The interviews with the next of kin revealed that good treatment and to be shown respect invoked security and made them appreciate the care. When the patient was spoken to as a unique person, the relationship with the carers was strengthened.

We felt that we had … good contact with the doctor, really good contact, direct … concise … and … yes … he could also say that … -We can't give any guarantees … and we don't expect that either we said but … life runs its course … (Study D, participant IX, wife).

The carers in the team experienced the communication needed to create a relationship as demanding. It required considerable commitment from them and made them emotionally concerned. When a good relationship had been established, both carers and next of kin described it as feeling satisfied with the care and caring.

Information enabling understanding

Communication as information emerges through the analysis from both the perspective of carers and next of kin. The carers described that information enables understanding, something they claim is required in the situation the patient's unexpected sudden death creates; a chaotic situation. The analysis shows that carers as well as next of kin pointed out that information should be given as soon as possible and repetition is described as crucial considering the situation and the possible shock of the next of kin. The carers also stated that they sometimes need to give the next of kin time, as due to shock they did not always take in what was said. The next of kin stated that they were shocked by what had happened and revealed that they were unsure if they understood the information provided or that they did not remember it. According to the carers, information might be needed around the clock, sometimes eye to eye and sometimes by phone, for information to be given straight away. The carers meant that it is possible to withhold or divide information if considered more advantageous for next of kin. The available time or rather lack of time is also considered to restrict the possibility to inform.

Of course, you always want to inform the relatives but sometimes you do not have the time to even call, and sometimes, they are at the department and you have consulting …or something else and I think most of us have this discrepancy and it is completely due to … lack of resources (Study C, participant II, physician).

The carers mostly described information as something they give to next of kin and of importance to create calm and security as well as prepare them for the patient's imminent death but some carers emphasized the importance of dialogue. Information is also described as a mutual sharing by the carers; both giving information to next of kin and also acquainting themselves with information, the next of kin have about the patient. The carers claimed to depend on this information to be able to give care respecting the patient wishes. From the perspective of the next of kin, their need for information is apparent from the analysis. They stated that they had many questions for the carers that needed to be answered. Some questions from them have no answers, something both the carers and the next of kin themselves are aware of.

That question … it is asked really often – how much time do you think he/she has left? It's like totally impossible (to answer). (Study B, FG II, EN).

The carers also depict information as something that is shared between the colleagues and where the team rounds serve an important function in communication. The responsibility to inform is said to be "someone else's" by the carers, that is, RNs and ENs, usually the physicians and that they can refer next of kin to the person responsible. It could be experienced as a relief to not be the one responsible for giving information. From the perspective of the next of kin, information is deemed as important both to be received from the carers but also to share between next of kin themselves. They want the information given by the carers to be straightforward but at the same time tactfully given. The carers from their point of view also stated that information should be given in a straightforward and clear way, be honest, and the message should be the same regardless of which carer the next of kin talks to.

Giving ground for unanimity

Communication is revealed through the analysis from the carer's perspective, as ground for unanimity when caring for patients afflicted by unexpected sudden death. Unanimity is, however, absent in the interviews with the next of kin. In the interviews with the carers, a total agreement shows that unanimity in care is particularly central and especially unanimity with next of kin. The carers also said that they can be in disagreement within the team; in fact, they state that it is even advantageous if disagreement is given space, so that different perspectives can come forth. The importance of unanimity is stressed; to work and communicate in a coherent way toward next of kin. Unanimity is said to create trust and security thus avoiding conflicts.

Unity is important in as much that you can disagree … in your personal point of view or own opinion, but then the team or the person responsible will naturally come up with which path to take and that's where you must be in agreement as you cannot. have different strategies in front of the patient, but ... to have put in the work beforehand is an advantage I think if you are not in agreement or have differing viewpoints (Study C, participant XIV, physician).

Disagreement among next of kin about how care should be performed and which decision should be made is raised as problematic by the carers.

Then, they can have different opinions ... the relatives so that it becomes (difficult)…who to inform among the relatives so it can also be ... some difficulties (Study B, FG III, physician).

Through the analysis, it is revealed that the carers regard it as difficult or sometimes even impossible to care in a way that makes next of kin confide in the carers. Means to achieve unanimity could, according to the carers, be talks, discussions, and to listen and compromise so that everyone involved can accept decisions about care, even if they are not totally happy about it. The carers try to be flexible toward the wishes of next of kin to create unanimity, as long as the wishes do not oppose the carers' perception of what is in the patient's best interest. Time emerges as an important factor in this; if the carers feel time for communication is lacking, it is according to them, harder to reach unanimity implying that a fast course of events in care entails a special challenge.

Preconditioning for decisions

To reach decisions in situations of unexpected sudden death by stroke, communication between all team members, and next of kin emerges as crucial. The analysis shows that the next of kin expressed relief at not having to be the one to decide on the care of their severely ill loved one, while at the same time, they voiced a desire to be involved in the decisions. They, however, stated that it is good to have a plan to stick to. The carers from their point of view argue that next of kin cannot direct the patient's care and be the ones to decide. This might, for instance, concern requests from next of kin. The next of kin communicate what they think is in the patient's best interest by expressing their wishes and requests on care. The carers, on the other hand, argued that they comply if they find the requests to be in accordance with the patients' best interest.

There are situations where you see that now we have to ... maybe turn the patient ... as they have been lying on this side for a number of hours, you may have passed by… these hours ... where you ... should have turned the patient but the relatives don't want you to, and you think that ... we'll let it go a few more hours and then you're there ... Now we have to do it anyway, so that ... the patient doesn't get other care problems instead ... and then you may have to go against the wishes of the relatives (Study C, participant XII, EN).

The physician has the overarching medical responsibility along with the power to make decisions and the carers in the teams are dependent on the physician to make wise decisions. The teams thus work together by being perceptive to each other's views and perspectives and discuss and reflect to reach certainty on decisions. It is stated that knowledge about the patient's own will as well as discussions within the team is a precondition to making the decisions. Care might, therefore, need to be given while awaiting decisions. In such cases, care is based on the carer's assessment of the patient's needs pending decision. Once decisions are made, it facilitates information to next of kin. The physician communicates the decision to the next of kin and the decision is, thereafter, followed by everyone in the team. The analysis also shows that next of kin expressed that they accepted decisions made when they trusted the physician to be fully in control.

This doctor, the senior physician who took care of grandmother in the emergency room there … that felt good … like he had … like he had control of the situation he knew what … how she was … and I think that … from that she got the best … care (Study D, participant VII, grandchild).

When decisions oppose the will of the next of kin, the carers regard it as essential that motive for the decision is explained in detail to next of kin.

Personalizing the patient

Communication between next of kin and carers was highlighted through the analysis as important for the carers to be able to get to know the patient despite a possible reduced consciousness due to the stroke. Next of kin are crucial in this, as they are likely to know the patient best and thus can convey how the patient was as a person and their will and desires.

Yes, it ... was very easy ... it was quite natural because she had made a decision like that herself (about her husband) ... so that eh … it was not difficult at all. (Study D, participant XII, son).

How well next of kin know the patient is of central importance for the picture they can contribute. The carers describe that they are totally dependent on this information, for the patient to appear as a unique person to them.

These patients that get so poorly, we do not get contact with them ... usually in a wakeful state ... and then we do not get to know the patient in that way ... and then you are totally dependent on the relatives telling you about the patient (Study B, FG I, RN).

Through the analysis, next of kin's communication with the carers is also shown as cardinal for the next of kin to be able to represent the patient. The patients are in this way being heard in care through their next of kin. The patient's own will might then be a starting point for the care, conveyed by insights from next of kin about how the patient would have wanted care to be given. The precondition for this, is according to the carers, in addition to the next of kin really "knowing" the patient, that patients have expressed their will in advance. This is something not many have done according to the carers, due to the unexpected and sudden onset of stroke.

How the patient themselves have ... or what wishes they have had since before then ... if they should have a drip or not ... and it's also the relative's bit ... if the mother has expressed that she wants to continue or not (Study A, nurse VI).

The carers meant that communication with next of kin is central for them to, in cooperation with next of kin, find out the best care for each patient. Through talks between carers and next of kin, respect for the patient's will and desire is possible to uphold.

Giving and experiencing support

Through the analysis, communication is shown as fundamental for both next of kin and carers to feel support in the sudden and unexpected situation. To listen to each other, to share, and make each other involved comes forth as essential and the carers stated that this requires time. The communication between the next of kin and the carers, and between the carers in the team, is significant to create confidence and trust. This is stated to be important due to the patient's sudden and unexpected illness and the uncertainty of the course of disease.

That you don't avoid it or like you do it fleetingly or fast ... but you engage yourself in that specific case and try to answer as many questions as possible and … you say that you're there for them … if you need to ask anything then we're here for you, and so on ... that I think yes, like they get the confidence that you still … want what's best for the patient (Study B, FG IV, physician).

Next of kin described that support covers both support from other relatives and from the carers. Support might be to sit and talk with the loved ones or the carers. This creates a connection that supports them in the difficult situation. The next of kin comfort each other and discuss things such as practicalities and what will happen. The communication with the carers was also described as essential for the next of kin to feel support to participate in care. The next of kin sometimes said that they forgot to take care of themselves and were then reminded by the carers. In this way, the communication resulted in next of kin experiencing support from the carers as their needs were noticed.

We went downstairs to get a coffee and grab something to eat because the nurse said that it was important that we shouldn't forget to eat and drink and it was really essential for us to feel that it was ok to do it ... we could do it then (Study D, participant VIII, wife).

Communication also shows the importance for the carers in the teams to find support in each other, for example, in demanding care situations like these, where the presence and continuity and to want what is best for the patient is required. The carers stated it to be crucial to listen and reflect in order to perceive the needs of patients, next of kin, or colleagues in the team. Showing patience and striving for a permissive climate was considered of value in communication to give and experience support in care and caring.

DISCUSSION

The results show communication and its meaning in unexpected sudden death by stroke as a merged entirety of the carers and the next of kin experiences. The meaning of communication in unexpected sudden death by stroke came forth in six themes with the overarching theme-revealing communication as the foundation for dignified encounters in care. This gives ground for preserving and upholding dignity referred to as absolute dignity with its values, for example, human worth[25] or Menschenwürde[26] in care for all involved parts; the carers, the next of kin, and not least for the patients. When acknowledging the next of kin's knowledge of the patient as a person seen in the theme personalizing the patient, a ground for individualized or person-centered care is enabled which also makes preservation of dignity of identity possible.[26,27] It is shown that communication is not restricted only to the spoken word but also entails how the next of kin and the carers act and interact and their intentions. The conscious strive to give ground for unanimity, the exchange of information to enable understanding, and giving and experiencing support are examples of communication acting beyond words in showing each other respect in the encounter.

Communication is shown as a ground for creating a relationship where trust is promoted. Forming a caring relationship has previously been shown as a motive for both nurses and patients to achieve trust in care.[28] Mutual trust has also been shown to be crucial for the exchange of information between carers and next of kin.[4] Information from next of kin makes it possible for the carers to "know the patient" through the next of kin, despite the patient's severe illness. This information is of importance for the carers to be able to personalize the often unconscious patient respecting and acknowledging the next of kin's familiarity of the patient in the encounter. Communication in this way makes care in the patient's best interest possible, even when the patients are unable to express themselves. This furthermore enables the patient to come forth as a unique person and upholds dignity in care.[26]

For the next of kin, communication as information given by the carers, enables them to understand the situation when death by stroke is an unexpected sudden death. In the theme, information enabling understanding the importance of timely and repeatedly given information in the encounter is stressed by the carers. The next of kin are often in shock due to the unexpected sudden event the stroke constitutes and might need time to grasp the rapidly arisen situation. The importance of timing in communication, such as giving information and preparing the family for the imminent death has previously been shown from the intensive care context.[29] These two contexts, the Acute Stroke Unit and the Intensive Care Unit (ICU) in part, share similar grounds for admitting patients; the patient's need for immediate care, often caused by a sudden event. This might explain the commonalities found between these contexts. On the other hand, all encounters in care contexts may comprise situations similar to this, as life and health at all times can change rapidly. When unexpected sudden death by stroke occurs, the initial situation is also characterized by uncertainty surrounding the outcome, prognosis, and survival. This affects the next of kin[3] as well as the carers in the stroke teams.[4,12] They all have to handle the uncertainty in the situation where the meaning of communication as shown in the themes, information enabling understanding, the possibilities to giving ground for unanimity and in preconditioning for decisions for making solid decisions despite the changing and unstable conditions, has a decisive role. This constitutes a major challenge in all care contexts where swift changes in patients' health condition and issues on life and death occur. Another challenge when uncertainty prevails is the giving and experiencing of support. Time is stated to be a necessary prerequisite for achieving this. Communication further enables mutual understanding during the whole course of events ensuring the patient receives proper and respectful care, that is, care in the patient's best interest, regardless of changes in the patient's condition. The importance for next of kin to be updated on changes in the patient's condition has previously been shown from ICU care in a study focusing on palliative care.[30]

Health care has been described as a distinct realm of power implying that all communication taking place in encounters in health-care context has to deal with aspects of power.[31] The patients and their relatives will meet care and carers as underdogs due to the health-care professionals' superior knowledge about the human body, diseases, and their treatments. This puts a strain on health-care providers to make efforts to obtain mutuality and equality for upholding dignity. The Swedish Patient Act (SFS 2014:821) states that all patients or their authorized next of kin should be given information about their health status, care and treatments, and to participate in all decisions about care. It is, therefore, of great importance that communication in the encounter between carers and next of kin works, to be experienced as dignified, not least in situations of uncertainty where life and death are involved.

The results show both the carer's awareness of their power and superiority in communication and their responsibility for the encounter.[31] At the same time, as the carers stress the need for unanimity, information foremost comes forth as one-way communication from their perspective. The carers claim to struggle to achieve unanimity with next of kin, but the possible and unfavorable situation of discord is also mentioned. The next of kin, on the other hand, seem to take unanimity between them and the carers for granted. This is interesting as the carers, in fact, have the power to enforce decisions and next of kin have no such power on medical decisions. It is therefore of great importance that the carers are aware of their ascendency and responsibility for the best care to be given to the patient. Discord between next of kin and carers will most probably not promote a dignified encounter.

Many of the aspects of communication in the present study show similarities with a study performed in a palliative-care context.[32] However, the aspects of communication related to unanimity, decisions, and support were not as prominent in that study. Could this be explained by the uncertainty created by the unexpected sudden death, the shock, the next of kin experience due to this, and the precondition these two circumstances constitute for care and caring in the present study? Uncertainty has previously been shown to affect the next of kin in various ways,[3,29] which in turn puts extra stress on the carers to manage the situation. The present study reveals the carers' conscious strive for handling the uncertain situation where communication is revealed as the foundation for dignified encounters in care despite the uncertainty and shock in next of kin. There may be cultural aspects to be considered regarding conceptions about dignity and the role of the family in care of patients in end of life[33] affecting the role of communication. As the majority of the participants in the present study had a Swedish background, cultural aspects need to be further explored.

Strength and limitations

Secondary analysis as method gave the opportunity to study the communication and its meaning in unexpected sudden death "in action," that is, through the participants' narratives about their experiences related to care in unexpected sudden death by stroke. If performing interviews specifically focusing on the meaning of communication, we would have risked capturing only the participants' preconceptions about the issue rather than the meaning as unfolded from the narratives. Aspects of the meaning of communication may, however, have been missed due to this. The focus of the analysis, communication, and its meaning in unexpected sudden death emerged as an issue in the studies from the ongoing project. The question posed in the present study is covered by the aim of the project and from that perspective, no ethical doubts were found against performing this supplementary secondary analysis.

Secondary analysis has been critiqued on epistemological grounds, for example, if data used in the analysis has been collected by other researchers.[18,34] The issue of "not having been there" is seen as a major objection to the method. The data for the present study were originally collected by the first author and the requested valuable first-hand relation to the interviewees to understand the data in its context is thus achieved.

Trustworthiness is achieved through the carefully performed and described analysis of data in line with what is proposed for the content analysis as method.[22,35] The quotations further enhance trustworthiness, where representation from Study A–D, next of kin and all professions, were strived for. The results of the study may be transferred to other contexts where patients dying an unexpected sudden death due to other causes than stroke, are cared for.

CONCLUSION

Communication shown as the foundation for dignified encounters in care and its meaning in unexpected sudden death, as experienced by stroke team members and next of kin enables the patient to come forth as a unique person and uphold dignity in care. It is a conscious strive for the carers to give ground for unanimity to handle the uncertainty in the situation. Communication means exchange of information to enable understanding as well as giving and experiencing support as preconditioning for decisions. The purpose is making solid decisions despite the changing and unstable conditions in which swift changes in patients' health condition and issues of life and death occur. In this way, communication makes care in the patient's best interest possible, even when the patients are unable to express themselves. Acknowledging the next of kin's familiarity with the severely ill patient will contribute to personalizing the patient to the carers and in this way be the ground for a person centeredness in care despite the patients' inability to defend their own interests. Through knowledge about the patient as a person, the foundation for dignified care, preserving, and upholding absolute dignity is given, expressed through respect for the patient's will and desires and derived through conversations between carers and next of kin.

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Conflicts of interest

There are no conflicts of interest.

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