

# End-of-life issues in acute stroke care: a qualitative study of the experiences and preferences of patients and families

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## Abstract

The aims of this qualitative study were to identify patients' and family members' experiences of acute stroke and their preferences for end-of-life care. Twenty-eight purposely sampled patients with an acute stroke who had high ( $n = 13$ ) and low ( $n = 15$ ) disability were selected from 191 sequential cases admitted to two general hospitals in north-east England. In addition, 25 family members of other stroke patients were recruited. Views about current stroke services and preferences for end-of-life care were elicited in semi-structured interviews. Communication between patients and family members and healthcare professionals was consistently highlighted as central to a positive experience of stroke care. Honesty and clarity of information was required, even where prognoses were bleak or uncertain. Patients and family members appeared to attach as much importance to the style of communication as to the substance of the transfer of information. Where decisions had been made to shift the focus of care from active to more passive support, families, and where possible patients, still wished to be included in ongoing dialogue with professionals. Where patients were thought to be dying, family members were keen to ensure that the death was peaceful and dignified. Families reported few opportunities for engagement in any form of choice over place or style of end-of-life care. No family member reported being offered the possibility of the patient dying at home. Uncertainty about prognosis is inevitable in clinical practice, and this can be difficult for patients and families. Our findings demonstrate the importance of improving communication between patient, family and health professionals for seriously ill patients with stroke in UK hospitals.

## Keywords

communication, end-of-life care, family support, palliative care, stroke

## Introduction

Stroke is a common and potentially life-threatening condition with several critical decision points at which difficult and important treatment choices need to be made, especially in the acute phase (first 30 days).<sup>1</sup> According to the World Health Organization, stroke along with coronary heart disease are the leading causes of death and disability globally.<sup>2</sup> Annually, 110,000 strokes occur in England, and 20–30% of patients die in the acute phase.<sup>3</sup> It is the third most common cause of death and represents a major expenditure in health and

social care in the region of £7 billion a year.<sup>4</sup> Stroke patients utilize over 2.6 million bed-days annually in acute, rehabilitation and long-stay facilities.<sup>1</sup> Despite this poor outlook, those who die following stroke in the United Kingdom seldom access specialist palliative care services, and responsibility for their care rests predominantly with stroke and rehabilitation specialists, general medicine and primary care. Palliative care services and hospices are closely associated with cancer care in the United Kingdom<sup>5</sup> and there are known to be inequities in access.<sup>6</sup>

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Recent government policy has recognized the need to improve the provision of end-of-life care for all patients including those with stroke.<sup>4,7</sup> There is evidence that patients dying following stroke have unmet needs, with high levels of symptom burden, psychosocial concerns and their families have needs for information about future care options.<sup>8,9</sup> A review of the literature indicates a dearth of evidence on patients' and families' preferences for end-of-life care, or on the best interventions to support them.<sup>10</sup> Models of palliative care developed in the context of cancer may not be applicable or appropriate for those with stroke.<sup>11</sup> The uncertainty of the dying trajectory, difficulties in prognostication and concerns about 'prematurely withdrawing' active interventions mean that the palliative care needs are often unrecognized until too late to be of benefit.

The current literature, then, demonstrates the absence of an evidence base about patients' and family members' views regarding their stroke experiences and end-of-life care preferences. In our study, which forms part of a larger investigation of palliative care needs in acute stroke,<sup>12</sup> we used interviews to explore patients' and family members' accounts of their experiences and views of end-of-life care, and we aimed to identify barriers and opportunities to improve care for this group.

## Participants and methods

The study involved a cross-sectional qualitative exploratory design owing to the limited previous research. Data were collected from patients and family members. Semi-structured interviews have the advantage of eliciting responses to key topics, while also allowing participants to share their perspectives.<sup>13</sup> Ethical approval was granted from the local NHS research ethics committee and research governance approval was obtained from the NHS acute care Trust.

### Sampling

Data were collected from two district general hospitals with specialist palliative care teams, in Sheffield, a large post-industrial city in north-east England. A purposive sampling method was used to select patients with an acute stroke who had high and low disability, drawn from 191 sequential cases admitted to hospital for stroke, none of whom were referred to hospital specialist palliative care teams.<sup>12</sup> Inclusion criteria included: adults with stroke either cerebral infarction or primary intracerebral, but not subarachnoid haemorrhage; confirmed by CT scan. Exclusion criteria included patients who were: children, without CT scans, unconscious, unable to provide consent and for whom assent from

the next of kin could not be obtained. Patients were recruited via the Stroke Clinical Nurse Specialists who routinely screened them on admission to hospital using the Barthel Index (BI), a standardized validated measure of functional status.<sup>14</sup> A BI score of 14 or below was used to indicate moderate to severe stroke-related disability.<sup>15</sup> Twenty-eight patients participated in interviews ( $BI < 14, n = 13$ ;  $BI > 15, n = 15$ ), (59% over 65 years), 68% male, median hospital stay 5 days (range 1–49 days). Participants also included 25 family members (45% spouses) of patients' hospitalized with acute stroke. These patients were similar in age range and gender, but unsurprisingly tended to have higher levels of dependence. Family members were included for two reasons: to elicit their own support needs and as proxies for patients who were unconscious, aphasic or had dementia.

### Data collection and analysis

Data were collected between October 2006 and June 2007, in hospital, with each interview taking approximately 20 minutes. We developed an interview schedule for patients and family members to address our aims, following a literature review<sup>9</sup> and our own experiences (Figure 1). Data were transcribed verbatim and participants were given a unique identifier. The data were analysed by using the principles of constant comparison where substantive issues were identified in the text and allocated a code.<sup>16</sup> This coding frame incorporated the experience and management of symptoms, individual stroke trajectories (including the provision of palliative interventions) and the experience of stroke services (including communication). This analysis was facilitated by using Atlas-Ti qualitative data management software (Version 5.2). Trustworthiness was established by independent coding of a subsample of transcripts by SP and CB, and then cross-checking codes and refining themes, until agreement was reached. The researchers were from different disciplines, and credibility was enhanced by further scrutiny from experts in qualitative methods and practising clinicians.<sup>17</sup>

- Knowledge and awareness of stroke
- Information sources
- Place of care preference
- Experiences since stroke
- Perceptions of the future

**Figure 1.** Topics covered in patient and family member interviews.

Quotes were selected for the results section that illustrate the main themes, and were broadly representative of our data.

## Results

All patients raised issues about communication and information provision about the stroke and most wished to be involved in medical decisions related to its management. Perhaps inevitably given the stressful situation family members were in, and the potential for a lack of certainty about patient outcome, communication between family members and health professionals emerged as a key theme in the analysis. Patients also described facing the uncertainty of recovery following the stroke, and for family members of more severely impaired patients, there was some realization of the life-threatening nature of their relative's situation. We present evidence for these two main themes:

- communication and information provision;
- facing uncertainty and end of life preferences.

### *Communication and information provision*

The majority of patients highlighted that they were satisfied with the provision of stroke-related information, which included individual patient–professional communication and the use of standardized written material. However, as the excerpts in Figure 2 indicate, the desire for information was variable, with some patients feeling overloaded with information. In addition, some patients indicated a wish to not know very much about their condition. Good communication was generally discussed in the context of enhancing interpersonal relationships rather than defined by the quality of the information that was being passed from professional to patient.

There were mixed responses from family members: while many were keen to praise clinical staff on their flexibility in providing useful information in an accessible format, others reported inflexibility which was usually perceived as a lack of available opportunities to talk to staff. Very few instances of poor communication were reported, although some poor inter-personal behaviour was described. Most family members focused primarily on the flow of information between staff and themselves. The importance of information clarity and good inter-personal skills were highlighted by them as essential. The importance of honesty was emphasized as the basis for evaluating potential future recovery or, in contrast, for those where the patient had a poor prognosis, the ability to comprehend the likelihood of impending death.

Overall, family members appeared to place a certain degree of trust in the ability of professionals to provide the 'right' amount of information for individual family members to cope with. One specific suggestion for the enhancement of communication between staff and family members was the use of an available 'named contact' to be able to reinforce information from the rest of the clinical team. This suggests that family member had a desire not only for motivated and expert clinical staff, but for staff who can communicate this motivation and expertise to them. One family member highlighted the use of a pre-prepared list of questions to ensure that time spent in discussions with medical or nursing staff was best exploited. There was little evidence of families seeking information from online sources because they expressed concerns about information flow especially too much in volume and too distressing in nature.

### *Facing uncertainty and end-of-life care issues*

Implicit in the accounts provided by family members was that palliative care for people dying from stroke was not planned or certainly not planned with their input. Family members highlighted a lack of certainty about prognosis from medical staff, although advanced age appeared to be used as a benchmark for accepting the possibility of impending death. So there was an assumption on the part of families that older people were less likely to survive. This perhaps reflects a wider issue relating to family members' uncertainty about prognosis after stroke. Some participants recognized that it could be difficult for professionals to present any certainty about outcome, but they appeared to be unclear about the reasons for this uncertainty. While some families found it harder to cope with information about the impending death of patients, all welcomed the opportunity to resolve the uncertainty. Importantly, no instances were identified where family members did not wish to know about potential prognoses or where honesty from professionals that these might be poor was not appreciated. Any uncertainty about prognosis was mirrored in uncertainty about the reasons for particular interventions, for example, there were concerns about the purpose of medication.

Unlike with cancer, the diagnosis of stroke appeared not to immediately trigger fears about dying, and none of the patients or family members reported requesting the initiation of palliative care. Where a patient's condition deteriorated the changing of the focus of care from active acute stroke care and rehabilitation to a general supportive approach was reported as problematic for some family members. Negative perceptions associated with shifting approaches to care were also mirrored in transitions within the stroke service itself.

### **Patients' views on communication and information**

Dr (name), I find I can speak to him. He's my consultant, I can speak to him very easily, he's a really, really nice chap to have a natter with and he will answer any of your questions. 5:10 (55:55 patient)

Well to be honest I've been bombarded with so much information from different people that I've not really wanted anymore! 8:4 (81:81 patient)

They've given me leaflets and I've read them, but I've got to be honest, I've not sort of wanted. How can I say? I've not wanted to forget it's happened to me, but I don't particularly... as far as I'm concerned, it's happened and I've got to get on with it and, you know, it could have been something worse that had happened to me, so, no I've not read into it, and I don't really want to, as long as I get the correct treatment, for what has happened to me, I'm more than happy. 5:11 (73:73 patient)

### **Families' positive views on communication and information**

When she was brought on to the ward and there was a young doctor who was on, she came up and gave me as much information as she could regarding what had happened to my mum and what tests she was going to have. She was really ... nice to talk to and asked if we had got any questions. It was nice she gave that bit of time to see if we were alright and told us what we needed to know. 7:1 (23:23 family)

Well the physio left a sheet of paper that tells you all about the stroke and you read through it and it explains what can happen to people, they can lose their temper through being frustrated cause they can't do anything and things like that. 2:5 (37:37 family)

... I've not been on the internet because I think you can find too much out on there, I might not want to know some of it. 19:4 (19:19)

### **Families' negative views on communication and information**

... basically it's to hang about until the doctor decides he would like to talk to you... 10:8 (72:72family)

In visiting times you don't see the doctors, all you see are the nurses and I know they are all really busy, I'm not saying they are not but you have to grab one and say on how has he been today they don't automatically come up to you and say he has had a good night or he was ill last night or whatever, you have to physically ask for that information. 19:12 (57:57family)

I got upset when all the registrars and the consultants and student doctors and everything were talking about (patient) over the top of him and they were saying obviously it's a really bad stroke and his chances of recovery are really slim and I am thinking if he is hearing this he is going to think why should I bother then... 19:17 (74:74 family)

**Figure 2.** Examples of patients' and families' perceptions of communication and involvement with decision-making.

For example, there were reported difficulties for some families in accepting that a transfer to a continuing care facility was being considered, with a fear that the patient was being abandoned. The importance of support within the family network in terms of liaising and

mediating communication with professionals, and in providing more diffuse emotional and practical support, was clearly evident.

In the cases where family members were interviewed during the final stage of the patient's illness, their major

### **Patients' concerns about impact of stroke on family**

I've been more concerned in my own head about how it's affecting (wife's name) than how it's affecting me... 1:18 (154:154 patient)

My wife has been through it all before with her husband, he died, sadly at 40's... 9:6 (27:27 patient)

I think I'd be better going out (home) because I'd be in my own environment and my own set up, I'd feel better anyway... 1:16 (142:142 patient)

### **Families' concerns about end-of-life issues**

At 89, I think my Mother's dying to be quite honest. I think that this is the beginning of the end, though it could go on for weeks, I don't know. If I had a husband at 40 who'd had a stroke, then I'd be on the net researching, because that would be a completely different scenario. But my Mum's 89 and I just want her to have a quiet, peaceful, pain-free, dignified ending. That's what I want for my Mum. 8:2 (46:46)

he was more or less saying she's had it like, I'm not saying he used those terms, but she's dying and that's it. Something like that and our (daughter) feeling that he was talking to her as if she was about a twelve year old girl, you know, and that's why she cleared him off, she says I'm not having him talking down to me. 1:25 (225:225)

Well we just haven't got any idea of how long, we don't know... (Doctor) couldn't tell us, he said sometimes they get relatives sat round the bed for days you know, or it could be hours, so I just don't know. 10:5 (38:40)

Explained it could go either way and that is as much as we've known isn't it? 11:3 (20:20)

they made it fairly clear that there is not much, well, no hope of recovery, so... She's 91 and hardly had a day's illness in her life, so she has done pretty well really... 10:4 (33:34)

the trouble is you don't know, you can't make a judgment of how bad it, you know it's bad, it looks bad, but how bad and the nurses really weren't able to be, to enlighten us on that, whether that was an ethical or professional issue I'm not sure, or whether they just didn't know. But I asked more than once. A bit frustrating... 10:3 (25:26)

What I want to know is all the medications she is on now, if she wasn't on this would she just die? Is the medication keeping her alive? That's an important part of the things we are trying to find out... 7:8 (53:54)

**Figure 3.** Examples of patients' and families' perceptions of end-of-life issues.

concern was that the patient was not in any form of distress (see Figure 3). This is similar to the situation where patients were thought unlikely to recover, but where death was not felt to be immediate. Here there was a desire that if death was inevitable, then this should be peaceful and dignified. One of the few explicit end-of-life decisions that families reported being engaged in was the decision regarding resuscitation. We found instances where uncertainties about prognosis and a lack of awareness about care and treatment

options, including the possibility of referral to a specialist palliative care team, may have compounded family members' difficulties in contributing to end-of-life decisions. Most families highlighted an awareness of the difficulties of balancing active intervention with potential outcomes. Where family members were aware of 'Do Not Resuscitate' orders (already made by the medical team), the difficulty of participating in discussions about their applicability was clearly evident. Families appreciated opportunities to consider and

The prognosis that I got from the doctor yesterday was that if the family were agreeing, I think they call it pegging, putting a tube into his tummy and how did we feel about it.

Now I have a personal feeling that I don't want my father going through any more distress if we are only extending the inevitable and they are not sure whether the nutrients he would get would be accepted by, you know, someone of his age. Obviously I want the best for my dad, the best treatment he could possibly have and if he recovered then fine I want him back but not at all costs. 9:2 (8:8)

I can't think of anywhere else he could be. I couldn't care for him could I? No it's the best place for him. 6:2 (43:44)

I would prefer her to be in a little side room of her own when she is so poorly. I would actually have thought she was so bad that for her it really doesn't matter too much, but I think that for some of the others who are clearly recovering it must be quite distressing to have people that bad in the same ward. 10:6 (48:49)

It's a difficult decision to make (Do not resuscitate), to answer, you need time to think about it, weigh the situation up and discuss with family members. 7:7 (49:52)

### Families' experiences of stroke services

I know they've got visiting times and I know they have got jobs to do in between and they may be busy, but if it is critical ... it shouldn't be a phone call ... get up here for the last final half hour. If she is really poor you should be able to come at any time, and they should tell you you can come any time you like. Obviously we know they don't want 20 people round the bed but there's a waiting room in there ... 14:4 (60:60)

From what I can gather it's just been all round good attention, they can't work miracles, my mother's had a major stroke and it looks to me as though she is getting the best possible attention. 7:13 (85:85)

I said, do you just want to put that PEG in there so you can move her out to a nursing home or whatever? 1:19 (147:147)

It was as callous as that. I asked her, they wanted her out, they wanted the bed, and I really felt that my Mother was just a piece of flesh that they were, passing from one system and that was just all it was. They weren't cruel to her, don't misunderstand me, they weren't cruel, they weren't inhumane, it's that care, it's about care. They looked after the people, but they didn't care for them. It's a very subtle difference. 8:3 (50:58)

**Figure 3.** Continued.

discuss within the family network the implications of a decision not to resuscitate the patient. Where family members were invited to participate in medical decisions, such as the insertion of PEG tubes or do not resuscitate orders, they reported concerns about how these decisions were made. Stories were recounted of difficulties in making these choices, although some families' had a clear vision of what constituted a 'good death'. Where death was a possibility for patients, no family members mentioned being offered the possibility of bringing the patient home to die. One patient felt that they would be better off at home in a more familiar environment. Generally family members thought that the hospital environment was suitable for palliative and end-of-life care, particularly if single side

rooms were available. This view emerged from concerns about the experience of other patients within the clinical environment and a wish to shield them from the dying person, not just their own needs for privacy and space to be with their dying family member.

### Discussion

Previous studies on palliative and end-of-life care in stroke show that physical symptom burden and psychological distress are comparable to those suffered by cancer patients<sup>8-10</sup> and family members have unmet needs for care and support.<sup>18</sup> Greater consideration is required on how to improve palliative and end-of-life care in stroke and offer greater support to family carers.

It was alarming to find that none of the patients were referred to specialist palliative care or offered other choices such as early discharge home, all strategies that have been highlighted as good practice.<sup>7</sup> Where patients were dying, family members were keen to ensure that the death was peaceful and dignified. Inevitably, dealing with families in crisis appeared to be complex, with the potential for negative family experiences. Uncertainty is inevitable in clinical practice, and this can be difficult for patients, families and professionals alike. Peer support may be important in maintaining hope, but may have some detrimental effect in accepting a bleak prognosis.

Communication between patients and family members and healthcare professionals was consistently highlighted as central to a positive experience of stroke. Honesty and clarity of information was required, even where prognoses were bleak. Patients and family members appeared to attach as much importance to the style of communication as to the substance of the transfer of information. Where decisions had been made to shift the focus of care from active to more passive support, families and patients still needed to be included in dialogue with professionals and be provided with suitable information.<sup>19</sup> The impact of stroke, and the necessary readjustment and mobilization of resources in families suggests that services need to consider in greater depth the family network, rather than cursory acknowledgement of a 'carer'.<sup>18</sup> There was recognition amongst patients and family members that timing of communication is difficult, but strategies for management of that time were highlighted, including the use of pre-prepared questions, and identification of a nominated individual to 'manage' communication with staff. Ensuring time for communication is realistically incorporated into stroke workforce planning models is absolutely essential.

No family members discussed the possibility of death at home, although this may reflect a lack of awareness about opportunities for this to be facilitated. Indeed there may be practical difficulties in providing a suitable environment to support patients in the terminal stages of stroke, and their families, in an acute stroke unit. These difficulties are both practical, including managing the needs of other patients, and reflect the pervasive ethos of care. The overarching practice framework within stroke services focuses upon active rehabilitation with an increasing acute care emphasis. Our data suggest that when active rehabilitation is 'withdrawn', patients and families can feel isolated and neglected. In addition, the location of terminal care also needs to be considered in the light of the government's choice agenda, to ensure equity between stroke and cancer patients.<sup>7</sup> It should be noted, however, that patients and families appreciated the

specialist nature of the stroke service, and valued the skills and expertise of the stroke team. A retrospective survey of bereaved family members has provided valuable insights into the symptom burden and the effectiveness of services (or not) in the final phase of life and at death<sup>20</sup>.

### ***Strengths and limitations***

Our study was designed to form the basis for further research throughout the UK on improving end-of-life care in acute stroke. It was therefore exploratory in nature and reflects the experiences of patients and families in only two hospitals in one city. We acknowledge that generalizations cannot be made but qualitative research has the advantage of allowing more nuanced insights to be revealed. We initially experienced recruitment problems in the pilot study because we found that stroke service staff equated palliative care with terminal care, and did not refer patients until they were virtually moribund. In the main study, our recruitment strategy included all patients admitted with stroke, leading us to believe that we have achieved an unbiased sample. However, as the interviews relied on ability to talk this excluded those who were aphasic, unconscious and disoriented, perhaps those most likely to die. Therefore, we have relied on proxy accounts from family members by necessity and also out of a desire to learn more about their experiences.

### ***Implications***

The NHS End of Life Care Strategy<sup>7</sup> provides some direction for the integration of stroke and palliative care, although this will principally benefit those people who die in the acute phase of stroke and their families. Our data suggest that patients who experience acute stroke also have needs and concerns which reflect the repertoire of palliative care, and these patients and their family should have access to compassionate end-of-life care before the patient can be described as 'dying'. In addition, we regard it as a priority that specialist stroke services increase their expertise in delivering general palliative care, perhaps by appointing an advocate for championing these skills within the team and further research is urgently required.<sup>21</sup> We suggest that more needs to be known about the experiences of family members who have witnessed the death of a patient with stroke.

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