Original Article

The End-of-Life Care Experiences of Relatives of Brain Dead Intensive Care Patients

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Abstract
Brain death is a traumatic and sudden event following a severe injury to the brain. Most patients with brain death spend the last days of life in an intensive care unit (ICU), where some families will be approached to ask for organ donation. This qualitative study was carried out with relatives of patients who had died of brain death in an ICU; all relatives were interviewed six months after the death. Twenty ICUs were recruited for this study. The next of kin of 130 patients who died during the study period were approached, and 30 (22%) agreed to be interviewed; one later withdrew. This paper focuses on the perceived palliative care needs of the 29 families. Participants valued the physical care their relatives had received, but communication and breaking bad news was a cause for concern. The facilities on many ICUs, for example, cramped relatives’ rooms and little privacy to be with the patients or to say the final goodbye, was a common theme to emerge. Bereavement follow-up did not routinely occur, and this was an identified factor noted by relatives. Families living through the period of brain death in a loved one may have particular needs in terms of end-of-life care and should be offered the support of a palliative care team through the last days of a patient’s life and into the period of bereavement. Staff training on how to communicate bad news should also be implemented as a matter of urgency. J Pain Symptom Manage 2008; —. © 2008 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.

Key Words
Sudden death, organ donation, palliative care, intensive care

Introduction
Brain death is a sudden and traumatic event that occurs either following a medical event, for example, severe brain hemorrhage, or following an injury, for example, a road traffic accident. Patients are brought into hospital and initially kept on a life support machine until a decision can be made about whether any intervention is possible or to switch off the life support machine. During this time, many relatives will be approached to consider organ donation. This is a highly stressful and emotionally distressing time for families. This article describes the perceived palliative care needs of families of patients who experienced brain death and had been subsequently approached for organ donation.

Health professionals frequently express extreme discomfort about speaking with families and a dying patient about death. Talking
about death with patients and their relatives has been identified as a training need in newly trained doctors, and three-quarters of house officers report inadequate guidance of any form in breaking bad news.3

The need to ask families to consider organ donation at a time of sudden bereavement compounds the communication challenge for doctors who believe that this is another burden for families to have to carry.4 Concern over increasing bereaved families’ burden, coupled with poor communication skills in talking about death, in particular brain death, not only means clumsy and ineffective bids to approach families about consent are likely, but also equally difficult conversations about the end of life of the patient.5,6 It is being increasingly acknowledged that the principles of palliative care can and should extend beyond cancer and that patients within the intensive care unit (ICU) can benefit greatly from palliative care approaches.7,8 This article reports data from a larger study exploring organ donation on ICUs and focuses on issues relating to the palliative and supportive care needs for families of patients admitted with brain death during this time.

Methods

Participants. One hundred and thirty-eight consecutive bereaved next of kin of potential organ donors were identified by senior unit staff from twenty ICUs in the Northwest of England and were invited by letter to participate in the study.

Procedure. Qualitative methods allow an exploration of how people have made sense of their experiences, without prior assumptions being made of what will emerge as important. Data analyses were based on the constant comparative method.9 The data for this study were collected by one of the authors (J. M.) who interviewed the next of kin and took extensive field notes at each interview. All authors reviewed each transcript and the emerging data, and contributed to the ongoing analysis. The research team did not have ethical approval to ask relatives to comment on the transcripts, but we believe that triangulation of the data and robustness of the data were maintained by the aforementioned approach. The team included expertise in clinical and health psychology and palliative care. The researchers worked between the accounts and the thematic coding framework to verify the meaningfulness and accuracy of the categories. The validity of each category was then sought by searching for confirming and disconfirming statements in relatives’ accounts. Record of emerging analysis was collated by another author (S. P.). Illustrative examples of experiences and opinions were derived from the accounts and the assignment of data re-checked. As a research team, we believe that the use of assessors from different professional and clinical backgrounds was an additional source of trustworthiness of the qualitative analysis.

Participants indicated that they wished to be involved in the study by sending a reply letter to the research team. Participants were interviewed in a place of their choice. Interviews took place six months following their relative’s death. An interview schedule of open-ended questions was devised following a review of the literature. First, participants were invited to describe, unprompted, their experiences and reactions to what had happened around their relative’s death. Following this, relatives were asked how satisfied they were with specific features of ICU care, such as how news of death was given, how they were approached about donation, and to describe their thoughts in reaching a decision. Recall about staff support and communication was probed for clarification and elaboration. Full ethical approval was obtained for this study.

Results

Of the 130 next of kin approached, 30 (22%) agreed to be interviewed. One participant later withdrew because of a subsequent bereavement. Only one relative was interviewed for each patient. The age and sex of participants consenting to an interview did not differ from those refusing ($\chi^2 = 3.77, P = 0.06$). Most ($n = 20, 69\%$) of the participants were spouses or partner to the patient. Six were parents, two were children of the deceased and the remaining participant was an aunt. Most relatives were females ($n = 21$), and the mean age of participants was 47 years (SD 9.8, range 32–72 years) and the mean age
of deceased relatives was 44 years (SD 15.2, range 14–75 years).

Of the 29 participants, four had objected to donation, and three had inquired about donation but had later been refused. The remaining 22 had given consent for organ donation. Several key themes emerged from the interviews as to the way care was given, the facilities, and communication about death and bereavement.

Care of the Patient and Relatives

Generally, relatives were satisfied with the care the patient had received once on the ICU, and much of this same care was also shown to the relatives.

“The attention the nurses gave her was incredible. She was full of tubes to keep her alive. The nurses talked to her, wiped her mouth. I will always be grateful to them, it was really moving.” [Fred]

“We were looked after so well, staff cared for us so well ... let the children hold their mother’s hand. The nurse talking to them, the children knew how serious it was.” [John]

For other families, the intensity of the workload on the unit meant that, although every attention was given to the practical needs of the relatives by staff, little attention was paid to their emotional needs.

“I didn’t talk with them ... they just asked if I wanted a cup of tea, wanted to wash, or wanted toast ...” [Alice]

“I would have liked someone to put an arm around me, to look after me, to ask if I wanted tea, seeing the state I was in, I was out of my mind. You need someone to lead you and someone to spend time with you.” [Edith]

Facilities. At such an emotional time, relatives described the need for a place where they could be away from the ICU. Most units had small rooms where relatives could stay overnight. Although small and cramped, these were usually appreciated by families. A major issue for relatives was the family rooms, often small rooms attached to the ICU, which was the only access relatives had to making tea and coffee or being able to get away from the ward.

“Waiting area, started off clean but by the end of the night, pretty messy. The amenities were very basic. There was a kettle because the coffee machine wasn’t working. It certainly was too small, too busy and it wasn’t acceptable.” [Nesta]

“I could not sit down because there weren’t enough chairs so had to stand while the doctor was talking to me. [Beatrice, on being told by the consultant that her child was brain dead in the middle of the family room]”

The layout and facilities of the ICU also caused problems for families who felt they did not have any privacy with their loved one in the period of time preceding the machine being switched off or the relative going to the operating theater for organ donation.

“The ICU was clean, not really busy. In the day people were around. There weren’t any separate rooms. There were curtains with privacy; it wasn’t good enough. Didn’t really have the opportunity to be alone, not really, it was a bit public. I would have liked to have a room. You were aware of others being around so you had to cry really quietly.” [Eunice]

Communication about Death. There were several elements to the communication experienced by relatives regarding their loved one’s condition and impending death. It appeared that, sometimes, staff did not appreciate the suddenness and intensity of the event that had brought the patient to their unit, and did not communicate sensitively with the families, as experienced by the families below.

“Her death was so sudden, so quick. The doctor said, ‘You know your wife is going to die.’ I was staggered. In a matter of hours she went from completely fine to being told that. I was totally gob-smacked, all too sudden. She was such an alive person...” [Tom]

“It was terrible being told that my son’s brain was ‘scrambled.’ ” [Eleanor]

There were several issues of relatives not understanding when the patients had actually died—was it at the time of the acute event or when the machine had been switched off?
difficulty in accepting that someone who still looked the same was in fact dead was also difficult for some relatives to comprehend.

“I was never told actually — I had to infer it. They said, ‘From the tests we have never seen anyone come back from this stage.’ What I would have wanted is, ‘F is clinically dead and the machine is doing everything.’ I couldn’t believe, because the body was warm and moving — they were going to take things from the body...it is hard not knowing if she is dead...Is she? ... I knew in a way, but was not told. They should have said, ‘F is now dead’ — told you straight ... I would have got my thoughts straight. I needed to be told.” [Alice]

_Bereavement._ Following the machine being switched off, the events varied. Some relatives were left on their own once a decision had been made.

“While I was in hospital I had loads of care and attention, but at the end I needed someone to take time with me. At the end, somebody could have asked, ‘How are you getting home? Who is taking you home?’ They didn’t and I don’t know how I did.” [Irene]

“A letter after the event, saying something like, ‘We understand how things are. In the meantime, here is a number... You are on your own afterwards. You have got time to think. It would be nice if they would see if you would like to attend a support group or answer questions, to know that you are not on your own. It would be good if they let you know straight away.” [Ethel]

Where staff did accompany relatives from the ward, this was greatly appreciated.

“In the end J [nurse] came to see us off. This helped a lot.” [Tom]

**Discussion**

Sudden death is very different from a terminal illness—there is no time for relatives to prepare themselves for the death or to have a chance to say the things they wanted to say. Patients admitted to hospital with brain death are what can be called clinically dead, but when on life support machines, to their families they appear alive—they are thus in a very similar situation to a patient with a terminal illness who is very near the end of life. Thus, it can be argued that the families of these patients require the same care as would be expected for any other family of a patient with a terminal illness. The findings of this study suggest that, although the technical care given in ICUs was not criticized, there is varied attention given to the emotional and practical needs of the family, both while in the ICU and during bereavement.

Although there was some evidence of good practice, several of the relatives commented about the apparently harsh and insensitive way that news was broken to them about the brain death of their relative. This information was often communicated within a short time of arrival at hospital, giving relatives little time to adjust to what had happened. There was little evidence that shared decision-making had taken place in any of the families interviewed, although this is widely acknowledged as good practice and is associated with relatives feeling a greater sense of satisfaction with the care given. There is evidence that the nature of information sharing depends on the ability of the families to engage based on intellectual capacity. We would suggest that relatives should be told of brain death according to the well-recognized principles of breaking bad news for other terminal conditions, for example cancer. The principles are based on first eliciting what the relatives may already know, establishing how much information the relative wants to know, and sensitively sharing information with the relatives according to their own pace and ability to absorb the information, and constantly checking that such information has been understood.

Palliative care focuses not only on the care of the patient but on that of the whole family. The most striking aspect of our research was that, although relatives perceived patient care to be very good, there appeared to be scant attention paid to the needs of the family. When care was given to the family, it was universally valued and remembered. Clearly, in ICUs, the nature of the care is highly technical, with very close attention being paid to monitoring of the patients. However, much of this care is delivered in a ratio of one nurse to
one or two patients, and there is a nurse in very close proximity to the patient at all times, inquiring as to how relatives are coping or as to how their needs could be incorporated into the routine nursing care. A striking feature of this study was the lack of multidisciplinary team professionals involved in the patients’ care. Not one of the relatives interviewed mentioned that they had been offered the services of a chaplain or social worker. It has previously been suggested that the presence of a chaplain on a transplant team can actually facilitate organ donation in addition to supporting families of all faiths and equally those of no particular faith.14,15

The facilities reported by relatives in the ICU were poor. In the ICU itself, there was a lack of privacy, and relatives were acutely aware that their own distress would upset others. This lack of privacy also made the final moments of relatives saying goodbye to their loved ones very difficult. Although it is not often possible to have single rooms on an ICU, greater attention to the need for privacy by relatives should be recognized. Relatives also complained about the poor respite and rest facilities available to families—one relative was unable to sit down while the news that her relative was brain dead was given, as there were insufficient chairs in the relative’s rooms. Relatives’ rooms were often small, cramped, and very basic in their facilities.

Bereavement care is a core aspect of palliative care, and palliative care teams routinely contact relatives offering advice and support following a death. In our study, this would have been greatly appreciated but was seldom offered. Participants wanted contact with the team which had cared for their loved one, but found it difficult to initiate this contact themselves. Many hospices send anniversary cards to relatives a year following the death and organize an annual thanksgiving service—such initiatives are greatly valued and can do much to support bereaved families.

We acknowledge that a limitation of this study was that of the 130 next of kin approached, only 30 agreed to be interviewed. These participants were, therefore, self-selecting to participate in this study and also gave retrospective accounts of their experiences six months after the event. However, the participants included both genders, a range of ages, different relationships, and there were representatives from each of the 20 ICUs. Additionally, analysis of the data revealed the major themes as reported in this article, and saturation was obtained. In future studies, it would be of value to recruit relatives prospectively and to gain accounts of their experiences while they were in the ICU and also to obtain the experiences of the clinicians involved in the patient’s care. Working in ICUs, where the patients are frequently young, is difficult for staff, and a study incorporating their views and support needs would be valuable.

Conclusions

From the results of this study, it appears that a palliative care team input into ICUs would be of value. The palliative care team could do much to facilitate the communication of information to relatives regarding brain death and by employing a multidisciplinary approach. Accessing other members of the palliative care team could do much to support families during the very traumatic time of the decision to terminate life-sustaining treatment and also during the bereavement process.

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JM carried out the interviews for this study, and the interviews were analyzed by JM, SP, and MLW. All authors contributed to the writing of this paper.

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