Balancing hope and despair at the end of life: The contribution of organ and tissue donation

Abstract

Purpose: Concern for the grieving family can moderate the intentions of critical care staff to advocate deceased organ and tissue donation. Conversely, benevolent actions may provoke distress through missed opportunities to save or transform lives. This article provides insight into the perceived benefits of organ and tissue donation for grieving families who experienced end–of–life care in the Intensive Care Unit.

Methods: Data were collected via semistructured, face–to–face or telephone interviews with 43 participants from 31 donor families. Audio recordings were transcribed verbatim and subjected to qualitative content analysis.

Results: The study findings affirmed the importance of person–centred end–of–life care. Donor families shared examples of good–quality care and communication that contained the hallmarks of compassion, respect, dignity and choice. We uncovered a trajectory of hope and despair in which the option of organ and tissue donation appeared to give meaning to the life and death of the deceased person and was comforting to some families in their bereavement.

Conclusions: Our study findings underlined the significance of donation decision making for grieving families. Organ and tissue donation has the potential to balance hope and despair at the end of life when the wishes of the dying, deceased, and bereaved are fulfilled.

Keywords: Bereavement, Family, Grief, Sudden death, Organ donation, Qualitative research

1. Introduction

Policy drivers for improved end–of–life care (EoLC) in the UK [1–3], together with a growing body of consumer evidence [4] underline the importance of personalised care for the dying
person and their family. Although most deaths are associated with progressive disease, a life-threatening illness or event may give rise to a sudden and unexpected death. In such cases, the option of organ and tissue donation is a feature of emergency and critical care and should be a normal part of EoLC for appropriate patients [5]. In the UK, the laws that govern organ donation are based on a voluntary opt-in system of explicit consent [6]. Morally and ethically, family members are actively involved donation decision making [7] and a collaborative team approach to obtaining family consent is advocated [8].

Intensive care unit (ICU) staff play an essential role in advocating deceased donation, yet personal attitudes toward the process are known to impact donation rates [9]. International research suggests that approaching the subject of organ donation with families of the critically ill can be challenging for the healthcare professionals involved [10–13]. An important concern is the distress that donation may cause for grieving families [13–16]. In contrast, bereaved families have refuted confrontation with an approach for organ donation [17–21] and apprehension about its impact on their grief [21–24]. A cross-sectional survey with a sample of bereaved family members in ICU concluded that organ donation neither hinders nor furthers the grief process [21]. Subsequent research suggests that the act of donation may ease suffering [22] assist families in their grief [23], and have a beneficial effect on the bereavement process [24].

This article draws on the findings from a national study of bereaved families’ experiences of organ and tissue donation, and perceived influences on their decision making [25]. Relevant study findings embodied in three global (principal) themes are presented. Our aim is to provide insight into the perceived benefits of organ and tissue donation for grieving families who experienced EoLC in the ICU.

2. Methods

2.1 Study design

The study was implemented via single, retrospective, qualitative interviews to generate rich, informative data about the experiences of the bereaved who gave consent to organ and tissue donation. The design feature of saturation is a recognised milestone for establishing sample sizes in qualitative inquiry [26]. However, its use has been challenged in terms of
attainability in applied research [26], plausibility across the various qualitative methodologies [27, 28] and as a generic marker of quality in qualitative research [28]. A sample size of 30 families was considered realistic within the timescale for completion of the study and the funding available for travel costs. As such, the concept of data saturation was not applied as an indicator of sampling adequacy. Purposive sampling gave preference to the most recently bereaved families but bereaved no less than three months and no more than 12 months at the time of recruitment to the study. Participants were offered the option of a face-to-face or telephone interview.

2.2 Study sample
A total of 12 National Health Service (NHS) Trusts, representative of five regional organ donation services in England agreed to take part in the study. We achieved an acceptance rate of 32% which is consistent with Sque’s experience of recruitment to this type of study [29]. Participants were recruited from hospitals in all the targeted regions and included representation from 10 NHS Trusts. The study sample comprised 43 participants from 31 donor families; 21 men and 22 women who were representative of a variety of family relationships. Of the 30 interviews, 12 involved two family members. Participants were bereaved a mean of seven months at the time of recruitment to the study, and most family interviews were held within one month of acceptance to participate. The demographics of study participants and their deceased relatives can be found in Table 1.

2.3 Data collection and analyses
A total of 30 interviews were carried out; 26 face-to-face and four by telephone. One family member expressed a preference to provide written responses to the topics covered in the study interview guide, and this was facilitated. Agreement was sought to audio record the interviews and to use anonymous quotes in any presentation of the research. Audio recordings were transcribed verbatim and subjected to qualitative content analysis [30]. This involved a systematic process of applying predetermined codes to the text and categorising the data into basic, organising and global themes [31]. The coding framework was based on pre-established criteria, namely themes derived from an integrative literature review carried
out as part of this study [32]. Transcripts were coded as individual units and then subjected to intercase analysis. Independent coding of a select number of transcripts (n=15) was undertaken by a second analyst, and any discrepancies resolved through discussion. Three global themes labelled Past, Present and Future captured the temporal dimensions of family donation decision making. The global theme of ‘The Past’ represented families’ prior knowledge, experience, attitudes, beliefs and intentions that may have influenced the donation decision; ‘The Present’ concerned the moment in time when bereaved families experienced the potential for organ donation; ‘The Future’ typified perceived expectations and outcomes arising from the donation decision [25].

2.4 Ethical considerations
Approval to conduct the study was obtained from a Local Research Ethics Committee (West Midlands – The Black Country, reference 11/WM/0313) and via NHS research and development departments in participating hospitals. Ethical considerations and practical strategies of relevance to research with bereaved families were consistent with a framework for ethical decision-making developed by the authors and reported in the literature [33].

3. Results and discussion
In this section, relevant study findings embodied in the three global themes are presented to provide insight into the perceived benefits of organ and tissue donation for grieving families who experienced EoLC in the ICU. Exemplar quotes, representative of the arguments being made, and relevant secondary sources of evidence are integrated to enhance the credibility of our interpretations.

3.1 A desperate situation
For all families, the option of organ and tissue donation took place in the context of a sudden and unexpected critical illness or event. In most cases, injury to the brain through trauma, hypoxia, or disease accounted for admission to the ICU. Fifteen potential donors were younger than the age of 60 and three were in their adult teenage years. As such, dying and death was emotionally depicted as untimely and premature. A key experience for many
families was the absence of any warning signs. Of note was the normality and routine of
daily life, suddenly and unexpectedly replaced by unprecedented crisis. Emotional reactions
included the following: shock, ‘It was totally unexpected’ (I: (Interviewee) 030); disbelief; ‘I
couldn’t believe it was happening’ (I: 010); denial; ‘I just kept thinking this must be a
mistake’ (I: 016) and guilt; ‘If I’d only gone home a bit earlier’ (I: 013). Family members also
described how they felt stunned, numb, lost, scared, helpless, devastated, concerned,
agitated or confused. Personal states such as being in a trance, functioning on autopilot, or
having no sense of time were also used to convey the nature of the experience. Some talked
about this time as being surreal.

‘I was totally ... I wasn’t there. It was like my body was there but the rest of me
had gone somewhere else. Do you know what I mean? And it was like I was in a
dream state. I didn’t think ... I couldn’t believe it was happening to me ... or
any of us really, but me more so really.’ (I: 019)

3.2 Care and communication in the ICU

Person–centred care is a core component of UK health policy [34] and has the potential to
enhance the care experiences of the dying and bereaved [35]. We identified numerous
examples of good–quality care that contained the hallmarks of dignity, compassion, and
respect; essential attributes to support a personalised care agenda [36]. Most families
appeared to have a high level of confidence in the expertise of nursing and medical staff and
appeared impressed with the provision and standards of personal care.

‘[M] the really lovely one [nurse] who found her the pink ... nightdress ... It was
pink with little tulips on and she was sort of like ... ‘I want this young lady to look
beautiful.’” (I: 027)

‘... They knew that [A] had died. They still treated him as if he was a living
person.’ (I: 019)

Some staff were affectionately remembered by name; professionals such as doctors, nurses
and Specialist Nurses in Organ Donation (SN–ODs) received individual praise or teams of
staff such as ICU were commended. The attitudes of staff came across as mostly caring,
supportive, sympathetic, empathetic, genuine, friendly, kind and considerate.

‘... The nursing staff, how caring they were in terms of being aware of what
you were going through, and trying as much as possible, the best they can, to
try and alleviate that, to help you get through it...’ (I: 030)
Previous research has shown that acceptance of death by donor families was closely associated with the precision of information about their relatives’ critical condition [37]. It was not unusual for families in our study to use terms such as serious, severe, critical, and catastrophic when recalling health care staff communications. They appeared to comprehend the tragic nature of the illness/injury and the reality of impending death. Some explained how understanding of their relative’s condition and prognosis was enhanced by graphic illustration. This included the use of a model brain, a drawing of the brain by hand, and a computed tomographic scan of the brain.

‘When you see a CT scan of a brain … There were no convolutions whatsoever on the top of the brain, and the interior part of the brain was huge. There was just an opening and just a void really which was just filled with blood. I knew that she wouldn’t survive it.’ (l: 012)

Timely discussions about prognosis can prepare families ‘emotionally, existentially, and practically’ (p.861) for the possibility of their relative’s death [38]. We found that most families reported satisfaction with the prognostic information they received. In particular, the receipt of clear, direct and honest information, without false hope was positively remarked upon.

‘They didn’t raise any false hopes, even when I first went down to the intensive care … The first thing that was said to me; ‘your husband is very, very ill’ … Silly I know, but I knew what they meant. So no, you were being prepared all the way from when he was first admitted there to when he actually died. The preparation was on-going for the fact that he was going to die’. (l: 022)

3.3 The option of organ and tissue donation

The interviews contained remarkable detail of the circumstances that led to the prospect of donation after brainstem death (DBD) or donation after circulatory death (DCD). It was possible to characterise families’ experiences as a trajectory of hope and despair (Figure1). Families recalled emotional highs and lows. For example, their relative was alive having survived a life-threatening situation but in a critical condition; the optimism of critical care was clouded with anticipatory grief; settled periods of physiological stability interspersed with instability and concern. There was also evidence of endurance over time followed by despondency as families came to terms with the negative results of brainstem death tests or acceptance of futility and circulatory death.
Hope is an important personal need of families of ICU patients [39–44], and a recognised EoLC intervention [45]. Verhaeghe et al. [44] described hoping as ‘a cognitive process in which the positive has a place’ (p.733). Consistent with previous research in Western countries [32], we identified families’ intent to turn a profoundly negative situation into something positive by giving their consent to donation.

‘... It was a positive moment in a terrible time. It was a very constructive thing. If you could cope with the practicalities and the rawness of it, it was a very, very constructive thing. Therefore organ donation, the people who do it should not be frightened of suggesting it and going forward of it ... I know I'm only one person out of millions, but if you're frightened of asking you're going to miss opportunities and people can always say no ... Well if you never ask you never get do you really.' (l: 029)

Twelve families agreed to DBD, and 18 families agreed to DCD. In one case, the criterion of death was not stated. In most circumstances, the main decision maker was the deceased’s legal next of kin. Eight families who participated in our study experienced nonproceeding DCD. This was described as a disappointment by some families and pragmatically accepted by others. A potential donor audit carried out in the UK in 2014/15 reported prolonged time to asystole and associated nondonation of solid organs in 42% of cases [46]. In such cases, tissue donation can offer solace, although our findings suggest that this was not always presented as an option. A participant whose relative died around 16 hours after the withdrawal of life-sustaining treatment emotively described her hope and despair.

‘You’d psyched yourself up for this and you’re thinking at least it’s not totally worthless, you know, somebody’s going to benefit from his death ... I felt guilty ... thinking oh God ... They’ve done all that and we’ve let them down ...’ (l: 015).

The psychological distress associated with a critical, life-threatening event meant that some families overlooked the possibility of donation and were appreciative of staff that brought this to their attention. Honouring the wishes of the potential donor was important to grieving families, and they recognised healthcare staff that helped to meet their needs.

‘Like I said I’m glad they come up and asked me because it’s not summat [something] I’d have thought of because of having to think about everything else ... You’ve got a million and one things running through your mind and you probably don’t even think about organ donation ... I would imagine a lot of people are exactly the same. They don’t think about it you know ... And so I was glad they actually come and asked ...’ (l: 006)
In contrast, an approach–request for donation was pre–empted by some families, whereas others were reliant on staff to ask; ‘I wouldn’t have initiated the conversation because I didn’t ... I wasn’t aware ... that it was a possibility’ (l: 018). One participant suggested that he; ‘almost felt glad they were asking’ and ‘felt it was right that they should ask’ (l: 012). A number of families expressed satisfaction with the sensitivity of the approach, for example; ‘very gentle’ (l: 020); ‘very delicately suggested’ (l: 004); ‘I felt it was done sympathetically’ (l: 012); ‘very tactfully’ (l: 025) and; ‘done in a very tender sort of way’ (l: 030). Effective communication and caring practice was outstanding for one family. Reflecting on the teaching room where the approach–request took place they said:

‘I don’t think it would have mattered whether we were ... sitting. In a ... beautiful suite or ... whatever. I don’t think it would have made any difference to the way in which we were spoken to, the caring way in which we were treated. I don’t think that would have made any difference at all. No.’ (l: 010)

The study findings suggested that some Trusts or individual employees were yet to embrace donation as a routine part of EoLC. One family member was surprised that no one in the emergency department asked him about his wife’s donation intentions. He talked at length about a distressing episode of care and impressions of his wife being left to die. When approached by the intensive care team and a SN–OD, his immediate response to the donation request was; ‘well yes, she is a donor’ (l: 005). He went on to describe the difference in emergency department and ICU care as:

‘... Just unbelievable ... How can I put it ... It was like having an old banger to a Rolls Royce’ (l: 005).

3.4 Perceived benefits for grieving families

Motivating factors behind the family’s decision to donate included a belief that their relative would ‘live on’ through others, acknowledgment of reciprocity, and a selfless desire to help or benefit others. Some families felt that the decision to donate was made easier when armed with prior knowledge of their relatives’ donation intentions, and determination was apparent when confronted with situations that threatened their relative’s expressed wish, such as interference by family members, the coroner, or the police. Many families placed their decision to donate in the context of trying to make sense of their relative’s death.
'I wanted them to use his organs ... I wanted to make sense of this ... If he wasn't going to live I wanted him to be ... I wanted his organs to be used to benefit somebody else. That was important to me ...' (I: 019)

Conceptualisations of donation as a ‘gift of life’ or ‘sacrifice’ [47] were implicit in families’ descriptions. However, there was no evidence to suggest that either assumed greater significance for families. This finding may have been different had the sample of participants included declining families. There was however, some evidence of dissonant loss [48].

‘Even though she’s left a legacy it don’t make it very easy that’s she’s not here ... I’d rather have my daughter back.’ (I: 011)

‘... In a way her life wasn’t wasted ... It doesn’t get rid of that personal loss.’ (I: 027)

A number of family members said the decision to donate had helped them in their bereavement, and indicated the reasons why (Table 2). Others simply said ‘no’ when questioned if donation had impacted on their bereavement or indicated indifference.

‘Organ transplant was just harvesting I suppose ... It’s like a horrible way to say it but its recycling ... And I suppose to some extent that’s the way you’ve got to think about it. You’ve got to be a bit clinical. You can’t get too washed up in emotions about it.’ (I: 012)

‘ ... It was ... a side-line to our grief, that’s all. It’s a ... separate issue.’ (I: 021)

Hearing or reading about the outcomes donation evoked contrasting emotions, probably best described as ‘bittersweet’. Transplant recipient letters and cards were valued and appeared to provide solace to families in their grief.

‘... The letter I received from the lady recipient was an absolute boost to me ... It picked me right up when I was probably at my lowest ebb.’ (I: 025)

‘A little dollop of good in a very dark time, extremely hard time ... When you get a letter like that and you can see what a difference she [E] made. You get solace from that ...’ (I: 027)

4. Summary discussion

The donation of organs and tissues for transplantation makes a unique contribution to saving and transforming the lives of people who are critically ill and injured. Fatefully, patients in the ICU represent the donor pool, and their families play a central role in the decision and consent to donate. In this paper, we have reported the EoLC experiences of a sample of families who gave consent to donation. Our research adds to the small body of
knowledge concerning deceased organ donation and its impact on subsequent grief in the bereaved [20–24]. Participants provided a rich, informative account of the circumstances in which organ and tissue donation was pursued and the perceived benefits of their participation in the donation process. The meaning attributed to the act of donation and perceptions of emotional–psychological benefit are known to influence bereaved families’ decision making [32]. We uncovered a trajectory of hope and despair in which the option of consent to organ and tissue donation appeared to give meaning to the life and death of the deceased person and was comforting to some families in their bereavement. Donor families acknowledged the skilled care and communication of healthcare staff who supported them in making a potentially life-enhancing decision. The reported positive experiences of care and support by hospital staff is encouraging amid public concerns about the quality of EoLC in acute hospitals [49]. This finding is also important in light of evidence concerning the impact of hospital care on donation decision making and grief [20] and an association with depressive and grief symptoms [21].

The reported findings should be viewed within the constraints of the purposive study sample and size. Recruitment to bereavement studies presents unique methodological and ethical challenges [50, 51]. Involvement is undoubtedly influenced by a grieving person’s mental or physical health, and acceptance rates of less than 50% are not uncommon [52]. Issues of personal vulnerability can lead to selection bias and this places limits on the generalisability of the research results [50]. Conclusions about sample characteristics in bereavement research suggest that sudden and unexpected death of a relative may have negatively influenced our acceptance rate of 32% [52]. Participation was voluntary and comprised only families who gave consent to donation after brainstem or circulatory death. The nature and strength of our conclusions may have been different had the sample of participants included a comparison group of declining families. We acknowledge the need for a larger study population and sample to measure the effect and strength of relationship between donation and family grief. There is also a clear need to further understand families’ bereavement support needs and, in particular, those who declined donation or experienced nonproceeding DCD. Obtaining the perspectives of families who do not donate remains a challenge for Transplantation 2020 [53] in ensuring that as many people as possible in the
UK receive the transplant they need. Our experience suggests that retrospective recruitment of this coveted population is dependent on the development of robust records of the family approach–request that allows access to declining families for the purpose of research.

The circumstances in which organ donation is pursued may be influenced by the attitudes and behaviour of health care staff and the grief experienced by the next of kin. Despite our acknowledged limitations in terms of what can be inferred from the reported study results, participant experiences may have relevance to healthcare staff and grieving families who encounter similar situations in the ICU. We conclude that organ and tissue donation has the potential to balance hope and despair at the end of life when the wishes of the dying, deceased, and bereaved are fulfilled.

Acknowledgements
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References
[2] Leadership Alliance for the Care of Dying People. One chance to get it right: Improving people’s experience of care in the last few days and hours of life. London: LACDP; 2014.


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* Written Response
Table 2
Self-perceived benefits of donation

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<td>‘It feels nice to, you know, selfishly gloat about it. Not gloat about it … but the kidneys have gone to someone. So, yeah it does make it a little bit better. It’s really helped, yeah.’ (I: 002)</td>
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<th>Acceptance of death and bereavement</th>
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<td>‘I think it’s made me … able to accept the bereavement … I think if we hadn’t done that, the donor system, I think there’d be a big hole there and I think the whole process would be more painful.’ (I: 004)</td>
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<th>A belief that the deceased person ‘lives on’</th>
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<td>‘I’ve not lost somebody because … There’s still part of her alive and well. And … believe me or not, that does help. It does help.’ (I: 005)</td>
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<th>A feeling that death was not in vain</th>
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<td>‘I suppose it has [impacted] in a way to know that he didn't die totally in vain and he did save some lives has helped, you know. Yeah to me I think it has.’ (I: 019)</td>
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</table>
Figure 1 Trajectory of hope and despair

The figure characterises a trajectory of hope and despair for families in the ICU after an unexpected critical illness or event.