



Surrogate Decisions

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

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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-centered 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.

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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 personalized 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 health care 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 3 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 recognized 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

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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 3 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 5 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 2 family members. Participants were bereaved a mean of 7 months at the time of recruitment to the study, and most family interviews were held within 1 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 4 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 categorizing the data into basic,

organizing, 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 were resolved through discussion. Three global themes labeled 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; and "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 3 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.

Table 1
Demographic data for participants and their deceased relative

Study code	Relationship to the deceased	Length of time bereaved (mo)	Relative's age/sex	Critical illness/injury
001	Husband/daughter	4	80/F	Brain hemorrhage
002	Son	7	61/F	Brain hemorrhage
003	Partner (female)	8	62/M	Myocardial infarction
004	Husband	9	66/F	Brain hemorrhage
005	Husband/sister-in-law	9	58/F	Brain hemorrhage
006	Husband	7	47/F	Hypoxic brain injury
007	Partner (male)	11	34/F	Brain tumor
008	Stepson	10	59/F	Myocardial infarction
009	Sister	4	38/F	Head injury
010	Sister/sister	11	61/M	Brain hemorrhage
011	Mother/father	12	34/F	Meningitis
012	Husband	8	52/F	Cerebral vascular accident
013	Mother/father	4	17/M	Head injury
014	Partner (male)	4	64/F	Brain hemorrhage
015	Ex-wife	6	65/M	Head injury
016	Daughter	4	53/F	Brain hemorrhage
017	Mother	4	39/M	Head injury
018	Mother/stepfather	9	19/F	Asphyxiation
019	Mother/stepmother	9	28/M	Myocarditis
020	Mother/father	5	30/F	Brain hemorrhage
021	Husband	9	65/F	Cerebral vascular accident
022	Wife	7	67/M	Myocardial infarction
023	Wife/stepdaughter	6	71/M	Myocardial infarction
024	Brother	8	54/M	Brain tumor
025	Husband	6	47/F	Brain hemorrhage
026	Wife	8	64/M	Brain aneurysm
027	Mother/uncle	10	18/F	Hypoxic brain injury
028	Mother/father	7	42/M	Motor neurone disease
029	Father/stepmother	8	21/M	Alcohol/drug related
030	Husband	5	63/F	Brain hemorrhage
031 ^a	Husband	Unknown	Unknown	Unknown

^a Written response.

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