



# Bereaved donor families' experiences of organ and tissue donation, and perceived influences on their decision making

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## ABSTRACT

**Purpose:** To elicit bereaved families' experiences of organ and tissue donation. A specific objective was to determine families' perceptions of how their experiences influenced donation decision-making.

**Methods:** Retrospective, qualitative interviews were undertaken with 43 participants of 31 donor families to generate rich, informative data. Participant recruitment was via 10 National Health Service Trusts, representative of five regional organ donation services in the UK. Twelve families agreed to DBD, 18 agreed to DCD, 1 unknown. Participants' responses were contextualised using a temporal framework of 'The Past', which represented families' prior knowledge, experience, attitudes, beliefs, and intentions toward organ donation; 'The Present', which incorporated the moment in time when families experienced the potential for donation; and 'The Future', which corresponded to expectations and outcomes arising from the donation decision.

**Results:** Temporally interwoven experiences appeared to influence families' decisions to donate the organs of their deceased relative for transplantation.

**Conclusions:** The influence of temporality on donation-decision making is worthy of consideration in the planning of future education, policy, practice, and research for improved rates of family consent to donation.

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## 1. Introduction

Currently there are over 7000 people in the UK on the active transplant list; however due to a lack of donated organs, 1000 people die each year or are too sick to receive a transplant [1]. Others will be forced to lead lives severely compromised by their organ failure and the uncertainty of organ availability [2]. In 2008, the UK Government Organ Donation Taskforce [3] recommended reorganisation of donation services, targeted at increasing organ donation by 50% in five years. Despite achievement of this target, further strategic work is essential to achieving improved rates of family consent [1]. Of continuing concern is the proportion of families who refuse to allow their relative's organs to be donated or overrule their relative's expressed wish to donate [1]. Further improving the rate of family consent could have a significant impact on the lives of many people and cost savings to the National Health Service (NHS) versus alternative medical treatments. The present rate of family consent to

donation in the UK suggests we are missing opportunities to support families in making a potentially life-enhancing decision.

This paper reports the findings of exploratory research carried out in the UK to elicit bereaved families' experiences of organ and tissue donation and their perceptions of how these experiences influenced donation decision-making. The study sought to build on previous evidence accrued by the research team: the influences on donation decision making [4]; the genesis of beliefs people bring to the donation discussion [5]; how people conceptualise the act of donation e.g. a 'gift of life' or a 'sacrifice' [6]; the decision-making process and bereavement issues [4] and any meaning-making of organ donation [6, 7]. To set our UK study in the prevailing Western worldview, we undertook an integrative literature review [8]. The review involved thematic network analysis [9] comprising the development of three global (core) themes of The Past, The Present and The Future [8]. These themes provided a concise temporal framework for the analysis and synthesis of new study findings.

For the duration of the study, the legislative structure for organ donation in all four countries of the UK was that of a voluntary 'opt-in' system of explicit consent to donation. Family involvement is important to the donation process, and this is practiced for moral, ethical, legal and

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procedural reasons. However, the role of the family differs according to whether the donation intentions of the deceased are known [10]. Reported outcomes of the donation discussion depict a family decision to: agree or decline consent to donation in situations where there is no indication of the patient's wishes; support or overrule the expressed wishes of the deceased.

## 2. Study design

A qualitative, exploratory design was chosen to generate rich, informative data that would lend itself to theoretical propositions as to why bereaved families agree to organ donation from a deceased relative. All permissions for this study were granted. NHS approval was given by the UK Health Department's National Research Ethics Service, West Midlands-Black Country Committee, Reference 11/WM/0313.

### 2.1. Objectives

In the case of bereaved families who had donation discussed with them, specific objectives were to determine:

1. Families' perceptions of how their experiences of organ and tissue donation influenced donation decision-making.
2. Whether families felt their information needs about organ donation and bereavement were met and if not, what was missing.
3. Families' views regarding any public or private recognition of donors and their families (as advocated by The Taskforce [3]).

### 2.2. Participant identification and recruitment

Ten NHS Trusts, representative of five regional organ donation services in the UK agreed to take part in the study. Meetings with regional and team managers of NHS Blood and Transplant (NHSBT) and Specialist Nurses-Organ Donation (SN-ODs) led to the identification of suitable study sites. Geographical spread was deemed to be important due to potential differences in local hospital practices. SN-ODs sent a total of 99 recruitment packs to eligible participants on behalf of the research team. Recruitment was carried out in a serial manner, region by region. Purposive sampling gave preference to the most recently bereaved families. Our eligibility criteria of three to 12 months bereaved at the time of recruitment was consistent with previous work by Sque [11].

Forty-three participants from 31 families who consented to donation were retrospectively recruited during 2012–2013. Participants represented a variety of family relationships, and were bereaved a mean of seven months at the time of recruitment to the study. Twelve families agreed to DBD, 18 agreed to DCD, 1 unknown. [For further demographics of participants and their deceased relative please see Walker and Sque [12]].

In accordance with NHSBT requirements and NHS Trust data protection protocols, families who declined organ donation were approached prospectively about recruitment to the study, once their visit at the hospital was complete. This procedure required the SN-OD to seek family members' agreement to be contacted about the research a minimum of three months post bereavement. Monitoring by the research team suggested a lack of compliance with the prospective recruitment strategy. Of the 108 families who declined organ donation at the 10 participating NHS Trusts, 14 (13%) were asked if they agreed to be contacted about the research, and six families agreed. One family member did not receive information due to a change of address and the remaining five family members did not respond to our invitation to join the study. Further access to family members who declined donation included ethical approval to extend the number of recruitment sites from 10 to 12. Two NHS Trusts proposed the identification of eligible participants via the SN-OD in association with the Trust bereavement service. This resulted in the implementation of a retrospective recruitment strategy involving the dissemination of 10 recruitment packs to

eligible participants. However, we experienced zero family response to our invitation.

### 2.3. Data collection

Semi-structured, audio-recorded interviews offered participants the opportunity to give an account of their experiences and to share what was important to them. Participants were offered the option of a face-to-face or telephone interview. Both methods have been successfully used with bereaved individuals [4, 6, 11]. An interview guide was developed from the literature to ensure completion of the research agenda. Questions were attentive to the objectives of the investigation and included items that illuminated: the genesis of families' beliefs about organ donation; the families' experiences of the request-approach and the discussion about donation; the course and outcome of donation decision-making, the nature of family involvement, perceptions of decision-making influences, and feelings about the donation decision; patient, and family care; sources of information and support about organ donation and bereavement. Participants were invited to provide a background to the circumstances leading to the potential for organ donation and this placed the participants' responses in context.

Once the research team received confirmation from a family member that they were willing to join the study, they were contacted by their preferred mode and a convenient date and time for the interview was arranged. Twenty-six interviews were carried out face-to-face and four by telephone. One family member provided a written response to the topics covered in the interview guide, having expressed this preference. Most interviews took place in the home environment. The interviews were mainly between 1 and 3 h. On completion of the

**Table 1**

Theoretical framework for the presentation of study findings.

| Global theme- the past  |   |
|---|---|
| Prior knowledge, experience, attitudes, beliefs, and intentions               |   |
| Organising themes   | Basic themes  |
| The will of the deceased person   | Knowledge/beliefs about the deceased person's wishes<br>Motivation to fulfil the wishes of the deceased person<br>Overruling the deceased person's wishes |
| Predispositions of family members   | Prior experience of donation/transplantation<br>Knowledge, attitudes/beliefs towards donation/transplantation<br>Expressed intention to be an organ donor |
| Global theme – the present  |   |
| The moment in time when families experienced the potential for organ donation |   |
| Organising themes   | Basic themes  |
| Intra/Interpersonal determinants  | Psychological distress<br>Protecting the deceased person's body<br>Influences of family/friends   |
| Comprehending the situation   | Information to support decision making<br>Knowledge, understanding and acceptance of death  |
| The donation discussion   | Timing of the approach<br>Nature of the request-approach<br>Characteristics of the requestor  |
| Patient and family care   | Specialist care and provision<br>Relationships with healthcare staff<br>Donation specific care and communication  |
| Global theme – the future   |   |
| Perceived expectations and outcomes arising from the donation decision        |   |
| Organising themes   | Basic themes  |
| Hopes and expectations  | Give meaning to life/death<br>Transcendence   |
| Forms of recognition  | Public and private tributes<br>Personal communication   |
| Perceived outcomes  | Follow-up care and communication<br>Bereavement issues<br>Commitment to donation  |

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