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## Abstract

Relatives of potential organ donors are the most critical link in maintaining organ availability, as they must express their lack of objection before organ retrieval may take place. The often sudden and unexpected nature of the death of a potential organ donor, plus acceptance of a non-stereotypical death, brain stem death, could be expected to create certain challenges for families; yet, their anonymity means little is understood about their experiences. This three-year, longitudinal study sought to clarify the needs of families throughout their decision-making and bereavement, to provide a rationale for further preparation of professionals involved in this sensitive work and the voluntary organisations, such as BODY, that seek to support them. It is the first detailed, longitudinal study of families with whom organ donation was discussed. It was sponsored by the British Organ Donor Society and funded by National Lottery Community Fund. The researchers worked closely with transplant co-ordination services and intensive care units throughout the UK.

Face-to-face interviews and two, self-completed, psychometric measures, the Grief Experience Inventory and the Beck Depression Inventory, were used to elicit the bereavement experiences of 46 family members who chose to donate their deceased relative's organs and three who declined donation. Participants who chose to donate were interviewed on three occasions at 3-5, 13-15 and 18-26 months post bereavement. Single interviews were carried out with participants who declined donation. Researcher's field notes aided reflexivity, provided context and explanatory rigour to judgements and decision-making, providing a credible audit-trail of the investigation.

Data were analysed using a constant comparative approach concerned with detecting and highlighting important similarities and differences between participants. Data provided strong evidence regarding issues surrounding sudden death and organ donation, such as identification of participants' needs (need was defined as the help participants felt they required or would have liked throughout their bereavement). HyperResearch 2.2.3 was used to store and work with transcribed data. Sque's theory of Dissonant Loss, Walter's Biographical Model of Grief and the Dual Processing Model of Grief provided the theoretical and analytic frameworks. Descriptive and multivariate statistics were used to analyse the grief and depression measures, using The Statistical Package for Social Sciences (SPSS).

Findings from the interviews indicated participants' bereavement needs during the hospital stay included: the need for correct, timely information, the need for contact with the deceased, the need to understand the diagnosis of brainstem death, the need to have their special role as next-of-kin recognised, the need for healthcare professionals, from all areas, to understand their 'emotional mind-set' at this time. Families needed easy access to both formal (transplant co-ordinators, support groups and bereavement organisations) and informal (friends and family) sources of support after leaving the hospital. They needed to hear from transplant co-ordinators about the use of the organs. Their need to hear about and from the recipients of their loved ones organs increased over time. They needed support and the opportunity to talk about the deceased with friends and families or bereavement support personnel.

Results of the psychometric measures indicated that participants' depression levels were elevated at 3-5 months post bereavement and reduced to minimal levels, for all but six participants, by 18-26 months. These six participants reported poor formal and informal bereavement support. The lack of such support could therefore have a consequence for ongoing depression and grief related distress.

The ability to interchange human organs and tissues introduces a relatively unexplored dimension to grieving that requires specific attention. Bereavement support must begin at the bedside and continue until it is no longer needed. This calls for a much greater integration of support services with a seamless transfer of care from the hospital to a support organisation specifically designed to meet the ongoing bereavement needs of families, whatever their decision regarding organ and tissue donation.

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Magi Sque, Tracy Long and Sheila Payne.

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## Operational Definitions

**Conditional donation** is a condition attached to the donation of an organ, for example, particular characteristics of an individual who may or may not receive the organ.

**Death certified by brain stem testing (BST).** Death entails the irreversible loss of those essential characteristics, which are necessary to the existence of a living human person. The diagnosis of death is regarded as the *'irreversible loss of the capacity for consciousness, combined with irreversible loss of the capacity to breathe'* (Working Party of the Royal College of Physicians, 1998, p4). Three phases must be worked through to establish death by BST: 1) a number of preconditions; 2) necessary exclusions; and, 3) a set of clinical tests, which assess the functional capability of the brain stem. Tests should be carried out by at least two medical practitioners who have been registered for more than five years, are competent in the field and not members of the transplant team. One of the doctors should be a consultant. Death certified by BST is a pre-requisite for cadaveric organ donation (presently, in very special circumstances, kidneys maybe retrieved following circulatory arrest).

**Donor card** is a card that can be completed and kept by an individual, to indicate the wish to have their own organs used for transplantation, following their death. UK/European Community driving licences also allow for this information to be recorded.

**Donotransplantation** includes the process of organ and tissue donation, retrieval, and transplantation.

**Donor and Recipient Transplant Co-ordinators** provide a 24-hour on call service to facilitate organ donation and transplantation. Their role includes providing advice and education: providing information to both the general public and health professionals, regarding organ donation and transplantation. Their roles may vary, with some transplant co-ordinators working with both donating and recipient services; while others work only with donating services (Donor Co-ordinators); and others have responsibility for recipients and their families (Recipient Co-ordinators). The majority of co-ordinators are based in Transplant centres.

**HPs** are healthcare professionals. The term is used for all healthcare professionals, except where specific titles for example, transplant co-ordinator, are used.

**Organ donation** includes tissue donation.

**Organs** are defined as organs such as the heart, lungs, liver, kidneys, pancreas and intestines.

**Organ donation process** includes the process of organ and tissue donation, retrieval (the surgical procedure or operation to remove organs or tissues). A potential donor will typically have suffered an injury such as intracranial haemorrhage, which may precipitate death. Organ and tissue donation is discussed with the next-of-kin who must show a lack of objection before organ retrieval can take place. The major organ donor remains on ventilatory support until the organs are ready for removal. Without ventilation oxygenated blood could not reach the organs. Transplant co-ordinators are primarily responsible for the organisational arrangements once a donor has been identified through to the

distribution of organs. In the UK distribution of organs is co-ordinated nationally by UK Transplant. The surgical removal of organs takes place at the donating hospital by designated transplant teams, when operating theatre time can be arranged, usually at night. Multi-organ retrieval takes on average about five hours (New *et al* 1994). The organs are distributed according to national regulation. Tissues such as corneas, bone, skin and heart valves may be retrieved many hours after asystole.

**Organ retrieval** is the surgical procedure, and process, to remove organs or tissues and distribute them.

**Participants** within this study are next-of-kin or family members of the deceased or the person that the deceased would expect to make decisions on their behalf.

**Presumed consent Opt-out** assumes that individuals have no objection to the donation of their organs after death, unless they specify otherwise in advance of their death.

**Tissues** are defined as body tissues such as corneas, heart valves, blood vessels, skin and bone.

**Transplant co-ordinating services** are NHS organisations that have local responsibility, within their regions, for organ donation and distribution. Transplant co-ordinators work out of co-ordinating services.

**UK Transplant** is a special health authority operating within the NHS. The Authority provides a 24-hour support service to all transplant units in the UK and the Republic of Ireland, for the matching, allocation and distribution of organs for transplantation and maintains a database of all patients waiting for an organ transplant. A further comprehensive database includes clinical information on transplant matters, which is used for analyses and audits of all organ transplants. UK Transplant provides a focal point for information on transplantation matters to service users, professional and collegiate organisations, health departments, media and the general public.

## **Organisation of the Report**

The report outlines the background, design and method of the study. The demographics of participant families and how they were recruited to the project is explained. The findings from the interviews with participants are presented. Two psychometric measures were used to further illuminate the bereavement experience of participants. These tools are explained. The findings are reported in direct response to the aims of the study, drawn from three serial interviews carried out with participants. The findings for each aim are summarised and recommendations for practice and service provision are offered. The results of the psychometric measures follow, with a discussion. The report concludes with a discussion, a critique of the study and recommendations for future research.