

**Exploring the end of life decision-making
and hospital experiences of families who
did not donate organs or tissues for
transplant operations**

Final Report for UK Transplant

On behalf of the Research Team

Dr. Magi Sque
Ms. Tracy Long

School of Nursing and Midwifery
University of Southampton

Professor Sheila Payne

Palliative and End-of-Life Care Research Group
University of Sheffield

Mrs. Diana Allardyce
Research Fellow
Formerly of University of Southampton

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Operational Definitions

Death certified by brain stem death testing (BSDT). Death is defined 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 steps must be followed before a diagnosis of brain stem death can be made they are: (1) that certain preconditions are met, and that they are not due to (2) specific exclusion criteria, and that (3) on clinical testing all brain stem reflexes are absent and the patient is apnoeic.

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 BSDT is a pre-requisite for organ donation from a deceased heart beating donor.

Donor card is a card that when completed indicates the individual's wish to donate their organs for transplantation, following their death.

Donor and Recipient Transplant Coordinators provide a 24-hour on call service to facilitate organ donation. Their role includes providing advice, education and information regarding organ donation and transplantation to both the general public and health professionals. Some transplant coordinators work with both donating and recipient services; while others work only with donating services (donor coordinators); and others have responsibility for recipients and their families (recipient coordinators). The majority of coordinators are based in Transplant Coordinating Centres.

National Potential Donor Audit (PDA) UK Transplant's National Potential Donor Audit began in January 2003, as part of a series of measures to improve organ donation. The principal aim of this audit is to determine the potential number of solid organ donors in the UK. Data are collected on every patient death in an intensive care unit.

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

Organ donation process includes the donation of organs and tissues, the surgical procedure to remove them, their allocation and distribution. Organ and tissue donation is discussed with the next-of-kin who must state a lack of objection before donation can take place. Once a donor has been identified transplant coordinators are responsible for the organisational arrangements through to the distribution of the organs. In the UK distribution of organs is coordinated nationally by UK Transplant. The organ donor remains on cardiopulmonary support, to maintain perfusion of the organs with oxygenated blood, until the organs are removed. The surgical removal of organs takes place at the donating hospital by designated transplant teams, and are distributed according to national allocation policies. Tissues such as corneas, bone, skin and heart valves may be removed many hours after death.

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

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

Transplant coordinating services are NHS organisations that have local responsibility, within their regions, for organ donation and distribution. Transplant coordinators work out of coordinating services.

UK Transplant (UKT) is part of NHS Blood and Transplant special health authority. UKT 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. UKT maintains a National Transplant database which includes details of all donors and patients waiting for, or who have received a transplant and audits and analyses the results of all organ transplants in the UK and Republic of Ireland to improve patient care. UKT also provides a focal point for information on transplantation matters to service users, professional and collegiate organisations, health departments, media and the general public. It maintains the National Organ Donor Register and has a remit to improving organ donation rates by funding initiatives in the wider NHS and raising public awareness of the importance of organ donation.

Executive Summary of the Report

What was the reason for the research?

Relatives of potential organ donors are the most critical link in maintaining organ availability for transplantation, as they must express their lack of objection before organ donation may take place. UK refusal rates of 40%, rising to 70% in non-white groups, are therefore of concern. This study, commissioned by UK Transplant is the first detailed investigation for the UK to explore the end of life decision-making and hospital experiences of bereaved adults with whom organ and tissue donation was discussed and who declined donation.

What were the aims of the research?

1. To explore the end of life and hospital experiences of relatives who decline organ and tissue donation.
2. To identify the impact of hospital care offered to relatives in terms of decision-making about donation and subsequent grief.
3. To assess the need for end of life bereavement support and the effectiveness of any support received.
4. To identify ways of enabling relatives to make culturally appropriate choices about organ and tissue donation that are right for them.

Who took part in the research?

Twenty-six relatives of 23 deceased individuals who chose not donate to their deceased relative's organs for transplant operations were recruited via three staged media campaigns in large urban areas of the UK and from four NHS Trust intensive care units.

How was the research carried out?

The research aimed to be firmly grounded in the worldview of the participants, giving full representation to their experiences and concerns and sought to present the widest view of the phenomena under study. Therefore the study used a retrospective, cross-sectional, design incorporating multiple data collections methods. Data was collected via single, face to face or telephone interviews, two psychometric measures (not reported here) and one questionnaire that focussed on demographic data which could be used for comparison with UK Transplant's National Potential Donor Audit.

What are the main findings of the study?

Objective 1. To explore the end of life and hospital experiences of relatives who decline organ and tissue donation.

- Findings suggest that on entering the hospital environment participants had certain expectations, which included, that their relative would be resuscitated or that 'something could be done'. Participants had usually experienced a sudden, unexpected change in the health status of their relative and therefore needed time to recognise: what had happened to their relative, the seriousness of the critical injury, that despite technological progress in medicine their relative would not survive, and finally, that their relative was dead based on neurological criteria even though the deceased body appeared viable and unscathed.

- The outcome of decision-making about donation did not necessarily depend on views held by the family, or the deceased, in life, except if the deceased had stated they did not wish to be an organ donor. Therefore positive views held by the family, and the wish of the deceased to be a donor did not guarantee that donation would take place. This finding suggests that organ donation depended in part on a number of factors converging in a particular situation such as:
 - circumstances at the time of death;
 - a lack of information about the donation process;
 - the timing and manner of the donation discussion;
 - the family's views about keeping the body intact;
 - a desire not to prolong the suffering of the deceased especially if the deceased had had long term medical intervention during their lifetime;
 - a need to be with the deceased and to witness the observable ending of life represented by cessation of the heartbeat.
- Protecting the body, which related to keeping the body whole and intact was the most frequently recurring theme underpinning a decision not to donate. Participants could not bear the thought of their deceased relative being 'cut up'.

Objective 2. To identify the impact of hospital care offered to relatives in terms of decision-making about donation and subsequent grief.

- The quality of care within the hospital environment did not impact on participant's decision-making. Participants overall were positive about the care that they and their critically ill/injured relative received.
- Open, honest and straightforward communication by doctors and nurses helped keep families informed about what was happening. Having someone to answer questions was an important factor in participants' satisfaction with communication and care.
- Visiting facilities varied from hospital to hospital with little standardisation of what was available. Adequate provision of facilities added to or detracted from participants' comfort during their hospital stay, but was not reported as a factor influencing donation decision-making.

Objective 3. To assess the need for end of life bereavement support and the effectiveness of any support received.

- Participants did not regret their decision to decline donation, but some expressed feelings of guilt and selfishness, which they attributed to: feeling that they were in the minority (i.e. most people donate), not helping others, not fulfilling the wishes of the deceased, and media pressure to 'give the gift of life'.
- Four participants may have made a positive decision to donate if they had had full access to information at the time donation was discussed with them; for example regarding the need for a post mortem and therefore the opening of the body that this necessitated.
- Participants would have liked an opportunity to 'explain' or discuss their donation decision with health professionals.
- Access to bereavement support was varied across geographic locations and the hospitals participating in this study. Provision ranged from no follow-up, to the provision of bereavement leaflets, to an extensive bereavement support service, although this was limited to parents. Primary Care Trusts provided limited access to bereavement care in the form of formal counselling services. Informal support was provided by friends and family members.

Objective 4. To identify ways of enabling relatives to make culturally appropriate choices about organ and tissue donation that are right for them

- Cultural factors are often perceived as being relevant only to ethnic groups. Whilst there were specific issues related to cultural beliefs, such as the need to keep the body whole, findings indicate that this was as much of an issue for non donating families living within a westernized belief system, as for those who had non westernized views.
- The discourse of ‘sacrifice’ may assume a greater significance than that of ‘the gift of life’ when a family is faced with a donation decision and may become a barrier to actualising donation, even if the family and the potential donor, in life, had positive views about donation.

What do the findings of the study tell us?

Contrary to the world literature findings show that the outcome of donation decision-making does not necessarily depend on views held by the family, but is influenced by a number of factors converging in a particular situation. Importantly the views of the family regarding protecting the body, which related to keeping the body whole and intact was the most frequently recurring theme underpinning a decision not to donate organs. It would appear that the need to protect the body may stimulate a tension between the notions of the ‘gift of life’ as supported by transplant policy and the ‘sacrifice’ of an unscathed body, which must be made if organ donation is to proceed. This may account for the inability of participants to agree donation even if they and their deceased relative, in life, held positive views about organ donation.

What are the recommendations?

Recommendations for policy and practice

There needs to be:

- 1) a recognition that families of potential organ donors are first, bereaved families, and need to be supported by staff who are educated to work with bereaved people;
- 2) a recognition that the outcome of donation decision-making does not necessarily depend on views held by the family about donation but on a number of factors converging in a particular situation;
- 3) constant and ongoing assessment of the family, the family dynamics and recognition of the main decision-maker. Individualised, ongoing assessment is crucial to fulfil the family’s needs, evaluate their ability to process and use information and ensure the discussion about donation is timely;
- 4) early involvement of transplant coordinators once the potential for donation is realised. The transplant coordinator needs to remain available to the family during their decision-making to support them and answer questions;
- 5) development of an assessment tool to guide the care of families with whom donation is discussed, potentially maximising the opportunity for donation;
- 6) a recognition that families who decline donation may have special bereavement needs. Information about local and national bereavement support should be provided to families before they leave the hospital;

- 7) an expansion and commitment to the non-heartbeating programme, which may help families to donate who wish to be with the deceased and witness the observable ending of life, represented by the cessation of the heartbeat;
- 8) thought given to the way organ donation is promoted to recognise the contribution of the donor and their family.

Recommendations for education and training

There needs to be:

- 9) a recognition by health professionals that in many cases the whole family is involved in decision-making although only one person may give voice to the family's views. Health professionals therefore need to be skilled at enabling family members to talk openly about issues and make choices, helping them to explore where they and their relative are in the dying process;
- 10) an appreciation and understanding of the two discourses that appear to underpin donation decision-making that of the 'gift of life' and 'sacrifice' and the tension that these discourses may exert on families during their decision-making about organ donation;
- 11) an understanding that the discourse of 'sacrifice' may assume a greater significance for the family at the bedside faced with a donation decision and this may become a barrier to actualising donation, even if the family and the potential donor, in life, had positive views about donation;
- 12) a recognition that the circumstances of loss and bereavement associated with organ donation are culturally challenging especially the post mortem procedures on the body;
- 13) further education to inform the public about the process of organ donation.
- 14) The propriety of the donation operation needs to be stressed in public education and in discussion with families.

Conclusion

This is one of the first studies to examine in detail the accounts of families who decline organ and tissue donation, and as such is a much needed addition to the body of knowledge and literature. This was a small study with a non-representative sample and therefore the findings must be viewed within the constraints of this small sample. More research designed to further enhance the understanding of the complex processes underpinning donation decision-making is urgently needed.

1.0 Background to the study

1.1 The shortage of donor organs

Globally there is a critical shortage of donor organs to meet the demands for human organ transplantation, giving rise to an escalating number of preventable deaths. The number of patients registered for transplants in the UK continues to rise, with 6,651 reported on the active² transplant waiting list in February 2006 (UK Transplant, 2006). The demand for organs and tissues is set to rise further.

Type 2 diabetes and diabetic nephropathy, precursors of end stage renal disease (ERF), are increasing in the UK population (DH 2004). Projected annual increases for ERF are 4.5% to 5%, giving rise to 45,000 cases in the UK in the next 10 years (DH 2004). ERF is a particular health issue for people from South Asian, African, and African Caribbean communities who have a greater susceptibility to diabetes mellitus and hypertension (Raleigh 1997; DH. 2001). Mortality from these conditions and renal disease is up to six times greater than in whites (Raleigh et al. 1996). Presently these ethnic populations are relatively young but as they age so the incidence of ERF is expected to increase. Kidney transplantation is a preferred, cost effective, therapeutic option for an estimated 40% of patients with ERF (The British Transplant Society 1998) as long-term renal dialysis leads to a poorer quality of life and significantly increased costs to the health service (Roderick et al. 1998). However, in February 2006, 5,737 people were still waiting for a kidney transplant (UK Transplant 2006); South Asian, African, and African Caribbean patients making up 52% of the kidney transplant waiting lists in some centres (Johnson 2001). UK Transplant (2005a) also report a 39% increase in the number of patients on the liver transplant waiting list at March 2005, over the previous year.

An understanding therefore of what motivates families of potential deceased organ donors to decline donation or offers insights into how they construe their decision-making experience is essential to increase organ availability.

² Excluding those suspended from the transplant list for health, personal or other reasons.

1.2 Research with bereaved relatives

Relatives³ of potential deceased donors remain a critical link in maintaining organ supply as organ donation is normally discussed with them and a lack of an objection sought, before donation takes place. UK refusal rates of 40%, rising to 70% among ‘non-white’ groups (UK Transplant, 2005b) are a matter of concern for the transplantation programme.

While it is accepted that the process of donation and transplantation is complex, demanding and emotive for those involved (Sque and Payne 1996; Sque 2000a; Sque 2001; Wells and Sque 2002; Sque et al. 2003; Sque and Wells 2004; Ormrod et al. 2005), research has concentrated on the physiological aspects of transplant procedures; the psychosocial processes, inherent in these events, being largely ignored. This means those psychosocial issues that encompass an often unexpected death and the removal of organs from the body remain poorly understood. Holtkamp (2002) maintains that “formal studies that address the impact of organ donation experience on the trauma-driven grief of relatives are virtually non-existent” (p189).

Studies carried out by researchers in UK and USA have elicited some factors predictive of families’ ability to agree or decline donation. By studying the hospital experiences of families who had donation discussed with them, the demographics of the family, and the demographics and wishes of the potential donor (MORI 1995; Jouan et al. 1996; Franz et al. 1997; Sque and Payne 1996; DeJong et al. 1998; Burroughs et al. 1998; Martinez et al. 2001; Siminoff et al. 2001; Siminoff et al. 2003; Sque et al. 2005; UK Transplant 2005b) the following factors have been identified as being influential in donation decisions:

- knowledge of the deceased’s wishes, particularly if their wishes had been discussed with the family, or the family believed they would have agreed or declined donation;
- not understanding death certified by neurological criteria;
- not wanting surgery to the body, fearing that the body would be disfigured;
- feeling the deceased had suffered enough.

³ The Human Tissue Act which got Royal Assent in November 2004 and will be implemented in April 2006 (for transplantation September 2006) states in Part 1, Section 2 that in the case of a child “appropriate consent means the consent of a person who has parental responsibility for him (the child)”. Section 3 states that in the case of an adult “appropriate consent” rests with “a nominated person” or “person who stood in a qualifying relationship to him immediately before he died”. There are a number of criteria listed defining qualifying relationships.

Factors associated with families declining donation included:

- ‘non-white’ ethnicity;
- divisions within the family about the decision;
- less satisfaction with the quality of care the deceased and family received in hospital;
- perceptions that the family was surprised, pressured or harassed about donation decisions;
- untimely information;
- individual needs not being addressed;
- feelings about not coping with the decision and wanting to be present when the ventilator was switched off.

Whilst the predictive factors identified above provide some information about families’ donation decision-making they do not provide deeper insights that could explain what facilitates, harnesses and drives families’ decisions. Importantly, little detailed information exists, particularly in the UK, about families who choose not to donate, their experiences of the donation process, their bereavement needs and how these needs are met; all issues that could have implications for organ availability. Sque et al’s (2003) study successfully illustrated the needs of families who donated organs and tissues but, due to low recruitment numbers, issues for families who did not donate were not fully explored.

Other work (Burroughs et al. 1998), which arguably may be limited, has shown that rather more donating and non-donating families regret their decisions than was previously thought. The way relatives are treated at the time donation is discussed has been shown to affect their donation decisions (Matten et al. 1991; DeJong 1998; Sque et al. 2003). Norton and Sukraw (1990) suggest that when the facts about organ and tissue donation are presented at the right time, and in the right way, relatives are helped to make the right choice that is closest to their own values and beliefs. Relatives who are comfortable with their decisions about donation may be less likely to have a complicated bereavement with unresolved grief reactions. Unfortunately there are no studies to show how families who decline donation view their decisions or experience bereavement. Nor is there information available about the possible benefits of decisions with which such families remain satisfied. Little evidence exists of the potential conflicts or difficulties faced by families who choose not to donate and if it is possible to resolve these issues so positive choices could be made about donation; decisions that may have some benefit to them in their bereavement.

2.0 Design and method

2.1 Aims of the study

To investigate the end of life decision-making and hospital experiences of bereaved adults with whom organ and tissue donation for transplantation was discussed and who did not donate.

Objectives

- 1) To explore the end of life and hospital experiences of relatives who decline organ and tissue donation.

- 2) To identify the impact of hospital care offered to relatives in terms of decision-making about donation and subsequent grief.

- 3) To assess the need for end of life bereavement support and the effectiveness of any support received.

- 4) To identify ways of enabling relatives to make culturally appropriate choices about organ and tissue donation that are right for them.

2.2 Overview of the study design

To address these aims and objectives the study used a retrospective, cross-sectional, design incorporating multiple data collections methods. The research aimed to be firmly grounded in the worldview of the participants, giving full representation to their experiences and concerns and sought to present the widest view of the phenomena under study (Denzin and Lincoln 2000). Participants were recruited via three geographically staged media campaigns and four NHS Trusts' ICUs, in the UK. Geographical spread was judged to be important due to possible differences in local practices and bereavement support.

2.3 Procedure for accessing potential participants

2.3.1 Hospital sites

ICUs in four NHS trusts, suggested by UK Transplant, took part in the study. Meetings with the research team and senior ICU managers at each participating hospital site facilitated ICU recruitment. Implementation of the PDA from April 2003 allowed families who declined donation to be identified. These databases were accessed by the liaison within the ICU who then sent out recruitment packs provided by the researchers to families listed. Three NHS Trusts sent out packs that contained: a Recruitment Letter

(Appendix 1), a Participant Information Sheet (Appendix 2), a Reply Slip (Appendix 3), and a stamped, addressed envelope for return to the researcher (Table 1). The fourth NHS Trust sent out recruitment packs which also contained a covering letter from the ICU project team.

Table 1. Location of ICUs, number of recruitment packs sent out and number of participants recruited to the study

ICU location	Number of recruitment packs sent out	Number of participants
North East	20	5
North West	15	2
Midlands	18	1
London	28	0
Total	81	8

2.3.2. Media

Advertising via the media has been shown to be an effective means of bringing the request for participation to the attention of the public (Sque et al 2004)⁴. Decisions regarding placement of advertisements were based on geographic locations (Table 2.) and focussed on routes that offered the greatest potential for contact with the target population particularly ‘non-white’ (Asian and Blacks) groups.

• ⁴ A pilot study was carried out to test a new method for recruiting families who declined organ donation by advertising in national and local media (Sque et al 2004). A local 13-day newspaper, radio, library and magazine advertising campaign was undertaken to ask non-donor families if they considered advertising a viable method for recruiting participants to a future study. Nine women and three men responded to the advertisement. Three respondents were members of the target group from a potential population of 1,111,708. Respondents were positive about a national advertising campaign as they regarded organ donation as an important topic for discussion. This project showed that nationally, there was the potential to recruit sufficient numbers of non-donor families to inform a project.

Table 2. Figures for ‘non-white’ ethnic groups, ONS Census 2001

Area	Total	Non-white	Per cent
Newcastle	259,536	17,852	6.88%
Birmingham	977,087	289,681	31.80%
Bristol	380,615	31,085	8.17%
Cardiff	305,353	25,729	8.43%
Liverpool (M’side)	1,362,018	39,080	2.87%
London	7,172,091	2,068,888	28.85%
Sheffield	513,234	45,017	8.77%
Southampton	217,445	16,586	7.63%

2.3.3 Radio stations

Radio stations serving minority ethnic populations were approached to broadcast an appeal (Appendix 4) or host an interview (Appendix 5) about the study.

2.3.4 Newspapers

An advertisement (Appendix 6) was prepared and published in 12 local and four national papers (Sunday Telegraph, Eastern Eye, Asian Times and The Voice). Advertising was focused around the large urban areas of Bradford, Birmingham, Bristol, Cardiff, Leeds, Liverpool, London, Manchester, Nottingham, Preston, Sheffield and Southampton. Advertisements requested potential participants to contact the researchers by telephone to discuss their participation in the research. Advertising took place between 31st March to 22nd June 2005, in three phases; London and Southampton, Midlands and the North, Cardiff and Bristol. An additional set of advertisements were run at the expense of the School of Nursing and Midwifery when a fault was detected in the website automated email that, although unlikely, could have affected responses to researchers via this route (in the event only one participant did use this route to contact researchers). The advertising schedule, newspapers and related costs are detailed in (Appendices 7a 7b, 7c, 7d). Appendix 8 shows the circulation of the newspapers in the stated areas and thus our

rationale for choosing the ones with the highest circulation for the study. Some newspapers elicited no response⁵.

2.3.5 Project website

Advertisements directed potential participants to a School of Nursing project website where they could view information about the project, see photographs of, and read the background of the researchers. Individuals wishing to contact the researchers could use an automatic email response facility via the website (Appendix 9). The website address was included in all the newspaper advertisements but not in radio appeals.

2.3.6 University of Southampton press release

External Media Relations at the University of Southampton issued a separate press release for each of the three phases of the study (Appendices 10a, 10b, 10c, 10d) and distributed the releases to the particular media outlets in areas being targeted in the advertising campaign (Appendices 11a, 11b, 11c, 11d, 11e, 11f, 11g, 11h). The press releases generated a great deal of interest in the study by the press, radio stations, and BBC Online and internet sites (Appendix 12).

2.3.7 Organisations

UK Transplant, The British Organ Donor Society and the National Bereavement Research Forum also advertised the study.

Potential participants responding to advertisements mainly contacted the researchers by telephone. This provided an opportunity for potential participants to ask any questions or clarify any concerns they had about the study. Recruitment packs were then sent to all interested, potential participants with a request to return the Reply Slip, indicating their willingness to join the study. Table 3. shows a summary of the responses to the recruitment strategies and number of recruitment packs sent out.

⁵ Eastern Eye, Asian Times, Liverpool Echo, Liverpool Daily Post, Birmingham Evening Mail, Birmingham News Group

Table 3. Summary of recruitment

Responses, recruitment packs sent out	Number
Total response to all recruitment strategies	77
General responses	53
General (interest in study etc)	29
Offering advertising space	12
Information on donating body to science	5
Information on joining Organ Donor Register	1
Including wishes in a will	2
Unknown	4
(unable to contact following voicemail messages)	
Target group response	24
Recruitment packs sent out as result of newspaper advertising	15
Recruitment packs sent out as result of radio advertising/ interviews	0
Recruitment packs sent out by hospitals	81
Hits on website www.nursingandmidwifery.soton.ac.uk/familybereavement	293

Table 4. shows the number of responses that elicited interviews.

Table 4. The method of recruitment and number of responses that elicited interviews

Method of recruitment that elicited interviews	Number of responses
Interviews as a result of successful newspaper recruitment	15 (18 participants)
Interviews as a result of successful hospital recruitment	7
Letter as a result of hospital recruitment	1
Interviews as a result of radio interviews and advertisements	0
Total interviews	23

2.4 Data Collection

Relatives who returned Reply Slips to the researchers indicating their willingness to join the study were contacted by telephone, and a date for a face to face or telephone interview agreed. Agreement was sought to audio-record the interviews. It was agreed with participants that if there were changes in the plans of either the participant or researcher, then the respective party would get in touch. A contact telephone number for the researcher was given to the participants. Provision had been made for the use of interpreters for participants for whom English was not a first language, however they were not needed as all participants spoke English.

2.4.1 Interviews

The date of the interviews were chosen to avoid any significant family events or anniversaries, such as ‘the date’ of the relative’s death, birthdays, family holidays, festivals or religious celebrations that may have caused families distress. Participants were interviewed at least three months post bereavement.

Interviews were carried out at a time and place that was convenient to the participants and the researcher (Kvale 1996). Three face to face interviews involved two participants. Two face to face interviews were carried out within the place of work of the participant, and one interview was carried out at the School of Nursing and Midwifery, University of Southampton, all remaining interviews were carried out in participants’ homes. Interviews lasted approximately two hours. One participant felt that due to ‘emotional strain’ he did not wish to be interviewed so he wrote responses to the topics covered in the semi-structured questionnaire (Appendix 13) and returned these to the researchers. Table 5. shows methods of participation in the study.

Table 5. Methods of participation in the study

Method of Participation	No. of Interviews	No. of Participants
Face to face interviews	13	16
Telephone interviews	9	9
Letter	0	1
Total	22	26

Prior to beginning the interview participants were given the opportunity to ask any questions or clarify any concerns they had about the study. All participants were encouraged to ask questions about the project before signing the consent form. Written consent (Appendix 14) for face to face interviews was obtained immediately prior to the start of each interview. Consent forms for telephone interviews were mailed to participants and subsequently returned to the researchers, as was consent to use the written information provided by one participant. Consent for telephone interviews was also audio-recorded at the beginning of interview. Participants were asked if they wanted their GP to be informed about their participation in the study. Those participants who did want their GP informed signed a consent form (Appendix 15) to that effect. The GP was then informed of their participation and sent information about the study (Appendix 16). Six participants chose to have their GP informed about their participation in the project. The Interview Guide developed by Sque et al (2003) (Appendix 13) was used to ensure completion of the research agenda. Participants were asked to share:

- the circumstances leading up to the death of their relative;
- their experiences in hospital;
- their views about the care that was provided both for the sick relative and the family;
- their experience of being informed about the death of the relative and any discussion about brain stem death and organ donation;
- how they made the decision not to donate;
- their reasons for not donating;
- any impact the decision had had;
- any particular bereavement needs they felt they had and the type and quality of bereavement care offered.

On completion of the interview the researcher agreed a convenient time to contact participants to discuss how they were feeling post interview, and answer any further questions they had about the research. A 'Thank you' letter (Appendix 17) and a Post Interview Questionnaire Evaluation form were mailed to participants (Appendix 18) three to four days following the interview, allowing participants time to reflect on their interview experience. Evaluations of the interview helped to keep the researchers informed about the impact of the interviews on participants. Evaluation forms were returned to the Chief Investigator and discussed with the research team.

2.4.2 Demographic questionnaire

After the qualitative interview was completed the researcher asked participants questions detailed in Appendix 19, Demographic Questionnaire. Specific data related to the deceased and their families were collected to allow comparison with UKT's PDA data.

2.4.3 Psychometric measures

After face to face interviews participants were asked to complete two psychometric measures, the Beck Depression Inventory (BDI-II) (Beck et al. 1996) and the Grief Experience Inventory (GEI) (Saunders et al. 1985). Due to insufficient data the results of these tools are not included in this report.

2.5 Memos and field notes

Concise, reflective field notes were written after each interview, and throughout the investigation, to record important points and to detail the context in which the interview took place; the dynamics of the interaction, analytical or methodological issues, ideas and theoretical insights for discussion with the research team. These field notes also served to aid researcher reflexivity, and provide explanatory rigour to judgements and decision-making, providing a credible audit trail of the investigation.

2.6 Pilot study

A pilot telephone interview carried out with one participant achieved the objective of giving the researcher confidence in conducting the interview using the interview guide and demographic questionnaire in context; the opportunity to identify any salient issues that might be relevant or important to the research such as the comfortable length of time for the interviews and the type and range of emotions that could be expected.

2.7 Data Analysis

2.7.1 Analysis of interview data

Following each interview, the audio-recording was transcribed verbatim. Transcripts were checked for accuracy by listening to the audio-recording. Listening to, and reading the transcripts several times facilitated recognition of important ideas and patterns, such as sequencing or repetition of experiences. Initially, a sample of five transcripts were analysed independently by members of the research team to develop themes and to delimit a coding strategy for the study. This coding strategy was used as a framework to

guide the analysis. The experiences of participants were analysed using a thematic approach concerned with detecting patterns in the data and highlighting important similarities and differences between participants' accounts. Concepts and ideas were labelled in line-by-line coding. Clusters of similar codes were grouped into themes. The identified themes were grouped and labelled as categories that explain the phenomena being studied. Categories were integrated to give a full picture of participants' experiences, bereavement needs, and support provision. Gift Exchange Theory (Mauss 1990) and Mongoven's (2003) ideas of sacrifice were used to inform interpretation of the findings.

2.7.2 Analysis of demographic questionnaire

Participants' demographic data were collated and used to inform the findings.

2.7.3 Rigour and trustworthiness

The researcher's field journal, used for recording field notes and developing ideas and decisions impacting on the research process, formed a research 'audit trail' that was used to ensure the rigour of the study and inform data analysis (Coffey 1999). The coding strategy implemented by the researchers was intended to ensure reliability of analysis.

2.8 Reporting the findings

Exemplar quotes are presented as evidence to support the findings. Exemplar quotes from transcripts are coded using interview and line numbers i.e. interview 001, line numbers 345-346 = (001.345-346). **I** = interviewer and **P** = participant.

Throughout the document single speech marks (‘ ’) are used for emphasis. Double speech marks (“ ”) are used to indicate direct speech.

3.0 Ethical issues

3.1 Ethical approval

The study was approved by South East MREC. It is important to note that this approval, even in light of extraordinary efforts to pre-empt any delays, took four months to complete, out of a 12-month project (October-February). Final approval was gained on 9th February 2005. Because Trusts were grappling with new research governance directives, each had independent and differing requirements needed to satisfy their LREC and R&D Departments.

3.2 Project management

We were aware of the sensitive nature of the research and theoretical debates that surround the ethics of interviewing any bereaved group or the people that seek to support them (Skinner Cook 2002; Sque 2000b; Stroebe et al. 2003). The investigators were researchers with considerable experience, both as part of their research work, and clinically, as health professionals, in supporting colleagues and the bereaved. Therefore, they were suitably qualified to carry out this investigation.

Frequent meetings took place between the Chief Investigator, Dr. Magi Sque and Research Fellow, Mrs. Diana Allardyce, to discuss the day to day progress of the project and agree action to be taken in relation to issues resulting from the research. Regular meetings also took place with the co-investigators, Ms. Tracy Long and Professor Sheila Payne.

An Advisory Group appointed to support the researchers in the development and progression of the project met twice during the project. Members were also consulted throughout the project as necessary. The members were chosen to ensure that the project was carried out sensitively, was clinically and organisationally appropriate, and had academic and scientific rigour. The final membership of the Advisory Group included individuals from UK Transplant, the funding agency, BODY, a supporter of the project, ICU liaisons and academics with experience working in the fields of bereavement and end of life issues. Considerable efforts were made to locate a non-donor family to join the Advisory Group but this proved not to be possible.

3.3 Support for the participants

The sensitive nature of the investigation made it essential that an experienced researcher conducted the interviews. Participants were told at recruitment that the interviews could be emotive and tiring, and that there was a need for them to establish a line of support and sources of help following this activity. Support could be found among family or friends. Where no such support was available, help from an appropriate organisation was suggested. Prior to each interview, the participant's post interview support was established. Information about local bereavement support organisations was compiled and offered to participants at interview if they thought it helpful. Evaluations of the interviews kept the researchers informed about the impact of the interview experience on participants. It was agreed that any issue that threatened the safety, or could cause harm to participants, would be discussed with the participant and a plan of action agreed. To acknowledge their contribution, participants were offered a summary of the research findings.

3.4 Support for transcribers

The Research Fellow provided support to transcribers affected by the distressing nature of the data; where necessary transcriptions were completed by transcribers less affected by the sensitivity of the material.

3.5 Support for the researchers

The potentially distressing nature of the interviews cannot be underestimated and made it essential for the researchers to have their own grief support from an individual/s with whom they felt comfortable, and who was suitably qualified to support them, e.g. a member of a bereavement team or individuals in the University support system. Support was also available from the Chief and Co-investigators. The sharing of support was important and drawn upon when a particular person was not available. This had the potential for sharing the burden of distress. The University of Southampton Lone Researcher's working policy, which concerns the safety of researchers meeting with strangers, on their own, was implemented for all the interviews.

3.6 Confidentiality and anonymity

Participating centres and participants were given the option to withdraw from the study at any time. Confidentiality and anonymity of data were maintained. Audio files were

kept in password secured computer files, downloaded to CD-ROMs and stored in a secure environment. Transcription was carried out by School of Nursing and Midwifery, University of Southampton approved transcribers. Transcripts were kept in a secure environment. Personal references were removed from transcripts and transcripts were allocated a reference code. Generic terms such as, the hospital, the coroner, were used when referring to an institution or organisation. Data will be stored for 15 years in line with University of Southampton policy.

4.0 Evaluation of interviews

Following each interview participants were asked to evaluate their experience and offer feedback to the researchers. Evaluation forms were sent to all participants except the letter writer. Twenty-three responses were received. The evaluations of the interviews are presented in Table 6. followed by some participants' comments.

Table 6. Participants' evaluation of the interviews

Question	Yes, quite easily	Only just	No	Total
1. Did you feel that you were able to cope with the length of the interview?	23	0	0	23
	Yes, very helpful	A little	No	
2. Did you find talking to Diana in the interview helpful?	14	6	1	21
	Yes, a lot	A little	No	
3. Did you feel the interview caused you distress?	2	10	11	23
	Yes, very understanding	Yes a little	No	
4. Did you feel that Diana was understanding during the interview?	23	0	0	23
	Yes, very easy	Difficult at times	Extremely difficult	
5. Did you find it easy to talk to Diana during the interview?	22	1	0	23

Some comments included:

“Diana was very sensitive to my feelings. I felt very emotional afterwards.” (005)

“I found Diana a very sympathetic, sensitive interviewer and appreciated the opportunity to talk to someone at length about our experiences with the distance of time, and in my own way.” (008)

“Extremely sensitive, kind, and understanding questioner - put up with uncontrolled reminiscence and ready tearfulness. This was not a sign of distress but a relief and a chance to go through in words memories which are deeply felt. I much appreciate the chance to take part.” (014)

5.0 Findings

5.1 Introduction

The findings will start with a description of the sample. This section will draw upon the information collected in the Demographic Questionnaire. Findings for participants asked about organ or tissue donation are discussed together as there were no major differences in participants' concerns about donation. The experiences of families will be presented according to the aims of the study. Three case studies developed from the data, with the aim of illustrating the nuances of donation decision-making and some of the particular issues at the heart of families' experiences are presented following the summary of this section.

5.2 Description of the sample

Participants were recruited from all the targeted regions in the UK and provided a broad spectrum of experience. Twenty-six relatives, who declined donation of organs and tissues of 23 deceased individuals, were recruited to the study: four mothers, six wives, two female partners, five daughters, four fathers, two husbands, two sons, and one sister. The known ages of participants ranged from 26-75 years and the ages of their deceased relatives from 5^{1/2} weeks to 82 years. Five relatives died in 1986-1999; four in 2000-2001; and 13 in 2003-2005; from a range of illnesses. Table 7. shows the demographic data for participants and their deceased relative.

Table 7. Demographic data for participants and their deceased relative

Participants		Relationship to relative who died	Relative who died		
Study code/ Number of participants N= 26	Year of death		Age (Weeks, months years)	Critical Injury/ Illness	
001	1	Father	1999	2yrs 10mts	Acute ileal obstruction
002	2	Son	2005	72	BH
003	3	Daughter	2004	68	BH
004	4 5	Father (a) Stepmother (b)	1989	28	SAH
005	6	Mother	2004	22	Cardiac Arrest
006	7	Mother	2000	5½ weeks	Bronchiolitis
007	8	Partner (female)	2004	56	BH
008	9	Partner (female)	2004	54	BH
009	10	Daughter	2003	43	BH
010	11	Father	2003	16	Meningitis
011	12	Husband	2004	21	Cröhn's; BH
012	13 14	Wife (a) Stepdaughter (b)	2000	39	BH
013	15	Daughter	2001	82	Stroke
014	16	Wife	2003	51	Aspiration pneumonia
015	17	Mother	1988	25	BH
016	18	Husband	2003	58	SAH
017	19	Daughter	1996	63	BH
018	20	Wife	2003	59	End stage COPD
019	21	Wife	2000	65	Lung cancer
020	22 23	Wife (a) Son (b)	1986	54	SAH
021	24	Wife	2003	57	Mesothelioma
022	25	Sister	2004	46	HI
023	26	Father (letter)	unknown	3yrs 6mts	septicaemia

Legend: SAH = Sub Arachnoid Haemorrhage, BH= Brain Haemorrhage, HI = Head injury

A participant's responses from one telephone interview did not record so this interview was eliminated from the investigation. Two participants did not fit the study criteria but were included in the study because their account contributed to our understanding of organ donation decision-making. One of these participants wished to donate organs of their deceased relative but due to medical contraindications was unable to do so. The second was not asked about donation when she perceived that her relative had died in circumstances that could have allowed this to happen (i.e. maintained on ventilator support), and her deceased relative wished to be an organ donor.

Some critically ill relatives were transferred from the one hospital where they were examined in A&E or briefly admitted, to specialist centres where they died. Six relatives died in general ICUs; five in neurological ICUs; two in Paediatric ICUs; two in Coronary care/High Dependency Units; four in hospital wards; two in hospices; one in A&E; and one place of death was unknown. Of these 15 were maintained on ventilator support. One of the deceased was registered on the NHS Organ Donor Register. Five participants were only asked about corneal donation, as this was the only tissue that could be donated.

Fifteen patients died within two days of admission to hospital; six dying within the first 24 hours. The shortest time recorded being a child who was declared dead within half an hour of her admission to A&E and the longest an 82 year old father who spend two weeks in hospital. Table 8. shows the number of relatives who died and the period of their hospitalisation.

Table 8. Numbers of deceased and period of hospitalisation

No. of deceased	No. of days in hospital
8	1
6	2
3	4
3	5
1	7
1	8
1	14
23	

Participants reported positive reactions to the newspaper advertisements and receiving letters from the ICUs. No participant was critical of either approach, one suggesting that the newspaper advertisement could have stated the anticipated benefits of the research. Participants joined the study for a variety of reasons: being interested in the process; thinking it was an interesting subject; just wanting to be helpful; and out of curiosity. Four participants thought that they were probably among a “tiny minority” that refused and reported feeling ‘relieved’ and less ‘guilty’ when they realised this was not the case.

Other participants wished to promote an understanding of why an individual may not wish to donate, and others appeared to want to share a change of views about organ donation:

“I thought it was totally correct and now I have just switched views completely, I don’t believe people should be cut open in this way. I realise somebody might die, it just seems so wrong now.” (010.479-484)

Four participants appeared to use the opportunity to talk about their deceased relative and their bereavement. One participant whose husband died in 2000 captures these feelings:

“I guess the fact that I am still suffering so much from P’s death, I really am, it is horrible.” (019.961-963).

5.3 Objective 1. To explore the end of life and hospital experiences of relatives who decline organ and tissue donation.

5.3.1 Introduction

Objective 1. covers the period from the onset of the critical illness to the decision made about donation. Participants' hospital experiences are presented in five categories: Finding out something is wrong, Hoping for recovery, Realising recovery is not possible, Confirming brain stem death and Deciding about donation.

5.3.2 Finding out something is wrong

Five participants had relatives with long term illness who died either on a hospital ward or in a hospice where death was not unexpected. For the remaining 18 participants the onset of their relative's critical illness was sudden and unexpected, "There were absolutely no warning signs" (008.87), with the relative being rushed to hospital in a car or ambulance. There are many instances in the transcripts of the suddenness of the onset of the critical illness and how these initial stages of the illness unfolded. Take for example the account of M's wife:

"He (M) collapsed on the drive and I thought he was having a fit and we called the ambulance, but by the time they came he was sort of coming around a bit. They took him to the hospital then he was talking a little bit and then he started like having fits again and then they took him to do an MRI scan. They had to sedate him to do it and he never came round after that, and they said he had had a massive bleed in his head, they said it was probably a small one while he was here (at home) and then a massive one and that he was actually brain dead when they did the scan." (012.12-19)

Notably in the case of four deceased children, the seriousness of the illness was not appreciated even though the children had all received medical care immediately prior to their emergency admissions to hospital. The outcome of this lack of recognition of the seriousness of the illness ended with all four children being rushed to, and dying in hospital. The mother of the 5^{1/2} week old baby explains her disbelief at the outcome of her baby's illness:

"I will never be happy. I just cannot believe in this day and age that you get babies dying of whooping." (006.851-852)

The very sudden and unexpected onset of a critical illness meant that participants were shocked and exhausted. Some talked about this time as being "surreal" "like a nightmare" or "being in a movie". One participant described his feelings at this time as a: "empty, desperate, disbelieving nightmare." (023.18).

5.3.3 Hoping for recovery

In the early stages of the illness participants thought that their relative would recover. Disbelief in what they were witnessing and a desperate wish for a miracle, were features of this hope.

“We just wanted S, to be ok and then we were feeling quite positive that she was coming round a little bit and you know that hopefully she would make a recovery, maybe even if her kidney failed but still a recovery.” (005.122-124).

5.3.4 Realising recovery is not possible

There always came a time during the relative’s illness when participants became aware either by being told or through their own feelings that there had been a serious deterioration or that recovery was no longer possible.

“I think to some extent we realised before we were told directly.” (020.541-542)

Participants were informed in a variety of ways. Sometimes they were told by the nurse or doctor. A typical example of how the serious nature of the relative’s illness was shared with participants is given below:

“When we got the CAT scan the neurosurgeon used the word ‘catastrophic’ and said, I think K, yes K and the children were here by then and we were in the relatives’ room and he showed us the scan and there was, kind of, it was a haemorrhage the size of a tennis ball in the middle of his brain, or one of the lobes, one of the hemispheres and he said ‘you don’t come back from this, if he survives he won’t have any function’; and so they said they were going to take him up to intensive care and put him on a ventilator and that we could go up and see him after that.” (008.225-234)

Whilst waiting for a diagnosis some participants seemed to spend time in ruminations about the outcome of the illness:

“I have to say that you worry about if L had survived what sort of life she would have had, because you know all these things flash through your mind. You know that if she has to be on dialysis or something you know if her kidneys are not working you know; there were so many things going through your mind you didn’t know whether it is right to ask about them or what you should do, you know.” (010.519-528)

5.3.5 Confirming brain stem death

Where critically ill relatives had been on ventilator support, death based on neurological criteria was discussed with the family when it became medically clear that the critically ill relative could no longer sustain life for him/herself. This was mainly done by doctors. Participants received information about brain stem death tests (BSDTs) in varying

degrees of detail but seemed generally satisfied with the explanation they were given at the time, although this participant would have liked to know more.

I: “You mentioned things about the brain stem testing, would you have wanted to know more about what they were doing and what happened?”

P: “Yeah I suppose I would. I didn’t actually ask what the tests were and I think may be that’s because I thought they might be quite sinister but I have no idea actually.” (008.822-829)

The following extracts illustrate the varying levels of information given to participants about BSDTs.

“They came in and sat with us. There was a nurse and I think he was a consultant. They came in and explained the results and what they had found and what was happening and that there was nothing more that could be done and that you know effectively she was brain dead. And they used the word dead, which I was taught to use (participant was a nurse), never to say passed away or passed over, because that can be a bit of uncertainty there where as when you use the actual word, although its harsh you know it does hit home.” (009.1300-1312)

“They explained exactly what they were going to do. They said that two doctors have to be there and they explained the test that they were going to do, you know and they did explain that in detail” (005.710-713)

“She (nurse) just said we did a brain stem test and she was, without the machine, she was dead like.” (016.99-100)

Two participants watched BSDTs being carried out, while another who would have liked to attend tests was advised by the ICU staff that the procedure was not ‘particularly pleasant’. This participant said:

“They were very good at explaining to us about the brain stem test about how the tests are carried out by two different teams of people and then they had to unanimously agree their reports if you like, they were done independently. That impressed me can I say, that did impress me, what didn’t impress me was the fact that I couldn’t see them.” (007.2547-2553)

5.3.6 Deciding about donation

5.3.6.1 The donation discussion

Participants were approached about organ donation at varying points during their relatives’ illness. Appendix 20 gives the details of who made the approach to the family and at what point in the illness trajectory. Families of potential tissue donors were all approached after the death of the relative. In 15 cases a doctor was involved in the approach and sometimes they were accompanied by a nurse or another doctor. In only

one case was a transplant coordinator involved. One participant raised the subject of donation with staff enquiring whether organ donation was an option as they knew that their critically sick relative wished to be an organ donor. Two participants informed ICU staff that their critically sick relative did not wish to be a donor. Tissue coordinators were involved in discussions with two participants. In two cases participants could not identify which health professional made the request.

One participant approached about organ donation in 1986 remembers being asked about donation in the corridor outside the ICU. All later reports indicate that the discussion about donation took place in a quiet, private area.

“I thought he (the doctor) dealt with it very well because there must have been 10 people in the room, anyway, a lot of people in the room, and he was very, you know, extremely open and relaxed... he said would you consider organ donation, or have you considered organ donation. I mean he introduced it very sensitively, asked me if it is something that P (deceased individual) had any views on, whether we had considered it and if not would I like time to consider it and I thought he did it very sensitively; so I said I would like to think about it, mainly because I wanted to talk to,...I didn't want to make a decision there and then I wanted time to discuss it with the rest of the family.” (008.289-297)

One participant said that although she carried a donor card, when she was asked to donate her father's corneas after his death, she was really shocked. Although this had been done sensitively she had been “very, very shocked by it” (013.272-273). She describes the sensitive way she was approached in the quote below but she was unprepared for the discussion carried out with two tissue coordinators whom she had not met before. She felt it would have been helpful to have been approached by staff she knew on the ward and who she had got to know over the two weeks of her father's hospitalisation.

“By you know by (tissue coordinator) cushioning it in the first place by saying, I know this might be an awful thing to be asking you now, you know when you've just had this and to be asking you this, but we need to be asking you this now. So that's why. So I can understand it, but I was, I really didn't know that's what they were going to say.” (013.286-291)

This participant reported that she was reluctant to make donation decisions as she did not know her father's wishes and this was a difficult subject to talk to her family about. She also felt that she needed time to recognise that he had died and to reason that: “OK maybe this is just now a body and we can actually use part of it.” (013.329-333)

Most participants reported that staff were “empathic” with their decision not to donate, “I think they understood exactly how, my feelings were” (006.484-485). However one participant reported that staff continued to ask if he would reconsider his decision. “Are you, is there any chance of you changing your mind, I said no” (016.298-299). One participant reported that the doctor who made the request: “was a bit sort of terse about it really, you know, she just said ‘right and she walked out” (017.1045-1046). Another participant thought the doctor was disappointed when he did not agree to donation, while another participant reported she believed the doctor thought the family “was awful” as they could not agree the donation of organs from her deceased daughter, who had been a kidney recipient herself. Three participants also reported that ICU staff’s attitude changed toward them once they declined donation; “They weren’t sympathetic after we refused” (022.474). One participant reported that the attitude of the ICU contributed to her feeling guilty.

Decisions about donation were most often family decisions. This appeared to be important to participants as they felt that the decision was shared and therefore the onus was not on a particular person. It seemed important too that all the significant members should have an opportunity to be involved in the decision as they may have had information about the beliefs and views of the deceased that the next-of-kin did not know about or may have forgotten. This was the case for one participant, a daughter of the deceased, who was not involved in the donation discussion but knew her mother wished to be an organ donor, however the decision not to donate had been made by her father before she had a chance to discuss it with him and she did not feel she could then change his decision. Two participants who were stepmothers were reluctant to make a decision without discussing it with their stepchildren. When this discussion did not happen donation did not take place.

“I mean T (sister of deceased) her husband, we all agreed together, when he went into the second hospital and they came, we agreed that whatever decisions were to be made, we all had a say.” (007.2185-2188)

The main decision-maker, who sometimes was not the legal next-of-kin, reportedly sought the views of other significant relatives such as people close to the deceased, and siblings or children. It seemed important to the main decision-maker that they did what they thought the deceased would have wished. A husband remembers:

“I know she said she didn’t want people cutting her up, she didn’t want somebody to have her eyes. We spoke about it when she was getting her bad headaches, cause she knew there was something wrong.” (011.440-444)

Most participants reported that they did not feel under pressure to donate but three, like this father and mother, felt pressured to donate. The father also recounts how unprepared he was to be asked about donation so soon after his son’s death.

We were completely unprepared for this...when we were only just learning of his death.” “There was pressure there and I think it is very wrong.” (023.letter)

And a mother recalls this pressure:

“Then he came (the doctor) and he said if you know, if you are changing your mind about the transplant you need to be doing it now because you know S’s blood pressure is fluctuating a lot and we need to do something quickly and I said we are not going to change our minds. You know it’s the decision we have made and we are sticking to it.” (005.724-729)

This participant reports a more helpful approach that gave the family time and the opportunity to discuss their decision:

“I suppose the point where he came and talked to us must have been the point where he said would you consider organ donation, or have you considered organ donation. I mean he introduced it very sensitively, asked me if it is something that P (deceased) had any views on, whether we had considered it and if not would I like time to consider it and I thought he did it very sensitively; so I said I would like to think about it, mainly because I wanted to talk to, well no, I thought I knew actually at that point, I thought I knew. No, I did know. I didn’t want to make a decision there and then I wanted time to discuss it with the rest of the family; so we did discuss it.” (008.283-298)

5.3.6.2 Factors influencing the decision about donation

5.3.6.2.1. The expressed views of participants and the deceased, in life, about organ donation

Findings indicate that, as shown in the worldwide literature and the PDA (UK Transplant 2005b), if the deceased had stated that they did not want to donate their organs and tissues and the participant knew their wishes, donation did not take place. What is less clear is why so many participants who had positive views of donation and who knew of the positive views held in life by their deceased relatives, declined donation. The expressed views toward donation of participants and their deceased relatives, at the time of decision-making, are tabulated in Table 9.

Table 9. The expressed views of participants and the deceased, in life, about organ donation

Participants			Relative who died			
Study code/ Number of participants N= 26	Relationship to relative who died	Expressed views about donation	Expressed views about donation	Age (Weeks, months years)	Critical Injury/ Illness	
001	1	Father	Positive	Unknown	2yrs 10mts	Acute ileal obstruction
002	2	Son	Positive	Negative	72	BH
003	3	Daughter	Positive	Positive	68	BH
004	4	Father (a)	Negative	Unknown	28	SAH
	5	Stepmother (b)	Negative			
005	6	Mother	Positive	Positive	22	Cardiac Arrest
006	7	Mother	Positive	Unknown	5½ weeks	Bronchiolitis
007	8	Partner (female)	Negative	Positive	56	BH
008	9	Partner (female)	Ambivalent	Negative	54	BH
009	10	Daughter	Positive	Positive	43	BH
010	11	Father	Positive	Unknown	16	Meningitis
011	12	Husband	Unknown	Negative	21	Cröhn's; BH
012	13	Wife (a)	Positive	Negative	39	BH
	14	Stepdaughter b)	Positive			
013	15	Daughter	Positive	Positive	82	Stroke
014	16	Wife	Negative	Negative	51	Aspiration pneumonia
015	17	Mother	Negative	Unknown	25	BH
016	18	Husband	Negative	Positive	58	SAH
017	19	Daughter	Positive	Positive	63	BH
018	20	Wife	Positive	Positive	69	End stage COPD
019	21	Wife	Negative	Unknown	65	Lung cancer
020	22	Wife (a)	Negative	Negative	54	SAH
	23	Son (b)	Ambivalent			
021	24	Wife	Ambivalent	Positive	57	Mesothelioma
022	25	Sister	Negative	Negative	46	HI
023	26	Father (letter)	Ambivalent	Unknown	3yrs 6mts	septicaemia

Legend: SAH = Sub Arachnoid Haemorrhage, BH= Brain Haemorrhage, HI = Head injury.

In this sample, even if the family and the deceased, in life, held positive views about donation participants reported that once the person with the ultimate responsibility for the decision had expressed their wish for donation not to take place there was no family conflict. Other relatives unanimously supported their decision.

“My stepmother, my mum died 30 years ago, and so my stepmother had been the only grandmother that you know the children had ever known and she just (said) ‘God oh please don’t let them touch her, don’t let them touch her I couldn’t bear it’...And so we were all in agreement. I think at the end of it all though I did feel it was my decision and whatever I accept the others would have had to go along with it because I had always been with S through

everything. I just felt whatever I had said they would have had to go along with it because mine would have been the final decision.” (005.752-767)

Relatives in these cases reported feeling a sense of relief that donation was not agreed. A son, for instance, although he acknowledged the benefits of organ transplantation explained that it was a relief to the rest of the family, that because their mother knew their father’s wish they did not have to entertain the idea of him being “cut-up” to used as “spare parts” as it was impossible for them to detach themselves from the person they loved and admired.

Decision-making was explicitly affected by the wishes of the deceased not to be a donor, which was known to the family in six cases. The family’s view was that the donation outcome had already been decided by the deceased. A wife explains:

“Yes, yes, yes it made it much easier, I didn’t have to wonder well what would A have wanted, I, I knew what, you know, what he wanted.” (020.323-325)

Participants, who had discussed organ donation with the deceased relative, in life, and where both had agreed that they did not support organ donation, made decisions in line with the wishes of the deceased. This wife held positive views about donation but knew her husband did not wish to be a donor.

“As soon as we realised (husband was dead) I thought well I know what the next question is going to be so I were ready, ‘Sorry but I’ve got to say no’, even though that is not my wishes...I saw the doctor approaching and he said we need to ask you about organ donation and I said well I can tell you straight away that his answer is ‘no’, I said ‘that it is not my answer that’s M’s answer’. (012.88-89, 551-553)

The experience with medical services in life of two of the deceased had led them to decide and to share with their family that they did not wish to be organ donors. Both cases refer to giving the organs to the ‘health system’ rather than a recipient as noted in this exemplar.

“We had talked about this in the past. Because Mum when she was pregnant with me, 50 years ago was one of the first people in the country to have a valvotomy, or so she thought. So any time there has been anything, she broke her leg went to hospital, and all they were interested in was her heart. So she’s had an entire lifetime of doctors zeroing in on the thing that was of interest to them, because, ‘are you still alive? Everyone else that had a valvotomy in 1955 is dead.’ And ignoring completely what was best for her. So she said ‘when I go the buggers ain’t having any of me. Not, nothing, absolutely not’. So it was clearly established from quite a long time ago that when she died, as she obviously was going to do, we were absolutely

verboden from saying that they could have anything, or even look at, or play with, or anything. Poke around in general as doctors always throughout her life tried to do, not necessarily in her best interests.” (002.61-78)

Some participants spoke of the difficulty they had in making a decision, especially when their wishes about donation were different from that of the deceased. This participant who had negative views of donation but knew that her partner wished to be an organ donor, reports on her decision, supported by his family, and her sense of relief at the decision outcome.

“It was a very emotive issue for me, because I’m not, although I’ve seen the benefits of it (donation), I don’t, my own personal view is for myself, I don’t wish to donate. So I was trying very much at that point in time not to think about my own wishes. I was trying to go back to the conversation that we’d had, and to respect C’s wishes, because at the end of the day, this was about him and not about me... I think with him it was kind of a relief that we managed to reach the conclusion of not donating.” (007.751-758, 2107-2109)

Understanding what influenced participants to decline donation, in light of their positive views of donation may help us to understand why populations that generally support organ donation and transplantation, deliver high refusal rates.

5.3.6.2.2 Timing of the discussion about donation

Participants⁶ reported that: “timing is of the essence...of paramount importance” (018.638-639, 1191). Because of the short timescale between the onset of the critical illness and death some families appeared unprepared and surprised about being asked about organ donation. Sometimes this surprise had to do with participants being approached, as they perceived, too soon following the death of their relative. They needed time to first recognise that their relative had died.

“I think the timing was very bad because I don’t think any of us were in a real state to make that kind of decision because you can’t, because when that (death) happens that makes you think oh he has really died and I don’t think you come to terms with somebody that has died right straight away you, I don’t think you can because they are still there, they are in there and you have to feel that is alright, you take this you take that and I, you know, I think when somebody dies it is a very difficult thing to accept that they are not going to be able to talk or see you again never mind taking part of his body.” (021.1601-1608)

Another participant was surprised to be asked about donation when the family was just expecting only an update on care.

⁶ Also see Case Study One and Case Study Two.

“Like I said, you know, with the doctor sort of coming in and just giving us, and saying he can’t help and then all of a sudden springing the question on us. (022. 865-867)

5.3.6.2.3 Protecting the body

Protecting the body, which related to keeping the body whole and intact was the most frequently recurring theme reported in 15 interviews. It was the primary reason reported by participants for not donating. Participants could not bear the thought of their deceased relative being “cut up”. Words such as “not interfered with”, “battered”, “a piece of her” “he’d not been touched”, “would have felt that his body was desecrated” were features of these participants’ accounts. This was especially true if the deceased relative had had long term medical intervention during their lifetime: “couldn’t bear the thought of her being touched again”, “I just didn’t want her rolled around”, “mauled around”, “didn’t want her to be butchered”.

Whilst the reason most participants stated for not donating was that they did not want their deceased relative ‘cut up’, this view appeared to be related to a number of underlying issues, for instance: the perceived violation of the body; the perceived desecration of the body; destruction of the perfect aesthetic image of the deceased; the participants’ memory of aesthetic destruction; the possible futility of the donation if the organs or tissues could not be used; and the perceived prolonged suffering of the deceased not only from their immediate circumstance but also if they had suffered with a long term medical condition. Examples of these issues follow.

The perceived the violation of the body

A father who carried a donor card describes here about his donation decision on behalf of his deceased daughter:

“I just couldn’t bear the thought of L being split open: it would seem to me a violation.” (010.1160-1161)

This participant subsequently stopped carrying a donor card stating that he would be unable to agree donation for any others of his close relatives, should he be called upon to do so.

The perceived desecration of the body

Two participants believed that surgery to the body would be tantamount to desecration. “If we had done that (donated organs) to G I would have felt his body was desecrated.” (004.1329-1330)

Destruction of the perfect aesthetic image of the deceased

Agreeing to donation appeared to be more difficult when the body was unmarked.

“Even after she died she still looked fine, there were no wounds or anything as though she had been injured in a car crash, stuff like that you know she was just perfect...Our L hadn’t been cut at all if you what I mean, so somehow in that circumstance it seemed wrong to let them do it.” (010.494-497,734-736)

The memory of aesthetic destruction

A participant stated that all she could think of was that for the rest of her life she would have a picture of her son cut-up.

The possible futility of the donation if the organs or tissue could not be used

Participants also did not wish to agree to donation unless they were sure the organs would be used. They were concerned that the body would be cut for no good reason if the organs were found to be non-viable.

“The one thing I was frightened of was putting him through for organ donation and then they couldn’t have used anything because that was explained to us that maybe they wouldn’t have been able to find something viable to use, or there being a need for it at that particular point in time and that was, if the truth be known, another part of the jigsaw that made up the decision, because that again would have been putting him through more trauma unnecessarily and I wouldn’t have liked that.” (007.2148-2156)

The perceived prolonged suffering of the deceased not only from their immediate circumstance but also if they had suffered with a long term medical condition

The concern that the deceased relative had suffered enough was reported in 10 interviews as a reason why donation did not take place, therefore participants appeared to attribute importance to this reason. A mother reports:

“I just felt that her little body had been battered so many times by these drugs and radiotherapy and everything else that she should just be allowed to die in peace.” (005.1038.1041)

5.3.6.2.4 Witnessing the observable ending of life (cessation of heartbeat)

Once participants realised that their deceased relative could no longer sustain life for themselves, they were anxious for the ventilator to be switched off so as not to prolong

their relatives' perceived suffering. Some families thought they had to wait too long for BSDTs to take place and for the ventilator to be switched off.

“They were very good, I mean they did explain, and I did understand that it was just getting to the point (to do BSDTs) well, I'd accepted it in myself, I knew, and I just wanted them to turn the machines off and just let her go. But I think my family were still holding out, but I knew. I knew so, and I just thought to myself right, if that's the case, then let's just get on with it and you know get it over and done with.” (009.811-817)

Participants reported that arranging to switch off the ventilator was a decision that ICU staff discussed with them and agreement was sought within the family:

“Well She (nurse) approached my Mum about it (shutting down the ventilator) with her being the next of kin and Mum says right well I will discuss this with the family... Then we went for a coffee and Mum brought it up in the room and said look, she explained the situation and we all voted to it basically and we all voted will it be best for him...and they (hospital staff) gave us our time on our own...that was good because I felt that that way that they weren't pushy or anything they left the family to make their own decisions. Very good I tell you, they were brilliant.” (003.393-414)

A predetermined time for when the ventilator was going to be switched off, gave the family time to say their goodbyes, “I do feel like I've got time to say goodbye to him properly” (008.958-959). It also provided the opportunity for families to spend time with the deceased, remain with them until they were disconnected from the ventilator, until the heart stopped beating and for some time afterwards, if participants wished.

“She was on the ventilator and they said that the ventilator, they advised that the ventilator should be turned off and what not, but they wouldn't do it until we were ready. We were all given time to sit with her and say our goodbyes and what not.” (009.1342-1352)

One participant recounts how distressed the family was when they had arranged to be with her mother when the ventilator was switched off and they missed it.

P. “I just remember somebody saying ‘do you want to be with her when the machine's switched off; or would you prefer us to do it’ and we said ‘oh no we want to be with her’; and they said ‘well can you wait there and we'll get everything ready and we'll call you through’, but the worst part was that when we went through she was already gone.” (017.920-926)

I. And how did that make you feel?

P. “Well quite, quite bad really because we'd wanted to be with her and I felt we were asked if we wanted to be there and we said ‘yes’ and as we walked through and looked at her it was a terrible shock.” (017.958-964)

Only one participant reported how having agreed not to donate organs, the family felt pressured into agreeing to have the ventilator switched off. She reports that hospital staff made the family feel that they were prolonging the suffering of the deceased by keeping

him on ventilator support “as if we were being cruel to him” (015.225). The families’ reluctance to switch off the ventilator, she reports, had to do with the normal appearance of her son and the short, sudden trajectory (within 24 hours) of his transition from health to death and that the family needed time to “accept” the death. She describes the difficulty she had equating death with the appearance of the deceased, which was the experience of some other participants.

“I couldn’t believe it because he looked like he was asleep and he didn’t look like there was anything wrong with him at all apart from perhaps he was on a life support machine, but all his colouring, because he’s got red hair and he always had plenty of colour, um all was there he didn’t look ill at all, so you just can’t accept it you can’t take that in.” (015.50-56)

She describes the “torment” that this picture of a “living person” conveyed and the difficulty it caused in making a decision to switch off the ventilator “And then you are thinking if that is the case then we killed him” (015.288-289).

The importance families appeared to attach to the moment the heart stopped beating appears to fit with a personal view of death founded on societal expectations of a still, cold, pale body (Iserson 1994) rather than death based on neurological criteria. Therefore being there at the physical end of life, marked by the cessation of heartbeat was important. A father recounts:

“We felt we wanted or needed him to die in our arms, as the ventilator turned off, and felt that this would help us in the many years to come, to know we had done the best for us emotionally.” (023.letter)

In four cases families reported their belief that health professionals deliberately prolonged the time the deceased remained on the ventilator as they suspected that staff thought they might change their decision not to donate. They particularly thought this as both the family and the ICU staff knew that the deceased was already dead or was no longer able to sustain life for themselves and therefore participants could not equate this to any value of remaining on the ventilator. A husband explains:

P. “As far as I was concerned they kept her alive obviously for four days so just in case she might, because they wanted her to become an organ donor.”

I. “And you think that’s the reason why they did it?”

P. “I know it was, yeah, absolutely. Because they were sure, one hundred percent she would not recover and yet they kept her alive.” (011.542-563)

A wife also reports:

P. “I said ‘no’, I had the impression that they did keep A wired up a day longer on the off chance that we’d think better of it, I think because first of all, they said they were going to, you know, disconnect him on the Tuesday and then they decided they would leave it till the Wednesday, well there is certainly no reason for them to leave and I, I mean this is only my speculation, but they thought, well perhaps we will give them a little bit more time to think about it but nobody actually said, said as much to us.”

I. “And they didn’t ask you again?”

P. “They didn’t ask me, they didn’t ask me again, never approached me directly, I did notice that particular doctor looking every now and again speculatively, I don’t know whether he wondered whether he could approach me himself but he didn’t, no one asked me directly only J.” (020.237-255)

“Not being clear how much of the ICU was for P’s benefit, our benefit or the possibility of organ donation”. (008.910-913)

In one case a wife reported that the doctor had continued to engage the family in discussions about medication to regulate her husband’s blood pressure when both the family and ICU staff believed that he was already dead.

5.3.6.2.5 Lack of knowledge about organ donation

Some participants reported a lack of knowledge about certain aspects of donation⁷. Participants lacked knowledge about the potential for donation and some thought that being in an older age group was a barrier to donation, “I don’t carry a card because I think I’ll would be no good to anybody you know as I get older, because I am, I am 64.” (021.690-692) as was long term illness. It was notable that the donor card carriers seemed to also have little knowledge of the donation process⁸. There seemed to be a general lack of understanding with regard to how autopsy and organ donation work together for each of their outcomes. A father recounts:

“Ultimately the saddest thing of it all is if I look back it now, I look back now and wish well maybe I could have done something different I could have reacted in a different way but I also think it is very difficult under those circumstances to try and guess how you are going to react. If it happened again to one of my other children I can’t honestly say that I would react in a different way. If the same situation was to occur, I guess because I know that he or she is going to have to have an autopsy, then I would probably say yes, take what you want it doesn’t really matter.”(001.147-161)

⁷ Also see Case Study One and Case Study Three

⁸ Also see Case Study One

Participants also lacked information about anatomy for instance in relation to corneal donation.

“I don’t know what I thought they were going to do. Were they just going to take a little bit off the top, or were they going to take his eyes out and, I just, I don’t know, that it was just the vision that they were going to take my dad’s eyes out and I didn’t like that.” (013.406-411)

This wife who was asked about corneal donation reported that she did not know where or what a cornea was except that it was part of the eye. Also due to her lack of knowledge she was unsure whether the corneas had actually been removed, although she had declined donation.

“I don’t know if I really, if they have taken them, I, I think they might have respected but I don’t know what hospices do I think they might respect your wishes because if I, if I opened his eyes in the mortuary and see them gone that would have upset me more and as his eyes were closed I am just assuming that he has still got his eyes.” (021.595-597)

Some participants also appeared to have no clear understanding about how organs could be used if the deceased individual had an infectious illness such as meningitis or sepsis.

“We said that surely these things would be no use because the infection and he tried to explain how they might be able to use the eyes you know.” (010.457-460)

“Surely if he has chronic septicaemia, the organs aren’t much good anyway”
(023.118-119)

Families found a lack of information about the status of the patient unhelpful. A lack of full information and not understanding their options about donation had a negative impact on the donation decisions of four families⁹.

5.3.6.2.6 Other reasons for not donating

One participant found the thought of another person having an organ of her partner difficult.

“I have this mental thing if, if I knew that there was somebody now walking around with a bit of C in them, I don’t know how I would deal with it, I don’t know whether I would feel this overwhelming urge to want to find out because at the end of the day if they’ve got a part of him which, it is probably the wrong way to look at it because he was him as a whole not a part of an organ, but I am glad that I don’t have that dilemma to deal with.” (007.2115-2123)

⁹ Also see Case Studies One , Two and Three

One participant was concerned that there was no choice about who should receive his wife's organs as he would only have wanted his wife's organs to go: "To save somebody's life who was a nice, honest, decent person. But not to just say sure, cut what you want" (011.425-427) He expresses his point of view:

"But you don't get a choice, you get that card, but that's not the point. They do what they want, they give it to whoever they want, but you ain't got no choice." (011.410-413)

One participant did not believe organ donors maintained on a ventilator were dead. Another believed that money spent on the transplant programme should be used to find ways of preventing or curing the diseases that could benefit from organ transplantation. One participant thought their child was too young to be considered as an organ donor.

5.3.7 Summary

- Findings suggest that on entering the hospital environment participants had certain expectations, which included, that their relative would be resuscitated or that 'something could be done'. Participants had usually experienced a sudden, unexpected change in the health status of their relative and therefore needed time to recognise: what had happened to their relative, the seriousness of the critical injury, that despite technological progress in medicine their relative would not survive, and finally, that their relative was dead based on neurological criteria even though the deceased body appeared viable and unscathed.
- The outcome of decision-making about donation did not necessarily depend on views held by the family, or the deceased, in life, except if the deceased had stated they did not wish to be an organ donor. Therefore positive views held by the family, and the wish of the deceased to be a donor did not guarantee that donation would take place. This finding suggests that organ donation depended in part on a number of factors converging in a particular situation such as:
 - circumstances at the time of death;
 - a lack of information about the donation process;
 - the timing and manner of the donation discussion;
 - the family's views about keeping the body intact;

- a desire not to prolong the suffering of the deceased especially if the deceased had had long term medical intervention during their lifetime;
 - a need to be with the deceased and to witness the observable ending of life represented by cessation of the heartbeat.
- Protecting the body, which related to keeping the body whole and intact was the most frequently recurring theme underpinning a decision not to donate. Participants could not bear the thought of their deceased relative being ‘cut up’.

Case Study One

Illness trajectory

L had been a very healthy child who complained of a tummy ache which continued for two days. Her parents realised that this could be serious. Unable to get an appointment at the GP practice they took her to the local cottage hospital. The doctor there sent her home with a suppository. She stopped breathing at home three hours later. Her father tried to resuscitate her while the ambulance was called. The ambulance took the child to the Accident & Emergency Department (A&E). The parents followed in their car. The mother realised the child had died but her father still hoped that she would be resuscitated. She was pronounced dead about half an hour later.

Donation discussion and outcomes

When the parents arrived at the A&E they were ushered into a back room and told their daughter had died. They had time to make a couple of phone calls and then two members of the A&E staff, who had been involved in the resuscitation, approached them and requested organ donation. The father carried a donor card but appeared to have limited knowledge of the organ donation process e.g. how long it would take, or what it actually involved. He reported that he and his wife were in a profoundly shocked state. His immediate reaction to the request was 'No'. His wife did not challenge his decision. He did not consider organ donation to be mutilating he just desired his daughter to remain 'whole', as she was. (He discusses the irony of this as they had her cremated).

Later in the day the father was informed that a post mortem would be performed. He believes that if he had had that information at the time organ donation was requested he would have said 'Yes' as he stated: "It wouldn't have done her any harm and it would only have benefited others". He also felt that he and his wife were unprepared for a donation request and the approach was like a "direct attack"; although he also describes the request as being made sensitively, matter of fact and with compassion. He also found it difficult dealing with people who one minute were trying to save his daughter's life and the next asking "to take a piece out of her". He felt the request was all too quick in the context of the trauma and grief of the day. He found the care and treatment in hospital "absolutely sensational". He felt the timing, the method of approach and the people involved should be considered on an individual basis. He felt he made the best decision for himself at that time with the information he had.

Factors that appeared to contribute to a negative donation decision

- **Need to keep his daughter 'whole' as she was**
- Witnessing the child's death
- Unrealistic expectations of resuscitation
- Lack of knowledge about the donation process
- The short period of time from having a child in good health to death
- Inappropriate timing of the request
- Being unprepared for the request
- Request for donation feeling like an attack
- Appropriateness of people making the request
- No chance for discussion with family members
- Lack of information about how the procedure for autopsy and organ donation worked

Case Study Two

Illness trajectory

C had been in good health. A month prior to his death, following a TV news item about organ donation he had told A that if anything happened to him he wished to be an organ donor. A did not support organ donation. One Sunday morning, while in bed, C complained of a pain in his neck. A noted his lips were blue, his eyes didn't blink and he appeared to have stopped breathing. She called an ambulance whilst trying to give mouth to mouth resuscitation. A was later concerned that her attempts to resuscitate C may have prolonged his suffering. C was taken by ambulance to the A&E where a CT scan confirmed he had had a cerebral bleed from a ruptured aneurysm. He was transferred to the High Dependency Unit in another hospital. C's condition rapidly deteriorated over the next two hours. A phoned his family, to come to the hospital. Surgery to relieve the intracranial pressure was carried out following a second CT scan. Post surgery C had a further bleed in recovery, lost consciousness and was transferred to the ICU where in the early hours of Monday morning he was put on a ventilator.

Donation discussion and outcomes

A doctor met with the family on Monday and told them that C would not recover. The family raised the subject of organ donation asking if it was a "viable proposition". A transplant coordinator came and discussed the donation process with the family. It was explained to them that C would remain on the ventilator until the donation had taken place and then it would be switched off, but that the family could not be there with him at that time. A reports that because of the suddenness of C's illness and all he had been through one of the main things considered by the family was "that we had to totally feel as if he'd gone". A said that the family took time to think about their decision. A said that she could not have left the hospital knowing the C was undergoing something else. "Because he would be on his own, I couldn't be there. I couldn't have seen him...so we felt that when the end was totally the end, we needed to be with him". So we finally decided not to donate.

The decision was passed to the transplant coordinator who returned to see the family and explained that some things could be donated after the ventilator was switched off. A reported that had they been told all the facts and given the options they may have viewed the situation differently as she felt that they wanted to respect C's wishes to be a donor but that: "We had reached an agonising decision, and really we didn't want to go back and re-deliberate it". "It was purely the fact that we couldn't be with him when the ventilator was then turned off." A also spoke of the difficulty of having differing views about donation from C: "And again when you've got different views, it is difficult to do." The ventilator was switched off on Monday evening with the family present.

Factors that appeared to contribute to a negative donation decision

- **The need to be with the deceased and witness the observable, physical end of life**
- Lack of knowledge about all donation options and the processes involved
- The short period of time from good health to death
- Concerns that resuscitation had prolonged suffering
- Feeling the deceased had been through enough
- The need not to prolong the perceived 'suffering' of the deceased
- Negative views about organ donation

Case Study Three

Illness trajectory

J and S had been married for 27 years. J had three adult children whom S had helped to raise. J had multiple health problems; celiac disease, osteoporosis, ischaemic heart disease, emphysema, leading to end stage COPD, and depression. He had recently had an operation for two, large, abdominal hernias. J and S both had positive views about organ donation and had discussed it. S carried a donor card and knew that J had carried one in the past. J was admitted to the hospital Chest Ward, following what S thought was a heart attack but turned out to be a cracked vertebra. His general condition deteriorated and he died eight days later from an apparent chest infection. The day of his death the hospital had telephoned S about six o'clock to tell her that J was poorly. S and her stepdaughter were with J when he died some five hours later.

Donation discussion and outcomes

Shortly after J's death while having some refreshment, provided by the ward, S was approached by one of the nurses who said that because of J's multiple health problems he could not be considered for organ donation but it was possible that his corneas could be used and would S be interested in donation. To which she answered 'yes'. S was advised that "the tissue nurse who does all the paperwork" would contact her. She agreed to this and the tissue nurse telephoned her the following day. During the time between the nurse's approach in hospital and the telephone call from the tissue nurse S reports that she began thinking, because nothing had been explained, if the corneas could be used because of the "tremendous" amount of medication J had taken during his many years of illness. She wondered what state the corneas would be in as she didn't "want him poked about for nothing". The tissue nurse was not able to offer any reassurances that the corneas would definitely be used. S received the paperwork the following day. At that stage S decided not to go ahead with the donation. She thought that J; "he'd had hell of a sort of innings health wise" and although she knew he had positive views about donation and she knew he carried a donor card in the past she was unsure whether he had agreed to corneal donation as she knew that had been in a separate box to fill in on the donor card. However if it could have been guaranteed that his corneas would be used she would have agreed but because this was not possible she decided not to donate; as she regarded this as "mutilating somebody unnecessarily", which would have made her feel guilty.

S said she was unprepared for the donation request, and while she realised that staff needed to ask while she was still in hospital she thought the timing was inappropriate, so soon after J's death and particularly while she was having refreshment. She also felt that the nurse who initially approached her could have been "more gentle" rather than just coming in with "I need to ask you...". She thought too that a leaflet about the donation could have been helpful as she did not have any further information about what was involved until the tissue nurse phoned her the following day. Alternatively it would have been helpful to meet with the tissue nurse in the hospital, there and then, when it could all be explained. As she described: "When somebody rings up at home and says oh I understand you've agreed to, you're considering donating your husband's cornea, you know, like it's a bit like you're giving something to Oxfam". She felt that having a discussion about the donation over the telephone was unsatisfactory; like ordering something from "Tesco online", whereas a more sensitive way of doing it she felt was required.

Case Study Three (continued)

She suggested that this could best be managed in a meeting with the tissue nurse at convenient location or having her/him come to her home. She also said that it would have been helpful to have the tissue nurse with her when she was completing the paperwork so the nurse could answer any questions. She also made the point that some people do find form filling daunting especially in situations such as following bereavement when they may find it more difficult to manage their own affairs. She felt it would have been helpful to have the benefits of corneal donation highlighted to her as she said: “I need, you need to be sold the idea”. She also felt that J’s children should have been involved in the decision-making, which would probably have meant they needed to meet with the tissue nurse as well, although she thought it likely that they would have felt J “had been through enough”. S also described the difference in agreeing to organ donation and signing a card when one was fit and healthy and the reality of being faced with such a decision when someone you care about had died and the fact that they would be “cut about”.

Factors that appeared to contribute to a negative donation decision

- **No guarantee that the corneas would be used**
- Futile mutilation of the body if the corneas were not used
- Deceased had suffered enough
- The reality of making decisions about donation after death where someone you care about will be ‘cut-up’ as opposed to subscribing positively to donation when in good health
- Unprepared for the donation request
- Inappropriate timing of the request
- A more gentle approach regarding corneal donation.
- Lack of information of what was involved in the donation
- Discussing the donation over the telephone
- Being sent the paperwork
- Unsupported in filling out the paperwork
- No one to answer questions
- No opportunity for the deceased’s children to be fully involved in the decision-making
- Benefits of corneal donation were not highlighted

5.4 Objective 2. To identify the impact of hospital care offered to relatives in terms of decision-making about donation and subsequent grief.

5.4.1 Introduction

This section reports important aspects of hospital care as perceived by participants; care given to both their critically ill relative and the family and any perceived impact this had on their decision-making. The findings are reported in three categories, Important aspects of hospital care, Communication and Visiting facilities.

5.4.2 Important aspects of hospital care

Poor hospital care of the deceased and family has been linked to a negative donation decision (Burroughs et al; Sque et al 2003). This was not a finding for this study. Participants with hospital experiences pre 2000 were more critical and did comment on some negative aspects of care such as being given information in corridors, not being given full explanations and sometimes poor staff attitudes. The point must be made that families post 2000 were full of praise for the care given in the units where their relative died. There are many examples in the transcripts of descriptions of the good quality of care provided to their deceased relative and themselves. A daughter talks about care in the ward where her father died.

“At (name of hospital) he received fantastic care. I have got to praise them no end, they were very, very good. There was one nurse between four patients; they were there for him if he needed anything they were there. They paid attention, when he wet himself they changed him immediately. Oh yes they were fantastic.” (003.149-161)

And after her father died:

“The nurse then turned her attention to looking after my Mum, which I thought was wonderful you know.” (003.358-360)

A wife discusses her husband’s good care in the ICU even in light of a slight conflict over a drug he was given.

“I have to say that the ICU staff I thought were excellent, I can’t fault them I can’t say that they did anything, apart from the fudging of the drug to keep the blood pressure up; I have to say that throughout they were sympathetic and sensitive and caring and you know I really appreciated, well we all appreciated that, we all thought they were excellent.” (008.490-496)

The ambulance services also received praise:

“They were excellent. The way they dealt with her, the way they dealt with me really. I’m a big chap and you get emotional its difficult isn’t it. They were excellent. Nothing short of excellent.” (010.266-269)

Families may have had issues about individual aspects of care such as:

- the delay in getting a bed in hospital;
- the perceived low standard of care delivered in certain departments of the hospital;
- concerns about previous hospital admissions;
- the attitudes of particular staff: “There were you know, they were a couple of, you know matronly, this sounds awful matronly women who never had time for all these old men and women, that’s what it felt like” (013.660-661).

In one case the mother of the deceased said she had been used to being involved in her daughter’s care and felt excluded when she had to leave her bedside. She explains:

“Oh they were excellent. The only criticism I would make is that because S had been ill a lot as a child I had always been with her. I have been with her for everything, chemotherapy, radiotherapy. Sat with her through the operations and I felt sort of quite excluded. Well they sort of well I am sorry but you have to go to the waiting room now. Oh I am sorry there is a ward round, you have to go to the waiting room. Oh I am sorry we want to sort of turn S over or do such and such, you have to go to the waiting room and I felt very excluded.” (005.253-267)

Another mother felt she was left ‘too’ alone with her baby and care was very inconsistent depending which staff were on duty.

“I was just left in a room...just me and her and the, the equipment kept going off and I had to keep going in. I had to keep reminding staff to feed her because she was being fed by nasal tube.” (006.336-339)

On the other hand participants spoke of the gentleness and compassion shown to them by the nurses. Support of hospital staff appeared to be valued as the most helpful thing in hospital. This support was defined as staff who were friendly, approachable and understanding, where the family felt they were not left on their own and that there was someone there who could answer their questions. A son tells his account of care:

“I would echo what mum said about the nurses there, I mean I’m not in a position to judge the medical care that dad got but certainly they seemed to be giving him every attention and they certainly gave us every attention they were very thoughtful, very helpful and I mean put us at our ease as much as you can with anybody in that situation, they were very understanding, very

friendly and rarely give themselves credit, in fact we wrote, we wrote to the hospital.” (020.465-473)

5.4.3 Communication

Open, honest and straightforward communication by doctors and nurses in keeping families updated, telling them exactly what was happening and working with the family in the way they wanted was an important aspect of care, commented on by families as being a very helpful part of their hospital experience. It was important that there were staff who could answer their questions and that they felt comfortable in doing so.

“You know as to what they said or what they did, I mean they were all very pleasant, very nice, and kept us informed and you know kept us up to date, and people were available if we had any questions. They always made sure, that if, they said if we needed anything just ask or if you don’t understand just ask. So I think from that point of view that was all fine.” (009.589-596)

Participants did comment negatively about the use of clinical language when talking about their relative or their condition.

“Can’t remember whether we were asking questions and were pushing for an outcome, but I think he said something like its unlikely that life will be sustainable. And I just thought that was just such a weird phrase. You know, you know I think that I would have preferred him to say something like, ‘we don’t think he’s going to come through this’, but ‘life is not sustainable’ seems very clinical to me. As if he didn’t matter. I know he did, because I know they cared for him very well. But I suppose we’re all very guilty in the different professions we’re in, in forgetting that their not just a patient, or they’re not just a criminal, they’re a person. You know, come what may, they mean something to somebody. That was the only thing to be honest from the intensive care staff that was just that little bit, you know. I mean the rest of the time, they were absolutely fantastic.” (007.479-498)

5.4.4 Visiting facilities

Facilities for families appeared to vary from hospital to hospital. There did not seem to be any particular standard with regards to provision for families of very sick people. Adequate provision of facilities to meet their daily living needs either added to or detracted from participants’ comfort during their time in hospital; for instance, a lack of proper hygiene facilities.

“You want to sort of have a quick wash and everything you sort of have to do it in the loo in the little sink...It would have made a difference if you have somewhere to sort of get changed and you know apart from trying to do it in the toilet sort of toilet cubicle.” (005.693-703)

Participants reported that accommodation for families varied from a small waiting room, to sleeping on pullout beds, sleeping in empty rooms, sleeping in chairs next to the

patient with extra blankets, to a bedroom with shower and facilities for the family to bathe, dress and rest. Most relatives used a relatives' room, which on occasion they shared with other families. Two participants suggested that visitors' waiting areas could be made more user friendly for children and older people.

Some units had facilities for families to make their own coffee and tea or provided a vending machine and drinking water facilities. In others nurses reportedly made the family tea and coffee, whilst in others families had to go to the dining area of the hospital to get a drink. Some participants had to depend on relatives to bring in food and to give them time to attend to their hygiene needs.

Some hospitals had restrictions on the number of people allowed to be at the bedside at any one time. Most families took it in turns to sit with the critically ill relative. Families valued unrestricted visiting and being able to be with the sick relative. "I was there the whole time. I was never made to feel in the way or anything." (007.312-313)

5.4.5 Summary

- The quality of care within the hospital environment did not impact on participant's decision-making. Participants overall were positive about the care that they and their critically ill/injured relative received.
- Open, honest and straightforward communication by doctors and nurses helped keep families informed about what was happening. Having someone to answer questions was an important factor in participants' satisfaction with communication and care.
- Visiting facilities varied from hospital to hospital with little standardisation of what was available. Adequate provision of facilities added to or detracted from participants' comfort during their hospital stay, but was not reported as a factor influencing donation decision-making.

5.5 Objective 3. To assess the need for end of life bereavement support and the effectiveness of any support received.

5.5.1 Introduction

Findings in this section describe participants' views regarding bereavement support services that were available and their effectiveness. Findings are reported in two categories, Dealing with donation decisions and Post bereavement support.

5.5.2 Dealing with grief and donation decisions

This research has, for the first time, described some of the particular bereavement needs of families who do not donate organs. Participants appeared relieved to find that they were not the only ones who did not donate organs; three participants believed that people who did not agree to donation were in a "tiny minority". As one participant explained when she saw the advertisement for the research in the newspaper it was: "...a bit of a relief because I didn't feel as selfish you know" (015.1840-1841).

No participant regretted the decision they made at the time of the relative's death.

"No. No I don't have any regrets on that at all. It is not something that revisits me at all." (007.2379-2383)

Four participants could potentially have made a positive decision to donate had they had the full range of information at the time of the discussion about organ donation or the circumstance of the critical illness had been different, but participants felt that they had made the best decision, for themselves, in the particular circumstances at the time:

"He (doctor) just said that in six months' time you may regret this decision and I said no because the decision we are taking today is the decision that is right today and I said I am a great believer in if you do something on that day it is the decision you have made because at that time it's the right decision and although it sounds horrible I know that that was still the right decision." (005.216-222)

Seven participants discussed being left feeling guilty or selfish. A wife explains following her decision not to donate her husband's corneas.

"I have always felt guilty ever since about that and I think it is because I wasn't given enough information or what, didn't have enough knowledge about it. I don't think it is one of the things that we see a lot of." (021.519-522)

This husband explains that he felt selfish not donating, especially as his wife wished to be an organ donor.

P: “Well I know the L would have wanted it you know, sometimes I feel a bit selfish.”

I: Why do you feel selfish?

P: Because I could have cured some one else’s in terms of life” (016.1139-1140)

There is evidence that participants who were with the relative when they became critically ill, and who may also have tried to resuscitate them or give some type of emergency assistance were profoundly affected by this experience. It did not appear to directly affect their decisions about donation but it seemed to impact on the degree of guilt that they experienced in thinking that they had not done enough to save their sick relative or, that by sustaining their life they had prolonged their suffering.

“I went through a rough time dealing with the fact that I resuscitated him, did I do the right thing, because all he ended up with was more pain, an operation, a long spell in, in hours, alright in hospital where if I hadn’t resuscitated him that morning, he was gone.” (007.966-971)

A daughter tells how her mother worried that she had killed her husband by allowing the ventilator to be switched off.

“My Mum feels very guilty because we made the decision to switch the ventilator machine off and she feels like she killed him. I often keep saying to her, we didn’t. What we did we did for kindness but she still feels guilty, which I suppose you would do.” (003.56-60)

A mother would have liked the opportunity to explain her reasons for declining donation:

“I wished that I had been able to explain my feelings why I was saying no without getting as upset and I wished the doctor had been more understanding of why I was saying no. I mean I’ve got to say when the doctor went away and I said to the nurse I said he thinks we’re awful doesn’t he and she said at the end of the day she said it is your choice and she just took hold of me arm and she said I don’t blame you.” (005.1009-1016)

Three participants said they would have liked a “debrief” opportunity with hospital staff to address questions that they did not ask at the time such as issues about BSDTs.

5.5.3 Post bereavement support

Post bereavement hospital care was perceived to have no consistent structure or standards. Ranging from no provision, to the distribution of bereavement leaflets, to a full bereavement service provided by a bereavement support unit for recently bereaved parents, which was available to participants who children died in the Paediatric ICU.

Parents whose daughter died in this unit were advised that the bereavement support services would be in touch with them. They were also offered the opportunity to put their daughter's name in book of remembrance and attend a memorial service for children who died in the unit. They were given a photograph of their daughter and a lock of hair.

Two families discussed the importance of the support of the hospital chaplain. For one family it was important for the deceased to have the 'last rites'. This was facilitated for the family at four o'clock in the morning. For the other, the chaplain was able to pray with the family and the dying relative and they joined hands in a 'circle of light'.

Although some hospitals did advise participants about what they needed to do following the death: "And the instructions at the end; what to do about, like you say registering the death, and what happens after here, and after that and everything, that was helpful" (009.1522-1525) there appeared to be a lack of coordinated advice from hospitals about procedures following death and a lack of bereavement support in the community.

One participant was told that someone from the hospital would contact her for a "debrief" about a fortnight after the death, but this did not happen. She thought it would have been helpful to answer those "small questions" and understand a bit more about the process of the illness that killed her relative. She would also have liked to use this as an opportunity to thank the ICU staff for their care. One hospital sent out condolence cards with the details of a hospital bereavement contact, which was appreciated by the participant.

Participants found informal bereavement support mainly among family, friends, neighbours "fantastic neighbours and things, they did the flowers for the church, and they were very, very good", workmates, and organisations like the church, the cricket club to which participants belonged. "People rallied round, popped down for a bit" (011.915-916).

Formal support such as counselling was arranged through primary care services or privately by the participant. Primary care waiting lists for counselling were two months in some cases. Seven participants had counselling as part of their bereavement support. In one case the hospital offered to arrange counselling should the participant feel that this

was necessary. Participants who tried counselling experienced varying degrees of satisfaction. One mother was told to return to the counselling sessions “when she was prepared to talk”. This mother had also used help lines for parents of bereaved children which she did find quite helpful. Some GPs were helpful in that they visited the participants at home, or facilitated a visit for participants at their surgeries, and where mentioned were supportive of participants decision not to donate.

Participants also used bereavement organisations such as CRUSE which they found helpful. And one participant called the Samaritans, on two occasions, in the middle of the night, just to talk. Charities such as the Meningitis Trust were very supportive and offered counselling. The participants concerned got involved with fund raising for the charity which they reported had been helpful to them in feeling they were doing something positive to help others.

In two cases schools did not appear prepared to support the children in their bereavement, which caused distress both to the children and their parent/s.

Local vicars also provided good support:

“My local vicar who I hadn’t got her christened because my other two are christened he very kindly came down and was very supportive. He helped me with the funeral arrangements. She is buried up the church just up there; let me choose a spot where she could go you know. He was very helpful.”
(006.781-786)

Participants who mentioned them were full of praise for the support given by funeral directors.

“They (funeral directors) were superb, yeah, very, very good.” (006.804)
“Oh the undertakers were brilliant” (007.1218)

“Oh they were wonderful...he was wonderful very professional but very kind and caring and thought of everything you know and he sort of said you know the only thing you’ve got to do is I want you to go and choose the flowers yourself because you know that will give you something to focus on and something to do and he was wonderfully kind hmm and you know sort of made it a day that you know went well and you know we have no worries about everything, everything was organised. He was very, very good.”
(005.1138-1153)

Seeing the body in the funeral director's chapel of rest was helpful in acting as closure for relatives who had only seen the deceased while they were on ventilator support:

“My daughter did (went to the chapel of rest) and she found it quite helpful cause she said it was closure for her, she said it finished it for me I realised you know that wasn't my dad that was a dead person kind of thing, it wasn't real to me that he died in the hospital. Because, I suppose, of the ventilation, I mean he did still look absolutely pink and healthy really.” (008.708-712)

5.5.4 Summary

- Participants did not regret their decision to decline donation, but some expressed feelings of guilt and selfishness, which they attributed to: feeling that they were in the minority (i.e. most people donate), not helping others, not fulfilling the wishes of the deceased, and media pressure to ‘give the gift of life’.
- Four participants may have made a positive decision to donate if they had had full access to information at the time donation was discussed with them; for example regarding the need for a post mortem and therefore the opening of the body that this necessitated.
- Participants would have liked an opportunity to ‘explain’ or discuss their donation decision with health professionals.
- Access to bereavement support was varied across geographic locations and the hospitals participating in this study. Provision ranged from no follow-up, to the provision of bereavement leaflets, to an extensive bereavement support service, although this was limited to parents. Primary Care Trusts provided limited access to bereavement care in the form of formal counselling services. Informal support was provided by friends and family members.

5.6 Objective 4. To identify ways of enabling relatives to make culturally appropriate choices about organ and tissue donation that are right for them.

5.6.1. Introduction

This objective covers issues of culture that influenced families' decision-making. The presentation of this section is different from previous objectives as we consider it more helpful to discuss these findings from a theoretical perspective contextualised by the supporting literature. Therefore this section begins with a discussion of the relevant literature and then presents the findings under two categories the first: Impact of culture on donation decisions, and the second Media influences, which discusses participants' perception of how organ donation is represented in the media and the effects this had on their views about donation.

Etzioni (1992) has pointed out the importance of culture in decision-making, which he believes is not an individualistic event taking place in isolation within the individual mind: but is motivated by values that are culturally embedded. He argues that decision choices are made on the basis of emotional involvements and value commitments. Information-processing is often excluded or is a secondary concern. The main context for making decisions lies in moral commitments, affects and social factors, such as norms and habits. The importance of emotions and values in the way they fashion choice, affect the information we are able to absorb, the way it is absorbed, and our interpretations suggests that information and reasoning may have limited roles.

5.6.2 Organ donation and the gift relationship

Early in the era of organ donation, donation began to be described as an act of giving, encouraging voluntarism and altruism especially when it became clear that a constant supply of organs would be necessary to meet the growing demand (Gerrand 1994). The 'gift of life' discourse enshrines the ethos of organ donation (Vernale and Packard 1990; Siminoff and Chillag 1999; Lauritzen et al. 2001; Kuczewski 2002). It is embedded in the rhetoric of the pro-donation lobby and the promotion, philosophy and legislation of a number of powerful organizations. In the USA for instance recognition was given to the nature of this non-commercial transfer of organs at both federal and state level in 'The Uniform Anatomical Gift Act' that constitutes USA legal requirements for donation (WHO 1991). The Human Tissue Authority set up to implement the Human Tissue Act (2004) that overhauled previous laws with regard to the use of human organs and tissues

has the 'gift relationship' as one of its guiding principles for the acquisition of organs or tissues from a living or deceased person (Human Tissue Authority 2005). More recently The Council of Europe and WHO endorsed a universal 'gift for life' logo at the launch of the First World Day for Organ Donation and Transplantation held in Geneva on the 14th October 2005.

Mauss (1990) described Gift Exchange theory, the first systematic study of the custom of exchanging gifts, following comparative research among ancient societies of the American Northwest, the islands of Melanesia and Polynesia. Gift Exchange is embedded in notions of ritual and obligation that may not apply fully to organ donation. Nevertheless, it does offer some insights into the processes of *reciprocity* and *kinship* shown to be important in the donation event (Siminoff and Chillag 1999; Sque 2000a).

Mauss (1990) argued that gifts were never "free" and that gift-giving behaviour could be predicted. He suggested that the act of giving a gift is a form of contract governed by three major concepts: *the obligation to give*, *the obligation to receive*, and, *the obligation to repay*. The act of giving therefore carries with it an expectation of reciprocity, which, if not fulfilled, can be detrimental to the givers and receivers through *the tyranny of the gift* (Fox 2002), the degree of responsibility and indebtedness that giving and receiving evokes. Mauss (1990) also suggested that in giving, one shares part of oneself. The gift carries with it part of the giver's nature or spirit that creates a bond between the giver and the receiver. He postulated that this, *spirit of the gift*, represents an inner, animate force in the object exchanged, invested with life and possessing the individuality of the giver.

Siminoff and Chillag (1999) argue that while the 'gift of life' slogan reflects the ethic of voluntarism and altruism on which the entire system of organ donation is predicated and may be useful in educating the public about organ donation, it has not proved effective in maximizing agreement to the donation of organs. Even in western populations where there is high public awareness about the benefits of organ transplantation (Johnson and Goldstein 2003) refusal rates remain high. Whilst organ donation has been widely represented by the discourse of a special and extraordinary gift this ignores both the context in which the family who must decide about donation finds themselves and the issues that impinge on their decision-making. The gift of an organ is precious and comes at a high cost through an often sudden and tragic death and the burden of donation for

the family. A key question to consider is the extent to which the 'gift of life' discourse provides an understanding of families' behaviour when faced with donation choices?

5.6.3 Organ donation as sacrifice

Mongoven (2003) has offered an alternative view of the process of organ donation, equating it to a 'sacrifice'. The notion of sacrifice has been handed down through the ages within religious traditions as an offering made valuable by a hard-wrought, difficult-to-relinquish gift or an offering aimed at maintaining connections between humans and their gods (Hubert and Mauss 1964). The act of sacrifice is complex and sacrifices can take many forms. However the overriding tradition involves the shedding of blood through the slaughter of an animal or human, often severing the neck, slitting the throat, removing the heart, or cutting the sacrificed object into pieces (Hubert and Mauss 1964). Hubert and Mauss (1964) describe sacrifice as having a number of stages involving those who make the sacrifice, the sacrificer, the object of sacrifice and the receiver of the offering. Furthermore, the sacrificer must be prepared to undertake the sacrifice and to be deeply affected by being present at the offering and the role they play in it. Such sacrifices, that affect the sacrificer directly, are termed *personal sacrifices* (Hubert and Mauss 1964).

Metaphorically, *personal sacrifices* are used to describe good deeds or signify gifts to other humans that are usually wrought at great individual expense. Mongoven (2003) proposes that organ donation fulfils the criteria of sacrifice. The bereaved family must make the often very difficult decision to relinquish the guardianship and protection of the corpse to allow the cutting up of the body and the removal of organs, albeit through a standardized surgical procedure, for the benefit of the recipient (Sque et al. 2003). Mongoven (2003) suggests that transplant policy which seeks to make donation a commonplace routine may leave the donors and their families invisible with the real costs and benefits of their sacrifice unrecognised.

Mongoven (2003) acknowledges two distinctive and important dimensions of sacrifice; namely the motivational and the cultic dimensions. The motivational aspect reflects the intent of the sacrifice, which in the case of organ donation is giving the 'gift of life'. The cultic aspect reflects the routinised, standardised means of achieving the donation through the certification of death using neurological criteria, keeping the body on

ventilator support and the cutting up of the body and removal of the organs at the donation operation. It is likely that the discourses of both 'gift of life' and 'sacrifice' play key roles in the complex family decision-making concerning organ donation.

5.6.4 Impact of culture on donation decisions

We have findings from only one participant who was not from a Westernised culture system. This participant explained that organ donation was not something that would be considered in her culture as it was important that the dead were buried "whole". It was an ancestral belief rather than a religious belief. In the following exemplars she explains first how the family was approached about organ donation and second why the family could not agree donation:

"Well he (doctor) just said you know, you know, your brother is in a very bad state, and there's very little hope but what we need you to do is, you know, do you want us to donate, do you want to donate his organs. He was very upfront. He didn't sort of beat about the bush you know. And that's when we said to him 'no, we won't do that, it's not our culture to do that'."
(022.786-793)

She expands:

P. "I think it's more just the Zimbabwean culture, you know that sort of thing. As far as we concerned when somebody is dead they dead, you never sort of cut around with their body and stuff like that, cause once you start doing that when they do bury them they're not whole...To a certain extent, although I think my, it would have been taboo, it's just taboo in Zimbabwe to sort of, do things like that."

I. "So I need to sort of understand what about it would be then taboo, would it be your religious part of your culture or more, more ancestral?"

P. "I think it's more ancestral, yeah, yeah." (022.809-843)

Other cultural expectations were relevant to donation decisions. Two of the most important were fulfilling the pre-mortem wishes of the deceased and not contributing to their perceived posthumous suffering; thus the need for death not to be prolonged, a gesture to relieve suffering, out of respect for the person. Callahan (1987) feels that our empathetic responses to the dead are in part due to the lack of our ability to identify with the dead. We are only capable of identifying with pre-mortem states. He highlighted the notion of harming the dead and the sentiment that it is possible to feel sorry for the dead person because we *do* think of the dead as they were ante-mortem. Therefore, it is possible to experience compassion for the dead and to feel genuine moral outrage at broken pre-mortem promises, which respect the wishes of the dead. Hence when the

wishes of the deceased not to be an organ donor were known donation did not take place.

Participants described their difficulty in accepting the diagnosis of death based on neurological criteria due to their relative's viable, unscathed physical appearance. Their appearance was in conflict with participants' westernized social expectations of death as represented by a still, pale, cold body (Iserson 1994) and therefore for some cessation of the heartbeat was the measure of death.

Another cultural issue for participants and their families was the post mortem dissection of the body. Feinberg (1985) details these sentiments in that a dead body is a natural symbol of a living person and when a corpse is 'cut-up' it looks very much like one is harming a real person, and horror is felt at the mere proposition of such action. This is the way we imagine the dead person and sorrow and outrage can justifiably be felt on their behalf. Richardson (2000) also commented on western societies' convention to protect the dead. Concern about the proper treatment of dead bodies is an inherent part of British cultural values (Richardson 2000). Such agreement may help to explain the need of participants for an early resolution to the question of death occurring (not to prolong perceived suffering); as well as their concern about the vulnerability of the body at the donation operation. Richardson (2000) surmised the difficulties for the human corpse to be viewed as an object for dissection as popular culture maintains a distaste for the deliberate mutilation or destruction of the corpse (Sanner 1994) especially in the case of the heart and eyes (Wells and Sque 2002), which personify identity and beauty (Kent 2002).

The protection of the physical body may be drawn from judicial punishments to the corpse. Inflicting damage and destruction upon corpses historically constituted a deliberate judicial breach of society's norms and values. Had the British people lacked a consensus attaching deep importance to post-mortem care and the integral disposal of the corpse, such punishments could have held no cultural meaning (Richardson 2000). The customary treatment of the dead meant that in the 18th and early 19th century, dissection represented not only the exposure of nakedness; the possibility of assault upon and disrespect towards the dead, but also the deliberate mutilation or destruction of

identity. Attitudes appear to remain much the same today (Sanner 1994). The deceased, therefore, should be treated with reverence and not simply culled for organs.

Cultural expectations did appear to have an impact on the aesthetic presentation of the dead body (Featherstone 1991; Foltyn 1995). The emphasis on the body beautiful in life requires the deceased to be made to conform to a socially presentable and acceptable image so how individuals look in death was shown to be important particularly when the deceased were very young children.

5.6.5 Media influences

Participants had mixed views about the way organ donation was promoted and reported in the media. However the overwhelming message was that the media contributed to people's perception of the organ donation process and they thought there should be much more public debate. They also felt the media promoted donation in a very positive light that and that this contributed to the feelings of guilt and selfishness they experienced.

“I think it is a great deal of propaganda in favour of donation and I think this is possibly what makes people feel slightly guilty when they say no I just know when you know sometimes as a child or they are appealing for someone to donate a part for this child and I think well that is all very well but somebody else's child has got to die to provide that part and I am uncomfortable with that idea.” (020.1043-1050)

Another participant felt that people were being “brain-washed” into thinking that organ donation was the right thing to do and that, “They make people feel ashamed” (004.1562) when it was not for everyone. The following participant reported her concern that organ donation was becoming a routine activity.

“I think from our point of view it is almost as though they accept it you know there is no discussion any more; that this is an accepted norm now that organ donation should take place. I must admit if organ donation came on the television I probably wouldn't watch the programme that's how I feel.” (010.1150-1155)

Although organ donation is not obligatory, it has been suggested here that there are subtle social pressures that enhance *the obligation to give*. Media coverage has increased the public's awareness of the need for donor organs by highlighting the purposeful nature of transplantation, often through well known public figures who have received a transplant. The emotive nature of these stories creates their own pressures on families that may become involved in the donation process.

Religious traditions also value the conviction that to give to others is supremely good. The consequences of such gift-giving are assumed to be beneficial to the donor, the recipient and the wider society (Vernale and Packard 1990). It is possible that for a time, the essential bonds of kinship common in early societies are rekindled (even if complete anonymity between donor and recipient is maintained) in an ultimate concern for another person. From this viewpoint, the more widespread the personal and collective commitment to the concept of a gift that makes us our stranger's keeper, as well as our brother's keeper, the more ideal society is supposed to be (Titmuss 1970).

Participants' accounts appear to indicate that media pressure and the way organ donation is promoted in British society was responsible for much of their self imposed feelings of guilt and selfishness, and may also have been influential in the perceived negative reactions shown to them by some hospital staff when they declined donation. Further exploration of how these perceived reactions were expressed would add to our understanding of this issue.

5.6.6 Summary

- Cultural factors are often perceived as being relevant only to ethnic groups. Whilst there were specific issues related to cultural beliefs, such as the need to keep the body whole, findings indicate that this was as much of an issue for non donating families living within a westernized belief system, as for those who had non westernized views.
- The discourse of 'sacrifice' may assume a greater significance than that of 'the gift of life' when a family is faced with a donation decision and may become a barrier to actualising donation, even if the family and the potential donor, in life, had positive views about donation.

6.0 Discussion

6.1 Introduction

This is one of the first studies to examine in detail the accounts of families who decline organ and tissue donation, a much needed addition to the body of knowledge and literature. This was a small study with a non-representative sample and therefore the findings must be viewed with caution (also see Critique of the study). Whilst our first recommendation may therefore be that a larger study needs to be carried out before any substantial recommendations can be made for policy or practice changes, we have confidence in the findings as they support and are supported by much of what is already in the literature. A number of new findings have also been elicited in relation to the target group. The first section Key factors impacting the decision about donation - will highlight the important findings of the study. Organ donation as gift of life or sacrifice - debates the theoretical interpretation of the findings; The donation discussion - describes important aspects of the discussion and is followed by a section on Post bereavement support.

6.2 Key factors impacting the decision about donation

This study has given exposure to a number of issues that may be helpful when seeking to address the low rates of organ donation in the UK. For the first time we have been able to observe that in opposition to the literature poor care of the deceased and family was not an issue for participating families. No participant mentioned dissatisfaction with care as a reason why they declined donation and almost unanimously were full of praise for the staff and care afforded to the deceased and the family. This is an encouraging, positive finding and may be indicative of improved family centred practice within the units concerned.

The study illustrates a profile of the views held by families who decline donation and their deceased relatives, about organ donation. An unexpected finding was how many of the participants and deceased relatives held positive views about organ donation. We therefore suggest that positive views of donation, and the wish of the deceased to be a donor does not guarantee that donation will take place. The findings suggest that organ donation depends in part on circumstances at the time of death influenced by factors such as; a lack of information about the donation process and the timing of the donation discussion.

Participants' responses, other than when the deceased wishes not to be a donor were known, appeared to be precipitated by feelings and concerns for the wholeness and integrity of the body, the most frequently reported reason for declining donation. Participants appeared reluctant to relinquish their guardianship and ability to protect the body. Richardson (2000) found that the protection of the physical body is a recurring characteristic of popular death customs. The cadaver is no longer the person; nonetheless, the expectation is that even after death the body is treated with care, respect and ritual reverence for the sake of the person whom it represented. Families in this study clearly were concerned about the treatment of the deceased and sought to continue to protect them.

6.3 Organ donation as gift of life or sacrifice

The data interrogated here supports the two pervasive discourses about donation as 'gift of life' or 'sacrifice' with the potential for the discourse of 'sacrifice' to assume a greater significance for the family at the bedside, faced with a donation decision. Participants whose positive views may well have embraced the 'gift of life' notion also used graphic imagery in relation to their perceptions of the donation operation. They appeared concerned about the cutting up, 'cultic' part of sacrifice acted out through the donation operation and the perceived prolonged suffering of the deceased. The cultic dimension of sacrifice in donation for these families demanded the removal of organs from a donor who although certified dead by neurological criteria, was maintained on a ventilator and may not have looked dead. This appearance could have made the imagery of a living sacrifice even more acute.

Even with knowledge of its decay Richardson (2000) argues that the corpse's position has been counterpoised by a profound conception of metaphysical attributes such as sentience, spiritual power, transitory existence, and an afterlife. A corpse can inspire solicitude and sentimentality, as well as fear; even when the living individual never may have done so. Portmann (1999) suggests that an underlying commitment to the preservation of the integrity of the corpse conflicts with the respect for life that can be given through the transplantation of organs. "We want to guard vigilantly the boundary our bodies created against others and at the same time to open the boundary to others" (p. 228). These societal pressures may create a dilemma and confusion for families faced with a donation decision. We propose therefore that the notion of sacrifice is compelling.

The manner in which sacrifice impinges on families' decision-making is borne out in the difficulties participants expressed about their decision-making related to 'protecting the body'. Their perceptions of the donation operation contributed to the *tyranny of the gift*, and may help to explain that while there is high awareness of the benefits of organ donation and transplantation in the public domain, in many countries; refusal rates remain high at the bedside (UK Transplant, 2005b).

Tutton (2002) reinforces the use of the gift analogy by suggesting that the discourse of gift has achieved a certain metaphorical resonance as part of a broader political discourse within healthcare systems that value social equality, altruism, community and a lack of commercialism. It could be argued therefore that the adoption of the 'gift of life' discourse may play its most useful role as a vehicle for transplant propaganda, which is designed to act as a driver for voluntary, altruistic donation based on valuing human life. This ethos counters commercialism and market-based exchanges, and potentially ensures continuance of the transplant programme and all that depends on it. However Moloney and Walker (2002) concur with Mongoven (2003) suggesting that the 'gift of life' discourse is linked to perceptions of life, rather than the death of the donor and the suffering of the bereaved family. If this is the case then within the 'gift of life' context the families' roles could be relegated to the mere provision of spare parts. This leads us to question that while transplant programmes depend upon the generosity of donors and their families they are not celebrated, centre stage. Further research may indicate that it may be time to recognise what is important to families, which has been shown to be the achievement of the donor (Sque and Payne 1996; Sque 2000a). There may be a need to shift the emphasis to promoting organ donation as a reflection of the achievement of the donor as 'a hero for life' rather than giving 'the gift of life'.

Monogoven (2003) also cautions that to make organ donation a commonplace, routine or ritualistic policy renders the donor's and the family's sacrifice invisible and deflects attention from the real costs and benefits of their sacrifice. If this is indeed the case then successful donation discussions with families need to appreciate the tension that may exist between their concerns about their 'sacrifice' and the motivation to give the 'gift of life'. The success of such discussions will be judged not in terms of a positive donation decision but a decision with which the family remains satisfied over time, whatever their decision about donation.

A deeper understanding of how the 'gift of life' and 'sacrifice' discourses compete at the bedside, and the tension that may exist between them, is required to provide information which health professionals can use to guide interaction with families on a more informed basis. This has particular implications for the nature and context of information transmitted to families about the precise nature of the donation operation.

The complexity of unexpected death, the multiple new experiences associated with the act and process of organ donation, make the initiation of discussion about donation and obtaining the agreement of relatives, problematic. Approaching a grieving family about organ donation is believed to be one of the most emotionally draining experiences in healthcare practice (Stoeckle 1990; Featherstone 1994). Maloney and Altmaier (2003) report findings that show that trained donation professionals report greater confidence in their ability to perform procedural tasks associated with the donation discussion than in their ability to manage affective or emotion laden issues related to the process. These recent findings suggest that donation professionals appear to continue to have difficulty in how to raise the question of donation with families, show a lack of understanding about families' decision-making process and their true motivations for considering donation. These and other reasons could contribute to the disappointing donation consent rates in many countries and herald the need for donation professionals to be thoroughly educated not only in donation procedure but in supporting the bereaved. Importance is, therefore, attached to the propriety of the donation operation and needs to be stressed during interaction with relatives, as well as in public education programmes; as there was misunderstanding among participants about the nature and outcome of the procedure, which often led to disturbing fantasies. An appreciation of the historical influences and cultural values attached to the treatment of the dead needs to form part of the theoretical underpinning of health professionals' education about donation. Healthcare professionals also need to reflect on their own feelings about the culturally-perceived, unpleasant aspects of donation, to be more effective in giving or facilitating care of potential donors and their significant others.

6.4 The donation discussion

The most important feature of donation decision-making is that decisions are made by bereaved families. Therefore the understanding that professionals need in supporting the bereaved cannot be underestimated (Doka 2005). Health professionals need:

- to recognise the role of the family in the illness trajectory;
- to be skilled at enabling family members to talk openly about issues and make choices;
- to help families explore where they are in this changing process;
- to recognise that families may not have the language or experience to make informed choices;
- to assist families in feeling fully involved in decision-making.

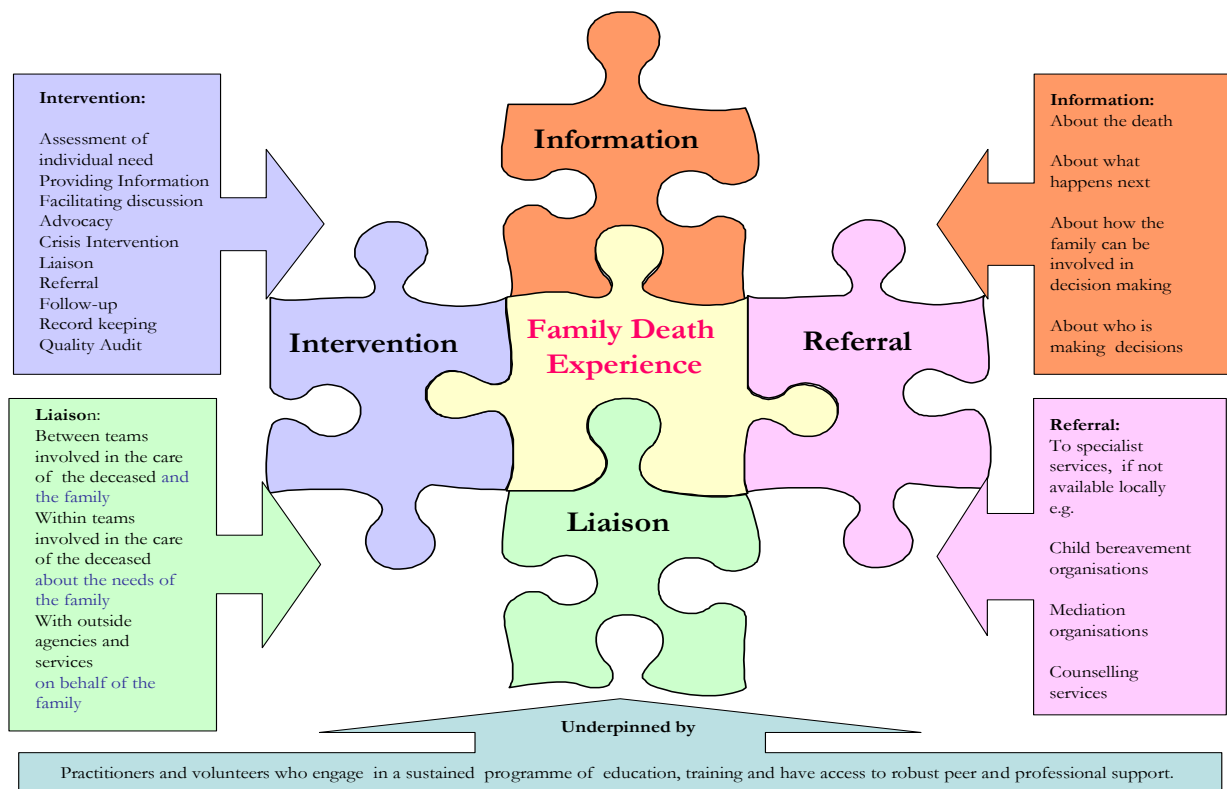
The timing and nature of discussions about organ donation were shown to be important to participants so families were not shocked or surprised; findings which are supported by Stoeckle (1990); Finlay and Dallimore (1991); Tymstra et al (1992); MORI (1995) and Burroughs et al. (1998). An important consideration here was that these were mainly suddenly bereaved families and they needed time to recognise that their relative had died. Families also needed certain information and explanations that were best carried out by experts in this field and who were qualified to support the family in their decision-making. The lack of transplant coordinator involvement was therefore surprising, particularly as PDA has shown that approaches involving transplant coordinators are more likely to end in agreement to donation (UK Transplant 2004). We would therefore recommend the early involvement of transplant coordinators and their continued availability to families during their decision-making.

The need to make a helpful approach to families also depends on careful and ongoing assessment of the family, understanding the family dynamics, who is influential in the decision-making and making sure that all significant contributors to the decision-making are involved (Sque et al. 2003). Families clearly needed full information to make a decision, one that they would not regret or feel guilty or selfish about, as these feelings appeared to have added to the burden of their bereavement and were sustained over long periods of time. We recommend that further research is needed and if it confirms the findings of this study then it might be possible to develop an assessment tool to guide the care of families with whom donation is discussed, potentially maximising the opportunity for donation. For instance some participants would have liked the opportunity to discuss their decision, debrief their hospital experience, get answers to those “little questions” as well as thank hospital staff. However the timing of a ‘debrief’ is important to allow it to be of maximum benefit to the bereaved.

6.5 Post bereavement support

Importantly this research identified that no special bereavement support was available to participants although they appeared to have particular bereavement needs that concerned: their decision-making and its outcome; the questions that remained about their hospital experiences; their lack of knowledge about organ and tissue donation; and, seemingly the unpleasant guilty and selfish feelings that they endured, either as a result of the perceived attitude of hospital staff or of their own volition. The bereavement care of families depends upon access to supportive, cohesive care and services. These services should be based on choices for the family that begin at the bedside of the dying person and extend seamlessly from the care facility into the community. Future service provision could best be guided by our model of Interlocking Bereavement Care (Figure 1) that focuses centrally on the family, assesses individual need and provides support that extends from the hospital or care facility into the community.

Figure 1. Model of Interlocking Bereavement Care



The model illustrates a proactive service that reaches out to bereaved people, who are often too exhausted by their grief to make voluntary contact, and which has the resources to provide the 'attention', 'time' and 'care' that is required to carry out individual needs assessment (Sque et al. 2003). This model of bereavement care offers families the opportunity to be involved in all aspects of end of life decision-making. These decisions are best supported by professionals offering a range of skills and who are trained to assess individual need, liaise within and between teams, intervene when needed and provide referral to specialist services where appropriate.

Hospital bereavement services need to be flexible enough to provide: assessment of need based on personal circumstances, crisis intervention, peer support, education and support in relation to practical advice, guidance and written information. It must also be flexible enough to incorporate referral on to agencies such as social care, psychiatric teams, support groups and other outside agencies, where they can offer an effective intervention. Such a service needs to have the appropriate quality monitoring and should seek to give support to other hospital staff in managing the events surrounding death.

Bereavement support needs to be provided within a team approach, involving personnel from various disciplines within the NHS; a team that has well defined aims in what is needed to provide a quality bereavement service; a team with strong leadership and a philosophy based on involving families in end of life decision making. Such developments will benefit bereaved families and would also facilitate an environment in which the potential for distress among its members is reduced and can encompass the realities of 24-hour care. However, the ability to effectively support families can only be achieved by practitioners and volunteers who are involved in a sustained programme of education and training and have available to them robust systems of peer and professional support.

7.0 Critique of the study

7.1 Recruitment of participants and sampling issues

Recruitment of the anticipated 40 participants was not achieved using recruitment via ICUs and the media. The advantages of using the media were seen to be its independence allowing potential participants to initiate the first contact. However, a sufficiently robust and geographically diverse sample was achieved that produced rich data to facilitate qualitative analysis but was not sufficient for analysis of quantitative measures. Recruitment via the media on a national scale did not achieve the expected targets as extrapolated from a pilot study carried out in the Southampton area (Sque et al. 2004). One might speculate that local loyalty or interest in the University might have generated more responses than could be expected on a national scale.

Although careful forethought was exerted in choosing a wide cross section of newspapers and targeting minority ethnic publications and radio only one ethnic participant came forward, this participant was recruited via ‘The Voice’ an ethnic publication. Newspaper advertisements generated a participant group that was outside the meaningful time parameters for the study i.e. before 2003. Whilst for this investigation the information they provided did contribute to our understanding of the phenomena under study, it was not ideal. Recruitment via the media did prove to be possible but difficult. The Sunday Telegraph provided the most, eight responses, which led to the recruitment of three participants.

The London ICU did not recruit any participants. It could have been due to the transient nature of the population in the city. It is notable that the ICU that sent a personal covering letter in the recruitment pack to potential participants achieved the highest number of participants to the number of recruitment packs sent out. This might indicate that such a personal approach could have been important to some participants and was influential in persuading them to join the study.

The sample achieved raises the issue of the type of participants recruited. This was a self selected sample and it was possible that the individuals who chose to join the study were people who had remaining issues about their bereavement experiences. Participants varied gave reasons for joining the study. Judging from the comments they made on their evaluation forms, some did appear to use the interview as an opportunity to talk and

reflect upon their experiences. Participants appeared to tolerate the interview experience well and felt able to tell their stories, reflect on their experiences and, more importantly, be listened to.

The sample consisted of 18 women and eight men. Stroebe and Schut (2002) suggest that gender differences in norms governing self-control of emotion in our society make it more embarrassing for a man to cry during an interview than a woman. Fear of this happening could inhibit the most deeply affected men from joining bereavement studies. The implications of this are that bereavement studies may over select on the least-affected men and the most-affected women. The extent of ethnic minority involvement in organ donation and the systems of support available to these groups are issues for further investigation as noticeably all except one participant who was White.

Sample recruitment of the bereaved can be problematic, which it was for this study. Parkes (1995) indicated the problems in obtaining access to bereaved people forcing researchers to use inadequate samples. We therefore suggest that prospective research with families identified from the audit of several ICUs will be necessary to achieve adequate samples from this group in the future.

This research must be viewed within the constraints of the small sample and the findings may not be transferable beyond the participants of this study. Despite this the reflected view of participants may have relevance to other families and individuals in similar circumstances. Credibility will be confirmed if the findings represent and have meaning for other families and NHS staff involved in organ donation.

8.0 Recommendations

8.1 Recommendations for policy and practice

There needs to be:

- 1) a recognition that families of potential organ donors are first, bereaved families, and need to be supported by staff who are educated to work with bereaved people;
- 2) a recognition that the outcome of donation decision-making does not necessarily depend on views held by the family about donation but on a number of factors converging in a particular situation;
- 3) constant and ongoing assessment of the family, the family dynamics and recognition of the main decision-maker. Individualised, ongoing assessment is crucial to fulfil the family's needs, evaluate their ability to process and use information and ensure the discussion about donation is timely;
- 4) early involvement of transplant coordinators once the potential for donation is realised. The transplant coordinator needs to remain available to the family during their decision-making to support them and answer questions;
- 5) development of an assessment tool to guide the care of families with whom donation is discussed, potentially maximising the opportunity for donation;
- 6) a recognition that families who decline donation may have special bereavement needs. Information about local and national bereavement support should be provided to families before they leave the hospital;
- 7) an expansion and commitment to the non-heartbeating programme, which may help families to donate who wish to be with the deceased and witness the observable ending of life, represented by the cessation of the heartbeat;
- 8) thought given to the way organ donation is promoted to recognise the contribution of the donor and their family;

8.2 Recommendations for education and training

There needs to be:

- 10) a recognition by health professionals that in many cases the whole family is involved in decision-making although only one person may give voice to the family's views. Health professionals therefore need to be skilled at enabling family members to talk openly about issues and make choices, helping them to explore where they and their relative are in the dying process;
- 10) an appreciation and understanding of the two discourses that appear to underpin donation decision-making that of the 'gift of life' and 'sacrifice' and the tension that these discourses may exert on families during their decision-making about organ donation;
- 11) an understanding that the discourse of 'sacrifice' may assume a greater significance for the family at the bedside faced with a donation decision and this may become a barrier to actualising donation, even if the family and the potential donor, in life, had positive views about donation;
- 12) a recognition that the circumstances of loss and bereavement associated with organ donation are culturally challenging especially the post mortem procedures on the body;
- 13) further education to inform the public about the process of organ donation.
- 14) The propriety of the donation operation needs to be stressed in public education and in discussion with families.

9.0 Further research

- Research designed to further enhance the understanding of the complex processes underpinning donation decision-making is urgently needed. In particular there is a need to explore the importance of the ‘gift of life’ and ‘sacrifice’ discourses to the decision-making process. Such research should include those families who choose not to donate as well as those who do. The extent to which timing of information may influence whether the positive sense of the donation process as a ‘gift of life’ is more powerful than the potentially negative construct of ‘sacrifice’ also requires examination. This calls for a larger qualitative study where these factors can be discussed in detail with participants.
- Research is needed to confirm, refute and potentially expand the findings of this study so that an assessment tool could be developed to guide the care of families with whom donation is discussed, potentially maximising the opportunity for donation.
- A prospective, ethnographic, observation study needs to be carried out to further our understanding of the minutiae of the dynamic interaction at the time of the approach and discussion about organ donation.
- We were only able to recruit one participant from an ethnic group this may be cause for concern that their needs with regard to declining donation may be overlooked. While we appreciate this may be a difficult population to access there is no reason to stop aspiring to understand their experiences. Recruitment could be further attempted using the PDA and local transplant coordinators.

10.0 Conclusions

The decision made by participants to decline organ or tissue donation appeared to be made in the context of deeply distressing concerns, which could be related to the cultic criteria of 'sacrifice'. Continuing to articulate organ donation within a 'gift of life' discourse remains over simplistic as it does not reflect the depth and complexity of the process. A decision to facilitate the removal of the vital organs of the deceased, who does not look dead, through post mortem surgical intervention upon the body, should never be underestimated.

Although the 'gift of life' discourse may remain useful for heightening public awareness about the benefits of donation this is not an adequate framework for understanding what is important for the family at the bedside faced with a donation decision. We argue that such decisions are more closely related to sacrifice. If this is indeed the case, sacrifice provides a potentially valuable theoretical perspective for explaining the decisions of families who choose not to donate. It may also have some value in explaining why in populations where there is high awareness of donation, refusal rates also remain high.

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For further information regarding this report please contact:

Dr. Magi Sque

School of Nursing and Midwifery

University of Southampton

Highfield

Southampton, SO17 1BJ.

Direct Telephone Line: 02380 597970

E-mail: m.r.sque@soton.ac.uk