

**Organ and tissue donation: Exploring the needs of families**

Final Report to the British Organ Donor Society  
and National Lottery Community Fund

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February 2003

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## Abstract

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

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

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

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

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

The ability to interchange human organs and tissues introduces a relatively unexplored dimension to grieving that requires specific attention. Bereavement support must begin at the bedside and continue

until it is no longer needed. This calls for a much greater integration of support services with a seamless transfer of care from the hospital to a support organisation specifically designed to meet the on-going bereavement needs of families, whatever their decision regarding organ and tissue donation.

### **Acknowledgements**

We wish to express our appreciation and gratitude for the support offered to us by the many people who participated in bringing this project to completion.

We would like to acknowledge and thank the participants for their central contribution to this investigation; individuals who so generously gave up their time to meet with Tracy over the three years of the project. Your willingness to share your experiences at such a difficult time is greatly appreciated. We are especially grateful for the kindness and hospitality that was always shown to Tracy.

We would like to thank all the transplant co-ordinators who helped to recruit participants and who offered good advice and on-going support. Your enthusiasm for this research and the willingness to use its findings is refreshing. We would like to personally thank: Helen Mandefield, Marie Cummins and all the team at South Thames Transplant Co-ordination Service; Antony Hooker and all the team at Birmingham Transplant Co-ordination Services; Jill Pallister and the team at Portsmouth Transplant Co-ordination Services and Sarah Stephenson, Rachel Clark and the team at Oxford Transplant Centre.

We would like to thank the following people and intensive care teams for their involvement and efforts in recruiting participants. Catherine Plowright, Dr. John Morris and the team at East Kent Hospitals NHS Trust; Juliet Hurley, Belinda Crawford, Dr. Plat Razis, and the team at Atkinson Morley's ICU; Sally Smith, Carole Ambrose, Dr. Casiano Barrera-Groba and the team at University Hospital, Lewisham; Dr. Christopher Male and the team at the Multiple Injuries Unit, Stoke on Trent and Dr. Kathy Rowan at the Intensive Care National Audit and Research Centre.

We would like to thank the project Advisory Team: Dr. John Evans (Chairman of BODY), Mrs Sue Tumber and Mrs Doris Dallimore (donor family members), Professor Sheila Payne, Professor David Field, Dr. Paul Roderick (academic support), Ms Marie Cummins, Ms Jill Pallister, Ms Rachel Clark (transplant co-ordinators) for their expert advice and support through all phases of the investigation. Thank you to Mrs Janet King, who as the project secretary, lent huge support particularly with transcription of audiotapes.

We would like to express our sincere thanks and appreciation to Susan Rogers, Research Administrator and Mark Simmons and Simon Baker in Finance, who have acted as our support network within the School of Nursing and Midwifery and who have patiently and graciously facilitated all our requirements.

We thank the British Organ Donor Society for sponsoring this project and the National Lottery Community Fund for funding it, giving us the opportunity to add to knowledge in this important area.

The contribution of continuing support by our families was greater than they realised.

Our sincere thanks to you all.

Magi Sque, Tracy Long and Sheila Payne.

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## Operational Definitions

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

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

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

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

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

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

**Organ donation** includes tissue donation.

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

**Organ donation process** includes the process of organ and tissue donation, retrieval (the surgical procedure or operation to remove organs or tissues). A potential donor will typically have suffered an injury such as intracranial haemorrhage, which may precipitate death. Organ and tissue donation is discussed with the next-of-kin who must show a lack of objection before organ retrieval can take place. The major organ donor remains on ventilatory support until the organs are ready for removal. Without ventilation oxygenated blood could not reach the organs. Transplant co-ordinators are primarily responsible for the organisational arrangements once a donor has been identified through to the distribution of organs. In the UK distribution of organs is co-ordinated nationally by UK Transplant. The surgical removal of organs takes place at the donating hospital by designated transplant teams, when operating theatre time can be arranged, usually at night. Multi-organ retrieval takes on average about

five hours (New *et al* 1994). The organs are distributed according to national regulation. Tissues such as corneas, bone, skin and heart valves may be retrieved many hours after asystole.

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

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

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

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

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

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

### **Organisation of the Report**

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

## **1.0 Introduction**

Relatives of potential organ donors are the most critical link in maintaining organ supply as they must express their lack of an objection before organ retrieval may take place; yet, little is known about their experiences of the donotransplant process. Limited information exists regarding their bereavement needs, and how these needs may adequately be met. Therefore, the roles of care professionals and supporting bereavement organisations such as the British Organ Donor Society (BODY), CRUSE and The Compassionate Friends lack guidance in developing informed methods of assistance (Finlay and Dallimore 1991).

The demand for cadaveric organs is growing, to give health benefits to certain individuals. The supply of organs and tissues for transplantation has not kept pace with demand. In the United Kingdom (UK) approximately only 700 individuals become major organ donors each year, while 6,477 people are waiting for suitable organs (personal communication, UK Transplant, January 2003). Corneal donations throughout the UK have fallen by 30% since 1995 (personal communication, UK Transplant, January 2003).

In part, the shortfall in donations reflects an increase in the number of individuals who could benefit from a transplant. Other researchers (Matten *et al* 1991; Salih *et al* 1991; Gore *et al* 1992; New *et al* 1994), state that the basis of the current organ shortage is not merely a problem of inadequate numbers of potential donors, but suboptimal use of the available donor-organ pool, exacerbated by the failure of health professionals to initiate the donation process. To increase organ supply, efforts must be made to facilitate donation. Also, not making relatives aware of the option of donation limits their choices. They may be deprived of fulfilling the donor's wish (Sque and Payne 1996; DeJong *et al* 1998; Martinez *et al* 2001; Wells and Sque 2002) or from finding some meaning in their often tragic loss (Pearson *et al* 1995; Sque and Payne 1996).

## **2.0 Background**

While it is accepted that the process of donotransplantation is complex and demanding for all involved, research has concentrated on the biomedical aspects of transplant procedures: psychosocial components receiving less attention (Sanner 1995). This means that the psychosocial processes surrounding these events, which could influence donation rates, remain poorly understood. The way relatives are treated at the time donation is discussed has been shown to affect their donation decisions

(Matten *et al* 1991; DeJong *et al* 1998). 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 best choice that is closest to their own values and beliefs. Nurses and doctors act as 'gatekeepers' for donation (Siminoff and Miller 1994; Sque and Payne 1994; MORI 1995; Evanisko *et al* 1998). Yet little is known about the importance of the nature of their contact with families in maintaining the availability of organs and tissues. Bereaved families may become community educators about organ donation (Salih *et al* 1991). This means that adequate bereavement support for relatives could positively affect donation rates. Presently in the UK the care of donor families is patchy and incomplete as there is limited evidence to explain the process of donation and its outcomes (Sque 1995).

Consideration of organ donation arises from critical injuries that lead to premature and sudden death. Sudden death robs relatives of the opportunity for anticipatory grief, and is known to lead to poor bereavement outcomes (Saunders 1993; Wright 1996). This is of concern as it has implications for the scale of human suffering, and therefore ultimately on healthcare provision. Sque's (1996; 2001) previous work, which represented a seminal study for the UK, used a cross-sectional approach to investigate the critical care experiences of donating relatives. Her work showed that the impact of sudden death and donation can create a need for bereavement support, but the mechanisms for assessment of need were ad hoc, and there was disparity in the provision of such support. Likewise, the study showed that nurses and general bereavement counsellors seemed ill prepared to help these families. There appeared to be a need for training development in this area. However, Sque's (1996; 2001), study was limited by being merely cross-sectional and included only those who agreed to donation. Relatives who did not agree, and whose experiences could well have an impact on their bereavement outcomes and donation rates, were not investigated.

Sque (1996; 2001), further suggested that the experience of organ donation could be explained as a bereavement characterised by a series of complex decisions that created conflicts and distress for the relatives involved. Some of these conflicts were: coming to terms with the loss of a relatively young person who was robbed of a future; deciding about giving consent for organs to be removed from a loved one, who, because they remained on ventilatory support, still appeared to be alive; saying goodbye to a loved one who did not appear to be dead; and coming to terms with disposing of a body when their loved one's organs were responsible for improving the quality of a recipient's life. The work

also proposed that decisions about donation might have consequences that affect the rest of donor relatives' lives. For instance, even as time went by, the effects of the donation were perpetuated in the desire for continuing information about the recipients. Klass *et al* (1996) and Walter (1996) theorised that, generally, bereaved people experience a strong need for continuation of a relationship with the dead person. It is possible that the way the relationship with the deceased continued to play a central role in donor relatives' lives, manifested in the often sustained yearning for information about recipients, because of the attachment (Bowlby 1980), they felt for the part of the donor that 'lived on'.

Other recent 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. Relatives who are comfortable with their decisions about donation may be less likely to have a complicated bereavement with unresolved grief reactions. Unfortunately, such issues can only be speculative, as there were no longitudinal studies to show how these regrets affected relatives' bereavement outcomes, nor was information available about the possible benefits of decisions with which families remain satisfied.

This study used a longitudinal, prospective, survey design, to examine the critical care experiences of relatives with whom organ donation was discussed, their perceptions of the decision-making process, and their emotional reactions to the death and donation. It indicated the needs of relatives throughout their decision-making about organ donation. An understanding of what the experiences meant to them and the identification of their bereavement outcomes and needs, were elicited.

### **3.0 Design and Method**

#### **3.1 The purpose of the study**

To investigate the experiences of bereaved adults with whom organ and tissue donation was discussed.

##### *Aims*

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

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

To assess the need for bereavement support and the effectiveness of any support received.

To compare the process of bereavement for relatives who agree to donation, and those who decline.

### 3.2 Participants

The age of participants ranged from 20-73 years, with a median age of 51 years (SD13). Fourteen mothers, eight fathers, ten husbands, nine wives, one partner, two sons, three daughters, one sister and one cousin took part in the study (N = 49).

#### 3.2.1 Gaining access to participants - Donor families

All donating families were recruited via four transplant co-ordinating services (Table 1).

Table 1. Transplant co-ordinating services that participated in the study and the time scale to obtain ethical approval

Transplant co-ordinating services	Date applied for ethics approval	Date ethics approval granted
South Thames	Gained prior to project commencing	Gained prior to project commencing
Oxford	April 2000	September 2000
Portsmouth	July 2000	September 2000
Birmingham	July 2000	October 2000

Transplant co-ordinators sent out recruitment packs to families. The packs were sent to families at approximately six-eight weeks post bereavement. The recruitment packs included a letter inviting the families' participation (Appendix 1) an information sheet (Appendix 1a) which explained the study, a reply slip (Appendix 1b) and a stamped, addressed envelope for its return to the researcher.

Participants who agreed to join the study were contacted by telephone and the first interview date arranged. Agreement was sought to audiotape the interviews. Participants were given the opportunity to ask any questions or clarify any concerns they had about the study. A contact telephone number for the researcher was given to the participants.

#### 3.2.2 Gaining access to participants - Non-donor families

Approaches to ICUs were facilitated through two transplant co-ordinating services participating in the project, that collected data on families who declined donation. Meetings with senior ICU managers (at a regional meeting) and collaboration with the Intensive Care National Audit and Research Centre (ICNARC) also facilitated ICU recruitment (Table 2).

Table 2. Intensive care units participating in the study and the time scale to obtain ethical approval

Intensive Care Units	Date applied for ethics approval	Date ethics approval granted
Lewisham	June 2000	July 2000
Atkinson Morley	July 2000	August 2000
Radcliffe Infirmary	April 2000	September 2000
John Radcliffe Paediatric	April 2000	September 2000
Banbury	April 2000	September 2000
Birmingham Adult	July 2000	October 2000
Birmingham Neurological	July 2000	October 2000
Kent and Canterbury Margate, William Harvey	November 2000	February 2001 (MREC)
North Staff Multiple Injuries Unit	November 2000	February 2001 (MREC)

Two procedures for recruiting families were used in response to the wishes of ICUs. Two ICUs sent out recruitment packs which included a reply slip for return to the researcher. Three ICUs sent out a letter requesting families' participation with a reply slip, to be returned to the ICU Link nurse or Consultant in charge. The names and addresses of the families who wished to take part in the study were then forwarded to the researcher who contacted families in the same way as for donating families.

### 3.2.3 Participants at Timepoint 1 (TP1), 3-5 months post bereavement-Donor families

Forty-one interviews with 46 donor participants took place at TP1. These were split into individual interviews (when a family member was alone) and couple interviews (where parents both participated in the interview). Thirty-six individual family members of which 16 were men and 20 were women and five couples (five men and five women) completed first interviews.

### 3.2.4 Participants at Timepoint 2 (TP2),13-15 months post bereavement-Donor families

Thirty-nine interviews involving 44 donor participants were carried out at TP2.

### 3.2.5 Participants at Timepoint 3 (TP3),18-26 months post bereavement-Donor families

Thirty-five interviews involving 38 donor participants were carried out at TP3.

### 3.2.6 Participants - Non-donor families

Two interviews with three non-donor participants were carried out at approximately one-year post bereavement. One individual family member (a daughter), and one couple (parents) were interviewed. No further non-donating families were recruited into the study (please see section 4.4.1).

Table 3. Shows the participants by age, relationship to the donor, and interviews they participated in.

Participant N = 49	Age of participant (Years)	Relationship to donor	Age of donor (Years)	Critical Injury	No of interviews completed
1	71	Husband	65	SAH	3
2	47	Partner	48	SAH	3
3	39	Mother	21	RTA	2
4	55	Wife	59	BSB	3
5	36	Daughter	59	BSB	1
6	Both 57	Mother/Father	23	RTA	3
7	53	Wife	40	RTA	3
8	47	Wife	52	BH	3
9	44	Mother	23	RTA	3
10	51	Husband	48	BSB	3
11	52	Husband	50	BH	3
12	50	Wife	57	BH	3
13	31	Mother	11	BH	3
14	70	Wife	70	BH	3
15	50	Husband	45	BH	3
16	31	Wife	41	BH	3
17	40	Sister	37	BH	3
18	24	Son	40	BH	3
19	52	Wife	53	BH	3
20	45	Husband	42	BH	2
21	51	Cousin	42	BH	3
22	52/50	Parents	21	RTA	3
23	74/71	Parents	43	BH	3
24	52	Wife	54	BH	3
25	54	Husband	48	BH	1
26	40	Husband	38	BH	3
27	71	Mother	44	BH	3
28	46/48	Parents	23	BH	2
29	50	Husband	52	BH	3
30	56	Mother	30	BH	3
31	50	Husband	50	BH	3
32	61/64	Parents	29	BH	3
33	42	Mother	17	RTA	3
34	28	Father/Partner	26/2	RTA	2
35	73	Father	34	BH	3
36	42	Wife	50	HA	2
37	20	Daughter	45	HA	3
38	52	Mother	18	HI	3
39	46	Husband	46	BH	3
40	52	Mother	34	BH	3
41	42	Son	72	BH	3
			Non-donor		
42	32	Daughter	50	BH	1
43	45/46	Parents	17	POC	1

Legend. SAH = Sub Arachnoid Haemorrhage, BH= Brain Haemorrhage, RTA = Road Traffic Accident, BSB = Brain Stem Bleed, HA = Heart Attack, HI = Head injury, POC = Post Operative Complications.

### **3.3 Interviews**

Semi-structured, face-to-face interviews were used to explore the study aims with participants (Appendix 2/2a). To assess the longitudinal impact of decisions made and care received participants were interviewed on three occasions over a 24-month period. Interviews took place post bereavement at 3-5 months (TP1), 13-15 months (TP2) and 18-26 months (TP3). The date of the interviews were chosen so as not to coincide with any significant family events or anniversaries, such as 'the date' of the donor's death, the donor's birthday or family holidays such as Christmas. The timing of the second interviews, carried out at 13-15 months post bereavement, was chosen so that the significance of the first anniversary of the death could be explored. After the first interview at TP1 a 'thank you' letter and an interview evaluation form was sent to participants (Appendix 3/3a). This helped to keep the researchers' informed about the impact of the interviews on participants. At TP2 and TP3 individual 'thank you' cards were sent to participants after each of the interviews.

### **3.4 Psychometric measures**

To further illuminate the bereavement experience participants were asked to complete two psychometric measures, the Beck Depression Inventory II (BDI-II) (Beck *et al* 1996) and the Grief Experience Inventory (GEI) (Saunders *et al* 1985). To aid clarity and interpretation, a description of these measures are presented immediately prior to the results for this part of the study in section 5.1.

### **3.5 Pilot Study**

A pilot study was carried out with four participants, three donating and one non-donating, to test the interview guide and the use of the psychometric measures. Subsequently minor changes were made to the interview guide, to promote clarity.

### **3.6 Data collection**

All interviews (except one interview at TP1 and one interview at TP2, which were carried out at the place of work of the participant) were carried out in participants' homes. All participants were encouraged to ask questions about the project before signing the consent form prior to the beginning of the first interview (Appendix 4). Verbal consent was obtained prior to subsequent interviews. The interview was audio-recorded using two battery-operated tape recorders with microphones attached. One of the microphones, a 'body' mike, was attached to the participant and facilitated good sound quality. The other microphone was a 'tabletop' mike, which facilitated recording of the researcher's

voice. To maintain privacy recording was stopped when telephones rang or visitors arrived. Recording was also stopped if the participant requested it.

### **3.7 Memos and field notes**

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

### **3.8 Analysis of interview data**

Following each interview, the audiotape was listened to several times until familiarity with the data was established. Familiarity facilitated recognition of important ideas and patterns, such as sequencing or repetition of experiences. Similarities and differences in the data and developing themes were noted in memos, which, with other field notes formed a preliminary analysis of the data. Thus, by the end of each interviewing sequence, a sound knowledge of the salient issues for participants was accrued. Interview data was transcribed verbatim. Transcription of the interview data facilitated analysis. HyperResearch 2.2.3 was used to store and work with transcribed data.

The experiences and bereavement outcomes of participants were analysed using a comparative, thematic approach focussing on detection of important similarities and differences between cases. Sque's theory of Dissonant Loss (1996; 2001), Walter's Biographical Model of Grief (1996) and the Dual Processing Model of Grief (Strobe and Schut 1998), which describes the oscillating nature of grief, provided the theoretical and analytic frameworks.

### **3.9 Analysis of psychometric measures**

The BDI-II and GEI measures were scored according to the instructions given by their developers (sections 5.1.2., 5.1.3). Due to the low recruitment numbers (three in total) the non-donating family data was removed from the analysis. Each participant obtained one overall score for the BDI-II, (potential score 0-63) each time they completed the measure. The GEI has 12 scales, three validity scales and nine bereavement scales (section 5.1.3). Each participant received a score on each scale, which were then compared with scores from subsequently completed measures. Descriptive and

multivariate statistics were used to analyse the matched data for 25 participants on the BDI-II and GEI measures, using SPSS, version 10.

## **4.0 Findings: Interviews**

### **Introduction**

The findings from the interview data are presented in this section. The findings are reported in direct response to the aims of the study, drawn from the three serial interviews carried out with participants. The findings for each aim are then summarised and followed by recommendations for practice and service provision.

### **4.1 Aim 1. The impact of initial care offered to relatives in terms of decision-making about donation and subsequent grief.**

Initial care is defined as care carried out during the hospital stay, from admission, through the discussion of death, confirmed by brain stem tests (BST), the discussion about organ donation, and either the transfer of the patient to theatre or the participants leaving the ICU. This section will outline the events that occurred around the collapse or critical injury of the deceased or how participants were informed of the injury. Participants described the responses and actions of the hospital staff and how they communicated about the illness, their relative's progress in hospital, and the discussion about death and BST.

#### **4.1.1 Learning about the critical injury**

The critical injury and subsequent death of their loved one was sudden and unexpected for all participants. Seventeen participants were with their loved ones, in their own homes, when they collapsed or became ill. These participants had been carrying out normal day-to-day tasks up to the point when their loved one collapsed. All of these participants accompanied their loved one to the Accident and Emergency Department (A&E). Twenty-three participants were contacted about the collapse of their loved one in one of the following ways: by the deceased's place of work, the police, a friend of the deceased who had accompanied them to hospital, a family member who was already at the hospital or hospital staff. All of these family members made their way to the A&E. One family were already in hospital when their loved one was transferred to the ICU.

#### **4.1.2 The environment of initial care**

In the A&E participants received information about the immediate condition of their loved one and what tests had or were about to be carried out. All the participants were shown into a private room, which for some families underlined the seriousness of the situation. This movement to a private space was a 'cue' to impending 'bad news' as families had seen this take place in television dramas.

“At that point I knew it was serious anyway cause just from the tele if someone gets put into a relative’s room you know it’s serious.” (si/r13286,13533)

Unfortunately, one family was informed that their son was *'fine'* and that he only had *'a broken leg'* when in fact he had sustained an irrevocable head injury. The informing doctor on this occasion had not carried out any discussions with other medical staff in relation to this patient. The nurse in attendance had to break the news of the head injury to the family. This was done immediately by the nurse and went some way to offset the incorrect information given.

Five participants were told about the death of their loved one in the A&E with subsequent BST taking place in the A&E. The critically injured relatives of the other participants were all admitted to the ICU via the A&E and discussions about death and BST took place in the ICU.

Where the death was confirmed in the A&E the deceased were transferred to ICU. No organ donor went to theatre directly from the A&E.

No matter where the discussion about the critical injury took place the most important issue raised by participants was the need for information about what was happening, what tests would take place and what the potential outcome would be.

#### **4.1.3 Initial care and information giving**

##### *4.1.3.1 Information giving*

Participants had information given to them verbally by medical and nursing staff. They were often given complicated information about the brain injury with very little prior knowledge of brain anatomy or function. This verbal information left some participants struggling to understand what the injury meant in relation to the quality of life for their loved one. A participant, whose loved one was undergoing an

operation for a bleeding aneurysm, remembered clearly what had been said to him as the doctor used an example which he could *'picture'* in his mind.

“The best way of explaining was, it was like a bicycle inner tube that had a bobble on it and what they were going to do was put a metal clip round the stem to the bobble to strengthen it.” (g/l 8109-8464)

Nine participants were assisted in understanding the nature and severity of the brain injury by more 'visual' means, for example:

- Being shown CT scans and x-rays and having the critical injury explained
- The use of an anatomical model of the brain to indicate the area of the injury, the damage caused and the consequences of the damage
- Being present when BST was carried out
- Being given a leaflet that explained the possible consequences of different types of brain injury

“He showed us the brain scan which was just amazing, all this black.” (t5322,5488)

“He brought in a model of the brain with removable bits which he took apart and showed us which bit was affected. That really put us in the picture.”  
(t/tbfieldnotes)

The understanding of these participants in relation to the injury sustained by their relative, was more detailed than those who had not received any of the above interventions, and these participants had fewer questions about the nature of the injury at two years post bereavement.

More importantly these participants felt that:

- Staff included them in a meaningful way in what was happening
- They felt fully informed and involved
- They understood how devastating the brain injury was and how unlikely recovery was

Only nine participants discussed receiving such 'visual' help, by means of the aids mentioned . The role of visual aids has not been highlighted in organ donation and yet they may have the potential to:

- Increase understanding of the nature of the brain injury
- Increase feelings of confidence in any decision which is made in response to BST
- Reduce post death 'fanaticising' about the nature of coma

#### 4.1.3.2 Brain stem testing (BST)

Death is an anatomically and physiologically complex process. BSTs are carried out to confirm cessation of all brain stem functions and are required to certify death (Powner and Darby 1999). Patients who have sustained irreversible damage to the vital centres in the brain stem have permanently lost the capacity to think, to be aware of themselves and their surroundings, to experience or communicate with others (Sullivan, 1999), and '*have sustained the irreversible loss of the capacity to breath*' (Working Party of the Royal College of Physicians, p 4). This medical diagnosis is presented to families who are faced with the reality of a body, that is warm and pink, that has a pulse and a chest that rises and falls. It is therefore not surprising that understanding death as certified by BST is an important factor in families' decision-making, and importantly has been shown to impact on subsequent grief.

All participants were made aware that BSTs would take place, but four participants were not aware that two tests were required. Two participants received explanations of the procedure from transplant co-ordinators: while the majority received this information from medical staff. A description of the way one participant was assisted in understanding the consequences of brain injury by the doctor keeping a lay perspective and using a combination of verbal and physical information is given below.

"He said look at it (x-ray) and he said we think we have to do tests. I am here to ask your permission to do a test, which we will then do again to verify the tester, and all that. But we think that the amount of damage, looking at the fact that there is no reaction and looking at this brain scan, it looks like the amount of damage that was done at the time was sufficient to kill the main physical part of the brain. He said I am talking about the side, the personality and things like that and the talking...I am talking about the things that do the main things." (g 32400,33335)

But even after such explanation participants still struggled with the connection between BSTs and death.

"And she (transplant co-ordinator) went through the procedure that the consultant and the doc, the surgeon have to do this stem test and then they do it again an hour later. And if there is nothing then he is declared stem dead, which I presume, I mean, I never got up to the point where I could, basically he's declared dead I presume." (m/g10695,11033)

Four participants were asked if they wanted to present at the BSTs. Two participants (and a son of a participant) who witnessed BSTs were initially apprehensive but they felt it confirmed what the medical staff had told them. Participants who chose not to be present at BST felt that the offer of this opportunity showed a desire by the staff to involve them in what was happening to their relative and to keep them fully informed.

“Yes. He (doctor) was absolutely brilliant. He said he had one set of tests and they had done the scan which showed that there wasn’t anything that could be done, and so after a period of time, I don’t know how long it was, hours, he was going to do another set of tests. And he said we could be in there to see them if we wanted to or not. And I think we were probably the only people ever said we wanted to be there. But from their point of view I think, I wanted to see what they were doing to him and I wanted to be sure that he really was dead.” (s/m12699,13235)

“Anyway. I don't know where the hours slipped by but somewhere around four o'clock the consultant anaesthetist Dr R. came and he was going to do the second lot of tests, and we were present while he did them. He said that he'd never done it with relatives present before. He explained it all in beautiful, simple language for my daughter J and didn't patronise or make her feel out of it because she was the only non-medical person in the room. I was glad that he let us stay. He did ask us did we want to leave? And I was glad because I felt J in particular didn't believe it. She kept saying I haven't finished with him yet, I haven't finished with him yet. I was glad because it meant that she would actually be sure, and I knew that I wanted them to be sure that there wasn't any hope at all, because I imagine that as we went through the process towards him going up to theatre that there'd be a lot of uncertainty. Was he really, was he really dead? I was really glad and grateful for that opportunity for them, particularly J. M has seen far more of it than I have, and I imagined she wouldn't have any doubts, but for J it would be much better like that. And Dr R was extremely gentle, extremely careful, used really helpful language and he also warned us that it would be a very long drawn out thing. He gave us a reasonable accurate picture of how long it would take for everything to happen.” (S34721, 36210)

Some families would appear to benefit from being offered the opportunity to be present for BST, as participants stated it helped them ‘be sure’ that their loved one is dead.

This opportunity would also allow the next-of-kin, who will have had donation discussed with them, to delegate this role to someone from the extended family who might have specific concerns about the reality of death, as with the daughter in the above quote. Families can always decline this offer if they feel they do not need this confirmation or because they are unhappy to see the tests carried out on their loved one.

A useful information aid to for some families may be the provision of a videotape to explain death certified by BST. This could be viewed with family members and a healthcare professional (HP) and would provide a medium through which questions about death and BST could be raised. This would allow clarification of issues and the opportunity to ‘discredit’ images related to coma that are incorrect in relation to BST such as, “*Well I heard you can wake up after two years in a coma*”.

During the interviews carried out at TP2 and TP3 some participants still had questions related to BST which underpins the need for families to have more help in understanding this 'non-stereotypical death'. If the ongoing debates, both neurological and psychological around the brain/mind interaction are considered, and how much is still being learnt about how brain function translates into physical action or how brain chemistry impacts on personality, there is little wonder that family members question how a brain injury leads to 'loss of personality' and the 'person' that they knew.

Participants expressed how staff frequently asked them if they had any question about what had been said. Staff were keen for families to ask questions, but as participants said, "*The trouble is at that time you can't think of any*" (and25424-25529). Families had not been in this situation before and simply did not know what kind of questions to ask, and what they might want to know later. A list of 'frequently asked questions', developed by HPs could be given to families. This information could then be sent out again, possibly by transplant co-ordinators, at a later date, as there is evidence in the interview data to show that bereavement leaflets were often 'put away' due to participants dealing with the immediate concerns following the death, such as the funeral arrangements and administration of the deceased's estate. Participants would benefit from a repeat of information after this period of activity. Sending out this information would serve a dual purpose. It could help to answer questions that may have become an issue and it would give family members a 'valid' opportunity to contact HPs if they want to.

The time of death was not always made clear to participants. If it was made clear in the ICU it was not always the same on the death certificate.

"When I went to collect the death certificate, that was quite traumatic getting the death certificate, and I had a look and I thought no they got the time wrong. I thought they'd got the time wrong like because the doctor said it would be twelve fifty that's when they did first brain stem tests. I'm certain it was wrong on the Death Certificate,...I do remember thinking God they've got it wrong. How could they get it wrong, something like that." (g/l 46059-46535)

Some participants were told that the time of death would be the time of the second set of BSTs. Others were told, correctly, that if the second set of BSTs confirmed the first set, then the time of death would be certified at the time of the first set of BSTs (Working Party of the Royal College of Physicians 1998).

Unfortunately, one participant, who had been told that time of death would be certified as the time of the second set of tests, noticed a different date (the day after the donation operation<sup>1</sup>) on the death certificate. This participant was told by the 'person administering' the death certificates in the hospital, that the time of death was 'when the ventilator was turned off' after the donation operation. Incorrect information about the time of death undermines the confidence that the families have in the healthcare system, and can impact on subsequent grief as this wife said, *"What date do I put on the headstone?"*. The dilemma was resolved for her by putting the date of when she believed her husband had died on the headstone (the day of the BST).

Terminology used by HPs may also undermine the acceptance of the irreversibility of the brain injury sustained, 'being kept alive on the ventilator', 'life support', and the term 'brain stem death' itself all collude to suggest that death certified by brain stem testing is inclusive to the brain and exclusive of the body. This misunderstanding can support the view that the loved one could recover with intensive rehabilitation.

#### **4.1.3.3 Summary**

When consideration is given to the time and training it takes for HPs to feel confident in their understanding of death certified by BST it seems unreasonable to expect family members with no medical background to understand this diagnosis in the time available. The fact that some participants were still unclear about what BSTs were, and how these tests related to the death of their loved one, at two years post bereavement, is testimony to the need for change in practice in this area.

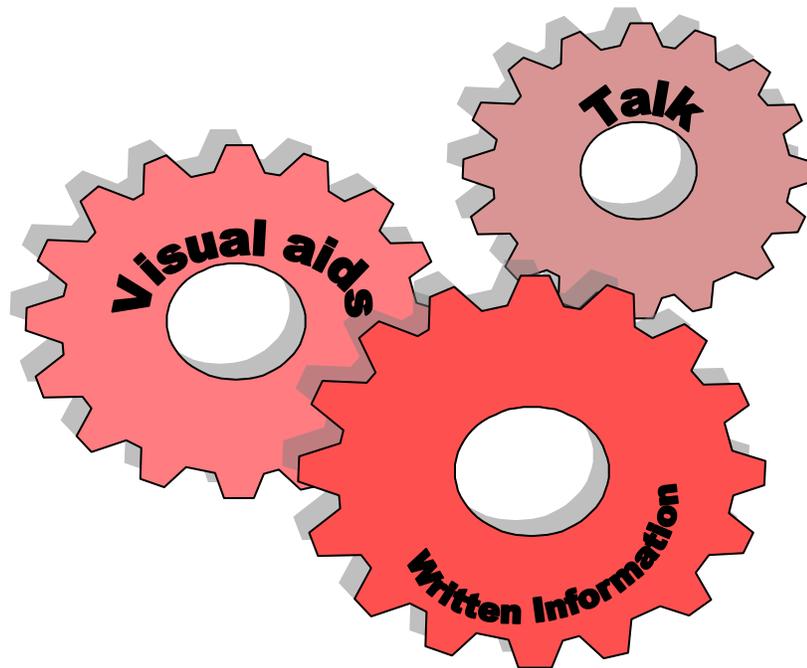
Initial information given to participants in relation to the critical injury sustained by their loved one had a lasting positive impact if it was correct, delivered in complementary ways and is responsive to individual need. Information that was offered in complementary ways that reinforced each other, for example, talk supported by written information appeared to have an impact on the quality of information retained at each interview time point. The addition of the use of information-aids, that had a lasting impact on those participants who experienced their use, could further strengthen this effect. Longevity of this effect could be enhanced by sending out repeat information at a time when family

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<sup>1</sup> This patient had gone to theatre at approximately 11p.m. and the donation operation had been completed by approximately 02.00 a.m.

members are more mentally receptive to it, i.e. after the funeral. Figure 1. shows that these methods can work together to enhance the understanding and retention of complicated information such as brain injury, brain anatomy and BST.

Figure 1. Information is best delivered in complementary ways that reinforce one another.



#### **4.1.4 Role of internal dialogue and unanswered questions on subsequent grief**

As stated above families need time to absorb the complexity of the information that is given to them. This is best facilitated by HPs understanding families' emotional mind-set. Interviews with the participants indicated how much time they spent in a form of 'internal dialogue'. This internal dialogue composed of 'recalling' the deceased and the life spent together, such as the last conversation with the deceased, 'hoping' that the loved one would survive, and, for some, bargaining with God. As time moved on in hospital these dialogues or ruminations included thoughts about possible brain damage and possible death. The nature of the emotional landscape in which the participant is living at this time is well described by the theory of Dissonant Loss (Sque and Payne, 1996).

The theory of Dissonant Loss was developed to explain donor relatives' experiences. The theory illuminates the conflict that family members experience throughout the donation experience as they strive to resolve conflicts stimulated by the uncertainty of the situation and the need to make what are,

due to the sudden death and questions with regard to organ donation, complex decisions. Dissonance was clearly articulated by participants as they learned the extent of brain damage and recalled their loved ones' expressed view of not wanting to survive with brain damage, and yet not wanting the loved one to die. Participants experienced conflict as they 'prayed for' survival and for the loved one to be whole, at a time when they were realising how extensive the brain damage was. Participants hoped for what were increasingly mutually exclusive outcomes. Their loved one to live, which is what they wanted, but be profoundly brain damaged, which is not what the loved one would have wanted.

"And I remember just praying that he wouldn't become a vegetable and praying that he would die, but that was hard because you are praying for your son to die and of course you don't want him to die. I had looked after patients who had been vegetables for years and I couldn't bear to think of him like that and just to have P and not be a vegetable was really important to me." (j11695,12171)

Participants who were not with their loved one when they sustained the critical injury showed greater 'hope' than those participants who witnessed the collapse of their loved one. Hoping was an initial barrier to absorbing the information provided, as participants indicated they did not want to believe what was being said.

"And I was just thinking positively you're going to wake up in a minute and be normal so I wasn't really, really giving those things any thought. Certainly not about him dying no I didn't really suppose, I wasn't accepting it. As I say I was going through the formalities of everything, playing along with it but ya, ya, not really." (mi29611,29938)

Realisation of what was happening came slowly to some participants and quickly to others. There is some evidence in the interviews at TP1 to suggest that those family members who were with their loved one when they collapsed had less expectation of survival than those who had not been with their loved one. Realisation stimulated participants to pay closer attention to what was happening with monitors and to begin to 'double check' or seek 'repeated reassurances' from medical and nursing staff. Participants who received non-contradictory information and patient explanations began to accept the 'inevitability' of death. This is not the same as acceptance of the death, which for many has not happened. Acceptance of the inevitability of the death meant the participant had to deal with feelings of loss of control, feeling bereft of hope and huge swings in emotions. These emotional swings stimulated ruminations as the participant spent time 'recalling' the deceased their 'attributes' 'achievements' and 'the quality of the relationship shared'. This was taking place at the same time as they were attending to (or attempting to attend to) the discussions and explanations taking place around them.

It is important that HPs acknowledge these internal dialogues or ruminations and give the family members time and space.

HPs who pre-empted thoughts and questions stimulated by these ruminations increased the participants' feelings of being cared for and that their individual needs were understood by the team.

"It was actually her that approached me and started the conversation and I really appreciated that because it made me feel more comfortable and it made me feel more relaxed in what was, you know, a really hard situation to deal with. And that nurse she looked after us through, I think, overall in the hospital, for I think it was two days, but it seemed like about two weeks. But she was brilliant, she was amazing, she was there every time, I don't know what sort of hours she was working but she was always really kind, really helpful. And all the doctors were as well you know if you had any questions they were more than happy to help you." (kb19210,19909)

In view of this internal dialogue and its impact on information processing it is essential that the informant gains the attention of the specific next-of-kin, acknowledges this 'special' role and focuses initially on their issues and questions. One participant, a son, described how the doctor, who had clearly noted the distress of his father, chose to speak to other family members. This unfortunately left a lasting impression on the father who felt that the doctor's behaviour showed a lack of understanding of the impact of the sudden injury, as well as a lack of acknowledgement of his role as husband. This lack of recognition of his role was the most potent memory, from the hospital experience, reported at his TP3 interview, two years post bereavement.

Father "I got annoyed about that because I felt he should have been speaking to me because it was my wife that was lying there. And I was annoyed." (/10,8929)

Two non-donating participants were also put in situations where discussions were conducted generally to a room full of relatives or took place in corridors where there were multiple distractions. These participants felt dissatisfied with the information giving (see section 4.4).

The following example of best practice shows how acknowledging the needs of the next-of-kin, recognising their need to understand what is happening to their loved one, and acknowledging them as 'the important' person in the patient's life, impacted on how this participant viewed the care he received at TP1.

"He was excellent. And what he did, he brought the scans in and put them up on the window. He didn't talk to the other people he spoke to me didn't he. And him and I, like

he explained everything to me and he answered my questions and whatever, and he was very good.” (s/r23899,24049)

Interviews at TP2 and TP3 document that positive memories, such as those above, remain positive, and negative memories remain negative, despite the passage of time. Time does not appear to change the impact of initial care and its effect on subsequent grief.

#### **4.1.5 Summary**

Sudden death and the discussion about organ donation make specific demands of the next-of-kin at a time when they are emotionally and cognitively ill equipped to respond. External demands such as receiving complex information, responding to HPs requests, the needs of other family members and the tasks of daily living are competing with internal demands such as, the unreality of the situation, the physical pain of loss, thinking about the deceased, the need to fulfil the wishes of the deceased and the need to make decisions about organ donation. It is important to record that most of the participants made decisions about organ donation without gaining a detailed understanding of death certified by BST and this may be due in part to their motivation to have the wishes of their loved one regarding organ donation fulfilled, this emotional need overriding their own informational needs. This appeared to have consequences for subsequent grief as interviews at TP2 and TP3 highlighted the number of questions resulting from a lack of information that could be remembered or a lack of information that could be accessed.

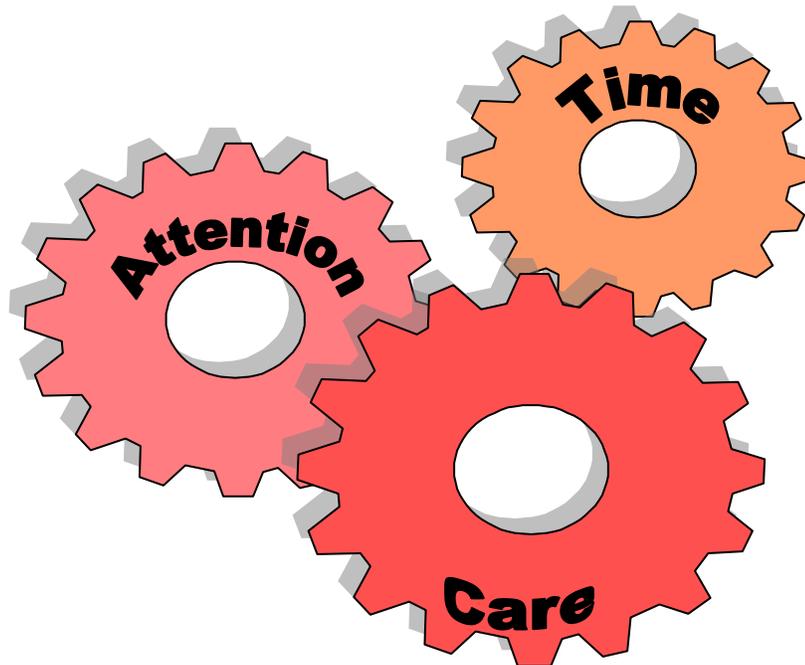
Participants needed:

**Time** - to understand and absorb the nature of the brain injury which had killed their loved one so suddenly, time to realise the inevitability of death, time to discuss this with other family members and to seek reassurances for any concerns.

**Attention** - to the special role that they had as next-of-kin, attention to their inner turmoil and the understanding that this could impact on how they process information.

**Care** - in the way, and the where, that information is presented and the understanding that this will ‘live’ on in their minds for years to come (Figure 2).

Figure 2. To enhance information processing and maximise the positive impact of initial care on subsequent grief the needs of the family require specific consideration.



#### 4.1.6 Role of patient care in decision-making and subsequent grief

A positive rapport among the family and the HP team before death was diagnosed appeared to facilitate the discussion about organ and tissue donation. This rapport was established by the care that the loved one and relatives received during the time in hospital. The quality of care demonstrated by HPs, and the resulting rapport developed, left lasting impressions on the participants and for most, these were positive memories, particularly in relation to the nursing staff and transplant co-ordinators. Twenty-five participants remarked on the dignity and respect with which their loved ones were treated by HPs and this emerged as one of the most important issues once death had been confirmed and the discussion about organ donation had taken place.

“I don’t think there is anything I could change certainly. I was absolutely amazed and impressed by the nursing staff in the hospital it sort of reaffirmed my faith in human beings actually because they were wonderful and I don’t say that lightly, they were absolutely marvellous. Like even though there was nothing that could be done for S and the remaining time was measured in hours and minutes they treated her just with total respect. They cared for her so well and talking to her, they were kind, they were gentle, and they were just absolutely unbelievable, they really were. That was the one sort of bright light really, in what was, and still is, remains the darkest part of my life.” (k/s36043-36759)

“I thought it was really important. It wasn’t like this was a piece of meat that they were keeping in good condition, this was still the person we loved”.  
(s/s55632-55860)

A comment made by participants at all interviews was how the nurses spoke to their loved one, explaining what they were about to do, that things might be hot or cold, or that someone was present. One participant found this ‘communicating’ with the ‘dead’ person difficult as it undermined his ‘transition’ from thinking of his wife as alive to thinking of her as dead. However, most participants were positive about HPs ‘talking to the deceased,’ but it is important to identify those families who may find this practice difficult.

The one area in which care seemed to falter was when other healthcare teams became involved with the deceased and participants or when participants left the ICU. Two participants were very distressed when the time that they had been told they would have with their loved one was suddenly cut short by the unannounced arrival of the theatre team, who immediately started preparing the deceased for movement to the theatre for organ retrieval. The theatre team did not acknowledge the participants, avoiding eye contact and verbal communication. This situation was further compromised by the nurse and transplant co-ordinator, with whom the family had developed strong bonds, being absent from the bedside.

“I felt angry about these people. All day I knew I had already lost I, but I felt angry that [our] last few moments had been invaded like that and I was also very aware of my daughter’s distress, both of them were very angry about it. It felt really important to me to hold onto, to hold onto my own feelings because if I had let them out it would have been even more difficult for my girls.” (si71172,71572)

It is essential that all HPs involved with families who agree to organ donation understand the importance of the ‘final moments’ spent with the deceased. Participants indicated how important this was for them. They also stated how hard it was to leave their loved one.

“It was important to us to have a definite fifteen minutes of no interruptions, nothing else, but just to take a turn each on our own if we wanted it, just to say our goodbyes.”  
(k/s34413-34805)

Families found it difficult to leave the ICU when they had said their goodbyes to the deceased. This difficulty is rooted in the image of the deceased supported by mechanical ventilation. Only one family was escorted from the ICU and hospital, with checks that they could drive home safely (some spouses’

insurance was invalidated by the death of their partner whose car they had driven to the hospital). This 'abandonment' was a lasting memory for one family who spoke of it at each of the three interviews.

"We came out of there, two of us, obviously really upset, and nobody came near us. We walked out, picked up our bags from the room and walked out of the hospital. Just had to leave him in that room." (j38709,38919)

A minority of participants (n = 3) remained in the hospital to see the deceased after the donation operation. A larger number returned the following day to see the deceased in the Chapel of Rest. Those who had not seen a dead person before were apprehensive about this. One participant was "*incredibly shocked*" as she had never seen anyone dead before but she felt her father looked "*absolutely stunning*". The transplant co-ordinators had told her that they would look after her father, and she felt they had done so. Most participants who saw their loved one after the donation operation were relieved that they had not been disfigured as this was a common theme of concern. Words such as '*rip*', '*chop*', '*tear out*' peppered the interview data. The genesis of the concerns that stimulate this language, in the light of little knowledge of the actual process of the donation operation, is an important area for research.

#### **4.1.7 Summary**

The concept of caring was used to describe the behaviour of the nursing team. Nurses were pivotal to the families overall experience in ICU. The communications and behaviour of medical staff either enhanced or detracted from this baseline. Participants specifically identified individual doctors if their communication was seen as good or poor, but no nursing staff received poor reports from participants. When participants were asked at TP2 and TP3 about their memories of the experience, they reported positive memories in relation to the care their loved one received with no donating families doubting that the ICU staff had done the best they could for the deceased.

The impact of initial care on decision-making appears to impact on subsequent grief. What the next-of-kin saw, heard and experienced remained with them as they left the ICU and was still available for discussion at two years post bereavement. The findings from interviews at TP1, TP2 and TP3 have amply illustrated families' needs in relation to the content and manner in which information could be best delivered. Complicated information needs to be *correct, presented in complementary ways* for example, a discussion supported by visual aids. Most importantly the information needs to be *responsive to*

*individual needs*, and so is best based on the assessment of individual needs. To facilitate bereavement that is uncomplicated by questions about the brain injury and subsequent death, families need *time* to understand the information given, *attention* to their inner emotional needs and *care* in the way and context that information is shared.

Assessment of needs best begins at the bedside with A&E or ICU HPs considering the families' immediate needs in relation to information, their need to see and visit their loved one, the type of support the family member has available and their emotional response to the unfolding situation. This assessment would facilitate the development of programmes of care, which if shared with transplant coordinators and bereavement support workers, could influence subsequent bereavement outcomes.

#### **4.1.8 Recommendations**

A greater use and development of visual information aids (e.g. a video that explains the nature of brain injury and death certified by BST).

- Written information and frequently asked question sheets (FAQs), to support verbal discussions about organ donation.
- The offer of the opportunity for family members to attend BST if they wish to do so.
- Clarification and standardisation of the time of death certified by BSTs.
- Identification of, and acknowledgement of, the person who the deceased would expect to make decisions about them (this may not be the legal next-of-kin).
- Assessment of individual informational needs, available support and emotional responses to the ongoing situation.
- Education of all HPs regarding the bereavement needs of families whose loved one has died suddenly.
- Integration of bereavement theory into HPs education related to sudden death and organ donation.

## **4.2 Aim 2. Ways of enabling relatives to make choices about organ and tissue donation that are right for them.**

### **4.2.1 Discussing organ donation**

End of life decisions remain with the living long after the death of a loved one and have been implicated in abnormal and complicated grief (Saunders 1993; Wright 1996). As families have a time limited opportunity to consider organ donation, it is imperative that the approach and discussion about organ donation facilitates a decision that will not be regretted later, as has been suggested by other authors (Burroughs *et al* 1998).

HPs play an important role as 'gatekeepers' to the donation process through discussing donation sensitively with families (Norton and Sukrow 1991), although some hesitate feeling that discussing donation is intrusive in the family's moment of grief (Kiberd and Kiberd 1992). Of the 49 participants that joined the project, forty-six agreed to donation and three did not. Participants had no objection to organ donation being discussed with them and did not feel that the discussion increased their distress levels as, "*The worst thing that could have happened already had*", the death of their loved one.

Assisting families to make decisions about organ and tissue donation that are right for them, requires HPs to understand the emotional landscape that is imposed on the next-of-kin by a sudden death. Sudden death not only robs the next-of-kin of a significant relationship without warning, but also robs them of many of their usual coping mechanisms, imposing a sequence of events that left participants feeling dispossessed of physical and psychological equilibrium. It is at this time that the topic of organ and tissue donation is necessarily raised.

In making an approach regarding organ donation it is reasonable to expect that not all family members will agree to donation, and it may be that the person making the approach will chose to 'back off' in the face of dissent. There is a risk here however that the person who will suffer the greatest consequences from a decision made at this time, will be left to struggle with this decision over time. The needs of the next-of-kin, or the person, whom the deceased would expect to make decisions on their behalf, must be

elicited even in the face of another family member who is forthright<sup>1</sup> and demanding. Those making an approach to families may need to speak to this ‘forthright’ person alone, and discuss with them, the possible consequences of a decision that may be regretted later because of the disproportionate influence of one person’s views. HPs involved in requesting should be prepared to investigate through gentle questioning, relatives’ views regarding organ donation, as this is a once in a lifetime decision, which once made cannot be undone.<sup>2</sup>

None of the donating participants had any regrets about donating their loved one’s organs. In fact for some it was and remained, “*the right thing to do*”. Some participants (n = 6) explained that they would have liked more time to reassure themselves that the nature of the brain injury was irreversible, but no one regretted their decision. In the interview carried out at 13 months post bereavement, one non-donating participant wondered if they might have made a different decision if the antecedents to the donation discussion had been different. The two non-donating families reported poor communication, poor knowledge of what was happening to their loved one and low rapport with HPs as particular issues from their hospital experience. Added to this, and importantly, one of the above participants and her extended family did not know the wishes of the deceased about organ donation. This lack of knowledge combined with the forthright views of one family member influenced their decision not to donate. As the above participant said on reflection, “*There are so many people out there who need organs.*” (Afieldnotes) one wonders if this decision was in line with her own values and feelings.

Nursing staff sometimes informally raised the subject of organ donation and participants were positive about this approach.

“One of the nurses said to me, if the worse comes to the worse, I will warn you, you will be approached about organ donation, and a member from the organ donor team will discuss with you about organ donation. Are your happy with that?” (b/b10404, 10632)

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<sup>1</sup> It is notable from discussions with HPs that sometimes one forceful family member may play a disproportionate role in the decision-making process and yet not be the one who will be most impacted by the decision.

<sup>2</sup> It is our understanding that transplant co-ordinators are encouraged to carry out ‘gentle questioning’ in relation to reasons why the family/individual does not want to proceed with organ donation. Gentle questioning may not be carried out when a transplant co-ordinator is not involved in the donation discussion. This questioning will help clarify views held by the family, and the deceased. Encouraging the family to articulate their views would indicate the strength with which these views are held. In facilitating a review of the views held, the HP can help reduce the risk of a decision being made that may be regretted later.

#### 4.2.2 The role of children in decision-making

During interviews the role of children in the discussion and decision-making about organ donation was highlighted. Children were present and actively contributed to decision-making in 14 cases (33% of the sample). The age range of children was 9-18 years and they were either the children of the deceased or siblings of the deceased. Decisions sometimes hinged on what the child thought<sup>1</sup>.

“ And then we said to her son [grandmother speaking], he’s nine, em, and he said ‘Oh no’ first of all, then we explained it to him. We wouldn’t have done anything if he didn’t want to.” (t/l 7200-7350)

One parent wanted to “*square it with the kids*” (k/s1758-1760) as he was aware that the children had never had a conversation with their mother about donating her organs, although he had had this discussion with his wife. This finding introduces another spectrum into the decision-making process, as children’s needs in relation to information about organ donation may be different to adults. This finding needs further investigation.

#### 4.2.3 Factors influencing the donation decision

##### 4.2.3.1 Decision-making when the views of the deceased were known

Knowing the wishes of the deceased in relation to organ donation was the most important influence on participants’ decision-making. Nineteen of the families who participated in the study knew the wishes of the deceased in relation to organ donation and therefore made decisions in line with those wishes. For these participants it was paramount that the wishes of the deceased were fulfilled, even when this was not in line with their own views (i.e. that the next-of-kin did not agree with organ donation). The evidence suggests that participants who knew the wishes of the deceased did not feel that they had to ‘make a decision’, but that they were fulfilling the wishes of the deceased by facilitating the donation.

“I said like you know it’s, that’s the way she wanted it. It’s an obligation to her.” (g/c17212,1709)

“It was S’s wish my own personal views on the matter didn’t, just weren’t relevant, they weren’t an issue. It wasn’t for me to alter anything that S wanted.” (k/g18289,18473)

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<sup>1</sup> Anecdotal evidence indicates that children are increasingly present during donation discussions. Personal communication with a Regional Transplant Co-ordinator involved with our present study suggests that children are present at approximately 60% of that service’s discussion with families. In some families the children’s/young people’s views guide the final decision (personal communication with Norwegian nurses at European Critical Care Conference, Paris, May 2002).

The urge to do everything for the deceased included having their wishes known. Five participants realising the seriousness of the critical injury and knowing that their relative wanted their organs donated raised the issue of organ donation themselves before BSTs were carried out. In cases where participants initiated the discussion about organ donation the following factors influenced their approach to HP: knowing the views of the deceased, being concerned that the family would not be asked, wanting to ensure that the staff knew the wishes of the deceased and being concerned about the impact on the HPs of asking the family and wanting to ameliorate this effect.

“So Thursday night I was actually talking to one of the nurses, must have been about midnight. I said she’s not going to make it is she? And the nurse said ‘No, she’s not in all honesty’, and I said well I’m just telling you that she always said she would donate her organs. So they didn’t actually ask me I told them. And on the Friday morning they had set the ball rolling. They were doing tests and send off this and that. The nurses were brilliant, absolutely brilliant and that was it really.” (a/m15166,15672)

It was important for participants to understand the critical injury and receive explanations regarding death and BST that fulfilled their individual ‘informational’ needs.

#### **4.2.3.2** *Decision-making when the views of the deceased were not known*

A ‘Yes’ decision, when the views of the deceased were not known, was influenced by the ‘attributes’ of the deceased and the view of them held by participants and the extended family as an ‘altruistic person’ who ‘cared for others’ and who ‘was always doing things for others’. In this situation the deceased was also understood to have a neutral stance on organ donation.

“And we said well no, we don’t think she had a donor card but she would have wanted her organs donated anyway. But we thought that because she was such an unselfish person, that she always thought about other people before herself, that we thought it would just be the natural thing for her to want to do. Because if she thought she could help someone else by giving something of hers, then she’d do it without a shadow of a doubt. We thought it was the best thing and we didn’t really have any problems with it either because we thought that if someone else is going to benefit from it then why not do it you know.” (b/b12425,12924)

Participants were also motivated to donate by a need to help others (in line with the lifestyle of the deceased) and the need for something positive to come out of the negative experience of this sudden death.

“I said at the end of the day I said to Dr T as well if there is only one good thing that can come out of this. If L can save some lives. I said if that’s the only good thing that can

come out of this nightmare then that's the way." (d/I13587,13828)

A 'No' decision in this study was a product of, in one case, of not knowing the wishes of the deceased combined with a poor rapport with HPs, poor communication about the brain injury, and a forceful family member who was anti organ donation. In the second case the 'No' was a product of a catalogue of poor care in the hospital preceding the deterioration to death, poor communication preceding the admission to the ICU, the complete breakdown in any meaningful relationship between the parents and the healthcare team preceding admission to ICU and a view that not enough had been done for the deceased. This family was pro-donation but were overwhelmed by events.

#### **4.2.4 Knowledge of the donation process**

Participants had very little knowledge about the organ donation process and how the system worked. They knew little about tissue donation and one husband believed that his wife's eyes would be removed for donation on the bed in the ICU. A father did not appreciate that his son would go to the operating theatres still connected to the ventilator. Participants had concerns about how their loved one would look after the operation, images of disfigurement were prevalent. One wife worried that her husband would not be given an anaesthetic (underpinning the lack of understanding regarding death) and that he may experience pain.

#### **4.2.5 How families got to know the wishes of their loved one**

Nineteen participants in this study had 'concrete knowledge' of the wishes of the deceased as organ donation had been discussed among family members. TV programmes; documentaries as well as drama prompted some of these discussions. Five participants mentioned the Ben Hardwick story as generating discussion. Seven participants explained that they had been blood donors and therefore organ donation fitted with their view of 'helping others'. Others were prompted by the presence of donor cards in doctors' surgeries. One wife indicated that a poster related to organ donation, that was in the interview room in the A&E department, had reminded her of her husband's wishes to donate. A mother discussed her daughter's request to have a donor card, that she had seen in the GP's surgery, and how this had reassured her about her daughter's wishes, when she made a decision to agree to donation. Another mother 'thought' her son had marked his passport to support organ donation. This was checked by the transplant co-ordinator and reinforced her decision.

Overall participants felt that there was not enough publicity or information easily available about the detail of organ donation. This topic was discussed more at TP2 and TP3 interviews, which may be a reflection of the participants' wish for information about the recipients and an acknowledgement of what their loved one had achieved in improving the quality of life of the recipient/s.

Participants were asked their opinion regarding 'Presumed consent Opt-out' and 'Conditional donation'. The majority of participants (n=37) felt presumed consent was a good idea and that it would facilitate discussions about organ donation. Participants felt that presumed consent should not replace the discussion, with families, regarding organ donation. Seven participants were not in favour of 'presumed consent opt out' and two were not sure. All participants were against conditional donation, although one participant was concerned about her husband's organs going to someone who smoked, *'I do hope that person is not a smoker'* (b/w45010,45045) as in her view smoking might damage the donated organs.

#### **4.2.6 The impact of donation on grief**

At all interview time points participants explained how donating the organs of their loved one, had in different ways, been a comfort for them. The comfort was gained from knowing something good had come out of a terrible situation and from the fact that the deceased had achieved something unique in giving life or improving the life of the recipient. Donating organs did not mitigate any of the painful emotions experienced by them. It did not help them in their grief, but it did provide some comfort. This feeling of comfort was also related to hearing about organ use and hearing from recipients.

"I was asked after one of the talks (done to HP) has it helped with the grieving process and I'd say no, it's helped very slightly with the recovery, but it didn't help at all with the grieving. It's a slight consolation prize because it's not a complete waste, but that's as far as it goes." (s/i52806-52843,52899-35015)

"And to hear that they went to a 20 year old lad and a 23 year old lad was a huge, huge comfort." (h/p17008-17029)

#### **4.2.7 Summary**

The findings of this study, which agree with other authors (Randhawa 1995), that families did not feel that being asked about organ donation increased their distress, or that organ donation should not have been raised by the healthcare team, should provide HP with compelling evidence to support their practice. It is important that the families' distress, anger or possible emotional outbursts, caused by the suddenness of the death, are not misinterpreted and allowed to become a barrier to facilitating

decisions that may impact adversely on bereavement. Families need every opportunity to reach a decision that will remain right for them. Information about grieving and its integration into the donation discussion process would help facilitate this. HPs' education needs to focus on individual differences, belief systems, stress reactions and therapeutic questioning, if they are to help families to make decisions, which support them through their bereavement.

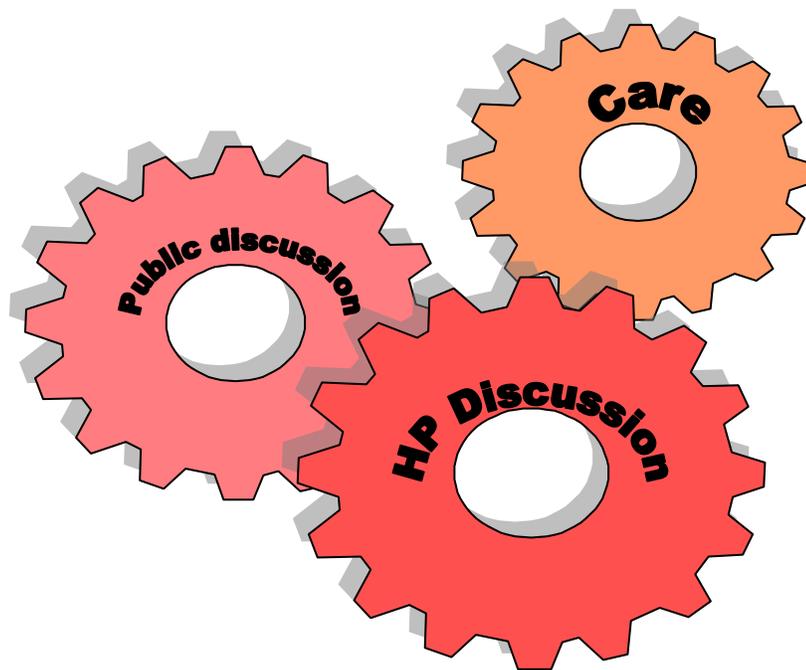
The role of children in the decision-making process needs to be investigated further as little is known about the impact on children/young people of being involved in sudden death and organ donation. Also the question arises about the influence of children on the behaviour of HPs and families.

Three issues are implicated by the findings in relation to helping families to make decisions, which are right for them. The first is the necessity for HPs to facilitate the discussion about donation, focussing on the possible consequences to the family of a decision that may be regretted later. Participants including the non-donating families felt that it was appropriate to discuss organ donation with them. They may have felt that the timing was poor or that the manner in which they were approached and donation discussed could have been better, but they recognised that the HP had a responsibility to raise the topic.

The second is the need for good care and communication in all areas of hospital care, as families will have to cope with these issues during their bereavement, whatever their decision regarding organ donation.

The third is the need to stimulate family discussion about organ donation before they are in the situation of a sudden death. These findings indicate the inter-play of factors within the hospital and society which impact on decision-making about organ donation (Figure 3.).

Figure 3. Illustrates how the issues of care and communication, and encouraging public discussion can underpin and facilitate the discussion by HPs regarding organ and tissue donation.



#### 4.2.8 Recommendations

The discussion about organ donation should be carried out by, and restricted to, those staff members who are comfortable and knowledgeable about this topic.

- A discussion regarding the donation decision should be carried out to reduce the possibility of a decision that may be regretted later.
- The recognition of the role of children in the decision-process and assessment of their bereavement needs.
- Greater publicity regarding the process of organ donation so that next-of-kin expect to be asked about this topic.
- The use of media to stimulate discussions about organ and tissue donation in society.
- Greater acknowledgement of the impact of organ donors in society

#### 4.3 **Aim 3. Assessment of the need for bereavement support and the effectiveness of any support received.**

According to Klass *et al* (1996) bereaved people need concrete assistance, support over time, people who can listen and recognise their ongoing needs for friendship, care and concern. They need people who can share the bond with the deceased and make that bond part of their ongoing relationship with the survivor. The needs suggested above illustrate the range of support that may be required by some bereaved people and serves to remind us that not all bereaved individuals have the same needs. The following section will discuss assessment of bereavement support needs, the nature of needs expressed by families in the interviews at TP1, TP2 and TP3, what formal and informal help was offered to families and by whom, the nature of the support that families utilised, both formal and informal, and their views on the impact of support.

##### 4.3.1 **Assessment**

There is an acknowledgement that distressed individuals need *physical, emotional and informational* support whilst within the hospital environment. This was reflected in the efforts made by HPs, especially nurses and transplant co-ordinators, to reduce the impact of possible ‘irritations’. Some of these were the needs of daily living, where to sleep, where to get food, parking charges etc. Nurses and transplant co-ordinators also supplied information, facilitated physical contact with the deceased, contact with a chaplain and acknowledged their individual loss. This area of bereavement support was carried out well by the majority of ICUs with an example of best practice highlighted below. Unfortunately some participants (two non-donating families) experienced poor practice where their needs were not met (section 4.4).

“The first few nights that room was taken I think and they just found a mattress. Put a mattress here we’ve got loads of bedding and pillows for you. Wasn’t enough for all of us but did what they could. Also another thing they did for us, which I don’t know if this is just part of what they did. Parking our cars, you have to pay, but they got all the registrations of all the cars and the Staff Nurse wasn’t it, she phoned down and said we want, and we were allowed to park all day. I know it’s not important but it is important.” (s/r19240,19440-19787,20110)

There was an acknowledgement that people may need *emotional support* on leaving the clinical environment as hospitals, Registrar’s and Coroner’s offices have generated ‘bereavement leaflets’ which were ‘offered’ to participants or extended family at certain time points following the death. These leaflets were usually distributed when the death certificate was being processed or when the family registered the death. In most cases the agencies listed were CRUSE, the Compassionate Friends,

Samaritans, GP Counselling services or Church groups. The view of the participants was that these agencies dealt with counselling and this was not what they felt they needed in the early months of bereavement as many were dealing with very practical issues. There was no assessment of or acknowledgement of practical needs such as issues around the administration of the death and the deceased's estate. Difficulties were experienced by participants in areas such as dealing with pensions, bank accounts and finalising details related to interment of the deceased and head stones. In some cases the time taken to sort out these issues was considerable and often delayed the impact of the loss of the deceased.

“But (when the grief finally impacted) it was the most horriblest, horriblest feeling I’ve ever had really, I just felt completely out of control. I couldn’t remember anything, I couldn’t, it was just like my brain was on overload and I just couldn’t take anything in.” (p 980,1210)

#### **4.3.2 The nature of the needs expressed by families at TP1, TP2 and TP3**

The emotions stimulated by the sudden death varied greatly for participants ranging from profound distress to inertia. Many participants felt overwhelmed by the things that needed to be done such as activities of daily living, shopping, cooking etc. This loss of emotional energy was a common theme in the early months of the bereavement.

“I couldn't cope with going out shopping.” (j 9180,9422)

Participants coped with the impact of these emotions in a variety of ways. On an internal level participants drew on personal resources that often meant them reducing other demands on their emotions. Many retreated into themselves moving through the early days of bereavement on “*autopilot*”. Some coped by keeping busy and “*focusing on the needs of others*” this included their partner or spouse, children or parents. Participants’ reports indicated that a large amount of time was spent thinking about the deceased. On an external level participants relied on partners, friends and family to help them deal with issues. As time progressed some participants felt increasingly alone with their grief as friends and family began to focus less on the death and the needs of the participant, whilst others felt that friends and family were their main support.

“We laid her to rest and that was it and since then I’ve been on my own.”  
(s/118835-18906)

“ All the way through you know our friends locally supported us. I didn’t think my brother and sister, my two brothers and sisters OK they kept in touch but they were very distant and didn’t ring up quite as often as you might have expected, but local friends they kept ringing up and surprising you really.” (t/tp36845-37259)

Whilst some participants experienced great difficulties in making decisions in the early months of bereavement, others actively participated in decision-making about changes in their day-to-day lives, even though this was difficult due to the ‘oscillating’ nature of their feelings (Stroebe and Schut 1998). Participants explained how their moods changed from periods of equilibrium to periods of profound sadness and despair. Participants found the unexpectedness of the mood swings disabling and disturbing.

“Up and down, very up and down. I’d go months, maybe a couple of months and everything would be fine and then, I think in the phase, alone phase, where I just want to retreat actually, come home and shut the door and don’t want to know anybody or anything. And then that seems to pass off and then I’d go through the phase of going out, friends, you know. Yes, it’s been like a roller coaster.” (r 1071,1461)

Participants reported feelings of anger, sometimes directed at the deceased, and sometimes at the apparent unfairness of the situation as they were left to deal with difficulties alone. This was particularly mentioned by parents whose spouses had died. While despair was the feeling often referred to close to the time of bereavement, loneliness and vulnerability were discussed as bereavement progressed.

“But it is, it’s almost an abyss, like an abyss, it doesn’t seem as if there’s any bottom to your misery, but of course there is, you know. It’s just as a means of escape because you’re in so much, sort of, not so much pain as acute discomfort. It is, you almost feel slightly nauseous, you know.” (m 24426,24716)

“I’m lonely, very lonely because as I say (deceased) was always with me. I can’t cope with people, that is one of my big drawbacks at the moment.”  
(j 965,1129)

Some participants had to deal with other ‘major changes’ in the year following the bereavement. This usually entailed moving house or dealing with a serious illness for themselves or a family member. Whilst these activities often distracted participants from their grieving they also served to re-emphasise the loss of the deceased and in some cases guilt was experienced, for instance, in moving from the house they had shared with the deceased. Guilt was also expressed when happiness and laughter was experienced.

“It was something that I’ve been waiting and waiting and waiting for and when it came, when it came to the day to move out I had split, I had split emotions. Part of me was happy to be going because I didn’t have to look across the field (where her daughter had been killed) any more but then the other part of me was thinking but we did have some good times here. And it sort, it, I felt torn and as I say I didn’t want to be the last one to shut the door on the flat but I was, I went up on my own and I walked round and I looked and I stood there and I said to her, ‘Darling if your going to come with me you come with me now and shut the door’.” (d/l 20079,20946)

For those who did not move, but who began to make changes to the home they had shared with the deceased such as changing the furniture or changing the decoration, a difficult area was dealing with how other people saw the changes. Instead of the support that they were expecting, the extended family often felt uncomfortable with changes being made by participants, suggesting that in some way the deceased’s memory would be altered by the change.

“They don’t understand it. No, no. Like I said the kitchen, was (husband’s name) kitchen, he had a stool, that instantly you notice the stools gone. They didn’t like it, you know, it was all, ‘Blimey where’s the stool gone?’ and you know it’s (husband’s name) stool and you’re like, I can’t cope with it being there, I can’t stand it being empty, it’s not fair, you know. And they’re like, ‘Ya but it was (husband’s name) you know, you should have it here,’ and it took ages for them to understand that they only come here for however long and I’m here constantly day in day out and I see it all the time.” (t 12751,14109)

Most families spent a period of time attempting to gain answers to questions that continued to be an issue after the bereavement. For the participants whose loved ones died in road traffic accidents there were questions that needed answers from multiple sources. Participants had to attend inquests and for most of these participants the inquest generated further questions instead of providing answers.

“I do regret the inquest that we didn’t ask the questions that I realise now that we should have asked but at the time we couldn’t ask because well we just weren’t there. And I feel we should have got help, we got no help from the police as to what was going on really. I mean they explained that it was going over the like the crash scene but there was a white car there and now we realise we should have asked where did the white car go why didn’t the police trace it up.” (jj/m64813,65640)

Of the families involved in inquests, only one family was offered the opportunity, prior to the event, to discuss the inquest proceedings, what their role would be, if they would be able to ask questions, and if so of whom.

All the participants reported on how quickly the year had passed since the death of their loved one. The year was marked by important milestones such as the deceased's birthday, wedding anniversaries, participants' birthdays, Christmas, Father's/Mother's day and Valentine's Day.

"Anniversaries probably (most difficult thing dealt with over year) but you know I've had (wife's name) birthday. March the 10th is (wife's name) birthday. I've had our anniversary, wedding anniversary, which would have been 20 years on the 10th of September. And the 12 months anniversary I suppose of the death." (a 5050,5489)

For most families Christmas was particularly difficult. Most participants chose to do something different for the first Christmas after the death. Christmas more than any other anniversary seemed to stimulate strong emotions associated with being a family. This has prompted the suggestion that this may be the most appropriate time of year to hold thanksgiving services for donors, recipients and their families or acknowledge the donor's contribution.

"Christmas was I dreaded Christmas it terrified me. Christmas Eve you know sitting here on my own putting the kids to bed, getting the presents out, you know doing all the things that we'd done together it frightened me. I done it, I got through it, I cried, I went to bed. Christmas Day, Christmas Day got taken over by (son) and (daughter) you know they were they were so excited it was Christmas Day, so you forgot the pain." (sc/s20133,22832)

"Christmas we went down to S's, she said well come and stay the night down there, so we went for two or three nights, which is completely different to the usual things cause they always come out here, so that helped because it was completely different." (r/m8609-887)

Participants explained how on passing the first anniversary of the death of their loved one they had "*got through all the firsts of everything*". One wife explained how being able to say that her husband had died "*last year*" instead of "*this year*" was an important marker for her.

The anniversary of the death was marked by most families, but in very different ways. Some families got together at this time, visiting the grave, spending time together, or handing over the results of fund raising to health or emergency service personnel.

"What I, what we did, I took the day off and I met with (wife's name) Mum and her partner (wife's name) brother and his girlfriend and R and M, his wife and we all went for lunch and we toasted L and just basically spent some few hours together. I went up the grave in the morning on my own and then we all met for lunch for a few hours, which was nice, and then they all went up to see L in the afternoon. I wanted to be up there on my own because I was a bit upset." (r/l 9668,10168)

Some participants preferred to be alone on the day thinking and talking to the deceased, reviewing photographs and memories. Some participants were apprehensive about the anniversary, being primarily concerned about how they would feel and cope with the day and for many it was less difficult than they had anticipated.

“So I had most of the day on my own. I had deliberately planned to be on my own and not have anything any, any professional or social contacts because that wasn’t what I had chosen. It was less difficult than I had expected it to be I think.” (s 31481,32475)

Some participants (n = 3) received a letter from transplant co-ordinators at the time of the first anniversary. This was a positive acknowledgement that the family and the deceased were being remembered. Whilst it would be incorrect to say that participants needed contact at the time of special dates, these dates were ‘specific’ times that participants found difficult. Participants were apprehensive about how they would feel and how other people would react. Remembering the families at such times would serve a dual purpose. First it would acknowledge their feelings of loss at this time and second it would give families a ‘legitimate’ reason to contact transplant co-ordinators or HPs.

#### **4.3.3 Summary**

The oscillating nature of grief (Stroebe and Schut 1998) impacted on the initial months of bereavement. Practical needs that participants felt unable to deal with, were universally fulfilled by family members or friends or not dealt with, whereby they remained a source of stress which participants still discussed at TP3 interviews. Initially most participants (n = 39) had regular contact with this support network, but as time moved on there was less practical help. Family and friends were the main source of informal support whilst transplant co-ordinators were the main source of formal support during the initial months of grieving.

The role of unanswered questions became increasingly important over time, whether the questions were about the nature of the brain injury, heart attack or road traffic accident. Families described the questions they felt they ‘should have asked’ at the time, but were too shocked to do so. These questions, like the ones above, often needed multiple sources of information, that participants felt were inaccessible. Participants who had donated frequently turned to transplant co-ordinators for answers to questions related to BST, but only two had received ‘written information’ about these tests at the interviews carried out at TP1. There appears to be an assumption, supported by the ‘type’ of literature

made available to participants that ‘counselling’ is what they needed and that it was readily available, when this was not always the case.

#### **4.3.4 Hearing about and from the recipients of donated organs**

Of the 46 donating participants, 36 discussed wanting to know about the use of the organs their loved one had donated. Thirty-five of these families had received a letter from the transplant co-ordinator outlining the use of the organs and supplying information about the age and gender of the recipient, within one month of the death. Twenty-five families received the letter soon enough to have it read out at the funeral, or to share with other family members at the funeral or cremation service.

None of the participants had heard from any recipients at the time of the first interviews (3-5 months post bereavement). Not all participants wanted contact from recipients at TP1, but all the participants ‘would have liked to hear’ or thought it ‘would be nice to hear’ by TP3. At TP2, 17 participants had received at least one letter from a recipient or a member of the recipient’s family. At TP3 this number had increased to 19. There was an overall positive response from those participants who had received letters or cards. Two participants delayed opening the letters as they struggled with the emotions prompted by the contact, but in both cases, as with other participants, the letters were an important recognition of the role the deceased had played in changing the recipient’s life. Participants found the contact ‘*helpful*’, ‘*comforting*’ and some felt ‘*proud*’ of their relative’s donation. Thirty participants wanted more information about the recipients and two participants would like to meet recipients at some time in the future.

“When I got it (letter) I was em, I read it, and I was a bit angry and I was jealous and I was thinking, you know, that’s my (wife’s) kidney and, I had all sort of mixed emotions and I didn’t really understand what I was feeling. A few days down the line I thought about it and thought about it and thought about it and I think it’s a wonderful, it’s given her (recipient), her life back, and that so important. All right the misery’s gone into my life. But you know (my wife) didn’t die in vain. I don’t know if that’s the right word, some goods come out of this mess. You know this lady said her life has changed and she always thinks everyday, a bit about, the, you know, the transplant and how grateful she is. I mean I understand all that and I think it’s wonderful now, but at first when I first got the letter I was just, because it all just rammed it in me face and I don’t like to think about it a lot.”

(s 3591,4541)

Participants who had not heard from recipients experienced emotions ranging from disappointment to anger. They sought to understand the reasons why recipient families did not write to say ‘thank you’.

They ultimately felt a *'thank you'* card was a small thing in relation to the *'gift of life'* offered to them by the donation of an organ. This led to possible regrets about the donation.

“Well I just hear nothing. I telephoned, I had a letter, I had a letter from, it's quite ironical, from the hospital in C where C gave birth, had a letter from an eye surgeon saying nothing. I've chased up my co-ordinator, he got in touch with the other co-ordinators but he said at the end of the day I can't force the issue, but I've heard absolutely nothing, so I presume they don't want to know, which is, that's probably the biggest, I mean, I'm not sure, I got quite upset, but not, I just think well what can you do. I actually think if I'd known, I would, I might have thought twice about doing it (donating), I know that sounds a bit selfish but to me we made the ultimate sacrifice, I mean the easiest thing to do was to say you leave (my wife's) parts alone, I think.” (a 8198,8785)

For those who had not heard from recipients the gift was not 'real' until a person who they could associate with had made contact via a letter. This contact seems to re-associate the deceased with a living person in that they are continuing to have an impact, a positive influence in the lives of others, as they did in life.

“Hearing from the recipients made it real. A real person is involved.”(M from tape)

For one participant the recipients had *“Become part of my life now whether they like it or not you know and I just want to know [how they are] it is important to me now.”* (s/15506-5658)

In the third interviews there was certainly more bitterness than in the first and second interviews about not hearing from recipients.

“Is it really that difficult to pick up a pen, or just get a card which says 'thank you'. I suppose the transplant co-ordinators do let the recipients know that I would like to hear and that it would not bother me?” (s[s] from tape).

Participants wanted to hear how the recipients were getting on, what the quality of their life was like and if the donation of their loved ones organs had made a difference to them. Participants who commented (n = 5) would like to have had the first names of the recipients as this information made the connection with a real person.

Two families were not sure if they wanted news of the recipients as not hearing meant that everything was OK.

“In my mind I can imagine them all living and leading happy lives.” (K from tape)

The majority of participants (n = 37) were prepared to hear news of the death of the recipient as this was known to be a possible outcome of donation. Participants felt that the recipient had been given a chance of life, and that they would want to know if they had died.

#### **4.3.5 Formal support - transplant co-ordinators**

All but one family who met with transplant co-ordinators during the hospital experience were unanimously positive about this experience. While some participants had to wait “*too long, too long*” to meet with transplant co-ordinators, those who did wait to meet with them were impressed with the care offered to them. One area of bereavement support which transplant co-ordinators were very aware of was the need for contact with, and mementoes of, the deceased. Two spouses were offered the opportunity to ‘lay down with the deceased’ which was a potent acknowledgement of the relationship that was shared. Families were offered hand and foot prints, which were positively commented on, as families had not thought of this themselves. Also parents who were offered locks of hair from their grown up child commented on how they would put this lock with the lock of childhood hair they already had. a joining together of the child and adult.

“And they actually offered me a lock of his hair, which was wonderful because I had a lock from when he was a baby and I put them together, and that was a thing I hadn’t even thought of.” (h/p28763-29028)

Transplant co-ordinators’ contacted participants promptly about the use of organs and the majority of participants appreciated this. As time went on contact with transplant co-ordinators diminished as families found it more difficult to ‘*pick up a phone*’ worrying that transplant co-ordinators were busy and should not be bothered. Individual transplant co-ordinators received praise at each interview time point in relation to responding the participants’ requests for information. This was tempered somewhat by the need for participants to initiate contact.

“I’ve spoken to (transplant co-ordinator) she sent me a letter the other day, I’ve spoken to her a couple of times. I’ve rung her, she’d rung me. She’s very nice, she’s great, because you know if I phone she’s not there, she’ll always ring me back, and she always, if I ask her to, find out anything, she’ll find it out and let me know. But she’s great, obviously she’s very busy but she always replies, or she’ll always speak to me, if she’s, or she’ll get back to me. She’s very good.” (s 19029,19527)

“But we both feel that, yes, you know, they were there at the beginning and then it’s sort of, you know, sort of, dropped off, sort of thing, and in a way I think when you’re in a state of shock. I think we would have liked, we would liked to have sort of heard quite a bit more. We know that the patient who had his heart died anyway, we did sort of know that, but we would have liked a bit more contact. I think we sort of felt that in a way it should have come from their side, just to sort of follow up quite a bit more. but you know, I know that everybody’s sort of busy these days but...” (t 10873,11478)

Contact by transplant co-ordinators at or around the time of the first anniversary was limited. Three participants received a letter mentioning this milestone and thanking them again for the donation. Those who had received a letter viewed it as a valuable moment of contact at a time that had varying degrees of significance to family members.

One transplant co-ordination service routinely made home visits after the hospital experience. This was well received by those families who had been offered or participated in a visit. When asked about this other participants felt they would have appreciated the offer of a home visit.

Individual transplant co-ordinators made efforts to keep participants up to date with the recipients’ progress. However, some participants only gained this information if they called the transplant co-ordinators and requested an update. Eleven participants would have liked more contact from transplant co-ordinators and these 11 participants would have liked the contact to be initiated by the co-ordinators.

There was a lack of knowledge about the system by which the recipients did make contact, or whether they were encouraged to do so.

Participants from two transplant co-ordinating services were invited to memorial services. Those who attended appreciated the service and considered it to be very moving. The participants felt it was an important recognition of what had taken place. Participants who chose not to attend were concerned that the service would be *‘full of sad people getting distressed’*. One participant had attended a service in which the name of her daughter had appeared in what she had initially thought was an order of service. The appearance of her daughter’s name was unexpected and initially caused distress. Her son was able to help her with this issue by remarking on how many names there were in the booklet and how many lives must have been changed for the good by the gift of the donors, such as his sister. This

incident indicates that the most well intentioned efforts of support services can have unexpected outcomes.

#### **4.3.5.1 Obstacles to contacting transplant co-ordinators**

- Lack of emotional energy, low mood, inertia
- Worrying that transplant co-ordinators are busy and have important things to do
- Speaking to an answering machine
- Mentally 'down-playing' their need to speak to someone who was there at the 'end' of their loved one's life.

#### **4.3.6 Summary**

Bereavement support for families who have been asked to consider donation should begin at the bedside and continue for as long as a need exists (Sque 1995). This places a requirement of care on transplant co-ordinators, as they are the link between the health service and the family. In many cases they were one of the last people to see the loved one before donation and the person who took responsibility to carry out last offices. They provided the 'reassurance' that participants sought that all would be carried out with dignity and care; they were the people 'trusted' to look after the deceased when he or she had left the care of the family. They were the gatekeepers through whom the family received information regarding the recipients and the avenue through which any information was returned to the recipient. A home visit to the donating family would be a positive initiative, as it would allow the transplant co-ordinators or bereavement support workers to step into the 'life world' of the next-of-kin. This would facilitate discussion about the families' experiences and bereavement with the possibility of identifying any specific problems for action or referral.

Receiving information regarding the use of the donated organs and tissues became an increasingly strong theme in interviews at TP2 and TP3. Participants and family members wanted to hear from recipients, but also wanted to hear about the outcome of the use of tissue such as eyes, heart valves, skin and bone. As these tissues can be stored families often waited months for any information about their use, if indeed they did receive any information. Unlike the speed at which the letters outlining the use of organs was administered, this information was poorly administered.

#### 4.3.7 Recommendations

- ICUs should seek early referral of donation opportunities to transplant co-ordinators so that families do not have to wait around for long periods.
- Early referral, by ICUs, so that transplant co-ordinators do not have to contact families by telephone to pass on information without having met the family concerned.
- Regular updates on progress of the recipient, even if no letters from recipients are forthcoming.
- Contact at or near the first anniversary of the death or at Christmas time.
- Home visits in the case where a spouse dies and there is limited family contact (as observed in hospital) as individuals in this situation may be isolated from support and unable to seek help.
- Specific consideration of the needs of bereaved children and their parents.
- The establishment of a bereavement service that can work with transplant co-ordinators to provide the recommended support to families.

#### 4.3.8 Formal support - bereavement organisations

None of the participants had accessed any form of counselling or support agencies specifically in relation to the death of their loved one at the TP1 interviews (3-5 months post bereavement). At TP2 interviews (13-15 months post bereavement) 10 individuals had accessed counselling with differing views on how effective this was. No other participants attempted to access counselling or support agencies at the TP3 interviews.

“We didn’t know whether we ought to send T for counselling. Other people were advising us and we sat down and talked about and said not ready yet together ya it’s not right we’re coping on our own in our own way.” (t/t/m1093,1309)

Most participants described the initial support of friends and family as being available, for some this support was “invaluable” and “sustaining”.

“Well we always a close family but even more close now. Well we see each other just about the same but they are always phoning to make sure I’m all right”. (p/e7230,7425)

“So you know I try not to feel sorry for myself. I have such amazing support from the family which you know how people cope I’m sure I’ve said this before how people cope without a family I can’t think it really is, it’s been wonderful”. (j/e1038,1277)

Some participants found that this support dwindled between six months and a year, leaving individuals feeling isolated and unsupported.

“They wouldn’t come to see me, they said they didn’t know what to say. They said they didn’t like, they didn’t like to walk into the flat it was (B’s) flat and him not be here.”  
(sc9671,9975)

As time progressed many participants felt increasingly alone with their grief as friends and family began to focus less on the death and the needs of the next-of-kin. The issue of people not knowing what to say was a repeated theme. Next-of-kin also began to worry about becoming a burden on friends and family.

“I was very lucky in having a lot of friends but that all tails off. The phone calls to see how you are, just popping to see you know see you’re OK. I still keep in touch with a lot of them but that tails off and when you, how can I put it, I go through a phase as well people can’t be bothered anymore you know and you’ve got to stand up and get on with your life. You can’t sit back in, I know some people do, but you can’t sink into self-pity. You have got to get on with it cause you’re afraid, you can’t keep going round your friends saying you know I feel really low, can I come round, cause you just become a pain in the end.”  
(a3906,4599)

The need to talk and the worry that they were becoming a burden to friends and family led some individuals to seek counselling. All but one participant who had obtained counselling felt it had helped them, even if they could not identify specifically what had helped.

Six participants approached CRUSE for counselling and had to wait to see a volunteer. The shortest wait was two weeks and the longest three months. One wife was seen by an elderly male volunteer and after initial reservations felt this had helped her.

“It’s ages ago actually, yes, it did help because there are times when I just want to waffle on and you don’t just want a nodding head to talk to. I mean Mum and Dad are great but you know you tend to think or I tend to think oh they’ve heard this a thousand times you know, and it’s yes love, well you know love. Whereas with the counsellor they will ask you questions as to well you know, perhaps, Why you’re feeling like you are? The little contact I did have did help.” (r/19063,9544)

A couple whose adult son had died accessed counselling via CRUSE. The father was satisfied with his contact feeling he had the opportunity to talk.

“Ya I got quite a nice lady who sort of let me talk.” (j/j18118,18167)

The mother was dissatisfied with her experience feeling that the volunteer involved did not want to give her the time she felt she needed.

"I did [go for counselling] and I felt, was really, really upset, not upset that I was talking about it, I was upset by the lady, and I knew it [counselling] wasn't for me."  
(j/j17922,18055)

She subsequently sought help via her professional body and through her GP was referred to a clinical bereavement counsellor.

A husband, who had approached CRUSE, after meeting with a woman volunteer for three weeks, went on holiday, planning to meet again on his return. The volunteer did not arrive and after phoning and getting an answering machine, this participant decided not to bother to seek help of this nature again. This participant had considered going to see a spiritualist to help fulfil his unmet needs.

"You need someone to support you at the beginning when you feel you can't talk to your family because they'll all get upset. Your friends are too embarrassed or don't want, too upset or don't know what to say, so you need someone you can just go to and say this is happening, that's happening and it's not there. Well I couldn't find it. I thought it was with CRUSE but that, all, as I say, let me down, so I don't really know, and they are not professional people. It's a professional that understands, the people at CRUSE although they do understand, they've all been through it, haven't they, but there are no standard ideas and they've all got their own ideas of what to do. It needs somebody who's got them [ideas] all together". (s/119372-20277)

Three other participants received counselling via their employment health care system, all were very positive about this experience.

One husband contacted the Samaritans on three occasions when he felt very low and was wondering how to carry on day by day. He stated that their service was 'excellent' because he felt that they had listened to him and had not offered any advice.

One daughter received counselling via the university she attended and was told that she seemed to be coping well.

One husband contacted a local bereavement group who had access to professional therapists, he was positive about this support.

One mother had attended a meeting of the Compassionate Friends, but was concerned at the length of time that most group members had been attending the group and how bitter they appeared. In her view *'they had not moved on at all'* she was worried that being part of this group might hinder her bereavement.

In two cases GPs made referrals to *'psychologists'*. Two participants were still receiving support at the time of third interviews (18-26 months post bereavement).

One participant and two members of another participant's extended family had been to a spiritualist and a spiritualist church as ways of seeking to gain some solace in their grief. The motivation here was to have some *'physical'* connection with the deceased again.

Only two participants at TP1 had received any information regarding BODY. They found this useful as it included information relating to the diagnosis of death certified by BST. Three participants had attended the annual BODY commemorative service and tree-planting ceremony about the time of the first anniversary of their loved one's death. Information about BODY was routinely sent to families by two transplant services.

"I'd got in contact with BODY. You'd given me that information and they'd done a tree planting, tree planting thing, and they'd done that for B and I went up to that. That wasn't quite how I imagined it but it was really nice. I cried through the service, it was, it was, very, there were just so many people there you know and I went up with B's nephew and his wife, they took me up and that was good." (sc/b22834,23269)

#### **4.3.8.1 Obstacles to accessing support**

The role of counselling was poorly understood by the majority of participants except those who had previous experience. Most people felt it was a way of getting advice on how to cope with the bereavement, rather than a listening ear. One spouse felt that contacting an organisation would cost money.

"No. I looked at it when you got a spiritualist and you've got your grief counsellors they always put a figure on it, a price, and I don't believe in that. If I want to go and help somebody I wouldn't want to charge, I wouldn't say it's costing x amount per hour or whatever. Because to me it looks like it's a money venture and that's what I feel with counsellors, that's what I feel with spiritualists, that's what I feel about these grieving counsellors that they have." (b/w28236,28706)

Reluctance to acknowledge feelings of needing to talk to someone and being unsure if it would help.

“I think the main thing that I wish should have done that I hadn’t done is gone to talk to a professional about things. I mean when I first talked to you I think that was the first time I really like talked about my Mum to someone like that in depth. I said to [girlfriend] like after I spoke to you I felt really tired but I felt good cause I’d spoken about it. I think if you go and talk to someone, with you know, that’s never met you before that’s got a fresh outlook on things I think it’ll help because, you know, I think it’s put a strain on my relationship with [girlfriend] because she’s dealing with everything. She’s dealing with my bad side, my good side and she’s dealing with all the stuff that goes with it and I think it puts unnecessary strain on the relationship.” (kb22587,23374)

Lack of emotional energy, low mood, and inertia will all impact on a person’s ability to access support organisations, especially as most organisations will not take a referral from a family member or HP on behalf of the bereaved person. Depression levels, as indicated by the BDI-II, at TP1 were borderline mild to moderate levels of depression for the majority of participants. At TP3, six donating families were still within the moderate to severe depression category as recorded by the BDI-II (see section 5.1.2). These levels could be a potent obstacle to accessing help, if this requires repeated attempts.

#### **4.3.9 Areas of specific need**

There is support within the interview data for the different focus of grief for parents whose child died and for partner/spouses whose partner/spouse died. For parents the loss of the child’s future achievements such as getting married and having children were a repeated theme. The loss of joy in ‘the now’ and the ‘future’, the loss of sharing these milestones was reflected in parents’ discourse.

“And obviously I wish he’d been able to get married and settle down and have children or whatever else he wanted to do. It wasn’t to be so.”  
(h 9288,9425)

This highlighted an area of specific need in relation to parents coping with the loss of a child, and trying to support siblings, or parents whose spouse had died and who were trying to support their children. Ten families with children under the age of 16 years had experienced the death of a parent (n = 7) or sibling (n = 3). Only one family with teenage children was referred to a support group for children, in this case Winston’s Wish, with very positive results. The volunteer visited the home, talked with the children, gave them leaflets and videos to watch and gave them each a memory candle. “*the kids were really touched by that*”. It is our understanding that this support agency is only available in limited geographic areas and therefore is not widely available. A mother tried to access help for her son via his

school and was told that no help of that nature was available. This is one area in which there appears to be a need for intervention by a third party as parents explained how they were struggling to cope with their own grief and did not know how to help their children.

Spouses and partners who had children and whose spouse/partner had died, also commented on the loss of joy in sharing the experience of watching their children grow up and get married with their partner, but the main issue for them was being alone and having to re-create their lives without the person with whom they had built a life.

“When I think about her and all the things we were going to do and our grandchildren and what she’s going to miss and what I’m going to miss, what they’re going to miss, I start to get angry, and the frustrating thing is there’s nothing I can do about it. I’ll watch the kids grow up, the two grandchildren grow up on my own, and hopefully she’ll be looking over my shoulder, but I have to believe that I will meet her again one day and I don’t believe in God. It’s difficult, I don’t know why I believe that because, but, I suppose you have to try and comfort yourself.”

(s 11385,11965)

In relationships where individual roles were well defined the remaining spouse, whilst dealing with the ‘feelings’ associated with their loss, also had to manage the ‘practical’ aspects of life more usually dealt with by the deceased. This was a particular issue for men in relation to domestic, child rearing and social issues and women in relation to jobs around the house.

“The thing is that there are such a lot of things to do in the house you see. It is very frustrating because you know I can’t even find people to do it, that’s the main thing. Then on the other hand you hear of so many people, sort of cowboys out there, can’t even, I can’t assess, you can’t assess people can you?” (t 14112,14342)

#### **4.3.10 Summary**

As stated above for those participants who did contact support agencies there was some time to wait. Another issue was the inability of family members to elicit help on behalf of their bereaved relative when they felt they could no longer provide the type of emotional support that was needed. Interview data indicated that participants felt that friends and family ‘needed’ them to be better, calmer, and unemotional as a sign that things were ‘OK’. Talking about the deceased in relation to what they used to do, or what they used to think about things, appears to be an area that family and friends were comfortable with, but talking about how the participant felt about the death, the pain and loneliness, the lack of the other person as lover, friend and confidant, was very difficult emotional ground upon which few people felt sure-footed.

Saunders *et al* (1985) suggest that strong stereotypical behaviour in our culture may put pressure on the bereaved to avoid expressing their emotions and yet the need to express these emotions remains. This may be the time when these issues could best be discussed with 'professional ' or trained 'lay' supporters, but such support was not always easily available. This is a particular worry as in this research the most 'distressed' individuals, at all three time points were also the most isolated in relation to social support and the most reluctant to seek support.

In the case of parents of young children whose spouse/partner dies specific contact should be made with an assessment of the sole parent and child/children's bereavement needs. Children were routinely not offered any support in their grief, this being left to the remaining parent to provide. Single parents discussed their concern regarding support for their children but how they were unable to take action as they felt '*bereft*' themselves and just did not have the 'emotional energy' to cope.

#### **4.3.11 Recommendations**

- Easier access to bereavement organisation, with a reduction in the use of answering machines.
- Referral of children to agencies specifically aimed at supporting children with bereavement is recommended.
- The development of referral systems which allowed family members to discuss their concerns about another family member with bereavement organisations.
- Information relating to the British Organ Donor Society and other support groups should be made more widely available.
- A greater integration of NHS services with bereavement support organisations.

#### **4.4 Aim 4. Comparison of the process of bereavement for relatives who agreed to donation, and those who declined.**

It was not possible to complete the fourth aim due to difficulties in recruiting participants who had declined donation of their loved one's organs.

A number of these difficulties became apparent during discussions with transplant co-ordinators and ICUs, about accessing this group of potential participants. A number of barriers were also encountered to recruitment that were not present at the time the research project was first planned.

##### **4.4.1 Barriers to recruitment**

- Concerns about the nature of the research, with particular concerns being raised by risk management teams within NHS Trusts.

This resulted in two ICUs who wished to be involved in the research being prohibited from doing so. This prohibition took place before the project was submitted to the Trust's Local Ethics Committee.

- A perception by ICU personnel that families who decline to donate organs are more distressed by this issue and that having made their decision, they should not feel that this decision is being questioned, which they felt was a possibility in this research.

This resulted in ICUs declining to be involved in the research and the possibility of families who may have wanted to participate not being offered the option of making that decision.

- Differing recruitment protocols. Donating participants responded directly to the research team. Potential non-donating participants were required by ICUs to respond to them in the first instance, they would then forward agreement letters to the Research Team.

This introduced a potential obstacle into the recruitment process as responding directly to the Research Team was specifically chosen so that participants understood that the researchers were impartial investigators. There was also concern that if families had had 'a bad experience' within the hospital, and the request for participation came from the ICU, the family may be less inclined to participate.

In total two non-donating families were recruited via one ICU that sent out nine recruitment letters. No non-donating families were recruited from any of the other nine ICUs.

#### **4.4.2 Follow up of Non-donor families**

As stated earlier some authors (Burroughs *et al* 1998) have reported that donating and non-donating families may regret their decision. Neither non-donating families had had any form of follow-up or support from HPs at the time of meeting with the researcher. In the case of the one non-donating participant the issues of family conflict, poor communication about the nature of the brain injury and BST were linked with not knowing the deceased wishes and led to the decision not to donate. For example there was a misunderstanding of the role of BST for this participant.

“And we were cross that, you know they would do the tests if we donated organs. Cause I suppose you are never given a one hundred percent guarantee, you’re always thinking, well what happens if she is’nt,[dead] you know. I felt they should have offered us them tests and not just because we were donating organs.” (aa 24916,25344)

One couple had begun counselling to resolve issues in their relationship triggered by their experience of perceived inadequate care of their son and poor information giving and communication by HPs. It is fair to say that this family may not have welcomed intervention from the health service, but no attempts had been made to assess their needs.

“We had had the most appalling seven days in hospital while he had surgery. No one was ever available to talk to us and on one occasion I saw the Sister tell the Consultant that we wanted to see him and we saw him leave the ward. I had to ambush him in the corridor later and he was just incapable of communicating. I just could not believe that a man in his position could get away with not being able to speak to people. We never really knew what was going on, in fact I read about the diagnosis in a text book and learned more in five minutes than I had learned on the ward in four days.” (aND5479,5853)

This young man who had surgery had to return to theatre for a drain to be inserted after which he suffered brain swelling and death confirmed by cessation of brain stem function. When asked about donation the family responded.

“I kind of felt underneath well they hadn’t tried their best for J, so yes, and I kind of didn’t want them trying their best for anyone else if they hadn’t tried for J. And I know it sounds irrational, but it was really, I didn’t want him messed about you know when I didn’t feel your doing the best for him.” (aaND41086,41427)

#### **4.4.3 Summary**

When families are faced with the request for organ donation it requires a decision, which once made cannot be reversed. The request alone triggers internal debates and conflicts, which are not resolved solely by making a decision (Sque and Payne 1996). Non-donating families are bereaved families who have experienced, what has been described as 'a tragedy unequalled by any other' (Stroebe *et al* 1993, p3) yet are not offered options for support as are donating, bereaved families.

## 5.0 Results: Psychometric measures

### 5.1 Description of the psychometric measures

Below there is a review of the measures. As stated earlier the BDI-II and GEI measures were scored according to the instructions laid down by the developers of the instruments.

**5.1.2 Beck Depression Inventory (BDI-II)** is a 21 item self-report instrument for measuring the severity of depression in adults and adolescents aged over 13 years and older. This version of the Inventory (BDI-II) was developed for the assessment of symptoms corresponding to criteria for diagnosing depressive disorders listed in the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders - Fourth Edition (DSM -1V; 1994). Diagnostic guidelines for the BDI-II when used as a screening tool are:

<b>Total score</b>	<b>Range</b>
0-13	Minimal depression
14-19	Mild Depression
20-28	Moderate depression
29-63	Severe depression

**5.1.3 Grief Experience Inventory (GEI)** – This tool was developed to meet the need for an objective multidimensional measure of grief, which is sensitive to the longitudinal evolution of the process of bereavement. There are 135 statements found to be frequently associated with grief and bereavement. The 135 GEI items yield scores on 12 scales, including three validity scales and nine clinical scales.

## 5.2 Results

### 5.2.1 Response rates for the BDI-II and GEI at TP1, TP2 and TP3

#### 5.2.2 BDI-II

Forty-five participants (98%) completed the BDI-II at TP1, 21 men and 24 women. Thirty-eight participants (83%) completed the BDI-II at TP2, 17 men and 21 women. Twenty-five participants (54%) completed the BDI-II at TP3, 11 men and 14 women.

### 5.2.3 GEI

Forty-five participants (98%) completed the GEI at TP1, 21 men and 24 women. Thirty-six participants (78%) completed the GEI at TP2, 15 men and 21 women. Twenty-five participants (54%) completed the GEI at TP3, 11 men and 14 women.

### 5.2.4 Questions for BDI-II and GEI data

What were the levels and duration of depression as recorded by the BDI-II at TP1, TP2 and TP3?

What were the levels and duration of bereavement feelings as recorded by the GEI at TP1, TP2 and TP3?

### 5.2.5 Exploratory and descriptive statistics for the BDI-II

The data were separated into the clinical summary categories indicated in the manual to illustrate both the level and duration of depressive symptoms (Table 4).

Table 4. Number of participants in each category of the BDI-II at TP1, TP2 and TP3

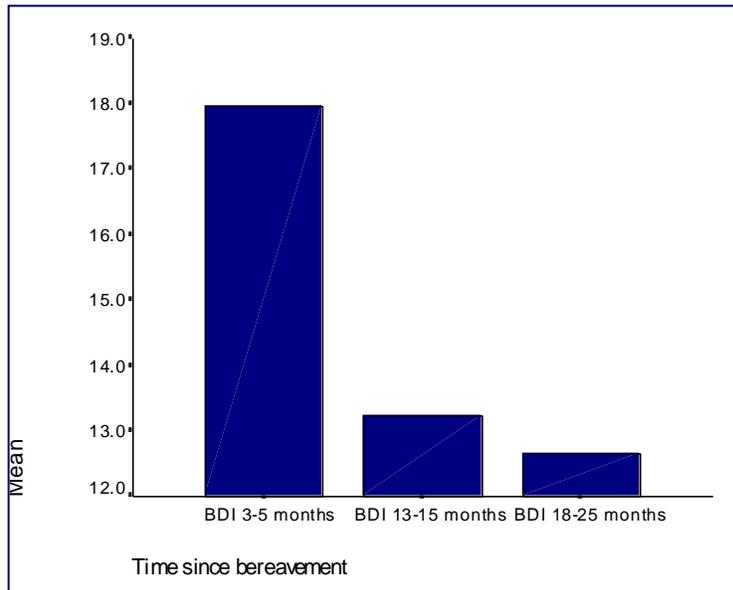
Range	TP1 n = 45	TP2 n = 38	TP3 n = 25
0-13 Minimal Depression	21 participants	22 participants	19 participants
14-19 Mild Depression	4 participants	6 participants	0 participants
20-28 Moderate Depression	10 participants	5 participants	2 participants
29-63 Severe Depression	10 participants	5 participants	4 participants

While we see the decrease in moderate to severe levels of depression on the BDI-II we also must note the loss of participants at TP2 and TP3. Exploratory and descriptive statistics illustrating the measures of central tendency and dispersion for example, the mean, median, standard deviation (SD), range and minimum and maximum scores are listed below in Table 5. with a graphical representation of the mean scores over time is shown in Figure 4.

Table 5. Means, median, standard deviation (SD) and range of scores for the BDI-II at TP1, TP2 and TP3

Descriptive Statistics	BDI-II score at TP1, 3-5 months post bereavement. n = 25	BDI-II score at TP2, 13 - 15 months post bereavement. n = 25	BDI-II scores at TP3, 18 - 25 months post bereavement. n = 25
Mean	18	13	13
Median	15	6	7
SD	14	15	14
Range	50	50	50
Minimum	0	0	0
Maximum	50	50	50

Figure 4. Bar graph showing the mean scores of the matched data for 25 participants on the BDI-II at TP1, TP2 and TP3.



Analysis of the BDI-II at TP1, TP2 and TP3 showed a significant reduction in scores from TP1 to TP2 as indicated by Friedman Test. Friedman Test = 13.284 (df 2)  $p = 0.001$ . In reviewing the median scores in Table 5, we can see that the reduction in scores between TP1 and TP2 is maintained at TP3.

### 5.2.6 Exploratory and descriptive statistics for the GEI

Exploratory and descriptive statistics illustrating the measures of central tendency and dispersion for example, the mean, median, standard deviation, range and minimum and maximum scores are listed in Table 6.

**Exploratory and descriptive statistics for GEI**

Table 6. Means, median, standard deviation (SD) and range of scores for 12 sub-scales of the GEI at TP1, TP2 and TP3

Descriptive Statistics	GEI Scales	TP1 n = 45					TP2 n = 36					TP3 n = 25				
		Mean	Median	SD	Range	Min/Max	Mean	Median	SD	Range	Min/Max	Mean	Median	SD	Range	Min/Max
Validity Scales	Denial	3	3	2	6	0-6	3	3	2	9	0-9	3	3	2	6	0-6
	Atypical Responses	7	7	4	15	2-17	7	7	3	12	1-13	7	7	3	12	2-14
	Social Desirability	4	4	2	6	1-7	4	4	1	5	1-6	4	4	2	7	0-7
Bereavement Scales	Despair	8	7	5	17	1-18	7	5	5	18	0-18	6	4	5	18	0-18
	Anger/Hostility	4	4	3	9	0-9	3	3	3	9	0-9	3	2	2	6	0-6
	Guilt	2	2	2	6	0-6	2	1	2	6	0-6	2	2	2	6	0-6
	Social Isolation	3	2	2	7	0-7	2	2	2	6	0-6	2	1	2	6	0-6
	Loss of Control	5	6	2	9	0-9	5	5	2	7	2-9	5	5	2	9	0-9
	Rumination	5	5	3	10	1-11	5	4	3	11	0-11	5	5	3	10	0-10
	Depersonalisation	5	5	2	8	0-8	5	5	3	8	0-8	4	4	2	7	0-7
	Somatisation	7	6	4	16	0-16	5	4	4	15	0-15	5	5	4	14	0-14
Death Anxiety	6	6	2	10	1-11	5	5	2	10	0-10	5	5	2	9	0-9	

The Friedman test for the GEI showed a significant difference in scores over time for the bereavement scale depersonalisation. In looking at the median score for this scale we can see the direction of difference is a decrease at TP3 (Table 7).

Table 7. Results of the Friedman test for the GEI showing the test statistic, degrees of freedom (df) and level of significance.

Friedman Test Xr2 n = 25	GEI Scales	Test results		
		Test Statistic	df	Significance 0.05
Validity Scales	Denial	0.785	2	p = 0.675
	Atypical Responses	0.828	2	p = 0.661
	Social Desirability	0.937	2	p = 0.626
Bereavement Scales	Despair	3.747	2	p = 0.154
	Anger/Hostility	4.261	2	p = 0.119
	Guilt	0.209	2	p = 0.901
	Social Isolation	0.092	2	p = 0.955
	Loss of Control	2.094	2	p = 0.351
	Rumination	0.026	2	p = 0.987
	Depersonalisation	18.131	2	p = 0.000 *
	Somatisation	5.091	2	p = 0.078
	Death anxiety	0.494	2	p = 0.781

\* Indicates a significant difference

### 5.3 Discussion of results from the psychometric measures

Increased depression levels, as recorded in this study at TP1, during bereavement have been reported elsewhere (Wordon 1988; Middleton *et al* 1993; Payne *et al* 1999) and is the commonest emotion along with sadness (Payne *et al*, 1999). However, depression scales may simply be reflecting the degree of depression, not the diagnosis of depression (Beck *et al*, 1996) and it is therefore important to differentiate between levels and duration of reported depressive symptoms (Payne *et al*, 1999). Depression levels overall had decreased by TP3, although two participant's scores increased from TP1-TP3 and six participants (including these two) remained in the moderately to severely depressed category at all three time points (three men in the moderately depressed category and three women in the severely depressed category). In reviewing the face-to-face interviews for these six individuals, it is notable that intense loneliness was an issue for all of them. Four of these six had in their view, poor support systems with few or no visits from friends and family. They reported feelings of isolation and vulnerability. These three spouses and one parent felt that with the death of their spouse/child that they had lost their main supporter, confidant and friend. Unlike other participants, who also felt these

emotions, these four did not have anyone else with whom they could share these emotions. Social support networks such as friends and family are considered to be one of the most important moderators of bereavement outcomes (Stroebe and Stroebe 1987; Stylianos and Vachon 1999) as the support of friends and family can help reduce the stress related problems of bereavement due to the deficits experienced when a spouse or partner dies.

A further concern is that these individuals consistently scored higher on the Despair scale of the GEI at TP2 and TP3, suggesting that the intensity of their feelings were increasing with time. The Despair scale (according to the authors) measures the most pervasive psychological expression of grief, characterised generally by pessimism, feelings of hopelessness and low self-esteem among other things. These expressions of grief were potently expressed in face-to-face interviews and supported by the BDI-II scores. Walter's Biographical Model of Grief (1996) suggests that people need to talk about the deceased, not just to ease the feelings they are experiencing but to be able to create a realistic biography of the deceased, a new understanding of the relationship shared, which they can take with them into their ongoing lives. This understanding of the relationship can only, Walter (1996) suggests, be achieved by talking to and with people who knew the deceased and who may challenge the views of the survivor. There is ample evidence in the interviews that participants wanted to and did talk about the deceased, but that this became more of an issue for some as time passed, and as shown above was not available to all. It is for participants such as these that an integrated NHS and bereavement donor family support agency is recommended within which, individuals and families could receive bereavement education and have their specific needs more fully met, both in the long and short term.

The reduction in scores on the Depersonalisation scale of the GEI, which measures the numbness, shock and confusion of grief particularly after an unexpected death, is a pertinent finding and supports the interview data for the majority of the participants. At TP2 and TP3 interviews many participants had made changes to their lives, new homes, redecoration, new relationships (n = 8) and whilst these changes had also prompted feelings of guilt, these feelings were often triggered by what other people thought and said about these changes. Overall making changes had helped participants to feel more in control of their lives.

## 6.0 Discussion

There is no single explanation of how people grieve and adjust to bereavement. Grief is as individual as the relationship that has ended. Grief will make differing demands on individuals and requires appropriate support systems. The ability to interchange human organs and tissues introduces a relatively unexplored dimension to grieving that requires specific attention (Sque 2000). Contemporary bereavement theories may provide a way of interpreting loss but none of them account for the difficult choices that were made about shaping the course of that loss, and its outcomes, which were part of participants' experiences.

Questions also arise in trying to interpret the post donation experience using Walter's (1996) theory for survivors to form a durable biography of the dead person, when part of them is perceived to continue living. Furthermore, the normal boundaries between the acceptance of loss, and attachment to the deceased individual and their body, may be complicated by the knowledge that part of the deceased 'lives on' or that their donation has been life-preserving or life-enhancing for another. This introduces a spectrum of needs that can only be fulfilled by a clear understanding of how critical injury, sudden death and organ donation can impact on initial and subsequent grief. This requires an understanding of the meaning of 'the gift of life' which appears to be of greater value than a mere physical object (organ or tissue).

The anonymity which surrounds the donor and recipient relationship appears to exist, in part, to protect the recipient from the possible searching behaviour described by Bowlby (1980) and, *mislocations*, when the deceased is seen as manifest in another person (Bowlby 1980). Families in this study did attribute importance to their relatives, 'living on'. Mislocations could lead to damaging effects both for the bereaved and the recipient. However, our present state of knowledge only allows speculation about the damage or comfort manifest in such thoughts and projections about the deceased, and donor families' relationship with recipients.

Walter's (1996) biographical concept highlights the interpersonal nature of grief and the importance of social support. Social support as demonstrated within this study often had an ameliorative impact on the intensity of grief symptoms and the ultimate outcome of bereavement. How does this fit with the role of the organ recipient? Clearly we are dealing with an irreconcilable tension. Had the recipients for some families become part of the donor's biography, which may help to explain the need families had to receive information about them?

Could it be that information about recipients provided participants with a sense of reassurance, that comforted them in knowing that their loved ones' organs had made a difference to the recipients' lives, which made donation worthwhile? Could this also explain the deep regret felt when the desired communication was not forthcoming from recipients? In so much that these families did not receive the reciprocity in the achievement of the donor, were unable to know that their gift was appreciated and valued, and did not receive thanks on behalf of the donor? They could not achieve closure by completing the biography of the donor and thus were denied the opportunity to construct a new relationship, integrating them into their ongoing life?

This suggests that the continued motivation for information about the recipients needs to be understood as compatible with healthy mourning. It needs to be viewed as contributing to the increased capacity for the relative to resolve grief conflict by playing some part in helping to complete the biography of the decedent (Walter 1996). Within the constraints of confidentiality, the continued benefits and value of the transplant, over time, could be communicated to donor families.

A careful assessment of bereavement needs is therefore recommended to form a plan of care that can be shared with relevant agencies and continued into the home situation to formulate support, which continues until it is no longer needed. As indicated in this study participants may need support in facing the reality of the loss and accepting the changed nature of the relationship with the deceased (Walter 1996), remaining connected to them (Klass 1996), but living without them and how to move on with their lives. It may mean finding ways of dealing with emotions generated by the death of the loved one, whilst knowing part of them 'lives on' and contributes to life elsewhere. This report indicates that these needs may not be fully met by the present support systems available.

Payne *et al* (1999) and Parkes (1993) suggest that the best people to help are those that share the common experience of a certain type of loss, as only they can provide the understanding and insight into the experience. Parkes (1993) further suggests that special bereavement services are more effective if they are integrated with the services provided by members of the caring professions. Collaboration with professionals tends to ensure that volunteers receive the expert assistance in training to be counsellors; while avenues are provided for dealing with individuals whose problems need professional skills. Could this be a way of providing integrated support for families through an integrated NHS and donor family bereavement support service?

## 7.0 Critique of the study

Bereavement research by its nature deals with sensitive topics of inquiry, such as in this study, sudden death, views regarding organ donation, grief and bereavement. It was noticeable by the questions asked of the Research Team by ethics committees that they were uneasy with this type of enquiry. However, Parkes (1993) urged researchers not to shy away from exploring difficult and painful situations, as an essential reference is required, from which knowledge, understanding, and further research can gain stimulus, flourish, and continue to unravel the maze of emotion and human complexity. Furthermore Parkes (1990, p36) suggested that:

“Any bereaved people who are not ready to talk will decline the invitation to take part...one of the problems of bereaved people is to bring something worthwhile out of the loss. I believe that most are glad to find that their experiences, however awful, can be of help to others.”

Evidence from our evaluation of the study with participants has lent credence to Parkes. When participants were asked what it was like to be part of this research all stated their desire to ‘help’ or to ‘make a difference’. A reflection perhaps of the type of people participating in the research. After the first set of interviews were completed a letter requesting an evaluation of interview was sent to the participants (Appendix 3). Responses show that the majority of participants (90%) felt that they coped easily with the length of the interview, found the interview helpful (64%), found it difficult at times to talk about their experiences during the interview (67%) and found the interviewer understanding (98%).

Primarily, one of the exemplar contributions and strengths of this study is that it was developed from data that provided a unique *emic* perspective of participants’ bereavement experience, reflecting their world-view. Therefore, it is expected to have relevance to the study of other individuals in similar circumstances. For the first time, the study provides longitudinal accounts of this experience.

This research has demonstrated the value in using the BDI-II and the GEI in helping to understand the nature of participants’ grief, and bereavement outcomes. The use of the two psychometric measures has added credence and strength to the findings of the face-face interviews, by providing a further interpretation of participants’ bereavement outcomes, in the range and depth of emotions they experienced, at various timepoints. The measures suggested agreement with Stroebe and Schut (1998) that the acute distress of bereavement is expected to decrease the further the individual is distanced, in time, from the loss, which appeared to be true for most participants. The measures were equally able to identify the individuality of grief, showing six participants who continued to experience a great degree of despair and depression, evidenced in their interview transcripts. The small sample size was a

constraint to making further associations and comparisons but for future bereavement researchers this combination of methods would appear to be a valuable mode of investigation. Another constraint of the study was the inability to recruit more non-donating families and to hear their stories, not only for comparison, but to identify areas of need specific to them.

This study has highlighted some of the needs participants faced throughout their decision-making and bereavement, and has provided a rationale for further educational preparation of health professionals involved in this sensitive work. It has attempted to address the paucity of information, and theoretical support needed to further an understanding of the donotransplant process, to provide effective, appropriate methods, to support families in their bereavement.

Overall the study has shown the difficulties encountered during the donation process, which is helpful to both families entering the system, health workers, and bereavement counsellors, who may work with bereaved families. By identifying these areas, through the explanation of past events, it has demonstrated where help may be focused.

However, the final critique of the epistemological excellence of this work must come from our audience, practitioners in the field, and the persuasiveness of our arguments.

## **8.0 Future research**

- Due to the poor recruitment for non-donating families and the need to investigate their experiences of sudden death and participating in a discussion regarding organ and tissue donation, and the impact (if any) of this discussion, on subsequent grief, further research is required. The piloting of a recruitment procedure that by-passed the need to involve ICUs is recommended.
- The genesis of the beliefs that individuals and families bring to the donation discussion has received scant review. By eliciting these beliefs a greater understanding to the barriers to organ donation may be elicited. Identifying these beliefs may also further illuminate the concerns raised by families in relation to the organ retrieval operation and its association with disfigurement of the deceased.
- The role of children and young people in the decision-making process was an unexpected finding. It has specific consequences for the provision of information aimed specifically at children, the impact of children on families' and HPs' behaviour, and the bereavement support needs of children. This finding requires immediate investigation.
- The piloting and evaluation of an integrated NHS and donor family bereavement support service to provide relevant grief support.

## **9.0 Conclusion**

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

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**What would happen to me if I take part?**

We are therefore asking you to share your experiences and any other issues of concern related to your bereavement. This would be done through an interview with a researcher. The interview would be carried out at a time and place, which is convenient to you and the researcher. The interview would be audiotaped to help us record the information correctly. The interview would be carried out at approximately 3-5months following your bereavement. The interview would be conducted using an Interview Guide and two questionnaires, which assess how you are coping with the loss of your loved one. The interview is expected to last no longer than two hours. Interviews of this kind can sometimes be emotive and you may feel tired after. The researcher is trained to support you, but we do need to ensure that following each interview you have someone who can be with you after the researcher leaves and who you can talk to.

**Would my taking part in this study be kept confidential?**

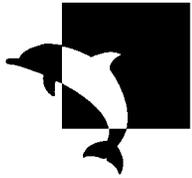
Anything you say would be treated as confidential. All information collected would be kept in the strictest confidence and would be secured against unauthorised access. Your name is not recorded anywhere within the study and no individual would be identifiable from the published results. You would be completely free to withdraw from an interview or the study at any time, without giving reasons. Audiotapes would be destroyed once the study is complete. If exceptionally, we wish to retain confidential information beyond the completion of the study we would undertake to let you know the reasons and seek your permission to do so. In view of this we need your consent to these arrangements. The researcher would explain the study before starting and you would have the opportunity to ask questions and you would be asked to sign a Consent Form agreeing to participate in the study and for the interview material to be used for research purposes under the stated conditions. This Information Sheet is for you to keep. You would also be given a Consent Form.

**Contact for Further Information**

The researcher, Tracy Long's contact number is at the top of this page should you need to discuss anything or have any further questions at any time.

Thank you for taking the time to read this information.

Dr. Magi Sque  
16.01.01. Version 3



**University  
of Southampton** | **School of Nursing  
and Midwifery**

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**Relative's Reply slip.**

**Study No**      **MREC 00/1/91**

**Name**.....

I would/would not be willing to talk to Tracy Long about my experiences.

Telephone contact number.....

Best time to telephone.....

### First interview guide used with donating and non-donating relatives

Could you tell me a little bit about...(the name of the deceased), the role they played in the family, and what they meant to you at the time of their death?

How did you become aware that something had happened to your relative?

***Please recount the events that subsequently took place.***

How would you describe the feelings you experienced at this time?

How did you feel you were treated by hospital staff?

How do you feel about the care and treatment you relative received?

Did you have to make any special arrangements to organise family life during this time? (Work, other children).

#### ***Involvement in Care.***

How do you feel about the facilities that were provided for you in the hospital?

How do you feel about the way in which nurses and doctors communicated with you?

How was brainstem death explained to you? (Check date on death certificate).

How was the topic of organ donation raised? **(Why was it important to donate/ not to donate (non-donating families) organs/were other relatives involved in the decision?) Has this decision caused you any concern?**

Did you have any concerns about organ donation? Who signed the consent form to donate? How did you/they feel about this? Which organs? Did it bother you to specify which organs?

Did you have any special needs following your decision to donate? And immediately following the operation? **(How and when did you decide to say goodbye?)**

Perception of time has been mentioned as a factor of importance in critical care and organ donation. Do you have any comments about this?

How did other relatives feel about donation? (Did this influence decision making?)

What helped you the most during your hospital experience? **(What caused you the most concern?)**

Did you receive any information about the recipients, and how did you feel about this? (Any home visits from Transplant Co-ordinators, any advice re support etc)

How has your life altered since this experience?

How do you feel about your donation decision? (How well do you think the media deals with this topic?)

Is there anything else you would like to tell me about your experience?

**Subsequent interview guide used with donor relatives**

How have you been since our last meeting?

What can you tell me about how you feel most of the time?

How is your morale these days considering what has happened (Is there anything that particularly helps?)

What about the rest of the family? How have they been coping?

Have there been any major events, changes, decisions you have had to face? (How do you feel you have coped with these?)

What sorts of things do you think might be helpful to someone else starting out on what you have been through?

How do you feel about donation now?

How would you describe your memories of that experience? (Are there particularly vivid recollections?)

Is there further information you would wish to have in connection with the donation?

Is there anything else you would like to share with me?



**Post Interview Questionnaire**

**1. Did you feel that you were able to cope with the length of the interview?**

Yes, quite easily

Only just

No

**2. Did you find talking to Tracy in the interview helpful?**

Yes, very helpful

Yes, a little

No

**3. Did you feel the interview caused you distress?**

Yes, a lot

A little

No

**4. Did you feel that Tracy was understanding during the interview?**

Yes, very understanding

Yes, a little

No

**5. Did you find it easy to talk to Tracy during the interview?**

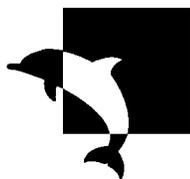
Yes, very easy

Difficult at times

Extremely difficult

**If you have any other comments please write below.**

**Thank you for completing the questionnaire.**



**University of Southampton | School of Nursing and Midwifery**

**Consent Form**

**Study No.** MREC 00/1/91

**Study Name:** The bereavement of relatives whose loved one died in an intensive care unit

Lead Investigator: **Dr Magi Sque,**  
Senior Lecturer, School of Nursing and Midwifery  
University of Southampton, Highfield, Southampton, SO17 1BJ

Researcher: **Tracy Long**  
School of Nursing and Midwifery  
University of Southampton, Highfield, Southampton, SO17 1BJ  
Direct line 02380 598224

**Please initial box**

1. I confirm that I have read and understood the Information Sheet dated 16.01.01 version 3 for the above study and have had the opportunity to ask questions.

<b>Yes</b>	<b>No</b>
<input type="checkbox"/>	<input type="checkbox"/>

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.

<b>Yes</b>	<b>No</b>
<input type="checkbox"/>	<input type="checkbox"/>

3. I agree that anything I may say during the course of the interview may be used as anonymous quotes in any presentation of the reseach (verbal paper presentation or paper publication).

<b>Yes</b>	<b>No</b>
<input type="checkbox"/>	<input type="checkbox"/>

4. I agree to take part in the above study.

<b>Yes</b>	<b>No</b>
<input type="checkbox"/>	<input type="checkbox"/>

Name of Participant

Date and signature

Name of Researcher

Date and signature

(1 to remain with participant 1 for researcher).