

Organ and tissue donation: Exploring the needs of families

Summary of the Final Report

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A three-year study to investigate the experiences of bereaved adults with whom organ and tissue donation was discussed.

Aims of the Study

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.

Method

Face-to-face interviews and two, self-completed, psychometric measures, the Grief Experience Inventory [1] and the Beck Depression Inventory [2], 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.

The impact of initial care offered to relatives in terms of decision-making about donation and subsequent grief. (i.e. care in hospital).

Sudden death and the discussion around 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 requests from healthcare professionals (HPs), 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. Findings from interviews with families at 3-5 Timepoint 1 (TP1), 13-15 (TP2) and 18-26 (TP3) months post-bereavement have amply illustrated their needs in relation to the content and manner in which information could best be communicated. 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 and/or understanding of brainstem death testing and how these tests related to the death of their loved one.

Initial information given to families in relation to the critical injury sustained by their loved one will have lasting positive impact if it is correct, given in complementary ways and is responsive to individual needs. Information which is offered in ways that reinforce each other, for example, talk supported by written information, appear to have an impact on the quality of information remembered at each interview time point. The addition of the use of visual information aids, which 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 reinforcing information at a time when family members are more mentally receptive to it, i.e. within the first few months following the death and donation. These methods can work together to enhance the understanding and retention of complicated information such as brain injury, brain anatomy and brainstem death testing.

Visual information aids

- 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 brainstem death testing (BSDT) was carried out.
- Being given a leaflet that explained the consequences of the critical injury.

Nurses and transplant co-ordinators were pivotal to the families overall experience in intensive care (ICU). The communication 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. 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.

Initial care was shown to have an impact on decision-making and subsequent grief. What the next-of-kin saw, heard and experienced remained with them when they left the ICU and was still available for discussion two years post bereavement. To facilitate bereavement that is uncomplicated by questions about the brain injury and subsequent death participants needed **TAC: Time** - to understand and absorb the nature of the brain injury that killed their loved one, 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 will 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 the minds of the next-of-kin for years to come.

Recommendations

- A greater use of and development of visual information aids (e.g. a video that explains BSDT that the family could watch with a HP).
- The offer of the opportunity for family members to watch BSDT if they wish to do so.
- Clarification and standardisation of the time of death certified by BSDT.
- 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 information 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.
- The integration of bereavement theory into HPs education related to sudden death and organ donation.

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

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 [3,4]. 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 [5]. The findings of this study, which agree with other authors [6], 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 HPs with compelling evidence to support their practice. Families may have felt that the timing was poor or that the manner in which they were approached and donation discussed was less satisfactory, but they recognised that the HP had a responsibility to raise the topic. 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 the nature of grieving and its integration into the donation discussion process could help to 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 that 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. The question also arises about the influence of the presence of children on the behaviour of HPs and families.

Three issues are implicated by the findings in relation to helping families to make decisions that are right for them: **1)** The necessity for HPs to facilitate the discussion about organ donation, focusing on the possible consequences to the family of a decision that may be regretted later. **2)** The need for good care and communication in all areas of the hospital, as families will have to cope with these issues during their bereavement, whatever their decision regarding organ donation. **3)** The need to stimulate family discussion about organ donation before they are involved 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.

Recommendations

- The discussion about organ donation should be carried out, 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.

Assessment of the need for bereavement support and the effectiveness of any support received.

The oscillating nature of grief [7] impacted on the initial months of bereavement. Practical needs, which 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 that participants still discussed at TP3 interviews. Initially most families (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 bereavement.

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 often needed multiple sources of information that participants felt were unavailable to them. There appeared to be an assumption, supported by the 'type' of literature made available to families that 'counselling' was what they needed and that it was readily available, when this was not always the case.

All but one family who met with transplant co-ordinators during the hospital experience were unanimously positive about this experience. Whilst 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 that transplant co-ordinators were very aware of was the need for contact with and mementoes of the deceased. These ranged from the opportunity to 'lay down with the deceased' to offers of hand or foot prints and locks of hair. These offers were all potent acknowledgements of the relationship shared and the person lost.

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 and 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.

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 [8]. 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 families sought that any thing done to the body of the deceased 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 is returned to the recipient. A home visit to the donating family would be a positive initiative, as it would allow the transplant co-ordinator or bereavement support worker to step into the 'life world' of the next-of-kin. It would facilitate discussion

about the families' experiences and bereavement with the possibility of identifying any specific problems for action or referral.

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 by transplant co-ordinators 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.

Those participants who did contact support agencies had to wait between two weeks and three months to see a counsellor or volunteer. A further 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 to discuss, 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 family members felt sure-footed. This may be the area where 'professional' or trained 'lay' supporters appear relevant and yet were 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 with young children whose spouse/partner dies, specific contact is recommended 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 provide for their needs.

Psychometric measures

Findings from the Beck Depression Inventory (BDI - II) [2], recorded that depression levels overall had decreased by TP3, although two participants' scores increased from TP1-TP3 and six participants (including these two) remained in the moderately to severely depressed category at all three time points. These participants reported feelings of isolation and vulnerability. They 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 six did not have anyone else with whom they could share these feelings. A further concern was that these individuals consistently scored higher on the 'Despair scale' of the Grief Experience Inventory [1] at TP2 and TP3, suggesting that the intensity of their feelings were increasing with time.

Recommendations

- Easier access to bereavement organisations, with a reduction in the use of answering machines.
- Referral of children to agencies specifically aimed at supporting them in bereavement.
- The development of referral systems that allow family members to discuss their concerns about another family member with bereavement organisations.
- Information relating to the British Organ Donor Society being made more widely available.
- A greater integration of NHS services with bereavement support organisations.

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. Donating families are grieving the death of their loved one, while part of that person 'lives on' elsewhere, contributing to the life of the recipient [12]. 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). This report indicates that these needs may not be met by present support systems.

Social support networks such as friends and family were considered to be one of the most important moderators of bereavement outcomes [7,9] as the help of friends and family helped to reduce the stress related problems of bereavement due to the deficits experienced when a spouse or partner died. Authors [10,11] suggest 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, that they can integrate and take with them into their ongoing lives. This understanding of the relationship can only 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 was not a support mechanism available to all. It is for participants such as these that a donor family bereavement support agency, working in association with transplant co-ordinators and ICUs could be particularly helpful, within which, individuals and families could receive bereavement education and have their specific bereavement needs more fully met, both in the long and short term.

Assessment of bereavement needs should begin at the bedside [12], with A&E and ICU HP assessing families' immediate needs for information, contact with their loved one, the type of support they have available and their emotional response to what is happening, to them and their loved one. This information could facilitate the development of programmes of care, which when shared with transplant co-ordinators or bereavement support workers, could influence the outcome of subsequent grief.

Assessment needs to continue into the home situation to formulate support that continues until it is no longer needed. As indicated families may need support in facing the reality of the loss and accepting the changed nature of the relationship with the deceased and how to move on with their lives [10]. It may mean finding ways of adapting to loss of the deceased, remaining connected to them, but living without them [11]. 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 type of care can only be offered within a comprehensive programme of a nationally available donor family support service with the aims of facilitating individual emotional support, peer support, bereavement education, crisis intervention [13], and appropriate information about or from recipients.

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