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Research with bereaved families: A framework for ethical decision-making

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Research with bereaved families: A framework for ethical decision-making

Abstract

Theoretical debates about the nature of grief and bereavement draw attention to the sensitivity of carrying out research with bereaved people, the possible threats that this may pose, and the ethical considerations required to ameliorate potentially damaging outcomes. The authors of this paper present a framework for ethical decision-making that has been successfully developed in the context of research with bereaved families. The discussion focuses on application and evaluation of the framework during research with family members who were approached about the donation of a deceased relative's organs and/or tissues for transplantation. Practical strategies of relevance to the processes of participant recruitment; the interview encounter and follow-up care in the post-interview period are identified and discussed. Concerns about the possible impact of bereavement research are balanced with the views of family members who gave credence to the therapeutic and cathartic benefits of participating in sensitive, death related research.

Keywords

Bereavement, sensitive research, ethical considerations, decision-making, organ donation

Introduction

Bereavement fulfils the criteria of a sensitive research topic that demands careful consideration of the ethical issues involved.^{1,2,3,4} Research has been defined as ‘sensitive’ if it poses an intrusive threat,⁵ explores an intensely personal experience,^{6,7} has the potential to arouse an emotional response^{6,8} and has risk implications for both the researcher and the researched.^{5,9}

Assessing the benefits of research, proportionate to the potential for harm is an essential role undertaken by UK ethics and governance committees.^{10,11} Despite the development of a more integrated and streamlined approach to the review process,¹² professional judgement is involved in the interpretation of standards for research.¹⁰ This can present a number of challenges for reviewers in an increasingly risk-averse climate.^{13,14} Consequently, investigators may come across individuals or groups who act as gatekeepers during the research process,^{8,15} experience variation in the verdicts of ethics committees¹⁶ and encounter decisions that are based on a priori assumptions.¹⁷ Overcautious reactions to bereavement research can restrict access to participants or data, impose requirements that undermine the research design or curb enthusiasm to proceed.² Protection appears to be concerned with the prevention of distress to participants who are asked to recollect what may have been an emotionally challenging or traumatic event.¹⁸ There is however evidence to suggest that research participation may serve the interests of the bereaved in a variety of positive ways.^{18,19,20,21,22,23,24}

This paper adds to the discourse and debate of ethics in bereavement research by presenting a framework for ethical decision-making, purposefully developed in the context of research involving bereaved families.^{25,26,27,28} The overall aim is to demonstrate application of the framework in a subsequent study involving family members who were approached about the donation of their deceased relative's organs and/or tissues for transplantation.²⁹ We contextualise issues of ethical importance by providing a background to the research topic and an overview of the study. This is followed by a discussion of key ethical considerations and associated practical strategies that form our framework for ethical decision-making (Table 1). Finally, we verify the appropriateness and acceptability of our strategic approach to bereavement research based on the reflective observations of study participants.

Background to the research topic

Organ and tissue donation after death makes an essential contribution to saving and/or improving the lives of thousands of people each year. Despite a ground breaking 50% increase in deceased donation in the UK over a five year period and related 30.5% increase in transplants,³⁰ the clinical demand for organ and tissues continues to exceed the supply. Research is essential to improving the quality and number of organs and tissues available for transplantation.^{31, 32} This includes understanding the psychosocial aspects of care and provision for families of potential donors.

Table 1. Framework for ethical decision-making

Ethical considerations	Practical strategies
Participant identification and recruitment	
Access, confidentiality	Formally obtain the support of a key person to undertake the role of identifying potential participants and disseminating pre-prepared recruitment packs on behalf of the research team.
Regard	Recruit potential participants in a serial manner, e.g. send out a maximum of five recruitment packs at any one time so that participants are not kept waiting for long periods before the research interview.
Respect, relevance	Consider participant inclusion criteria of bereaved no less than three months and no more than 12 months at the time of recruitment to the study.
Compassion	Include a covering letter that introduces the study in a personalised way by taking familiarity into consideration.
Informed choice	Provide clear written and web-based information about the researchers and the study. Include an invitation to contact the researcher. Demonstrate timely responsiveness to any potential questions or queries.
Non-coercion	Provide a minimum of 10 days for participants to decide about joining the study.
The research interview	
Choice, respect	Agree a convenient date, time and venue for the research interview. Avoid dates that coincide with any significant family events or anniversaries.
Safety	Implement a study site policy for researchers working alone in advance of the interview encounter.
Safety, support	Competent researcher with experience of conducting sensitive research interviews and supporting the bereaved.
Choice, privacy	Provide the option of an interview face-to-face or remotely, for example via telephone.
Informed consent	Provide an overview of the study and present opportunity for participants to ask questions. Explain how the interview will proceed. Obtain written agreement to audio-record the interview and to use anonymous quotes in any presentation of the research. Provide participants with a copy of the signed consent form to keep.
Support	Discuss and agree avenues of post-interview support prior to the interview commencing.
Support	Observe/listen for signs of distress during the interview. Discuss the option of pausing the recording or stopping the interview. Plan a natural break for refreshments.
Confidentiality, anonymity	Ensure audio-recordings and transcripts are securely stored and electronic data is password protected. Assign a study code at the point of transcription.

Table 1. Framework for ethical decision-making (continued)

Ethical considerations	Proposed strategy
Post interview follow-up care	
Support	Arrange a convenient time to telephone the participant (normally in 24 to 48 hours) to check on any issues the interview may have raised and to answer any questions.
Support	Compile information about local support organisations. Offer this to participants if they consider it helpful and/or direct them to appropriate professionals to discuss any issues of concern.
Support	Establish if participants wish their General Practitioner (GP) to be informed about their participation in the study and obtain written consent to proceed. Provide GP with information about the study at the time of notification.
Appreciation	Send participants a personal thank you letter and offer an executive summary of the research findings.
Involvement	Provide participants with an opportunity to evaluate their experience of participating in bereavement research.
Support	Determine support for the researcher from an individual with whom they feel comfortable, and who is suitably qualified to provide support. Plan a debriefing session after each interview encounter. Utilise reflexive notes to guide the discussion.

In the UK, obtaining family consent to donation after brain death (DBD) or controlled circulatory death (DCD) is an integral part of donation process. Families are typically exposed to a critical care situation and decision-making takes place in the context of personal grief and bereavement. DCD involves the planned decision to withhold or withdraw life-sustaining treatment and follows the confirmation of death using cardiorespiratory criteria. This contrasts with DBD that takes place after the

diagnosis of death by neurological criteria.^{33,34} The mode of death may be sudden and unexpected and this can give rise to pathological grief. Death for which individuals are unprepared can be physically and mentally disabling and the risk of complicated bereavement outcomes has been recognised.^{35,36} This draws attention to the importance of well-designed and accomplished bereavement research.

Overview of the study

We designed a qualitative study to elicit bereaved families’ experiences of organ and tissue donation, and perceived influences on their decision making.²⁹ Participants were recruited from 12 NHS Trusts, representative of five regional organ donation services in England. The study sample comprised 43 participants from 31 families. An acceptance rate of 32% is consistent with the Chief Investigator’s (CI) experience of recruitment to this type of study. Unusually for bereavement research, there was an equal number of men (n=21) and women (n=22). All participants had experienced donation decision making in the context of a sudden and unexpected critical illness or event. Twelve families agreed to DBD and 18 families agreed to DCD. One participant provided a written response. In this case, the criteria used to confirm death was not disclosed. Participants were bereaved a mean of seven months at the time of recruitment to the study.

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9 Data were collected via semi-structured, face-to-face or telephone, audio-recorded
10 interviews. Both methods have been successfully used with bereaved individuals.^{23, 26, 37}
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12 Participants were asked a series of open questions based on an interview topic guide.
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14 Data collection and analysis took place iteratively. The majority of interviews were
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16 carried out face-to-face (n=26) and were held in the participants' own homes. Audio-
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18 recordings were transcribed verbatim and subjected to qualitative content analysis.³⁸
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20 This involved a systematic process of applying codes to the text and categorising the
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22 data into themes based on the ideas of Attride-Stirling.³⁹ Reflexive field notes, in
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24 conjunction with a project diary provided a credible audit trail of the investigation.⁴⁰
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29 Approval to conduct the study was obtained from a National Research Ethics
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31 Committee (West Midlands - The Black Country, reference 11/WM/0313) and via NHS
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33 Research and Development departments. In undertaking the research, we ensured that
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35 priority was given to the dignity, rights, safety and well-being of participants. This
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37 involved the application of pre-determined practical strategies in response to ethical
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39 considerations of relevance to the processes of participant identification and
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41 recruitment; the interview encounter and follow-up care in the post-interview period.
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45 46 *Participant identification and recruitment*

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48 National studies that have the advantage of obtaining a cross-sectional sample of
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50 participants may be dependent on the involvement of staff with authorised access to
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personal information and contact details about the study population. Effective communication was fundamental to identifying and obtaining the support of a key person who would responsibly undertake the role of locating and contacting research participants on behalf of the research team. Specialist Nurses for Organ Donation (SN-ODs) identified eligible participants according to the study inclusion/exclusion criteria and disseminated pre-prepared recruitment packs. Recruitment was carried out in a serial manner, region by region. This involved SN-ODs sending a maximum of five recruitment packs at any one time so that participants were not kept waiting for long periods before the interview was realised. Purposive sampling gave preference to the most recently bereaved families, but bereaved no less than three months and no more than 12 months, at the time of recruitment to the study. These parameters were carefully considered to obtain a balance between respect for a period of mourning and a salient account of personal insights.

Each recruitment pack contained a covering letter from the SN-OD that introduced the study in a personalised way by taking familiarity into consideration. Further content in the recruitment pack included: a letter of invitation to join the study from the CI; an information sheet explaining the study; a reply slip and a stamped, addressed envelope for the return of the reply slip to the researchers. Potential participants were supplied with the email address for the researcher, should they prefer to use the electronic mail system. Content explaining the study contained pertinent information and advice such

as an invitation to contact the researcher to discuss any aspect of the research; assurances about withdrawal from the study at any time and the maintenance of personal anonymity and confidentiality. The information sheet also directed potential participants to a webpage that provided information about the researchers and the study. A telephone voice message service and electronic mail were important back-up systems to family contact with the researcher. If the family member decided to participate they were asked to return the reply slip in the pre-paid envelope within 10 days or confirm their wish to participate by email. Subsequent access to the names, addresses and contact details of participants was restricted to members of the research team.

The interview encounter

All interviews were carried out by a senior researcher with considerable experience, both as part of her research work, and clinically as a critical care nurse in supporting the bereaved. Family members who confirmed a willingness to join the study were contacted by the researcher and a convenient date, time and place for a face-to-face or telephone interview, was arranged. It was agreed that if there are changes in the plans of either the participant or researcher, then the respective party would get in touch. The date of the interview was chosen so as not to coincide with any significant family events or anniversaries, such as 'the date' of the deceased's death, birthdays, religious celebrations or holidays. The researcher agreed a date and time to contact the participant

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before the interview to determine final arrangements. The study site policy for researchers working alone was implemented in advance of the interview encounter to promote personal safety.

Immediately prior to beginning the interview, the researcher provided an overview of the study and explained how the interview would proceed. All participants were given opportunity to ask questions about the study. Written consent was obtained prior to the start of face-to-face interviews. Consent forms were mailed to participants and returned to the researcher in advance of a telephone interview. The consent process included agreement to audio-record the interviews and to use anonymous quotes in any presentation of the research. Participants were given a copy of the signed consent form to keep.

There is always potential for participants in sensitive research to feel some distress when discussing aspects of their experiences. Participants were informed that the interview could be emotive and tiring and avenues of post-interview support were discussed and agreed prior to the interview commencing. The majority of participants suggested that support could be found among family and friends. Participants were asked to make the interviewer aware if they wanted to pause the recording. This was also offered on occasions when the participant became distressed and agreement to continue was sought. Many participants were supportive of taking a short break during the interview at the suggestion of the interviewer. Audio-recordings and interview

transcripts were securely stored in a locked cabinet and electronic data password protected. Interviews were anonymised at the point of transcription by assigning a study code.

Post-interview period

On completion of the interview, the researcher arranged a convenient time to telephone the participant (normally in 24 to 48 hours) to check on any issues the interview may have raised and to answer any questions. Information about local support organisations was compiled and offered to participants if they thought it helpful and/or directed to appropriate professionals to discuss any issue of concern to them. Participants who wanted their GP to be informed about their participation in the study gave written consent to this effect. GPs who were informed about their patients' participation also received information about the study. To acknowledge their contribution, participants were sent a personal thank you letter and offered an executive summary of the research findings.

The emotive nature of the interviews also made it essential for the researcher to have their own support from an individual with whom they felt comfortable, and who was suitably qualified to support them. Debriefing sessions with the CI provided an opportunity to reflect on aspects of the research interviews, analyses and interpretations of data.

Participant evaluation

Following each interview, participants were invited to complete a short evaluation questionnaire comprising five closed questions and an invitation to write any comments. Evaluation forms were mailed to participants at the time of sending a personal thank you letter. This was normally sent three to four days following the interview to give participants adequate time to reflect on the event. Thirty-one questionnaires from 27 families were returned to the CI. The results of participant evaluations are presented in Table 2.

Participants positively evaluated their experience of the research interview, this being the focal point of their involvement in the study. The option of telephone or face-to-face interview had the capacity to elicit family experiences and we found little difference in the description and quality of participant responses. Interviews commonly lasted between one and three hours and the participant’s voice was dominant in most transcriptions. The majority of interviewees suggested that they were able to cope with the length of the interview. This may have been attributed to the use of a topic ‘guide’ that allowed family members to talk about their experience in a way that made sense to them. Many families shared photographs and personal memorabilia that helped to place the meaning of their experience in context.

Table 2. Participants' evaluation of the interviews**Questions**

Did you feel that you could cope with the length of the interview?	Yes, quite easily	Only just	No
	28	3	0
Did you find talking to NR in the interview helpful?	Yes, very	A little helpful	No
	25	5	1
Did you feel the interview caused you distress?	Yes, a lot	A little	No
	1	18	12
Did you feel that NR was understanding during the interview?	Yes, very understanding	Yes, a little	No
	31	0	0
Did you find it easy to talk to NR during the interview?	Yes, very easy	Difficult at times	Extremely difficult
	31	0	0

NR= Named Researcher

Recollections of the events that surrounded deceased donation were distressing for families at times. More than half of the participants (58%) suggested 'a little distress' and over two-thirds (39%) said they experienced 'no distress'. There was evidence to suggest that memories of the deceased and the events surrounding their death evoked emotional reactions.

'It's difficult when I talk about C [wife]. It's very difficult to keep on one wave length or I keep going off here or there ... I can't think of words that I need to use ... Sometimes stringing a sentence along. It still is

sometimes very difficult when I'm talking about things and about C. So if it's been a bit disjointed, I'm sorry ... It has been upsetting because I've been talking about my wife.' (Interviewee 012)

'It's an emotional thing isn't because we're reliving it.' (Interviewee 023)

Positive comments were received about the conduct of the interview and the empathic understanding of the interviewer.

'Although this was a very difficult subject to research, I feel [interviewer] approached it with both sensitivity and understanding. I hadn't appreciated how difficult I would find the session but [interviewer] had worked very hard from our initial phone contact to prepare me for possible distress and I was able to link back to this both during and post interview. Thank for allowing me to take part in this research and hope my experience will help others facing hard decisions in the future.' (Interviewee 015)

'I found it surprisingly easy to share my experiences surrounding R's [brother] death, due to mainly the very sympathetic manner in which it was conducted. It was a pleasure to meet [interviewer] and I hope that we have been able to help a little with your research into what is a very difficult subject.' (Interviewee 010)

During the concluding part of the research interview, family members were asked how they felt about receiving an invitation to participate in the study and whether they perceived any personal benefits. Generally, a decision to participate was immediate and participation was perceived as therapeutic.

'I immediately thought; 'oh okay yeah, that's good' ... Its good that there is research into you know, the impact of it [experience of approach about donation] so I felt good about it ... It's good to talk about it ... Its part of the grieving process isn't it?' (Interviewee 024)

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‘Relieved actually. When I first saw it, obviously I was reminded that my mum had gone but I had such a view, and my brothers and sisters didn’t want to talk ... and didn’t understand how I felt ... I think it’s helped to get my views out.’ (Interviewee 016)

‘Your request came through and I thought; ‘well this is something with no - no risk whatsoever that I can do’ and so I’ve done it ... I think speaking to you today has done me good. I’ll tell you that much.’ (Interviewee 025)

Some participants saw the interview as opportunity to discuss their bereavement, and reflected on the personal benefits of talking to a stranger.

‘The selfish part of my agreeing is ... because I don’t know you, and you don’t know me. And it’s just a case of being able to speak about it quite unemotionally you know, to somebody who just let me just pour my heart out. Well not quite pour my heart out, but talk about it objectively ... I think it does help to talk about things.’ (Interviewee 030)

Some family members suggested that the interview was the first time they had re-lived their experience as a whole. Others appeared to have benefited in terms of piecing together their experience, and their responses gave indication of renewed understandings.

‘The first time we’ve talked about the whole thing from start to finish. I mean you sometimes go over in your mind and you think about it, but you don’t talk about it.’ (Interviewee 010)

‘It’s nice to sort of put the pieces together isn’t it? ... To just work back through ... Sort of makes you think really.’ (Interviewee 019)

‘You’ve made me stop and get the sequence of things in my mind and to reflect you know, how well H [wife] was looked after and to see the positive result ... I think I’ve changed my attitude about wanting to know about how well people [recipients] are doing ... You’ve sort of made me

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think ... I think I would like to know ... That would be valuable yes,
because it's lovely to tell the family.' (Interviewee 004)

Reflective comments also gave insight into the motives behind participation. Family members joined the study for a variety of reasons: wanting to be helpful; to help or benefit other people who may be faced with the same decision; to share positive and negative aspects of their experience; to contribute to improvements in potential donor and family care; to influence the donation process, such as staff approach to families; to acknowledge healthcare staff and SN-ODs, and to raise awareness of organ donation. The same selfless attitude was apparent with regard to participation in the study and their decision to consent to donation.

Conclusion

Enabling the bereaved to make a contribution to research is essential to the planning and development of services that are responsive to individual needs. A sensitive topic for research invariably involves vulnerable people and concerns about the impact of participation can lead to conservative judgments when assessing the benefits and risks. The reported findings in the paper draw attention to the strength of the participant's voice in determining the ethical acceptability and appropriateness of practical strategies designed to support the future delivery of high quality bereavement research.

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Declaration of conflicting interests

‘The authors declare that there is no conflict of interest’.

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