a message only to have someone respond that 'your loved one was a drunken bum and doesn't deserve to be grieved.' An internet predator might pretend to be a known group member and say outrageous things. Hopefully, we can forewarn individuals and minimise damage if this happens.

INTERNET GROUP ADDRESSES

The following is a list of a few of the internet support groups. These have sufficient members and activity to offer the best chance of positive interaction for bereaved people.

alt.support.grief – message board
compassionatefriends.org – chat groups
death-dying.com – message boards
fortnet.org/widownet/ – email groups, message boards, chat groups
griefnet.org – email groups
groww.org – chat groups
juliesplace.com – email groups, message boards (for teens and children who are bereaved siblings)
petloss.com – one of the best support sites on the web (companion animal loss)
webhealing.com – message boards (called message index and found on 'discussions' page)

BC

LETTER TO THE EDITOR

Dear Editor

As a bereavement worker and a regular reader of your excellent magazine, I would like to congratulate you on the article, 'A response to the death of a pupil'. I am a school governor of thirty years' experience, and Vice Chair of the Gone Forever project which works with adults who are involved with children and young people who have been bereaved. We have for some years campaigned for teachers to be trained in issues surrounding bereavement and loss in their initial teacher training. We firmly believe that if a grieving child is handled sensitively during its school life, the effects of loss may be lessened. We come across so much unsympathetic handling and resultant problems in our work at the Gone Forever project.

Any help you can offer at this crucial time when the Initial Teaching Training Syllabus is being reviewed would be most welcome. I have already drawn the attention of the Secretary of State for Education and Employment, David Blunkett and Lead Officer on the Review, Hugh Baldry, to the article.

Keep up the good work.

JILL MOORE
Vice Chair, Gone Forever Project
School of Education, 23 Collegiate Crescent
Collegiate College Campus
Sheffield S10 2BP

Researching the bereaved

An investigator's experience (part I)

Magi Sque PhD BSc RN DipNEd RNT
Lecturer in Oncology and Palliative Care
European Institute Health and Medical Sciences, University of Surrey, Guildford, Surrey, UK

This article looks at the process of interviewing bereaved relatives of organ donors and the potentially painful nature of such research. The sensitivity of the topic made access to relatives difficult, while a central concern was the impact of the investigation and the possible threat that it posed to the participants and myself. I found that my background and personal approach influenced my interactions with the interviewees and the course of the research work.

Every year, of the 700,000 individuals who die in the UK, only approximately 900 will become 'major organ donors'.[1] The relatively small number of donating families and their anonymity mean that little is understood about the experience of having a relative in a critical care situation that ends in donation. The purpose of this study was to elicit an understanding of the nature and meaning of the organ donation process for relatives of 'major organ' donors. I carried out audiotaped, narrative interviews with 24 donor relatives. As most research could be regarded as sensitive to some party involved, I believe there is a special point to be made with researching topics that are expected to be both physically and mentally distressing for the individuals involved.

There is another matter that must be made to contextualise the potently painful nature of the interviews I conducted. Within the context of bereavement, donor relatives are at high risk of aberrant bereavement outcomes because the tragic and sudden nature of donors' deaths may be difficult for families to reconcile, especially as donors are relatively young and previously healthy. Families are necessarily approached about organ donation when their grief may be all-encompassing and when thinking and concentration is a problem. However, if donation is to take place, families need to make a number of decisions on behalf of their deceased relative. These decisions may be problematic because they concern an operation on another's body, yet the time to debate the issues is constrained.

Relatives are asked to accept a nonstereotypical death (brainstem death) as death. The implications of brainstem death transcend the usual experience of the lay individual. Potential donors maintained on a ventilator may not look dead and often have no external manifestations of injury; they tend to be unscathed, resting, warm and florid, and their chest moves as if they are breathing. They may even move occasionally in other ways if a spinal reflex is activated. Their time of death becomes an arbitrary decision made by the attending physicians. Not only are relatives asked to accept this situation as death, but they are asked to agree to the removal of the very vital organs that would normally maintain life.

EDITOR'S NOTE

The importance of carrying out systematic studies of bereavement in all its forms cannot be over-estimated but ethical and practical considerations need to be taken into account in all our plans. Magi Sque has chosen an unusually difficult topic, the grief of people after organ donation. She shows how the many obstacles to research in this field can be overcome.

THE PROBLEM OF PAINFUL TOPICS

Gaining access to participants

A number of authors have addressed some of the issues involved in interviewing participants about sensitive life events.[2-6] Painful topics impinge most compellingly on the aspects of the research process related to ethical and legal matters, politics and access. Moreover, research into bereavement is complicated by a number of special concerns. Ethical considerations limit some research in view of the assumed distress that most bereaved people experience. Sample recruitment of the bereaved can be problematic. Samples are typically low, with response rates of 50%.[7] It is likely that recruitment rates are affected by a number of factors that may include: the level of distress experienced by participants; the 'loss effect' or negative impact of bereavement on health and mortality[8] ; the need to talk; the willingness to discuss the loss (particularly with strangers); the general ease in communicating with other people, especially about such a profoundly personal and, probably, painful event; and the willingness to 'drag it all up again'.

Very little recruitment-rate data exist for donor family interview studies. Comparisons are problematic because of the focus of the interview,[9] the methods of recruitment,[10] and the lack of statistical information.[11] Pelletier[12] reported a 29% recruitment rate (7/24 families). The 38% recruitment rate (16/42 families) for the present study was greater than that reported by Pelletier[12] and comparable with rates for general bereavement studies.[8,13] It must be noted, however, that only six families in this study definitively refused to take part. Earlier studies[14,15] reported respectively 71% (12/17 families) and 73% (32/44 families) recruitment rates among families after kidney donations. These high response rates may be due to: the then accepted cultural compliance with the medical profession; local access to participants; the newness of the donation procedure; and the fact that it was only possible to donate kidneys, so no emotive factors related to the heart or to multi-organ retrieval were involved. Increased anonymity, greater population mobility, the cultural values of increased privacy attached to death, along with the outcomes of unexpected grief and agreeing to organ donation, can be expected to result in smaller recruitment figures for studies with donating relatives.

Parkes[16] highlighted another problem in gaining access to bereaved people. He pointed out that, while 'gatekeepers' do need to be cautious in checking the credentials of the researcher and the ethical validity of the research, they tend to err on the side of being overzealous, depriving bereaved people of the opportunity to help in well-founded research, thus forcing researchers to use inadequate samples.

This point was given considerable credence by the 'blocking' that I encountered of access to donor relatives by their self-appointed 'gatekeepers'. Only three of the seven transplant co-ordinating units I approached agreed to facilitate the recruitment of donor relatives. Four units denied access owing to the sensitive nature of the research.

Recognising the possibility of distress

Interviewing participants about their painful experiences could induce distress in the researched and the researcher, due to the reciprocal nature of their relationship.[6] Distress could have affected my role as a researcher in helping participants to complete their accounts and note gaps or areas for further clarification. Thus, in implementing the investigation, one of the main concerns was the possible threat it posed to the participants and to myself.

While 'gatekeepers' do need to be cautious in checking the credentials of the researcher and the ethical validity of the research, they tend to err on the side of being overzealous

The data quality could also have been affected because each interview was a jointly-constructed, context-based discourse in which both my values and those of the participants helped to give meaning to the research. Therefore, if the investigation was to take place, threats needed to be minimised, managed and mitigated, without compromising the outcomes. Caplan[17] summed up my concerns on the issue of disclosure and intrusion imposing restrictions to personal liberty. He suggested that control over one's life entails control, to some degree, over what is known by others about oneself and also control over crucial, private areas. By raising these painful experiences the research had the potential to invade, distort or destroy this private world of both the participants and myself, leading to what Goffman[18] termed a 'mortification of self' (a changing or remaking of a person by invasive exposure, as embodiments of self are violated).

There had been no studies of this nature carried out within the UK that could guide my expectations. However, some reassurance was drawn from Hutchinson *et al*[19] who found that people who could not tolerate talking about a topic, would not do so. Soukup[20] reported that post-donation interviews were a therapeutic experience for participants and, often, the first occasion that families had to reflect upon their experiences. Coupe[9] reported families' genuine wish to be helpful, and Hutchinson *et al*[19] suggested that the intrusion may even be welcome. Colin Murray Parkes, an experienced bereavement researcher, wrote:

> 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.[21]

PREPARATION FOR INTERVIEWING

Factors which may affect objectivity

In-depth interviewing using narrative accounts is a valuable and problematic method of data gathering.[3,6,22,23] On the one hand it allows the participant a flexible approach to give his or her account, and the researcher is able to use probes and questions appropriate to the participant's knowledge. However, its empirical value remains questionable concerning the type of data that are collected and the extraneous effects of the encounter upon the researcher and the participants. Cowles[2] suggests that, if objectivity is problematic in most research, it is perhaps even more so when the topic is sensitive and the researcher has face-to-face contact with vulnerable people. These problems may be sited in: the researcher's technical abilities; the motivational and cognitive factors of the researcher and participants; the ambiguous nature of truth; the temporality and liminality of human beings' interpretation of their lives; and the historical, sociocultural and contextual constraints.[22] Payne and Westwell[24] agree that the interviewer has a major impact upon the quality of the data generated during the interview. Holloway and Wheeler[25] suggest that the researcher becomes the main instrument for conducting the research interview and, therefore, the collection and quality of the data depend mainly upon his or her technique and abilities.

The researcher's presentation and demeanour may have the effect of altering the very aspects of the situation they are trying to study. In researching sensitive and painful topics (such as organ donation) the researcher must very quickly establish a trusting and comfortable relationship with the participants that will allow them to talk freely.[24] In an attempt to establish such a rapport, interviewers may become the subject of social support and, thus, help to reduce the intensity of bereavement reactions or temper experience. Furthermore, the effect of talking about the bereavement can be seen as giving social support, which has been shown to be helpful.[26–30] Such social support, nonetheless, creates methodological difficulties through the promotion of ameliorative effects on the research outcomes.

Other extraneous, therapeutic effects (which alter the account) may occur because narration provides a vehicle through which participants are able to communicate the complexity of their lives. As they are part of the events, telling may illuminate many issues that help them to make sense of their past and present experiences. A new understanding may, in part, be responsible for some of the therapeutic benefit that can result from interviewing through narratives as participants are encouraged to give a full account, limiting the fracturing of experience as opposed to reducing the experience to a question and answer format. It is not often in everyday life that someone will spend an hour or more with another person focused on a topic in which only that other person is interested, being sensitive towards seeking to understand their viewpoint.[6] Hutchinson *et al*[19] indicated the emotional relief, and the renewed sense of purpose, self-awareness, empowerment and healing that can arise from such an encounter.

Ethical considerations

De Raeve[5] has questioned the entitlement of researchers to engage with a research population such as the bereaved, who may be, consciously or unconsciously, hoping for help. She asks if it is justified to make data collection for such a group the 'principal aim' and care the 'sideline' or whether research should be judged only retrospectively, having made care 'the focus'. Bereavement researchers could be seen as stepping into a social and emotional vacuum and tapping into the participants' isolation. The interview also gives participants an opportunity to seek information from the interviewer, which, if imparted, can in itself have beneficial effects in eliminating latent misunderstandings and securing pertinent knowledge. Kvale[6] and de Raeve[5] suggest that it may therefore be difficult to separate a research interview from a therapeutic interview. Both may promote increased understanding and change, the difference being that the research interview emphasizes intellectual understanding, and the therapeutic interview personal change.

The need for support and information

There are special considerations that affect the researcher who is involved in bereavement studies. The expected sad nature of the work needs people who are qualified to carry out the investigation.

Systems need to be set up to give support to the researcher and the participants, if it is required

Researchers may need a period of preparation to allow them to feel confident in their skills at obtaining information from bereaved people and helping them in interview situations, should this become necessary.[16] Researchers also need to be well informed about the subject of the research, in this case, the organ donation and transplantation process. Indeed, one of the motivations for participants to join a study may be to elicit explanations to unanswered questions. Most importantly, researchers need to appreciate the limits of their skill and knowledge. Actions must be thought through to cope with these situations and contingencies developed to deal with them.

Systems need to be set up to give support to the researcher and the participants, if it is required, to cope with their own grief, and to help the researcher to maintain the tenacity and resilience to return to this sad data over time.[5]

Other areas of consideration are arrangements to deal with difficulties (such as participant dependency) and the relinquishing of situations that may call for a separation of professional and investigative roles.[31] Reflective time for the researcher is needed in the research timetable to allow for recovery between each sad interview experience.[2] The handling, storage, access, use and dissemination of sensitive material should be agreed upon by the researcher and the participants.[16]

Pre-interview arrangements

To minimise, therefore, the probability of 'mortification of self', a special programme of preparation was necessary. The interviews were expected to be potentially emotive and distressing, and I prepared to support the participants through any distress that they might experience. Although I am a qualified nurse–teacher who has had experience over 27 years of interacting with bereaved families (in both clinical and personal situations), I felt it was necessary to undertake a short counselling course,[32] and to attend a study day on 'Helping the bereaved'. Counselling skills were important in the interview situation, such as the art of listening, paraphrasing, reflective summarising, and using open questions. I also undertook a full programme of orientation to the process of organ donation and transplantation, and I arranged a support system for myself. A colleague, who was a member of a hospital bereavement team, agreed to support me. It was also helpful that the project supervisor had a nursing background and was experienced in bereavement research. The sharing of support was important, should one person not have been available if required, as it had the potential of distributing the distress[2]

Information from bereavement support organisations, such as the British Organ Donor Society, Cruse Bereavement Care, and The Compassionate Friends, was compiled and taken to each interview for use with participants, if they thought that it might be helpful. If a donor relative wished, I decided that I would initiate a contact with a support organisation designed to serve their need; I would not leave any relative in apparent distress, and I would be prepared to contact the participant's general practitioner if they were extremely upset or expressed suicidal intentions. The participants' 'support system' was always checked so that they were not left without sources of help. A concise and reflective ethnographic report was written about each interview to record important points about its context and to act as a developmental tool for my own interviewing skills.

THE PILOT INTERVIEWS

Specific preparation for the interviewing role was obtained through pilot interviews carried out with two donor families. These families had made donations several years previously, had had time to reflect on their feelings, and had spoken publicly about their experiences. My objective was to explore salient issues and gain confidence in conducting such an interview. I also became aware of the many roles that the participants would expect me to play in interviews of this kind. Just two of these were of the counsellor or therapist type: 'I found the interview very helpful to me, just to talk to somebody who understands was most welcome; in a roundabout way it was a sort of therapy.

The pilot study also taught me how important it was to consider my choice of clothing to wear during the interviews. For the first interview, I thought I would dress cheerfully, so I wore a black and red cotton dress and a red jacket. During the interview, the participant told me that, for her daughter's funeral, she had requested that no one should wear black. She also said that, owing to the bloodstains on her daughter's clothing, she could not tolerate the colour red and asked that no red flowers be sent to the funeral. She confided that it was many months before she could tolerate red because it reminded her of all the blood on her daughter's clothes, the result of the road traffic accident in which she had been involved. Needless to say, I felt very uncomfortable with my demeanour and, subsequently, wore only pastel colours for interviews!

'I found the interview very helpful to me, just to talk to somebody who understands was most welcome; in a roundabout way it was a sort of therapy

Undoubtedly, my professional background had an impact on interactions with participants and the pursuance of the research agenda. I felt that identifying myself as a nurse was an important element in developing rapport with relatives in this delicate situation. They knew I had a knowledge of the hospital environment and many of the issues that surrounded their experience. I felt that my professional background had prepared me to conduct such interviews with sensitivity and empathy as far as it was possible. BC

The second half of this article will be published in the Spring 2001 issue of Bereavement Care.

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References

1. United Kingdom Transplant Service Support Authority Statistics prepared by UKTSSA from the National Transplant Database maintained on behalf of the UK transplant community. Bristol, UK: Statistical Services, September 1998.
2. Cowles KV. Issues in qualitative research on sensitive topics. *Western Journal of Nursing Research* 1988; **10**: 163–179.
3. Smith L. Ethical issues in interviewing. *Journal of Advanced Nursing* 1992; **17**: 98–103.
4. Lee RM. Doing Research on Sensitive Topics. London, UK: Sage, 1993.
5. de Raeve L. Ethical issues in palliative care research. *Palliative Medicine* 1994; **8**: 298–305.
6. Kvale S. Interviews: An introduction to qualitative research interviewing. Thousand Oaks, CA, USA: Sage, 1996.
7. Stroebe M, Stroebe W. Who participates in bereavement research? A review and empirical study. *Omega* 1989; **20**: 1–29.
8. Stroebe M, Stroebe W. The mortality of bereavement: a review. In: Stroebe M, Stroebe W, Hansson RO (eds). Handbook of Bereavement: Theory, research and intervention. Cambridge, UK: Cambridge University Press, 1993: 175–195.
9. Coupe D. A study of relatives', nurses' and doctors' attitudes to the support and information given to the families of potential organ donors [Thesis]. Cardiff, UK: University of Wales College of Medicine, 1991.
10. Tymstra TJ, Heyink JW, Pruim J, Slooff MJH. Experience of bereaved relatives who granted or refused permission for organ donation. *Family Practice* 1992; **9**: 141–144.
11. La Spina F, Sedda L, Pizzi C *et al.* Donor families' attitude toward organ donation. *Transplantation Proceedings* 1993; **25**: 1699–1701.
12. Pelletier M. The needs of family members of organ and tissue donors. *Heart and Lung* 1993; **22**: 151–157.
13. Parkes CM, Brown R. Health after bereavement: a controlled study of young Boston widows and widowers. *Psychosomatic Medicine* 1972; **34**: 449–461.
14. Fulton J, Fulton R, Simmons RG. The cadaver donor and the gift of life. In: Simmons RG, Marine SK, Simmons RL (eds). Gift of Life: The effect of organ transplantation on individual, family, and societal dynamics. New Brunswick, NJ, USA: Transaction Books, 1987: 338–376.
15. Morton JB, Leonard DR. Cadaver nephrectomy: an operation on the donor's family. *British Medical Journal* 1979; **i**: 239–241.
16. Parkes CM. Guidelines for conducting ethical bereavement research. *Death Studies* 1995; **19**: 171–181.
17. Caplan AL. On privacy and confidentiality in social science research. In: Caplan AL (ed). If I Were a Rich Man Could I Buy a Pancreas? and other essays on the ethics of health care. Bloomington, IN, USA: Indiana University Press, 1994: 71–84.
18. Goffman E. The mortification of self. In: Flacks R (ed). Conformity, Resistance and Self-determination. Boston, MA, USA: Little, Brown, 1973: 175–188.
19. Hutchinson SA, Wilson ME, Wilson HS. Benefits of participating in research interviews. *IMAGE Journal of Nursing Scholarship* 1994; **26**: 161–164.
20. Soukup M. Organ donation from the family of a totally brain-dead donor: professional responsiveness. *Critical Care Nursing* 1991; **13**: 8–18.
21. Cartwright A, Seale C. The Natural History of a Survey. London, UK: King's Fund, 1990, p36.
22. Sandelowski M. Telling stories: narrative approaches in qualitative research. *IMAGE Journal of Nursing Scholarship* 1991; **23**: 161–166.
23. Parahoo K. Nursing Research: Principles, process and issues. London, UK: Macmillan, 1997.
24. Payne S, Westwell P. Issues for researchers using qualitative methods. *Health Psychology Update* 1994; **16**: 7–9.
25. Holloway I, Wheeler S. Qualitative Research for Nurses. London, UK: Blackwell Science, 1996.
26. Stroebe M, Stroebe W. Social support and the alleviation of loss. In: Sarason IG, Sarason BR (eds). Social Support: Theory, research, and applications. Dordrecht, The Netherlands: Martinus Nijhoff, 1985, pp439–462.
27. Stroebe W, Stroebe M. Bereavement and Health: The psychological and physical consequences of partner loss. Cambridge, UK: Cambridge University Press, 1987.
28. Littlewood J. Aspects of Grief: Bereavement in adult life. London, UK: Routledge, 1992.
29. Stylianos SK, Vachon MLS. The role of social support in bereavement. In: Stroebe M, Stroebe W, Hansson RO (eds). Handbook of Bereavement: Theory, research and intervention. Cambridge, UK: Cambridge University Press, 1993, pp397–410.
30. Walter T. A new model of grief. *Mortality* 1996; **1**: 7–25.
31. Robson C. Real World Research: A resource for social scientists and practitioner researchers. Oxford, UK: Blackwell, 1993.
32. Coyle A, Wright C. Using the counselling interview to collect research data on sensitive topics. *Journal of Health Psychology* 1996; **1**: 431–440.
33. Finch J. 'It's great to have someone to talk to': the ethics and politics of interviewing women. In: Bell C, Roberts H (eds). Social Researching: Politics, problems, practice. London, UK: Routledge and Kegan Paul, 1984: 70–87.

BOOK REVIEW

GRANDPARENTS CRY TWICE

Help for bereaved grandparents

Mary Lou Reed

New York, USA: Baywood Publishing, 2000. $23.95hb

Grandparents can often be the forgotten mourners within a family after the death of a child, and this is made more apparent by the limited amount of self-help literature available for them in this situation. Mary Lou Reed writes candidly about her own personal tragedy and offers support that may help to lessen the feelings of isolation of others.

Grandparents may experience three- and sometimes four-fold grief – their own grief, grief for the dead grandchild, grief and worry about their adult child, and the grief of any surviving siblings. At the same time, their role as grandparents may be very important within the family after such a traumatic loss. Reed uses her own experience in negotiating the grief process to educate bereaved grandparents about it and describes how they can help themselves through healing rituals. She normalises the physical and emotional pain of bereavement by pointing out that it is an individual experience. As a grandmother herself, Reed recognises the needs of the entire family after a child's death, especially any surviving siblings for whom she offers advice to help them to understand the loss of a brother or sister. She also highlights the need for social support and suggests how support and encouragement may be obtained from friends, organisations and literature.

Bereavement counsellors and clinicians may find this book useful in understanding the complexities of grandparent bereavement, while bereaved grandparents may identify with Reed and find solace. BC

Linda Drew
Researcher