Researching the bereaved

an investigator's experience (part 2*)

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**The first part of this paper appeared in* Bereavement Care *Winter 2000 issue. Reprints are available free to new subscribers from the publishers, Cruse Bereavement Care.*

THE INTERVIEWS

All the relatives interviewed were most hospitable. Finch stated that, in her experience, this indicated the participants' willingness to talk, being welcomed into their home 'as a guest and not merely as an inquisitor' (p73)[1].

The impact of the recruitment letter was assessed at the beginning of each interview. This procedure was inspired by the lack of guidance available about the construction and evaluation of study recruitment letters, particularly when sensitive, potentially painful topics were to be raised. Usually, recruitment letters are sequestered in the appendix of research studies, without comment on their acceptance or effectiveness. Although the letters did come as a surprise, they were found to be 'gently phrased and put together'.

> It spelt out quite simply, in simple terms you know, you would like to come and meet me, and everything else, and also you understood the problem, by saying, you know, sorry to approach you at a time like this in all of the stress you are going through and all the rest of it, you know, and, but I find it quite an acceptable letter, quite acceptable, no problem.

The letter seemed to bring comfort to some of the participants and appeared to highlight a problem of bereavement follow-up:

> I was quite pleased to receive your letter actually... I took comfort from your letter in knowing full well that somebody else out in the big wide world still cares, about people like myself.

Either over refreshment or during the interview, participants invariably showed me photographs of their deceased relative, which allowed the person to become real to me and the interview to be, consequently, more meaningful. There was no doubt that, for many of the participants, the interview acted as a kind of therapy, giving them the opportunity to tell their story and accrue information: 'The effect of talking with you was, though, quite therapeutic. I felt much more at peace by the time you left.'

My education about the technical aspects of donation and transplantation proved very useful because the interviews gave participants opportunities to seek information from me. The giving of information potentially had its own therapeutic effects in eliminating misunderstandings and securing pertinent knowledge. Information requested by participants was usually given at the end of the interview, unless it would have disrupted the flow of the interview not to do so at the time of the request. The following extract records the benefit of giving information: 'Very informative, I learnt a lot, which helped, as there were many unanswered questions from the hospital, which you helped us on.'

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Nursing knowledge was useful in maintaining the flow of the interview but it was sometimes problematic for me when errant practice was disclosed. A reflective memo states:

> This was a very difficult interview to maintain the researcher's role and not slide helter skelter into the nurse's role for the reasons of expressing my own anger at the poor caring skills employed by so many of the care professionals. Like the young staff nurse who told the family that she did not and would not donate N's organs if it was up to her, as N looked so much like her boyfriend and she would never let anyone touch her boyfriend...

There were often tears. Participants were always given the option of terminating the interview but in no case did a participant request that the interview should be abandoned. Parkes[2] stated that newly bereaved people are vulnerable and the strong emotions that shape their judgement could lead them to agree to take part in research, which they subsequently regret. Alternatively, they may refuse to join a study, which, in a calmer frame of mind, would present no problems. Therefore, Parkes attaches importance to the information that is given to bereaved people about a proposed project. He suggests that those who are invited to take part in research should receive a document that gives a full explanation of the study, the identity and qualifications of the researcher and the organisation through which the research is conducted, their rights as participants, and confirmation of ethical approval for the study. From this viewpoint, setting up the interviews and discussing with participants what to expect was found to be crucial to satisfactory outcomes.

When participants wept, because we had talked about this possibility before the interview, it all seemed very natural. An extract from my reflections reads:

> During the interview B talked freely and generously about S's death and what it meant to him. At one point he wept for a long time, which was fine, as we had discussed that this might happen.

What was a new experience for me was being present with men who wept so openly. Western perceptions of male attributes governing emotion may mean that men do not always get the required bereavement support. A husband stated:

> You enabled me to talk about S (his wife) in a way which was not possible with my family and closest friends. The interview helped me to put things in perspective and took some of the darkness away.

Stroebe[3] suggests that there are differences, both psychologically and physically, between the way men and women grieve, although she is aware that more research is needed to understand the gender differences. She purports that men tend to rely on problem-focused strategies of coping, such as distracting themselves from painful thoughts by work, play or becoming involved in new experiences. Women, on the other hand, usually use emotion-focused strategies, such as dwelling on thoughts about the dead person, crying and talking about the events surrounding the death. These differing behaviours could affect the willingness of men and women to join bereavement studies.

Parkes and Brown[4] were not able to show particular differences in the health or psychosocial adjustments of a group of refusers from participants in a longitudinal study of widows' bereavement experiences. However, Stroebe and Stroebe[5,6] found more profound depression in widowers who refused to join a longitudinal study, while widows who refused were less depressed than those who participated. They suggest[6] that the gender differences in norms governing the self-control of emotion in our culture make it more embarrassing for a man to cry during an interview than a woman. Fear of this happening could have led to those widowers who felt most depressed and, thus, more likely to cry during the interview, refusing to participate. The implications of these findings are that bereavement studies may overselect the better-recovered widowers and the poorer-recovered widows.

Far more surprising were the interviews that proceeded without emotional arousal, when it was not clear how the participant might react later, such as the 18-year-old mother whose husband was killed when she was six months pregnant. The sadness was sometimes compounded by other issues, such as a mother's distress that her son's last year of life was spent in prison and she worried that he had been buried naked because she did not take any clothes for him to the funeral home.

INTERVIEW EVALUATION

The first nine participants were asked to review a summary of their interviews (to validate my interpretation) and to share their perceptions and feelings about the interview. Once it was established that, in general, I was doing the participants no harm[7] and had a good grasp of the issues, I decided to stop the summaries because they did not appear to add any clear benefits to the research. It may have been upsetting for participants to review this painful material in hard copy and could have complicated the methodological outcomes[8]. Instead, all participants were offered a summary of the research findings, which was sent to them in due course, as requested (only one participant did not wish to receive a summary of the research).

I continued to write to thank participants and to ask for their evaluation of the interview. I felt comfortable with this approach because it gave them an avenue for further communication. Evaluation of the interviews by participants kept me informed about the psychosocial impact of their interview experience. In support of this action, Coyle and Wright[9] suggested that it is unethical for a researcher to raise sensitive issues with participants, restimulate painful experiences, and then simply 'exit stage left'. 'Thank you' and 'evaluation' letters were purposively sent three to four days after the interview, giving participants adequate time to reflect on the event.

Apart from the benefits, the participants did find the experience difficult, but they had no regrets about taking part if it would help someone else

Comments about the interviews showed that, apart from the benefits derived, they did find the experience difficult, but they had no regrets about taking part if it would help someone else; this supported Parkes'[10] earlier point.

REFLECTIONS

Scientific rigour is often enhanced by explicating the personal, and exposing the vulnerability, attributes and beliefs of the researcher[11,12]. Therefore, reflecting on these constraints and the effects they undoubtedly had on the research process helped me to be less blinded by my own subjectivities, such as the undue importance that may have been attached to particularly emotive areas of the research. These reflections were very helpful to me by placing each interview in context and could be regarded as a layer of the interpretative process (involved in the production of knowledge) that was opened for public scrutiny.

In the light of the above, I was able to gain the co-operation of the participants who received me into their homes, appeared to talk freely and openly to me about their experiences, and were grateful for the opportunity to express their sorrow and to talk about their deceased relative. I felt privileged to have been allowed to share in what, for them, was a poignant, rueful and intimate experience.

I felt very humbled by the generally excellent way in which they had managed their situations, mostly without the help of outside agencies. My demeanour as a mature woman, plainly and neatly presented, I believe, also helped to sustain trust in me. Being a mother allowed the parents of donors to feel that I could identify with their feelings. I enjoyed the interactive process with participants and valued the opportunity to glimpse into their lives, although the stories were all tainted with sadness.

At times I felt guilty about my comparative riches. For instance, I was deeply touched by a young mother whose baby son had died as a result of an unusual accident. She told me how resentful and angry she felt when she saw other people, including her own sister, with their children; somehow, I felt almost guilty that, as far as I knew, my sons were at home and well.

I would like to share with readers the flavour of the nature of the interviews and the feelings a father had about the death of his son and his organ donation:

> It's not a reward that you get, it's something that happens as a result of a loved one wishing to give their organs to somebody else. They give their organs to somebody else so that they can have the gift of life and what they give to us is almost, not an easy road in grief, but a different road through grief, a less harsh road, and a less final death, because it is a death filled with different emotions. It's filled with the joy of knowing good has come out of his death, as opposed to us having to know that, just, ah, nothing has come out of his death, only pain and sorrow and sadness and also knowing that it is not only the recipient that receives, it's their family, their friends... It is a tremendous thing, it ripples out to hundreds of people... Almost unending the relief and saving of pain that just giving something that is not needed can produce.

CONCLUSION

With the worldwide shortage of cadaver organs for transplantation, interest is becoming increasingly focused on the psychosocial impact of this rare and unique experience, to learn not only how organ availability may be increased by a better understanding of the donation process for families but how health professionals can help families to make decisions about donation that are right for themselves. This article has tried to explicate some of the concerns in interviewing this group of bereaved people. Certainly, careful consideration needs to be given to the risks of entering into such a sensitive area of research, which has the ability to affect the organ procurement programme. Clearly, preparation and support, both for the participants and the researcher, is essential, as well as a certain tenacity by the researcher not to be deterred when faced with the difficulties of access to samples and low participant response rates. There needs to be sensitivity to how any potentially damaging outcomes may be ameliorated and an acceptance of the probable benefits of such research to the participants.

Reprinted from Nursing Ethics *2000;* ***7****: 23-34, by kind permission of the author and publishers. The research upon which this* *paper is based was supported by a Department of Health Nursing Research Studentship.*

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The Grief and Bereavement Center, São Paulo, Brazil

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Innovators are often expected not only to launch new initiatives, but also to lead their field in terms of quality and keeping up to date. Brazil's first bereavement centre is now in its fifth year at the Pontifical Catholic University of São Paulo and a tradition of excellence is indeed an essential part of its reputation.

Our Grief and Bereavement Center officially opened in January 1996 with a grant from the São Paulo state foundation for research support. This was sufficient to provide us with a PC, printer, TV, 2 VCRs, all the material to work with this equipment and, best of all, funds for research. Our structure was, and still is, based on three things: research, psychological intervention, and services to the community of which the most important is training.

Initially the grant supported three undergraduate and two postgraduate researchers. However, we were as yet unrecognised by the university and, during our first year, we had a number of indications that our new research centre was better known outside its walls than within. This seems to be a common reaction to the work of those who are trying to do something really innovative in a traditional setting. The implication was 'why do research on themes related to death, dying, grief and bereavement in a country which has a widespread image of having a happy and problem-free populace?' - ignoring of course the violence, poverty and other disagreeable matters which it is more comfortable to keep far out of sight.

PRESENT SITUATION

Time has gone by and a lot of work has been done. Now we have a bigger and noisier staff: a co-ordinator, six undergraduate and 16 postgraduate researchers, and 11 psychologists engaged in clinical training. We have introduced a new subject into the undergraduate psychology curriculum, 'Research in death and bereavement', and we also run two courses each semester for postgraduates. All three courses are elective and have more interested students wishing to enrol than there are vacancies. Our staff constantly appears in the media when the opinion of an expert on death in the community is necessary. A book is due to be published in May 2001, with articles written by the PhD candidates and the co-ordinator of the centre. Four conferences have so far been held in 1996, 1997, 1998 and October 2000.

SERVICES TO THE COMMUNITY

In the beginning, the community (hospital staff, funeral directors and carers within families) did not know exactly what to expect and, therefore, what to ask from us until two unfortunate accidents made us more visible. In June 1996, a strong gas explosion destroyed the whole of a restaurant and most of a shopping mall in an industrial town in Greater São Paulo killing 42 people and injuring about 300. It was the eve of Brazilian Valentine's day and the mall was crowded with young people buying presents for their partners. We offered to work with the grieving families and the injured, many of whom had lost limbs and bodily functions. Then, in November 1996, an air crash just 42 seconds after take off from São Paulo regional airport killed 99 people – passengers, staff, and people in houses hit by the aeroplane. We offered to work with this grieving community as well. Both accidents had had a big impact on the whole country as most people were related to someone involved, and so the media coverage was enormous.

Now our laboratory is the main point of reference in Brazil for those working with and researching matters relating to death, grief and bereavement. The laboratory co-ordinator, and sometimes other members of staff, are constantly being asked to lecture or to participate in scientific events. We are also invited to give interviews for TV, radio, newspapers and magazines, so that now it is becoming more normal for these matters to be discussed openly and for members of the public to understand the need for psychological support in some grieving situations.

Increasingly proper space is dedicated to discussions and presentations on themes related to grief and bereavement at scientific events in this country: to mention just two, the biannual conference on psycho-oncology and the annual conference on psychology and hospitals.

INTERVENTION

Since 1996, 198 bereaved people have received psychotherapy treatment at the training centre of the university. In this group, the majority of the people were