



social research UPDATE

- The emotional impact of research on the researcher and the effect of personal relationships on research outcomes are considered.
- The difficulties of crossing the personal/professional boundary are contrasted with 'contract research' conducted on a more commercial basis.
- While there are risks relating to neutrality and academic freedom, the benefits of cooperation, trust and emotional engagement can result in a successful outcome for all.

Personal agendas in emotionally demanding research

Anne Grinyer

On March 17th 1999, a young man called George died from osteosarcoma at the age of 23. George had been ill for four years and had given up his university studies to return home to be cared for by his parents Helen and Geoff. The challenges faced by George and his family during his illness led his parents to believe that George's age and life stage contributed to the tensions and changes in the family dynamics that had a profound effect on all concerned. After George's death—and at his behest—his parents set up a charitable trust in his memory to support research on the impact of life stage when a young adult is diagnosed with cancer.

George was the son of close family friends; indeed I had known his parents Helen and Geoff since before his birth and have a clear memory of George as an infant being brought to visit me in hospital after the birth of my second child. George's father is an academic at the same university where I teach in the Institute for Health Research so this department was a 'natural' starting point for him and Helen—a hospital social worker—to make an approach regarding the research and where it might be situated. The Director of the Institute suggested that I would be a suitable person to undertake the research; however, at this stage he knew nothing of my pre-existing friendship with the family. Nevertheless, both Helen and Geoff appeared to feel comfortable with the idea that I should take on the project and approached me with enthusiasm.

My initial response was rather less than enthusiastic. At this early stage my reaction was an emotional one rather than being an intellectual analysis of potential problems. I would be working with and for, not only close friends, but friends whose son had died and whose death was the rationale for the research. Although no overt pressure was exerted to undertake the project, I nevertheless felt a certain expectation both from my department and from the family that was difficult to resist. It was thus with some trepidation that I accepted, but attempted to mitigate the effects of personal engagement by persuading a colleague who did not know the family to collaborate as a co-researcher.

What are the implications for a researcher under such circumstances? Should their position be regarded as a benefit or drawback? Is it even possible to anticipate the impact on the course of the research, the viability of the complex relationships and the credibility of the outcome?

The Emotional Impact on the Researcher

Clearly a project based on such an emotional and emotive topic has ethical challenges from the outset (Grbich 1999). Thus during the design phase of the research great care was taken to select a methodology that would allow participants to engage in the research with minimal intrusion and distress on their part. The narrative correspondence method suggested by my

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co-researcher and used successfully by her in previous projects, (Thomas 1998, 1999a, 1999b) allowed participants to remain in control and write about their experiences where and when they chose and to submit their accounts without the pressure or demands of a face to face interview.

During the design phase of the research the emotional well being of the participants was the primary concern and they were invited to (and did) contact any member of the project team for support should they require it, but I had not considered the impact of the narratives on me as the researcher. Young and Lee (1996) argue that the role of emotion in the research process is not accorded the recognition it deserves and this is endorsed by Hubbard *et al* (2001) who address the need for research teams to develop strategies to 'manage' the emotions of researchers throughout a project. They suggest that while there is now a widely accepted understanding that participation as a respondent in research carries with it an emotional component and a consequent need for the researcher to be sensitive and aware of the ethical implications, there is little corresponding awareness of the emotional impact on the researcher.

Hubbard *et al* suggest that one of the reasons that the impact on the researcher is low on the list of concerns is that there is an assumption that we tend to 'screen ourselves out' of projects that we consider personal danger areas (2001:120). While Hubbard *et al* say that researchers may not always anticipate emotional challenges, this project held many that I was only too aware of.

The emotional impact of research is examined through the use of case studies by Hallowell *et al* (2005) based on the 'emotion work' (Hochschild 1983) between the researcher and bereaved or dying participants. I, too, was affected by the anguish of the parents as they wrote about the illness—and in most cases the death—of their sons and daughters. In addition, there was the need to manage another emotional dimension, because underlying my engagement in the field was a pre-existing relationship with the founders and funders of the project, never articulated between

us nor acknowledged to a wider academic audience. Yet it was this relationship that also provided my emotional support during the project, an albeit informal arrangement, but one that seemed more apt than provision from a more objective source.

Agendas

Thus far the focus has been on the 'effect on' the researcher, but under such circumstances what are the 'effects of the researcher? Clearly all research is shaped to some extent by the position of the researcher and objectivity and neutrality is impossible to achieve (Stanley and Wise 1983). While reflexivity (Darlington and Scott 2002) should position a researcher in relationship to the project and acknowledge pre-commitments and prior experience; there is nevertheless usually an attempt to minimise researcher effect.

However, what may be less frequently addressed is the pre-existing relationship that the researcher has with the research topic and its commissioners or funders. My research was in its broadest sense 'contract research' that carries with it expectations from the 'client' that it will fulfill certain criteria. Indeed having previously written on the complex agendas and pressures experienced by researchers who are expected to produce findings that suit the purpose of the funder (Grinyer 1999), I was well aware of the issues in a different context. However, in this case the agenda was neither political nor profit related, nor was it seeking justification for practice or policy. Nevertheless, the research was predicated upon the hopes and expectations of a family who had set up the charity and the research project in memory of their dead son. In the event my findings supported their supposition that life stage was a significant factor, but findings that challenged this might have been difficult to manage, particularly in such a sensitive area and with friends.

Before the draft of any publication was submitted for peer review, I felt a self-imposed obligation to seek 'approval' from George's parents, despite there being no explicit agreement to do so—a process to which this paper has also been subject. The

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article has also been read by my original co-researcher. To what extent does this have an impact on academic freedom? In the event, their observations were only ever helpful in assessing with sensitivity the way in which such material might be read by other parents whose young adult children had had cancer. Nevertheless, the potential for compromising academic freedom exists.

Under such circumstances the pressures relating to more commercial contract research seem relatively routine. For example, it might be acceptable, even expected, to draw up a contract between a commercial client and the researcher specifying such issues as the ownership of data, control of dissemination, the process of approval for publication, the scope of the project and evaluation (Grinyer 1999). However, this may be more difficult to broach when undertaking research for long-standing friends.

The project was also supported by comparatively modest funding contributed by donations from individuals raising money through events such as sponsored runs and car boot sales—a contrast to the large scale projects funded by public bodies with hundreds of thousands of pounds. Yet this too represented another agenda. While expenditure must always be justifiable whatever the source of funding, the knowledge that a young person had run a marathon or undertaken a sponsored cycle ride to support the research sometimes seemed like a heavy responsibility.

Outcomes

It is with some relief that, five years on, I can report that the project has been a 'success' in that it has more than met the initial expectations, resulted in a number of publications (Grinyer 2004a, 2004b, 2002, Grinyer and Thomas, C. 2004, 2001), invitations to speak at prestigious conferences, has had an impact on policy and practice and reportedly been of use to parents whose young adult sons and daughters have cancer. Yet the rewards of such a project being successful can bring a whole new and unanticipated set of issues for the researcher to deal with at

an emotional level. In this case success was based upon the loss, pain and tragedy of the families who trusted me with their stories, and the death of a young man whom I had known all his life. Every time I have been tempted to take pleasure or satisfaction in any academic accolade I am reminded of this. Yet the problem of success for researchers whose data are based on the painful experiences of their participants is not an issue I have seen discussed in methods texts. Interestingly, it is only I who see this as a problem; it is not problematic to Helen or Geoff, to the Trust Board, nor as far as I am aware to any of the participants. Indeed all of these interested parties are pleased that the research has been so productive. As Helen says, it would have been terrible had it been a failure.

Discussion

It may be that the issues faced during this project are not unusual but unique. Nevertheless, it seems that a number of the identified challenges may face researchers in some form under other circumstances, so what can be learnt from the experience?

Firstly, should a researcher who is emotionally involved with the topic and its funders agree to take on the project? I suspect that emotional involvement may frequently be the case but it may remain unacknowledged. Indeed, in some instances a pre-existing relationship may be the only way to negotiate access. Adopting a reflexive position, I cannot claim that my pre-existing relationship with George's parents has not shaped my approach or my interpretation of the data. My personal need for their 'approval' of my actions and the research output may also have affected my decision-making. Yet no researcher works in a vacuum without subjectivity and without both their own and others' agendas shaping the process. While the outcome here may be the product of agendas more personal than is usually the case, this does not, I believe, devalue the result nor damage its credibility.

The risks are manifold both professionally and personally for a researcher under such circumstances. However, the relative neutrality of my co-researcher in the early

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stages was crucial in terms of mitigating the risks. To some extent her involvement also provides a comparison to the emotional impact on me. In her own words:

I certainly was 'relatively neutral', though... emotionally involved with the data... I was at a 'distance' from Geoff and Helen, and this meant that I could just fulfil duties as a researcher undertaking sensitive research—without other baggage. I suppose this meant I was a 'stabilising' influence in the research team. So the 'emotional labour' wasn't so hard for me.

Although her involvement did not last the length of the project—she was my co-researcher only for the first year—her initial participation in discussions, negotiations and the research design were immensely beneficial. Thus even after her withdrawal, strategies had been agreed in a way that acted as a foundation for the ensuing four years.

Conclusion

Paradoxically, the success of the project can be attributed at least in part to those very relationships that put it in danger. The commitment of all concerned to generate and disseminate knowledge that would contribute to a fuller understanding of the issues, coupled with long standing trust and friendship, suggests that research carried out under such circumstances can be rewarding and productive. Nevertheless, it would be remiss not to afford due recognition to the potential implications of personal agendas, acknowledge them from the outset and attempt to negotiate some strategies for resolution should the need arise.

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