Cancer the Bogeyman and Me: Reflexivity and Emotion in ‘End of Life’ Research

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**ABSTRACT:** This paper explores the embodied nature of training in social anthropology and reveals how, while working in multidisciplinary teams and drawing on research methods and approaches more commonly associated with other disciplines, one might still be ‘outed’ in one’s interpretation and analysis. I draw on the experience of working on a project exploring methodological issues and challenges to conducting research with terminally ill cancer patients to reveal the importance of situating ourselves as researchers firmly within the prejudices of our own societies. While personal experience of losing a parent to cancer should have alerted me to other ways of seeing cancer, I was nevertheless obliged to confront sociocultural constructions of cancer and recognise them as my own. Through understanding the power of ‘imagined experience’, I gained further insight into how intersubjectivity and reflexivity are crucial to the research process.

**KEYWORDS:** multidisciplinary research; cancer experiences; intersubjectivity; reflexivity

**Introduction**

To those of us who work outside academic anthropology, the timeworn and highly irritating distinction between applied and ‘theoretical’ research is one that we feel obliged to argue against in order to demonstrate value to our so-called ‘academic’ peers. In some ways, this paper is yet another attempt to chip away at this distinction, albeit in this journal perhaps only managing to preach to those who already know better. I hope that this paper will go some way to explaining how one can remain an anthropologist, retaining strong theoretical interests, while also having the privilege to engage in research that has the potential to make a real difference to the everyday lives of our participants. However, rather than ‘applied’ versus ‘academic’ anthropologies, I regard myself as doing both.

This paper provides a reflexive account of being a full-time researcher employed on a multidisciplinary research project. It is an account of an anthropologist stepping outside their own discipline, adopting research methods more often associated with sociology or other social and health sciences, while maintaining a strong disciplinary identity. By taking an ethnographic approach to the research process, I illustrate how anthropological training influenced my research and analysis. During this process, I made connections between different kinds of knowledge and experience that lent a greater insight into the ways that our own research practice becomes entwined with constructions of health and illness.

Although the research methods of the main study that I refer to below did not involve participant observation, my research was nevertheless informed by literature in anthropology.
related to reflexivity, such as Okely and Callaway’s (1992) edited collection, *Anthropology and Autobiography*. Drawing on that strongly anti-positivist approach, particularly Cohen’s (1992) exhortation to draw on all the resources that we have to inform our interpretations, I draw on my experience of losing a parent to cancer and combine this with interviews with researchers and focus groups with users of cancer services, bringing all this together in an analytical form to show connections between memory, experience, emotion and how this impacts on research. Going beyond distinctions between ‘self’ and ‘other’, I present an account of research that drew on intersubjectivity to an extent that rendered these boundaries even more problematic and fluid than is usual in ethnographic research. In this paper I reveal how research projects or topics that strongly connect with our own experience render the self/other distinction impossible to make as well as ill-advised.

Although I also draw on other research project experience, the main study that I refer to aimed at exploring the methodological issues and challenges of conducting research with the terminally ill. This involved conducting semi-structured interviews with thirty researchers and two transcribers of ‘end of life’ interviews, as well as focus groups with cancer survivors, hospice patients and a group of partners of terminally ill cancer patients. The project steering group (principal investigator and others named on the research grant who secured the project funding) consisted of a sociologist, two academic clinicians (General Practitioners or GPs), two consultants in palliative medicine, two academics with nursing backgrounds and a patient representative who also happened to have a doctorate in social work.

What follows is something of a pastiche of memory, experience and talk that informed my analysis. I shall begin with some autobiographical recollections that had a significant impact on the interpretive process, following this with the more ‘conventional’ interview and focus group material, before bringing them together analytically.

**Autobiography**

Dad had been poorly for quite a few months before he finally went to the doctor and was referred for chest x-rays. It was a few weeks later that he ended up being admitted to hospital with severe chest pains. It turned out that he had pleural mesothelioma—a form of cancer in the lining of the lungs caused by exposure to asbestos. As he lived alone, some distance away, my husband and I arranged for his treatment to be carried out in Edinburgh and he came to live with us.

He died eight months later.

I got a letter from Maggie’s Centre in Edinburgh a month or so later inviting me to a bereavement counselling group. (Maggie’s Centres is a charity that aims to support people living with cancer through the provision of individual and group psychological support, addressing information needs of patients and their families.) But although it probably would have helped to have talked about his death, I didn’t take up the offer. I felt that my experience of cancer would not compare with that of others and I didn’t think I had a right to talk about what I regarded as a ‘good death’ when I imagined that everyone else in the group would probably have had much worse experiences of dying. Dad was in pain, but it was well controlled. He did have one major crisis that I try not to think about, but then he was admitted to hospital to be assessed and to have his medication adjusted. The morning after being admitted to hospital, he got up to have a shower, went back to bed, and quietly died. The consultant said, ‘His heart simply stopped beating.’

Two years later, I was offered the position as research fellow on the Macmillan study. Despite this previous experience of cancer, the night before the interview I tossed and turned for hours
worrying that I wouldn’t be able to bear doing the research—especially the part that involved going to a hospice to recruit patients. Although my father had remained mobile and coherent right up to the end of his life, I believed that his was an extraordinary experience of cancer—one that I imagined did not bear much relationship to the majority of cancer experiences that have fuelled the fear and horror of cancer that resides in the popular imagination (see Clarke and Everest 2006; Sontag 1978).

Nevertheless, as someone who had been so closely affected by cancer, I was partly motivated by those sentiments that we often hope to tap into when recruiting participants into health research: I wanted to ‘give something back’ by contributing to a study that might in some way improve research related to patient needs at the end of their lives and by extension, cancer services.

Ethnographic Encounters with Research

Interviews with Researchers

I initially conducted semi-structured interviews with researchers experienced in ‘end of life’ research (particularly in cancer). These researchers varied in expertise from very junior researchers to senior academics responsible for managing large research teams, which allowed our analysis to capture a broad range of perspectives on what methods were being used and what the challenges to doing research in this area might be. Background disciplines ranged from nursing and medicine through to sociology, anthropology, psychology, social work and social policy. The net was cast wider when one senior researcher said that actually, there wasn’t much difference in doing research with the dying or in the field of cancer since other areas of social research can be just as challenging and emotionally demanding. Indeed, Addington-Hall (2002) argues that the ethical challenges of researching palliative care populations are shared by researchers of other ‘vulnerable’ groups. The particularity (or otherwise) of research with the dying was a thread that I picked up on in the first few interviews and began to weave through the subsequent interviews. This theme also affected the ongoing selection of interviewees as the sample of researchers was broadened to include researchers who had done work in other areas such as disability research, research with disadvantaged and marginalised population groups and so on.

Although I developed an interview schedule to guide the interviews, the research team agreed that an iterative approach, responding to interview material and adapting according to new questions suggested by preliminary analysis was the preferred way forward. In this way, although it was a long way removed from the unstructured interviews that are so much a part of fieldwork in social anthropology, I was allowed nevertheless some freedom to develop the line of questioning and I was not shackled to an unchanging interview schedule. Just as in my doctoral fieldwork, participants talked about unexpected issues that the research team had not thought to ask questions about and these were followed up in subsequent interviews.

Some of the main issues raised by researchers were around the methodological challenges of doing this research rather than focusing on the research techniques per se, as discussed elsewhere in an overview of the study (Kendall et al. 2007). They faced particular challenges in recruitment, attrition (loss of participants through death, deteriorating health or other reasons) and how this research can sometimes have an emotional impact on researchers. Our major conclusion was that although there are societal barriers to conducting research with the terminally ill, we should not mark people who are dying as different and deny them the right to participate in research. This is done by the gatekeeping tactics of clinicians, nursing staff and ethics committees. On the surface, clinicians and nursing staff may support researchers in recruiting from their wards or prac-
tices, while subtly placing barriers in their paths. Additionally, while ethics committees have an important role to play in the regulation of research, they must balance their duty to prevent harm to NHS staff and patients with the problems of taking a paternalistic stance that may deny people the right to choose for themselves whether or not to talk to researchers (ibid.).

The majority of researchers who work in the field of palliative care research mentioned the emotional impact of their work and there are some good discussions in the literature around this (Beaver, Luker and Woods 1999; Lawton 2001; Rowling 1999; Seamark et al. 2000; Seymour and Skilbeck 2002:). Most researchers spoke of the need to budget for counselling sessions for researchers and the importance of peer support and debriefing. A few researchers also indicated that there was a need to be mindful of transcribers as they could be affected by long hours of typing up what might be quite distressing interviews.

Interestingly enough, although almost every researcher said something about the emotional demands placed on researchers by doing research with people who are dying, hardly any of them had ever actually used the services of a counsellor. Most did their debriefing in the pub with fellow researchers. But despite this, my colleagues and I argued elsewhere that one should be wary of dismissing the need for counsellors as this may be more of an indication of the potential stigma associated with needing to seek help in this way (Kendall et al. 2007). However, talking to researchers from other fields gave an interesting balance to this picture. One person described how harrowing it was to do research with people with degenerative diseases and others talked about research areas outside health and illness, such as in child abuse and domestic violence. The picture that emerged quite clearly was that cancer research did not hold the monopoly on emotion, and they too employed the same attention to sensitive practices and ethically informed processes of research.

Indeed in another of those illuminating research moments, one of the researchers emphasised that there were strongly positive sides to doing research in the field of palliative care. She spoke of the privilege of being allowed to spend time with someone for whom time is a scarce resource, witnessing the power of enduring relationships and being able to contribute in a small way as a researcher to improving the care of the dying. Furthermore:

You just meet people as people and they respond to you as people, whether they are at the end of life or whether they have a particular cancer or whatever, it doesn’t make any difference, they respond to you and you respond to them as you would anybody else. So the only problem has come from other people looking at my work and saying gosh it must be difficult, it must get you down at times and actually I say it is not the case at all. (Researcher Interview 30)

Focus groups

Now I shall move on to connect the discussion of emotion with how it feels from the other side, in other words, how research participants might feel about taking part in research. One focus group consisted of three women who had survived cancer treatment and were active patient advocates. In asking them how they might feel about taking part in research if they were nearing the end of their lives, all three women responded with very positive, strong comments about the value of this. One woman spoke of her experience of taking part in research interviews when she had been very ill and how it had helped her to talk about things more deeply. She said that nobody else would talk about her fears. Another of the women said that everyone is afraid to talk to you: ‘No one ever asks how you feel’ (Cancer Survivors, Group 2).

Another of the focus groups consisted of four older men who were day patients at a local hospice. One of the major things that I took away from discussions with this group was the
way in which we (as researchers) may inadvertently construct people as patients, as carers or otherwise. For instance, in a research design that focuses on sampling representatives of particular ‘patient’ groups, we distinguish patients from their friends and families and indeed from anyone who might be involved in their care. When I probed around the issue of how best to find out about the lives and experiences of these older men, one of the participants said that actually, if I wanted to know about him and his life, the most important thing about him was not his cancer, but the fact that he was an ‘old man’: ‘As a matter of fact I think my ailment [is] secondary to my old age’ (Day Hospice User, Group 1).

This was a statement that had a major impact on how I viewed the project of exploring research methods in cancer and palliative care research.

Reflexivity, Meaning and Analysis

By putting together fragments of autobiography, research interviews and focus groups, we can reveal different layers of what cancer might mean in contemporary society. Although it’s difficult to talk about the loss of a parent in positive terms, my father had what contributors to the British Medical Journal might refer to as ‘a good death’ (Clark 2003). Nevertheless, I was still fearful of what pain and suffering I might encounter during the research. (And in some ways, I think I was right not to assume that my experience was the same as others, as some of the researchers clearly illustrated the sometimes deeply distressing experiences that some cancer patients have). But at the same time, although researchers generously shared their experiences and sensitive insights into research with the dying, there was still an underlying notion that somehow cancer was a special category of illness that required particular emotional support and included significant challenges. Furthermore, despite my family experience that challenged received stereotypes of cancer as a ‘bad’ way to die, I too was convinced that cancer was a terrible disease that brought the most extraordinary pain and suffering.

In fact, the words of the hospice user were probably one of the most illuminating of the whole study: his underlying message was to think of him as a person, an older person who lived alone, rather than as a person who had cancer. This message also came through from the former cancer patient who said that no one ever asked her how she felt when she was being treated for cancer. Finally, the researcher who commented that you just respond to people and they respond to you whatever their circumstances also suggested that there is a need to break down cancer as imagined, before we can ever hope to engage with the person.

Cancer is very much constructed as a bogeyman (an evil spirit or entity that is used to invoke fear)—as something lurking, that will be out to get a great many of us—and while societal attitudes have changed from the days when cancer was a word that was whispered or denied, it seems to me that we as researchers are nevertheless still prone to putting the person into a black box with the disease label upon it (Sontag 1978). For instance, studies comparing representations of cancer and cancer experience in the media clearly illustrate how the person diagnosed with cancer automatically assumes special qualities by virtue of the fact that they have this diagnosis (Dixon-Woods et al. 2003; Seale 2002). However, what cancer means varies with individual experience across different cancer types, as my own personal experience of cancer should have alerted me to from the outset.

As Kleinman and Fitz-Henry (2007) note, to understand the self and subjectivity, this must be located within individual experience. By extension, understanding individual experiences of health and illness should be an exercise in intersubjectivity: ‘To talk about subjectivity, then, we must build our conversation around the fact, … that the subjective is always social..."
and the social, subjective. This dialectic of intersubjectivity, not just the dialectics internal to the self, needs to be taken up in subsequent framings of experience (ibid.: 64). Furthermore, I would argue for an intersubjectivity that firmly places the subjectivity of the researcher within the same frame of vision as the subjectivity of our research participants. In this way, the distinction between self and other that remains implicit in much anthropological research, becomes more precarious and less sustainable, particularly for those of us who conduct research ‘at home’ on topics that have resonance with our own lived experiences. While it is certainly not new to argue for a subjective anthropology, blurring the distinction between the self as researcher and the self as fellow sufferer, as another who has experienced pain or loss, is perhaps a little further from the mainstream.

**Ethnography of Research**

Coming to these conclusions represented something of a meander through the social sciences for me as a researcher. By the time that I took up this post it was a couple of years since my doctoral work in anthropology. I had since been employed on two short-term contracts working within multidisciplinary teams. From the moment that I left the familiar territory of academic anthropology I was obliged to learn a new research vocabulary, to unlearn (or at least keep to myself) much of the training that allows anthropologists to include a broad range of sources of ‘data’ in our interpretation and analysis (see also Greene 2001; Gooberman-Hill 2003).

While anthropologists strive to go beyond what is said and situate interview material within wider social contexts, this is not the norm within health services research (Lambert and McKevvitt 2002). Indeed one of the things that I realised early in my research experience with colleagues from other disciplines, was how little importance was placed on fieldnotes and observation of context. Although in each of the projects that I have worked on people have paid lip service to the technique of writing short fieldnotes to record the context of the interviews (the setting and any other observations), there appeared to be a tendency to then focus on interview transcripts as the ‘evidence’ and to mistrust anything that was not audio recorded.

In health services research in particular, qualitative research is often conducted through the distorted lens of a quantitative paradigm, so that, for instance, there are deep concerns around the ‘rigour’ of the research process and as Lambert and McKevvitt (ibid.) suggest, there is a tendency to equate the use of qualitative software packages to thoroughly analysed research material. However, the experience of analytical techniques that includes a PhD in social anthropology, manual ‘coding’ of health research interview transcripts for recurrent ‘themes’ (see for instance Miles and Huberman 1994), as well as the use of qualitative data analysis software such as N-Vivo, has offered an insight into the processes that are used and how we come to be constrained by them. While one might expect that coding text would engender a close engagement with the interview material, in fact it is best equated with those early approaches to studying kinship that sent generations of undergraduates running from the mechanistic horrors of a field of study where the people had been miraculously removed. So too does ‘coding’ run the risk of snuffing the life out of the words of our interview participants.

By the time that I came to work on the Macmillan study, then, I had used my anthropological training more as a means to observe the techniques and theoretical underpinnings drawn on by my colleagues than to actually use it explicitly in my own research. I had conducted what amounted to a long stint of participant observation: I learned the language (although,
of course, could not claim complete fluency), learned to blend in with the ‘natives’ and had even started to use the word ‘data’. Coming to the Macmillan study I had both the language and a greater confidence in my ability to translate my own methodological concerns. Now looking back on this ‘fieldwork’, I realise that I was a bit like an anthropologist returning to the site of their PhD research, with a new authority, much less angst and a greater armoury of research techniques to launch the new project.

Now I feel confident to explore the same-ness and difference of these various research encounters. I have learnt much from colleagues about gaining access through gatekeepers, gaining and maintaining consent, preparing appropriate information sheets/materials, securing approval from ethics and research governance committees and so on. These were all research skills and knowledge related to working within health and illness in the U.K. Being involved in this kind of research also required me to read up on how to talk about research methods as my anthropological vocabulary was not recognised and I was subjected to the tyranny of having to talk about certain aspects of research methods or be suspected of ignorance. As a social anthropologist working within applied health sciences, one is met sometimes with a certain amount of suspicion simply because our discipline seems to have developed in such an insular fashion, on the one hand drawing on and learning from other disciplines, but on the other, doing a very poor job of disseminating our disciplinary insights and perspectives outside our own discipline. Perhaps we suffer in the U.K. from the very much smaller number of anthropology departments compared with sociology. Coming to work on the Macmillan study marked a turning point for my experience of multidisciplinary working. While I had previously resented the methodological dominance of sociology in applied research, I soon realised that sociologists also railed against the constraints of a biomedical paradigm.

Conclusion

Reflecting back on the experience of conducting research within the palliative care field taught me a great many things. Firstly, that as an anthropologist, my analysis will always be informed by a wider notion of what constitutes ‘data’ and that reflexivity and intersubjectivity will always be an integral part of my research practice. My own experience of being the main carer of a parent with terminal cancer connected in unexpected ways with the experiences of those who participated in the research project. It served to enhance the understanding that as researchers, we too remain deeply embedded within the society that we are enculturated by and our knowledge and experience is bound to reflect this. Despite experience that should have alerted me to alternative possibilities, as well as my training as a social scientist, I was still fearful of what contact with cancer patients might bring. I believe it is partly the direction that the research took in response to the commissioning brief (to focus on people affected by cancer at the end of life), and partly misguided expectations that drew us initially down the path of regarding cancer and research in this field as some sort of a special case. Fortunately, our research participants informed us otherwise.

As researchers we too are affected by socio-cultural constructions of the societies that we live in and are just as vulnerable to allowing ‘imagined experience’ to have an influence on how we approach the field of study. We have to be able to explore our own prejudices, our emotions, in order to see how embodied notions of the person, health and illness impact on the way that we might approach our research. In my own case, I learned from my own subjectivity and, I hope, managed to put ‘Cancer the Bogeyman’ to rest. However, while my anthropological past surfaced through the use of reflexivity and a wider notion of what constitutes research ‘evidence’, I now know that
the holism and iterative approach to research that we claim as one of our hallmarks is not the sole provenance of anthropology. My collaboration with the medical sociologist on the Macmillan study taught me that sociologists too can be anti-positivist in approach, engaging in fluid research designs. So I am left with wondering what is left that is different? Is it purely about the methodological language that is used, or does it go beyond this?

While I have deconstructed the Othering connected with a diagnosis of cancer, there are strong parallels to the way that I have come to see my role as an anthropologist working within multidisciplinary teams. Alterity is something that we often extend to those outside our own disciplinary boundaries, and yet I hope that while I have demonstrated how anthropology is still a strong influence in my research practice, I have learned and drawn on techniques from other disciplines in the process.

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