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PEER-REVIEWED ARTICLE

Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics

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ABSTRACT

Within ethnography, observation and participation are interwoven as sociological research practice that involves watching, listening and asking questions about people's daily lives and experiences, and the meaning they attach to these. For ethnographic researchers a close and regular engagement with participants raises both practical and ethical challenges related to intrusion, relationship boundaries and issues of 'attachment' on leaving the field. Research that has the added dimension of profound sensitivity may also present the researcher with the challenge of managing the impacts on them of emotional stress caused by watching people's discomfort and suffering. This article discusses the author's methodological reflections on an ongoing ethnographic study of a cancer drop-in centre, focusing on the ways in which emotion and empathy shape researcher-respondent rapport. An underpinning theme of the discussion is the potential for emotion deluge and fatigue on the part of the researcher and the consequent need to establish self-care strategies.

KEYWORDS

Cancer, emotion, empathy, ethnography, participant observation

Introduction

This article is a methodological reflection on some of the ethical and practical dilemmas of qualitative health research on sensitive topics with potentially vulnerable participants. The context for the discussion is an ongoing long-term ethnographic participant observation study of a cancer drop-in facility run by a community hospice trust in the South of England. Dickson-Swift et al (2006: 853) argue that qualitative health researchers immerse themselves in the settings they are studying and it is this aspect of 'immersion' that is central to the critical reflections on process and method that continue to engage the author in the ongoing conduct of this research. Much comment in this area has tended to view sensitivity within research primarily as an ethical issue (Alty and Rodham, 1998), particularly its effects on research subjects that Rager (2005) contends are generally well protected by research protocols. The effects on researchers, however, have been less well documented, with some commentators (Sword, 1999; Dickson-Swift et al, 2007, for example) calling for a closer scrutiny of the emotional elements that contribute both to the conduct and output of research in sensitive domains.

The possibility that emotion, as well as reason, can be privileged within the research process to positively contribute to high-quality outputs is the position taken by Gilbert (2001a). She argues that 'it is an awareness and intelligent use of our emotions that benefits the research process' (Gilbert, 2001a: 11) contrasting traditional approaches of managing,

avoiding or making invisible emotion in pursuit of 'good' research, with the claim that it is dishonest for a researcher *not* to draw on their own emotional experience in the telling of the research story. However, for inexperienced or lone researchers working on sensitive topics, this opportunity for positive integration of their emotional responses as part of the epistemological process may not be feasible, particularly if they are experiencing emotion fatigue and are working with little support or supervision (Gilbert, 2001b; Johnson and Clarke, 2003; Rowling, 1999). Because the traditions of science, that adopt the dispassionate language of researcher neutrality and objectivity, have dominated the early development of sociological research, researchers have been enjoined not to feel but to think (Campbell, 2002: 16). This is the mantra of purist positivist research that remains difficult to reject in favour of personal and individual perspectives that are theoretically unpopular and subject to suspicion and sceptical scrutiny by large parts of the academic research community, particularly those working in the medical, physical and engineering sciences.

Ethnography is one qualitative research approach that deliberately sets out to place the person of the researcher, including their emotional and affective experiences of research (Campbell, 2002: 123) and the personal experiences of research subjects, as central to the research endeavour. It seeks to report what is observed and transacted in the field, recounting what was said and done and why events occurred. It is a highly interpretive method and does not claim to represent truth, in any positivist sense, but rather offers accounts of social phenomena that are filtered through the subjective and personal experience of the ethnographer. And it is this approach that is felt to be the most appropriate for the goals of this study.

The discussion begins with a brief review of some of the recent literature on methodological aspects of researching sensitive topics, both within and outside the health-related field. This will be followed by information about the study, drawing out both the variegated features of an insider researcher presence (Labaree, 2002) and the ongoing nature of the research to highlight the 'preliminary' character of the reflections recounted herein. The next three parts of the article will consider the constitutive effects of emotion and empathy work on the reflective practice (Finlay, 2002) of building rapport, gaining trust and on the blurring of boundaries compounded by the presence of the researcher in multiple guises – as volunteer, researcher and participant. The need for emotional capacity building on the part of the researcher, as a particular form of emotional labour that provides underpinning theoretical insight (Hochschild, 1983), emerges as a key theme. The issue of departure, both from the perspective of the researcher completing phases of the research and 'leaving' research subjects and, in this context, the withdrawal of research subjects through deteriorating health and, in some cases, their death as the final leave taking (see Kellehear, 1990) raises particular emotional concerns. The ethical implications of researching sensitive subject areas are considered (Rosenblatt, 1995) in relation to both researcher well-being and to leaving the field with 'unfinished business' remaining (Burr, 1996: 172), which has the dual perspective of impacts for both researcher and research subjects.

Qualitative research with vulnerable subjects

The notion of vulnerable subjects within qualitative ethnographic research traditions has been widely documented (Liamputtong, 2007). Kontos and Naglie's (2006) application of the performance paradigm to the care of Alzheimer's sufferers, Campbell's (2002) critique of the emotional impact of researching rape, Enosh and Buchbinder's (2005) focus on narrative styles within domestic violence research and Jacobsen's (2005) exploration of the potential for a very broad inclusion in the category 'vulnerable' within social research, are recent examples. Less saliently vulnerable subjects are those identified by the researcher to be at low risk of negative effects from research participation but, because of the unpredictable nature of much qualitative research, these too can be adversely affected by the conduct of research (Watts, 2006).

Much of our understanding in this area is drawn from the feminist canon, which has

highlighted the complex theoretical and practical dilemmas of qualitative research that seeks to retain participants' voices within the epistemological process. Researcher sensitivity to issues on a number of different levels is a feature of feminist enquiry that makes public the private and intimate experiences of women in their roles as workers, partners and carers (Edwards and Ribbens, 1998), and engagement with this literature has been an underpinning influence on the author's standpoint in respect of this study. Furthermore, acknowledgement of the researcher as an active agent in the production of knowledge has been central to feminist writing, rejecting as it does the supremacist claims of positivist knowledge that for many years was dominant in sociological enquiry. Sword (1999) develops this theme to argue that much qualitative research is personal work, with the researcher having a vested interest in the research topic that will inevitably influence the data produced. The sense that 'detached concern' (Fox, 2006: 944) is either realistic or necessary for the effective conduct of sensitive research has been widely debated (Fox, 2006; Rager, 2005; Dickson-Swift et al, 2007) and it is the contention of this piece that emotion work may constitute what Katz and Mishler (2003: 35) describe as 'one of the many ways to do qualitative research' in the field of medicine and health care.

Although there is potential for significant emotional distress for all parties engaged in the various domains of sensitive research, this does not necessarily lead to damage and, as Corbin and Morse (2003) argue, it is the skill and ethical awareness of the researcher that may be pivotal in yielding benefits to both the researcher and participants from the process. The's (2002) experience of using ethnographic research methods to monitor the illness trajectory of lung cancer patients in the Netherlands reveals that treading the narrow path between researcher detachment on the one hand and personal involvement on the other can allow for flexible research practice that maintains both participant and researcher congruence in the face of compelling emotional demands.

The aims, setting, method and subjects of the study

The aim of the study is to explore how both cancer sufferers and cancer survivors (included in this category are those who have been bereaved through cancer) make use of a community cancer drop-in facility operated by a local hospice trust located in the South of England. It focuses on the reasons people give for coming to the centre and how they make sense of the support they receive particularly in relation to ongoing treatment. This is my first experience of conducting research on sensitive topics with my earlier work focused on the very different world of the built environment sector (Watts, 2006; 2007a). It is intended that research findings will contribute to a review of the drop-in service as it develops and attracts wider take-up of its provision.

I have been drawn to this topic of enquiry because of my professional role as a death studies educator but also because of my life experience that includes early and unexpected multiple losses. I am not in any sense an impartial observer and bring to the research my own issues connected to my inherited history. Specifically, when working with participants I look to my inner self and my fears, searching for comparability of experience. Questions of shared feelings nag at me because I am troubled about my own relationship to what I want to learn. This concern is difficult to articulate but is rooted in what can best be termed as an unspoken hierarchy of 'authentic' fear with my anxiety about being a potential cancer patient in stark contrast to the reality of the daily lived fear of participants. This negative emotion, that I feel unable to voice within the research setting, has prompted much reflection on the issues of loss and suffering, particularly the nature and experience of suffering that Cassell (2004) argues occurs when a person is confronted by their impending death. This leaves me to speculate about how I would react to cancer in my family. How well would I live with a life-limiting illness? These questions and others preoccupy me, and my research journal indicates that any sense of belonging that I have with the participant group is based on my own fears about pain, loss and death. This is shared and I am vulnerable too. A further question is relevant; does my fear obstruct or influence the data gathering and analysis? The latter is only at a very

early stage but the data collection is ongoing and there have been moments when I have not wanted to hear any more from those at the drop-in. This clearly suggests that I am exploring these issues and interpreting the data through the prism of my own biography with my emotions and fears constantly shaping the data.

The drop-in centre offers twice-weekly afternoon sessions with variable numbers attending although a group of roughly ten 'regulars' on both days seem to constitute a core group. There is a very wide age range represented amongst users of the facility with the youngest currently being thirty-two and the oldest, eight-eight. Proportionately there are more women than men who use the service and nearly all the volunteers are women. The centre has a manager and fundraiser, with informational and practical support provided by a team of dedicated volunteers, a now well-documented and familiar feature of the cancer landscape (Lawton, 2000; Armstrong-Coster, 2004). The volunteer efforts of a range of health and therapy practitioners contribute to a portfolio of different treatments available to users of the drop-in, with reflexology, Indian head massage and aromatherapy being the most popular.

Initial contact with the centre was by serendipity, through engagement with the work of the local voluntary sector in an unrelated area. The opportunity to visit the centre and become an informal volunteer helping with social aspects of the drop-in sessions was a pre-cursor to the researcher role and this has now been ongoing for six months with a further twelve months projected. It is this volunteer function that has shaped the participant observer role and has been the key influence in determining method and framing an insider approach to data collection (Watts, 2006). The methods being used are a mix of participant observation and informal (Hammersley and Atkinson, 1995: 139) and guided (Mishler, 1986) conversations with users of the twice-weekly drop-in sessions. Because these interactions are not interviews in the accepted sense, audio-recording of these is neither possible nor appropriate, particularly given the public space in which they occur and the associated ethical concern of confidentiality. Also, some of the data is drawn not from conversations between participants and myself, but from listening to talk between group members and from watching their body language. I can recall the clear discomfort shown by one man as one of the younger female group members, with advanced breast cancer, described the detail of her continuing bouts of sickness during ongoing chemotherapy treatment. He was physically squirming in agitation in his chair and his unease was almost palpable. I later learned that his chemotherapy treatment was soon to begin. These observational elements of the research are illuminating and this confirms Jones and Somekh's (2005) claim that observation is an important, but often under-rated, method of data collection. The making of detailed notes in the form of a research journal (Rager, 2005) constitutes the documentary data and a narrative approach to data analysis, following a broadly grounded theory paradigm (Glaser and Strauss, 1967), will inform the analysis.

Following approval from the management committee for this study I set about planning the ethical framework for the conduct of the research, with particular initial attention directed towards the issues of confidentiality and anonymity for participants. Concerns, however, about ethical rigour in the design and conduct of this research have, as the research has got underway, centred on the issue of informed consent and have been experienced as far from straight forward. Asking individual participants to sign consent forms, as one way of acknowledging the researcher aspect of the author's presence, has not felt very meaningful. Instead, a brief outline statement of research interests has been made available at the sessions and, as part of interaction with new users of the service, taking care to refer to research as well as volunteer features of my role, has contributed to ethical conduct. That said, I am still not fully confident about the ethical aspects of the research, not least because the volunteer self appears often to overshadow the research self, with the latter appearing to be of minimal relevance to participants who, unlike Peel et al's (2006) participant sample, demonstrate very scant interest in the enquiry. I am, therefore, currently exploring ways of raising the researcher profile to strengthen the ethical dimension of the study, with the intention of reporting on these, along with the research findings, once the study is complete.

The language that outlines the context of the research and methods used is deliberately framed in the present tense. This is because the methodological critique presented is a reflection on work in progress rather than a comprehensive synthesis of research completed. The discussion that now follows is an attempt to engage the reader primarily with continuing methodological concerns rather than with emergent themes from the data: that would be premature and may well form the subject of future writing.

Emotion

Pitts and Miller-Day (2007) suggest that the development of rapport with their participants is a priority for empirical researchers in the field and Gaglio et al (2006) argue that this is an essential component of successful qualitative research in the health care sector. A further consideration, however, is that rapport is mutually constructed between those who can empathise with each other and is developed through a willingness of each to look into the world of the other. The subject of cancer can be emotive, evoking as it does a sense of one's mortality (Morris, 2001; The, 2002). An ethnographer getting to know participants and building rapport in the context of what, for some, is their dying is not an emotion-free endeavour. What, for this research, has been the most emotionally challenging aspect has been participants' telling and re-telling of their cancer stories, often in very raw terms as 'wounded story tellers' (Frank, 1995), with dependence on, and an almost desperate loyalty to the professional role of medic, rather than to any individual doctor or physician, clearly evident (Kellehear, 1990). This tenacious and powerful faith in medical treatment seems to be unshakable even in the face of advancing disease.

In the case of participants either with active disease or in remission (only two thus far have described themselves as recovered from cancer), the story begins with a narrative describing their symptoms that led to diagnosis and subsequent experiences of treatment regimes, hospital visits, continuing medication and the uncertain and non-linear path to remission. Armstrong-Coster (2004) found a similar pattern in her ethnography, with participants displaying a particularly heightened recall about the first presentation of symptoms and all the emotions these raised. The emotion that has dominated participants' narratives in this study is fear, and their dread of what is to come has been almost tangible and, for some, brings an attendant need for reassurance that, as one participant put it, 'it's all going to be all right'. The seeking of reassurance is emotionally distressing because whatever response I give, it will not be the one they covet which is the promise of cure and the certainty of longer life. Whilst they continue to hope I am sometimes laid low in spirit and my enthusiasm for this research work is temporarily diminished. This leaves me questioning whether, despite now regular attendance at these sessions, I can even begin to enter their world of cancer that feels like a very distant land.

Although a majority of users of the cancer drop-in are supported by friends, family and neighbours, the most striking feature of accounts to date has been the isolating effect of cancer. The sense I have of their 'aleness' in dealing with the physical and social reality of the disease has been very powerful and is illustrated by the following comment from one participant 'You can't keep talking about it to people, can you? You just have to get on with it the best way you can'. This awareness of the ways in which cancer separates has been difficult to deal with and respond to. At times I have found myself 'walking on eggshells', as both a listening and a feeling agent, in the narrative encounter and specifically in the co-constructing of positive possibilities even in the face of some participants' rapidly deteriorating physical and emotional bodies. Central to this has been the realisation that it could so easily be me, or my loved ones telling the cancer story, and it is this inescapable sense of cancer as a lottery, in which my emotional reactions are rooted. This has given rise to feelings of guilt and disappointment at what I have come to regard as my own emotional self-centredness. On one occasion I can recall the compulsion to retreat from the research engagement altogether, feeling overwhelmed by feelings of threat to the ontological security of myself and 'mine'.

Elsewhere I have written about the personal within death and dying education (Watts 2007b) but I now also have an appreciation of the emotional impacts on the person of the researcher working with those who are dying or living with life threatening illness. In this emotionally charged terrain I find it difficult to see how researcher detachment (Fox 2006) can be maintained, particularly within ethnographic research conducted over a long time span and through which attachments are formed and friendships made. Thus far the impact of emotion on me as the researcher has caused me to consider that emotional engagement, far from undermining or devaluing research practice, may authenticate it in ways similar to the positive effects of emotion work in some aspects of palliative care nursing practice (Li and Arber, 2006). Emotions act as a 'doorway' to the inner terrain of people. This 'doorway' can be open or closed and in respect of this research it has been mostly open, enabling me to feel with participants some of their anxiety. On one occasion, for example, I found myself worrying with a participant about a forthcoming scan they were due to have and this seemed to result in a co-constructed emotional space where we both could begin to talk about some of the most difficult 'what ifs'. Within highly sensitive research of this kind, without a shared emotional space that offers the possibility of trust, a shared narrative space may be difficult to establish.

Authentication derives from an understanding of the data that is informed by the emotional exchanges between the researcher and the researched, which includes elements of self-disclosure on the part of the researcher in the creation of a shared narrative space (Liamputtong, 2007: 72). Emotional difficulties experienced by participants in telling their stories with, for example, tearful episodes and problems with fragmented discussion of events, have alerted me to significant aspects of accounts that I may have overlooked without this emotional engagement.

Empathy

Empathy is closely connected to emotion work in developing and sustaining rapport within qualitative research relationships. The instrumental application of a rapport model to interview methods, in particular, has provoked debate about the ethical issues of sincerity, friendship, reciprocity and the commodification of emotion or human feeling within sociological research (Duncombe and Jessop, 2002). Such concerns extend to methods beyond interviewing and have relevance for ethnographic observational research where trust is built between researcher and participants over time and becomes the basis on which disclosures are shared in an atmosphere of safety. This safety, however, may hold dangers for participants, particularly those who are vulnerable and not fully cognizant of the research in which they are a player. Safety can also lure the researcher into investigator behaviours that are intrusive, breaching participants' right not to be made aware of their innermost thoughts and feelings (Duncombe and Jessop, 2002). During the past six months I have observed the stamina of participants' optimism that is at the root of recovery narratives, which serve as a refusal to die. With one participant, an eighty-year-old woman, this intransigent optimism has been sustained despite her obvious increasing frailty. Her ability to attend the drop-in underpinned her engagement with what I see as 'relative hope' epitomised by the phrase 'I come because I can'. I perceive relative hope as a group metaphor for continuing survival and one that is shared by all participants. The temptation on my part to interrogate the rationality of the phenomenon of relative hope is prompted by both safety and familiarity within the research relationship but is tempered by an understanding that relative hope is all that remains of the future for some attendees at the drop-in. Whilst not yet having a full grasp of the meanings that may attach to this concept, it nevertheless is proving useful for building understanding of what Coreil et al (2004: 905) term 'member-group fit'.

Empathy behaviour has both verbal and non-verbal components and I have found each to be significant in different ways; for example, the power of touch to ease emotional distress is a technique I have used to settle participants in their story telling, which they often find stressful and painful. For me this creates a further connection to participants and their

embodied discourses of illness. The careful use of language that reflects the needs and preferences of this research population (Thulesius et al, 2003) together with maintaining eye contact with them are the combined techniques I use to 'do' empathy, which I understand to be the giving of one's whole attention as committed presence, being alongside, with the ability to feel with the other (Liehr, 1989). Listening with concern and compassion but without judgement and absorbing the feelings of others are further features of my empathic approach that are centred on the participant rather than on me as researcher (Campbell, 2002:138). As the study has progressed my research journal reveals that I seem to be doing much less of the talking and less direct questioning of participants. Initially I think I would have found this troubling, feeling that I was not sufficiently focused on the goal of data collection; now, however, I am conscious that participants often seek me out to tell me how they are getting on with their lives, which often seem to involve crisis and profound anxiety. When uncertainty and exhaustion combine under the weight of fear about the future, the reliable presence of someone genuine, warm and empathic can provide a useful counterbalance (Egan, 1990). This leads me to reflect on the ways in which empathy and emotion can be seen as instrumental tools of both data collection and analysis in researching sensitive topics. Also, I now recognise that feelings (both mine and participants') can be reconceptualised as a form of data to be analysed as part of the research process. This includes the possible impacts on participants of disclosure of my own personal life experiences (Liamputtong, 2007), producing an interwoven assemblage of individual subjectivities.

One impact of empathy and the associated trust placed in me by participants has been a heightened awareness of my epistemic responsibility that points to the need for boundaries (Dickson-Swift et al, 2006) that Gilbert (2001a: 12) argues involves 'maintaining a clear internal sense of difference from the other'. My experience has been that this also involves creating a sense of emotional balance, taking care to be close, but not too close, to participants, ensuring that I can retain the filtering and distilling functions that are core to the agency of the qualitative researcher when conveying the stories of participants. Added to this, it is useful to be aware that boundaries in ongoing research relationships are not static but may shift over time as a function of the changing personal circumstances both of the researcher and participants. The propensity for friendship arising from regular contact between researcher and subjects in qualitative social research is a boundary issue and one that has been discussed in the literature (Duncombe and Jessop, 2002) in relation to both temporary (Gilbert, 2001a) and simulated friendship and the power balance present in research with sensitive subjects that usually operates in favour of the researcher. Empathy is not synonymous with friendship and avoiding false or insincere friendship contributes to ethical research conduct.

My final reflections on this topic consider the view that it is shared experience that promotes empathy and rapport (Duncombe and Jessop, 2002). Those whom I encounter at the drop-in appear to have their cancer experience as the current key signifier of their identity. That is why they are there, to act out their cancer role in a dedicated legitimate space. If shared experience is the determinant of empathy then someone who has not been affected by cancer will struggle to empathise with those who have. I have been puzzled by this proposition and this has prompted me recently to settle on an alternative, more satisfactory, understanding of empathy encapsulated in the phrase 'empathy is what someone *is*, not what someone *does*'. Its intrinsic attribute is relational. It is an intuitive connectedness to others that, without words, communicates interest in and care about others. This meaning of empathy rather contradicts my 'doing' of empathy described above but is one that, as the study progresses, I am increasingly more comfortable with and may well explain why I find myself doing less of the talking and questioning as discussed above. Within this paradigm empathy is not a learned behaviour but is the intuitive relational self, rooted in an affirmative disposition of being that is difficult to deconstruct, yet which most of us are able to recognise when we meet it.

Exit

Discussion in the literature about ethnographers completing their fieldwork and having to halt interaction with their research subjects has centred on the possible impacts for participants from what could be seen as a form of harm or exploitation, with a focus on implications for responsible ethical practice (Taylor, 1991). Focusing on impacts on researchers, Stebbins (1991) poses the question of whether researchers ever actually 'leave the field' in relation to the often lasting emotional consequences of working with sensitive topics. For this discussion, however, it is the impacts on the researcher of the curbing of relationships that provides the focus, particularly possible implications for the depth of engagement with participants as the study develops. The need to keep in view that the well-being of the researcher is just as much an ethical concern as that of participants is apposite, as is the need for reflexive approaches that contribute to what Doucet and Mauthner (2002: 141) characterise as 'situational ethics'.

Although this study has not yet even reached the half way stage the issue of exit has already presented itself in a number of ways. Soon after my volunteer work had begun I was away on holiday for three weeks and, on returning, was told that two of 'the regulars' had died and a third had weakened and was finding it difficult to attend the drop-in sessions. This unexpected news was saddening and, despite the psychological preparation I had made in anticipation of these losses over the period of the study, the sense both of the anguish for the bereaved families, and of seeing cancer as an emotional roller coaster, was very profound giving rise to 'compassion stress' (Rager, 2005: 423). As a lone researcher, there is limited opportunity to talk through my feelings at a peer debriefing (Sampson and Thomas, 2003; Rager, 2005) and this has made me aware of the importance, within sensitive qualitative research of this kind, of self-care strategies and establishing a support network where feelings of distress can be unloaded. The possible usefulness of accessing professional support by researchers experiencing emotional distress is addressed by Corden et al (2005) whilst Hubbard et al (2001) identify the benefits of research teams in this regard, highlighting the ways in which these can provide a safe shared space for taking seriously the negative emotional effects of research. In the case of this study, the manager of the drop-in sees emotional support for volunteers, as well as for users of the service, as part of her responsibility but this, too, has proved difficult because of the guilt I have felt for drawing on both her time and energy in this way.

The disruption to social patterns of interaction within the small society of the drop-in caused by the death of fellow sufferers that have been members of the group sessions operates on a number of levels. On one level I have observed denial whereby those that are now missing are not referred to and, on another, the reluctant but reconciled acknowledgement of a similar potential fate for them voiced by one participant as 'they (the medics) can only do what they can do'. In the face of these losses efforts to remain cheerful and positive on the part of all of those involved at the drop-in sessions is a demanding form of emotional labour (Hochschild, 1983) but is congruent with the dominant survival interest of group individuals and their families.

Concluding remarks

The research on which this article draws continues to present methodological challenges in a number of ways, not least of which is the need to reconcile the intention of researcher integrity (Watts, 2008 – forthcoming), that stems from an ethics of care approach (Gilligan, 1993), with ethical contradictions and imperfect solutions to practical problems despite careful efforts to make the right choices. Qualitative research can be a messy business, particularly ethnographic work that is very much a front-line activity and one subject to many variables, most of which are likely to be beyond the control of the researcher. Emotions, both of the researcher and participants, as one variable of this type of research, may also be difficult to manage, and awareness of the potential for feelings to 'disrupt' even the most

carefully made plans, should form part of the ethnographic researcher's ethical and practical toolkit.

Using the time and energy of people who are dying or bereaved for research purposes raises ethical concerns that are centred on the potential 'unnecessary exploitation' of research subjects. However, other research has shown that the research medium of crafted conversation can be significant for potentially vulnerable participant populations in a number of ways, including bringing about positive cathartic effects (Watts, 2006: 400). The primary utilitarian value of participants to the research enterprise is mediated in this case by the volunteer effort being devoted to the work of the centre in its support of patients. In this sense, I can claim mutuality as a form of ethical research practice (Watts, 2006: 400) replicating the approach of other researchers working in this area (for example, see Lawton, 2000).

Participant observation, as ethnographic research method, connects well the dual roles of volunteer and researcher and allows for a flexible, responsive approach to a range of situations within the research setting (Sharkey and Larsen 2005: 186). However, because I do not have and never have had cancer or been bereaved to cancer, I am not a full 'insider' at the drop-in sessions, with this status reserved for those who suffer. The extent, therefore, to which, as an ethnographer, I can be integrated into the 'host' community (Ezeh, 2003) of suffering, is a source of on-going reflection. Frank's (2001) question to the wider health research community of whether we can research the lived reality of suffering, which resists articulation, is also one for this research.

This article contributes to the call by Kinard (1996: 69) for 'more published accounts of investigators' experiences in dealing with the effects on researchers of conducting studies on sensitive and emotionally laden topics'. It particularly draws attention to the difficulty of maintaining emotional balance in sensitive qualitative research that I understand to mean not being too close or too distant, with researcher reflexivity an important methodological tool within this 'balancing' process. The issue of providing 'emotional protection' for both new and experienced researchers working on sensitive topics is an area that would benefit from further exploration.

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