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# **Ethical and Practical Challenges of Participant Observation in Sensitive Health Research**

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## **Abstract**

Participant observation is now increasingly used within qualitative health research and has been found to offer opportunities for the collection and synthesis of rich data about health and illness experience. This method, often used over an extended period, enables the researcher to build an in-depth understanding of the research context and can be the basis for the development of relationships between the researcher and the 'researched'. Researcher familiarity in the field, however, can give rise to ethical and practical tensions. This article reports on the ethical and practical challenges of participant observation at a cancer drop-in centre focusing on issues connected to the dual role of the researcher as both volunteer and researcher. It highlights the methodological practice of reflexivity as one way of the researcher maintaining an ongoing ethically engaged presence in the field.

**Keywords:** cancer; ethics; ethnography; participant observation; practical challenges; researcher and volunteer roles

## **Introduction**

Methodological debates about social research in terms of rigour, bias, quantitative versus qualitative approaches, epistemological rather than practical drivers and the ethics of research practice continue to exercise commentators both within and outside the academic community. Hammersley (1993) points to criticisms of social research that centre on the obviousness of findings that continues to call into question the value of undertaking research within the social sciences (Gage, 1993). Within the domains of health and health care there has in recent years been much discussion about what are and are not appropriate methods, especially concerning the superiority of quantitative or qualitative approaches and what can legitimately be claimed as evidence to support health care practice (Kerridge et al, 2008). Where, for example a treatment or therapy is without substantial evidence it is not difficult, within the context of evidence-based professional health practice, for this to be seen as lacking substantial value. Clinical trials, systematic reviews and survey research have traditionally been the research instruments underpinning much health research with terms such as randomisation, blinding, experimentation, sampling protocols and probability dominating the language of the medical and health research literature.

In recent years philosophical and practical debates about the measurability of outcomes related to a range of methods in health research have led to increased interest in how studies are both designed and conducted and whose interests they serve (Bastian, 1994; Chalmers, 1995). A plurality of both quantitative and qualitative methods in health research has been applied in different ways as required by the issue under investigation. Debates about appropriateness of method clearly have practical

and epistemological dimensions that are also inextricably linked to ethical matters, particularly connected to ensuring that research participants are protected from harm and distress and are fully informed and freely consenting participants. The concept of vulnerability is useful in reminding us that, in the context of health research that seeks to involve people who may be ill and anxious, care needs to be taken to ensure that all research participants are able to make autonomous informed decisions about participation in health studies. With an increase in the use of qualitative data collection methods within health research, the person of the researcher has attracted attention in relation to issues such as rapport and trust (Watts, 2008). These issues feature prominently within participant observation that historically is rooted within ethnographic research traditions drawn mainly from the realm of anthropological enquiry.

Participant observation, as one social research method, is the subject of this critical commentary that adopts a case study approach to explore some of the ethical and practical challenges of this method within a sensitive research context. The article proceeds in four parts; the first traces the development and application of participant observation methods focusing on its ethnographic attributes that were of particular use in the research context that frames the article. The second part considers a range of ethical precepts that shape health care research, particularly in respect of potentially sensitive areas. The third part outlines the research project that forms the basis for this commentary highlighting issues of researcher immersion in the field and the challenges presented by the volunteer role of the researcher in relation to the conduct of research. Discussion of the complex ethical and practical dilemmas presented by the participant observation method comprises the fourth part. The conclusion draws together the main themes and argues that participant observation allows for a flexible responsive approach to a range of situations that may arise in sensitive health research pointing to the ethical significance of reflexivity as a key methodological tool.

### **Participant observation**

Sharkey and Larsen (2005: 186) argue for the legitimacy of ethnography within health care research with 'its role being to illuminate, understand and ultimately interpret and present a range of perspectives – patients', carers', practitioners' and commissioners''. They highlight its powerful potential for uncovering the dynamics of relationships and behaviours in social settings and for making explicit the unspoken rules and values of social interaction. Ethnography provides a window to the experiences of both individuals and groups and is not confined to a single disciplinary tradition; indeed, Atkinson et al (2001) point to flexibility as a core strength of ethnographic enquiry. The essence of ethnography is the immersion of the researcher in the field and Dickson-Swift et al (2006) draw out the issue of immersion as an increasingly important feature of much qualitative health research. For immersion to be achieved the prolonged participation of the researcher in the life of a group is necessary with a role of participant observer achieved through developing empathy with the culture, values and behaviour of the group (Punch, 1993). Because of the opportunity for immersion in the research context, ethnography is often represented as the method best suited to reduce the gap between experience and the objectification of subjects. Wilkinson (2005) argues that this is especially so in the case of researching personal suffering that resists articulation because it goes beyond that which we can say or understand. Whilst not all ethnography uses participant observation (interviews

and focus groups are alternative methods), this method, nevertheless, remains central to the rooting of ethnography in the first hand exploration of research settings (Sharkey and Larsen, 2005).

Participant observation developed from motivation on the part of sociologists to describe and understand the patterns of life in different parts of society using non-obtrusive methods (Tesch, 1990). A feature of non-obtrusiveness is familiarity that Punch (1993: 190) argues is developed and nurtured through regular presence by the researcher amongst the group which, in his case, led to him 'being as familiar as a piece of furniture'. This suggests that 'not being noticed' in the role of participant researcher may dissolve an onlooker status with significant benefits for data collection. From an ethical perspective, however, the gradual invisibility of the researcher in the field may be an issue of concern. There is also the related question mark surrounding the extent to which individuals consciously modify their behaviour in the presence of the observer. This issue is a function of the host community/researcher dynamic that Ezeh (2003) argues is shaped by the degree to which integration between the two is achieved. This aside, my view supports that of Becker (1970) who believes that people do not maintain a 'front' or act for long and that what they are engaged in preoccupies them and is more important to them than the fact that an 'outsider' is present. In other words, with the 'newness' of the researcher's presence still to the fore, participants may deliberately alter their behaviour but as time goes on this presence becomes lost from view.

The issue of integration of the participant observer into the host community functions along a continuum of 'otherness' that is a feature of the way in which the relationship between the researcher and the researched is conceptualised and managed and role boundaries established (Ramazanoglu and Holland, 2002). Punch (1993), for example, contends that a complete observer role, that he argues is predicated on distance between the researcher and host community, is a fiction because he or she is always a player in the situation. Recent commentators (see Watts, 2008) argue for the elimination of distance as a way of developing acceptance and trust and Punch (1993) makes the point that single-person research often enables easier access, a less threatening profile, low intrusiveness in the setting and a high capacity for personalised relationships. There may, however, be practical and ethical dilemmas in balancing participant and observer role elements. Writing in the context of nursing research, Morse and Field (1995: 189), for example, highlight how conflict can arise in the prioritising of participant and observer tasks. The participant as 'doer' is expected to 'pitch in' within the research setting, making it difficult to focus on observer tasks such as writing in a field diary, seen by others as 'doing nothing'. This presented as an ongoing issue within the study as discussed below.

The techniques of participant observation have been widely discussed in the literature across a range of settings and topics. The explanation of these that I favour is also the simplest I have come across; it is the assertion by Punch (1993:194) that as a participant observer 'all you have to do is watch and listen'; Geertz (2004) characterises this as the researcher 'being there'. This watchful attention in the field, it is claimed, connects researcher and participants and helps to build rapport (Duncombe and Jessop, 2002; Watts, 2008). This activity, however, is not an effortless undertaking as the narrative that follows later in this article illustrates. It also is one that O'Toole and Were (2008) argue has multi-dimensional elements, with spatial,

material and cultural elements often overlooked by observers in their distilled perspectives on the social world. A further empirical challenge to ethnographers concerns interpretation and presentation of findings that extends beyond the claim for legitimacy derived from 'being there' such that if we had been there, would we have seen what the participant observer saw and arrived at the same conclusions? This raises the issue of validity that Hammersley (2004: 243) addresses by his comment that 'there is not a single valid description of a situation or culture. Descriptions do not capture reality; at best they simply represent those aspects of it that are relevant to the purposes motivating the enquiry'. No method can provide a guaranteed pathway to truth and there are no guarantees of validity whichever research instruments are used whether within or outside the positivist tradition. All research is subject to pragmatic and practical decision-making and, although research protocols and ethical guidelines are a valuable resource, their prescriptive application in the field may not always be viable or desirable.

Within health research there has been a growing trend towards a multi-method approach to research design with a resulting increase in the use of a range of qualitative methods that Iphofen (2005: 17) reminds us focus, not on biomedical matters, but on people and social issues. All research conducted with human participants has ethical implications; these are complex and extensive and space does not permit a detailed or exhaustive critique of these. What follows, therefore, is discussion of integrity that contributes to ethical conduct as well as consideration of principles that are concerned with proper research behaviour that is centred on making the right choices.

### **Ethics of research in sensitive contexts**

Historically, the exposure of unethical behaviour in which vulnerable participants have been exploited or harmed has tainted social research. Such incidents have highlighted the importance of establishing codes of conduct and the implementation of ethical reviews that Stanley and McLaren (2007: 35) state aim 'to protect the rights, health and well-being of research participants, utilising an approach that is sensitive to diversity, cultural values and the social and cultural context in which research is conducted'. The category 'vulnerable' has broad application and may, for example, include young children, adults with learning difficulties and people with life-threatening illness. Addington-Hall (2007), in discussing ethical issues in palliative care research, explains how patients receiving palliative care are vulnerable because of increasing levels of dependency and shortened life expectancy. She defines vulnerability in terms of research ethics as "the increased potential that one's interest cannot be protected" (Addington-Hall, 2007: 5). The increased widespread requirement for formal ethical regulation of research through the review processes of ethics committees is aimed at achieving acceptable ethical standards in research conduct. Regulation and emphasis on ethical governance has developed as a response to the growing awareness that research participants can be adversely affected in a myriad of ways by participating in research (McDonach et al., 2009; Munro, 2008). Hammersley (2009), however, questions whether the quality of research outputs will be negatively impacted by such regulation and Crow et al (2006) voice specific concerns about the assumed relationship between rigorous ethical research practice and the collection of good quality data.

As part of professional health care practice the ethical principles of respect for autonomy, beneficence, non-maleficence and justice shape the context for decision-making in relation to care practice and options for treatment (Beauchamp and Childress, 2009). These principles are now also routinely applied to health research as the basis for ethical research design and conduct, with particular emphasis on research participants willingly taking part having received and understood information about the research, including the nature of their involvement and any attendant risks together with the possibility that they can withdraw their participation at any stage. At the root of these precepts is the objective of eliminating harm to participants with the concept of harm meaning not just physical harm in terms of their safety, for example, but psychological distress, invasion of privacy and threats to their well-being (Bryman, 2004).

Within qualitative research, much of the debate about disclosure by participants of deeply personal information to researchers (with this seen as a source of potential harm) has centred on the use of structured/semi-structured interviews conducted in private space and usually audio-recorded. For example, some writers discuss how participants can be lured into saying more than they intended (Finch, 1984), especially where trust and rapport has been established between researcher and participant, with this of particular concern in relation to vulnerable research populations who may be viewed as the victims of unintentional exploitation (Liamputtong, 2007; Watts, 2008). Where full information is given to participants who are then judged able to give informed consent, the actual experience of being interviewed may give rise to unexpected negative emotions that even the most sensitive questioning on the part of the interviewer cannot fully guard against. Similar displays of negative emotion can form part of social interaction of a group that is under the research lens (The, 2002), though this response derives from the everyday interactions of the group rather than from the carefully orchestrated research encounter that is the semi-structured interview.

Where it is a group that is the subject of exploration, the researcher/participant dyad is replaced by the group dynamic, with the group including the person of the researcher. This is the context of most participant observation that seeks to explore and describe the 'every day' behaviour of a particular group that often, in the case of ethnography, stretches over a long period of time. Given the open and public nature of interactions and the duration of much participant observation research, the researcher is likely to come into contact with a wide spectrum of people, and ensuring that everyone in the setting has an opportunity for informed consent is not practicable because it would be extremely disruptive of the 'usual' workings of the setting (Bryman, 2004). Punch's (1993) commentary about his experience of participant observation research with police in Amsterdam points to the ways in which gaining informed consent from participants in public research spaces is likely to, at best, be incomplete and always contingent upon the specific attributes of the setting. Bryman (2004: 512) makes the further point that 'even when all research participants in a certain setting are aware that the ethnographer is a researcher, it is doubtful whether they are all similarly (let alone identically) informed about the nature of the research'.

Given the limitations for informed consent in some ethnographic research, ethical research conduct will often hinge upon the issue of confidentiality that is an underpinning precept of most qualitative research (auto ethnography is one exception)

and is a basic requirement within health research. Confidentiality aims to give research participants anonymity such that their identity is concealed (Christians, 2005) and is an issue at all stages of the research process. It is particularly important for vulnerable participants who are stigmatised or socially marginalised such as in the case, for example, of people with HIV/AIDS (Dorrell et al, 2009) with researchers required to strip out the identifying characteristics of participants in reporting. In some cases it may be necessary to decide whether the reporting of some kinds of sensitive information can be ethically upheld as, in certain circumstances, this could enable the potential identification of subjects. Clearly, this could lead to partial reporting of findings but researcher responsibility to protect participants' identities is a pre-eminent ethical principal that should take precedence.

### **The study and its methods**

The empirical research on which this article draws was based in a community hospice trust that is housed within a local community centre in an urban area in southern England. The trust has been constituted as a non-clinical service aimed at providing informational, social and therapeutic support to cancer sufferers. It has no medical facility, no in-patient unit and no employed clinical staff so it feels very different from a traditional hospice. The emphasis is on meeting social rather than clinical need in an informal environment. The aim of the study was 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 the trust. It focused on the reasons people gave for coming to the centre and how they make sense of the support they receive, particularly in relation to ongoing treatment. The research was autonomous and non contract-based (Hammersley, 2000) and the main findings from the research have been fully reported in other writing (see Watts, 2009a and 2009b).

The trust operates twice-weekly afternoon cancer 'drop-in' sessions that comprise a non-professionally led service. Variable numbers attend with as many as forty to fifty accessing different elements of the sessions during the afternoon. Some attend specifically to have a complementary therapy treatment and do not socialise with others present, some just 'pop in' to pick up a leaflet or get particular information. Others stay for the whole afternoon, talking to the volunteers and those using the service, drinking tea, playing cards and board games and generally chatting, sharing news and views. There is a very wide age range represented amongst users of the facility and over the course of the research the youngest was thirty-two and the oldest, eighty-eight. Proportionately, more women than men use the service and nearly all the volunteers are women. The trust 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 narrative (Lawton, 2000; Armstrong-Coster, 2004). The voluntary efforts of a range of health and therapy practitioners contribute to a portfolio of different treatments available to users of the drop-in; reflexology, Indian head massage and aromatherapy being the most popular. Other professionals are invited to run one-off information and advice sessions on particular aspects of cancer care.

Initial contact with the centre was serendipitous through engagement with 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, were a pre-cursor to the researcher role. For the duration of the study my 'volunteer time' was taken up with making tea, offering round cake and biscuits, setting up and joining in board games, playing cards, running quizzes, tidying up and generally chatting to those attending the sessions that run for three to four hours in the afternoon. These can be seen as unexceptional 'everyday' tasks but, despite their ordinariness, they were conducted in another culture – the culture of cancer with me, as a non-cancer participant, not a full member of the group and it is this volunteer function that has shaped the participant observer role. The research was conducted over a fifteen-month period, enabling the development of close relationships with many of the participants. This long and close familiarity with the setting and participants framed an ethnographic research approach and other writing (see Watts, 2008) has discussed its particular features in some detail.

The methods used were a mix of participant observation and informal conversations with users of the twice-weekly drop-in sessions. Because these interactions were not interviews in the accepted sense, audio recording of these was neither possible or appropriate, particularly given the public space in which they occurred and the associated ethical concern of confidentiality. Also, much of the data have been drawn, not from conversations between participants and myself, but from listening to talk between group members and from close observation of the social interaction within the group. These observational elements of the research have been highly illuminating, confirming Jones and Somekh's (2005) claim that observation is an important, but often under-rated, method of data collection. The making of detailed handwritten notes in the form of a research journal (Rager, 2005) constitutes the documentary data. Other writing (see Watts, 2008) discusses the practical challenges of recording participants' accounts in my journal as I tried to capture their words and phrasing in pursuit of authenticity. On occasions this was a hurried and slightly fraught activity as discussed below. A broadly narrative approach to data analysis, following a grounded theory paradigm (Glaser and Strauss, 1967), has informed the thematic analysis which was ongoing throughout the data collection.

Following approval for the study from the trust's operational manager 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 about ethical rigour in the design and conduct of the research initially centred on the issue of informed consent and were experienced as far from straight forward. Asking individual participants to sign consent forms, as one way of acknowledging the researcher aspect of my volunteer presence, was thought not to be manageable on a practical level, especially for participants whose attendance at the sessions was fleeting, as they picked up information they wanted, maybe drinking a quick cup of tea for a few minutes. Instead, a brief outline statement of research interests was 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, contributed to ethical conduct. The statement set out the aims of the research and explicitly referred to confidentiality in reporting findings, reassuring participants of full anonymity. Despite this practical ethical intent, it is important to state that it was not possible at *every* encounter with new attendees at the sessions to explain the academic as well as volunteer reason for my presence and there is no doubt that this has resulted in an ethical shortcoming of the study.

Using the time and energy for research purposes of people who are dying and also of those who are bereaved, raises ethical concerns that are centred on the potential unnecessary exploitation of vulnerable research subjects (de Raeve, 1994; Barnett, 2001). 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 to include 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 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 replicating the approach of other researchers working in this area (for example, see Lawton, 2000).

Users of the drop-in sessions were drawn from a broad cross-section of the cancer population. The majority were those with active disease who were receiving treatment, mainly chemotherapy and radiotherapy. A second group was comprised of 'ex-cancer' sufferers whose treatment had ended and who were in remission (only once in fifteen months did I hear the word 'cured' used by any member of this group). Although in remission, most of this group appeared to be taking some form of medication as part of their recovery and rehabilitation regime and some remained traumatised by the biographical disruption initiated by life-threatening illness (Bury, 1982). A third category of attendees comprised those who had been bereaved to cancer and several of these had become volunteers at the drop-in, often devoting significant amounts of time to helping set up the sessions, bake cakes, give lifts to session users and contribute to fundraising activities. Andersson and Ohlen (2005) found that recognition by professionals of caring attributes of hospice volunteers, is an important way of affirming their efforts and this was very evident at the centre. Different aspects of the cancer identity and experience were thus represented in this small research population.

### **Ethical and practical challenges of 'being' in the field**

A detailed description of the research setting has been outlined above in order to situate discussion of some of the challenges encountered in the data gathering process. The first of these concerns the issue of informed consent that is an underpinning precept of ethically sound research, particularly in the field of health. As discussed above, access to the field was straightforward because of my volunteer work at the drop-in; I was known to the manager and had already established friendly relationships with other volunteers and many users of the service. My role as an academic with an interest in end-of-life care was understood and I was thus seen as a credible researcher. Designing the study involved discussion with the manager who was interested in how the drop-in could develop and improve its service and, as an already established 'caring' volunteer, my proposed researcher role was regarded as 'safe' and unlikely to disturb participants. The issue of informed consent, however, presented me with a particular challenge that has both ethical and practical dimensions. Sessions were usually very busy with people coming and going and each week there were new attendees. Obtaining informed consent from all those who attended was not practical, particularly as some of those who came to the drop-in stayed only briefly and had limited involvement in sessions. Ultimately the decision to prepare an information leaflet about the research and make this widely available

was a pragmatic approach informed by research that was to be wholly undertaken in open public space. Despite the public nature of the research setting and the commitment to rigorous protection of confidentiality in reporting findings, failure to secure informed consent from every participant, remains an ethical compromise. Although the attention to full confidentiality may in some measure ameliorate this, the account of informed consent as a practical as well as an ethical issue serves to highlight the difficulty of drawing the line between ethical and unethical research practice.

The issue of a dual identity for the researcher in the field, specifically the parallel roles of volunteer and researcher, constitutes the second major challenge. Initial connection to the research setting was my role as an occasional volunteer at the drop-in sessions in helping other regular volunteers with a variety of tasks from tea making to joining a team for a board game. Although I tried to give time to the sessions as often as possible, there was no pattern of commitment and I went as time allowed. Over a period of a couple of months my interest in the sessions increased and, as I began to get to know some of the regular attendees, the potential for this to become a site for research about models of day care for cancer patients gradually developed, and over a relatively short period my role as volunteer was augmented by that of researcher wanting to explore both individual and collective experiences of cancer.

As researcher I was listening and seeing 'differently', specifically with the purpose of learning about the culture of the drop-in and its place in the lives of participants, seeking to record a running description of the setting. However, lack of interest in the research by participants seemed to render the researcher role invisible. At some level, I began to question whether in reality I had somehow migrated into a covert researcher, as that aspect of my presence was barely acknowledged. One could ask why this was a problem but, given the impracticality of securing informed consent for all those who attended the sessions, I became increasingly concerned about the authenticity of my presence impaired by what some might see as 'disguised observation' (Erikson, 1967). Specifically there was concern about the reality that those coming to the drop-in did not have the option of 'opting out' of any observations I made. Because the element of disguise was not in any way intentional, the charge of deception would not be valid but comments in my research journal highlight my perception of this issue as an ongoing research dilemma and one that I could not ever fully reconcile. I attributed the lack of recognition of the researcher role to the fact that my behaviour at the sessions did not alter once the study had commenced so, from the perspective of participants, there was little significant material difference to the nature of my presence. My regular and familiar participation at the sessions meant that I was in very comfortable dialogue with participants and this appeared to remove me from having an onlooker status (Punch, 1993). An exception to this concerns tensions around the mechanics of recording data and field notes in my research journal and this constitutes the third major practical challenge of the data collection process.

Although involved in the familiar volunteer routines, I was at the same time watching and listening closely to conversations between individual participants as well as the general talk amongst the group. Recording particular comments and accounts of events presented as a significant challenge throughout the study. I was

aware of the importance of recording data as promptly as possible, not just for accuracy but also to ensure that data was not lost due to my failure to remember that Lofland (2004) argues occurs all too readily within qualitative observation research. However, doing this whilst trying to make tea or be an attentive 'Scrabble' player proved difficult. One reliable strategy was to briefly absent myself by a visit to the toilet where I would quickly record my notes. On occasions, when I wanted to take longer over this I would slip out to my car parked at the back of the centre and sit there getting as much down as I could, taking care not to be absent for too long. For reasons that I have never fully understood updating my journal in the presence of participants never seemed an option; this reluctance may have been connected to ambivalence about me being observed in non-volunteer mode. It may also be a function of not wanting participants to feel objectified (being written about) by this overt researcher activity. Also, there was always a lot to do so visibly taking 'time out' to sit and write felt inappropriate (Morse and Field, 1995). One very practical strategy that helped to make the data recording a little easier was to ensure that I always wore an item of clothing with a pocket where I could discretely keep my notebook and pencil. Rummaging around in a bag for these items each time I wanted to make some notes would have added significantly to the stress surrounding this basic but essential data collection task. This strategy contributes to what Cassell et al (2009: 517) term 'phronesis', as practical wisdom based on practical rationality that goes beyond a legalistic ethical conformity but, instead, is concerned to build contextual knowledge and practice.

## **Conclusion**

Discussion of the ethical and practical challenges of the data gathering process for the study offers further insight into the complexities of participant observation and, in particular, extends the conception of what Code (1995) terms as 'knowing responsibly' that she argues is shaped as much by the quality of research relationships as by accountability for the gathering, analysing and reporting of data. While recognising that this study has some unusual features, the evidence here goes some way to highlighting both the benefits and challenges of full research immersion (Dickson-Swift et al, 2006) in the field characterised by dual roles, in this case those of both researcher and volunteer. The benefits of substantial and regular contact with participants whilst undertaking 'ordinary' volunteer tasks enabled me to make observations in a way that, as a 'static' onlooker, might otherwise have been awkward and obtrusive; this volunteer presence also framed the research as essentially relationship work. The implications of this for analytic and interpretive processes in respect of potential conflicts of interest, that include high levels of subjectivity and ongoing ethical ambivalence, are critical but are methodologically accommodated within reflexivity that is concerned with researcher transparency in relation to theoretical, epistemological and personal assumptions that inform research.

Reflexivity through all stages of the research process underpins ethical conduct as part of a holistic model that includes the elements of rationality and emotion directed towards ongoing evaluation and reconsideration of the process. The reflexive empirical researcher is likely to draw on a range of theoretical models to guide decision-making that also draw attention to ethical dilemmas that may not be easily resolved. This case study highlights the ways in which the researcher, as ethical thinker, utilises principles to guide research practice and use of required

improvisational skills but, ultimately, it is the specific circumstances of research as “context-dependent” (Cassell et al, 2009: 517) that inform decisions and conduct. We are reminded that where the researcher is the ‘instrument’ and the ‘objects’ of research are human beings, ethical, social and practical issues are inextricably linked. The case study also leads to a wide concept of ethical research practice focusing on relationship work as instrumental to ethical research conduct throughout and beyond the research process.

## References

- Addington-Hall, J. M. (2007) ‘Introduction’ in J. M. Addington-Hall, E. Bruera, I. J. Higginson and S. Payne (eds.) *Research Methods in Palliative Care*, Oxford: Oxford University Press, pp. 1-9.
- Andersson, B. and Ohlen, J. (2005) ‘Being a hospice volunteer’, *Palliative Medicine*, 19(8), 602-609.
- Armstrong-Coster, A. (2004) *Living and Dying with Cancer*, Cambridge: Cambridge University Press.
- Atkinson, P., Coffey, A., Delamont, S., Lofland, J. and Lofland, L. (eds.) (2001) *Handbook of Ethnography*, Thousand Oaks, CA: Sage Publications.
- Barnett, M. (2001) ‘Interviewing terminally ill people: is it fair to take their time?’ *Palliative Medicine*, 15(2), 157-158.
- Bastian, H. (1994) *The Power of Sharing Knowledge: Consumer Participation in the Cochrane Collaboration*, Oxford: UK Cochrane Centre.
- Beauchamp, T. L. and Childress, J. F. (2009) *Principles of Biomedical ethics*, 6<sup>th</sup> edition, Oxford: Oxford University Press.
- Becker, H. S. (1970) *Sociological Work*, London: Allen Lane.
- Bryman, A. (2004) *Social Research Methods*, 2<sup>nd</sup> edition, Oxford: Oxford University Press.
- Bury, M. (1982). ‘Chronic illness as biographical disruption’, *Sociology of Health and Illness*, 4 (2), 167-182.
- Cassell, C., Bishop, V., Symon, G., Johnson, P. and Buehring, A. (2009) ‘Learning to be a qualitative management researcher’, *Management Learning*, 40(5): 513-533.
- Chalmers, I. (1995) ‘What do I want from health researchers when I am a patient?’, *British Medical Journal*, 310, 1315-1318.
- Christians, C. G. (2005) ‘Ethics and politics in qualitative research’ in N. K. Denzin and Y. S. Lincoln (eds.) 3<sup>rd</sup> edition, *The Sage Handbook of Qualitative Research*, Thousand Oaks, CA: Sage Publications, pp. 109-164.
- Code, L. (1995) ‘How do we know? Questions of method in feminist practice’ in S. Burt and L. Code (eds.) *Changing Methods: Feminist Transforming Practice*, Peterborough, Ontario: Broadview Press, pp. 13-44.
- Crow, G., Wiles, R., Heath, S. and Charles, V. (2006) ‘Research ethics and data quality: the implications of informed consent’, *International Journal of Social Research Methodology*, 9(2), 83-95.
- de Raeve, L. (1994) Ethical issues in palliative care research. *Palliative Medicine*, 8(4), 298-305.
- Dickson-Swift, V., James, E. L., Kippen, S. and Liamputtong, P. (2006) ‘Blurring boundaries in qualitative health research on sensitive topics’, *Qualitative Health Research*, 16(6), 853-871.

- Dorrell, J., Earle, S., Katz, J. and Reveley, S. (2009) 'Growing up with HIV: the experiences of young people living with HIV since birth in the UK' in S. Earle, C. Komaromy and C. Bartholomew (eds.) *Death and Dying: a Reader*, London: Sage, pp. 237-244.
- Duncombe, J. & Jessop, J. (2002) 'Doing rapport' and the ethics of 'faking friendship' in M. Mauthner, M. Birch, J. Jessop & T. Miller (eds.) *Ethics in Qualitative Research*, London: Sage Publications, pp. 107-122.
- Erikson, K. T. (1967) 'A comment on disguised observation in sociology', *Social Problems*, 14, 366-373.
- Ezeh, P-J. (2003) 'Participant observation', *Qualitative Research*, 3(2), 191-205.
- Finch, J. (1984) "'It's great to have someone to talk to". Ethics and politics of interviewing women' in C. Bell and H. Roberts (eds.) *Social Researching Philosophy: Politics, Problems, Practice*', London: Sage, pp. 107-122.
- Gage, N. L. (1993) 'The obvious of social and educational research results' in *Social Research: Philosophy, Politics and Practice*, London: Sage Publications, pp. 226-237.
- Geertz, C. (2004) 'Being there' in C. Seale (ed.) *Social Research Methods: A Reader*, London: Routledge, pp. 236-240.
- Glaser, B. and Strauss, S. (1967) *The Discovery of Grounded Theory*. Chicago: Aldine.
- Hammersley, M. (1993) 'Introduction' in M. Hammersley (ed.) *Social Research: Philosophy, Politics and Practice*, London: Sage Publications, pp. vi-xiii.
- Hammersley, M. (2000) 'Varieties of social research: a typology', *International Journal of Social Research Methodology*, 3(3), 221-229.
- Hammersley, M. (2004) 'Some reflections on ethnography and validity' in C. Seale (ed.) *Social Research Methods: A Reader*, London: Routledge, pp. 241-245.
- Hammersley, M. (2009) 'Against the ethicists: on the evils of ethical regulation', *International Journal of Social Research Methodology*, 12(3), 211-225.
- Iphofen, R. (2005) 'Ethical issues in qualitative health research' in I. Holloway (ed.) *Qualitative Research in Health Care*, Maidenhead: Open University Press, pp. 17-35.
- Jones, L. and Somekh, B. (2005) 'Observation' in B. Somekh and C. Lewin (eds.) *Research Methods in the Social Sciences*, London: Sage Publications, pp. 138-145.
- Kerridge, I., Lowe, M. and Henry, D. (2008) 'Ethics and evidence-based medicine' in J. Johnson and C. De Souza (eds.) 2<sup>nd</sup> edition, *Understanding Health and Social Care: an Introductory Reader*, London: Sage Publications with The Open University, pp. 243-247.
- Lawton, J. (2000) *The Dying Process*. London: Routledge.
- Liamputtong, P. (2007) *Researching the Vulnerable*, London: Sage.
- Lofland, J. (2004) 'Field notes' in C. Seale (ed.) *Social Research Methods: A Reader*, London: Routledge, pp. 232-235.
- McDonach, E., Barbour, R. S. and Williams, B. (2009) 'Reflections on applying for NHS ethical approval and governance in a climate of rapid change: prioritising process over principles', *International Journal of Social Research Methodology*, 12(3), 227-241.
- Morse, J. M. and Field, P-A. (1995) 2<sup>nd</sup> edition *Qualitative Research Methods for Healthcare Professionals*, London: Sage Publications.

- Munro, E. R. (2008) 'Research governance, ethics and access: a case study illustrating the new challenges facing social researchers', *International Journal of Social Research Methodology*, 11(5), 429-439.
- O'Toole, P. and Were, P. (2008) 'Observing places: using space and material culture in qualitative research', *Qualitative Research*, 8(5), 616-634.
- Punch, M. (1993) 'Observation and the police: the research experience' in M. Hammersley (ed.) *Social Research: Philosophy, Politics and Practice*, London: Sage Publications, pp. 181-199.
- Rager, K. B. (2005) 'Compassion stress and the qualitative researcher', *Qualitative Health Research*, 15(3), 423-430.
- Ramazanoglu, C. and Holland, J. (2002) *Feminist Methodology: Challenges and Choices*, London: Sage Publications.
- Sharkey, S. and Larsen, J. A. (2005) 'Ethnographic exploration: participation and meaning in everyday life' in I. Holloway (ed.) *Qualitative Research in Health Care*, Maidenhead: Open University Press, pp. 168-190.
- Stanley, R. and McLaren, S. (2007) 'Ethical issues in health and social care research' in A. Leathard and S. McLaren (eds.) *Ethics: Contemporary Challenges in Health and Social Care*, Bristol: The Policy Press, pp. 35-52.
- Tesch, R. (1990) *Qualitative Research: Analysis Types & Software Tools*, London: Routledge Falmer.
- The, A-M. (2002) *Palliative Care and Communication: Experiences in the Clinic*, Buckingham: Open University Press.
- Watts, J. (2006) 'The outsider within: dilemmas of qualitative feminist research within a culture of resistance'. *Qualitative Research*, 6(3), 385-402.
- Watts, J.H. (2008) 'Emotion, empathy and exit: reflections on doing ethnographic qualitative research on sensitive topics', *Medical Sociology Online*, 3 (2), 3-14.
- Watts, J. H. (2009a) 'Meanings of spirituality at the cancer drop-in', *International Journal of Qualitative Studies on Health and Well-being*, 4(2): 86-93.
- Watts, J. H. (2009b) "'I come because I can". Stories of hope from the cancer drop-in', *Illness, Crisis & Loss*, 17 (2): 151-168.
- Wilkinson, I. (2005) *Suffering: a Sociological Introduction*, Cambridge: Polity Press.

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