Learning from challenges in the recruitment of patients with advanced cancer from hospice day care

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Background: The background literature suggests that recruiting patients with advanced cancer from hospice day care to participate in a research study may be challenging.

Aim: This paper describes such challenges and considers whether those faced by researchers in this study reflect those recorded in the literature.

Method: Six hundred and twenty-six patients with advanced cancer from hospice day care units in the north-west region of England were recruited as part of a multi-centre mixed methods study to determine the prevalence, aetiology, and natural history of depression and demoralization.

Results: A number of challenges were reported (i) data collection sometimes presented researchers with ethical dilemmas, although the ability to respond appeared to be influenced by disciplinary background and training, (ii) emotional impact of the research may force researchers to face a variety of emotional responses, and (iii) dilemmas relating to the setting and maintenance of role boundaries included determining the level of emotional connection required to establish relationships of trust between researchers and participants, and imbalances in power and status.

Discussion: Many of the challenges faced by researchers to recruit patients with advanced cancer from hospice day care to participate in this research study were similar to those described in the literature.

Conclusion: Most researchers reported that the overall experience was positive, although a number of moral and ethical dilemmas required ongoing reflection and continuing support and supervision to resolve. It is hoped that other researchers engaging in similar forms of research in the future can learn from the challenges that have been identified.

Keywords: Quantitative, Advanced cancer, Hospice, Palliative care, Recruitment, Access, Research, Ethics

Introduction

The background literature suggests that recruiting patients with advanced cancer from hospice day care to participate in a research study may be challenging. This paper reflects upon the experiences of a group of researchers involved in a multi-centre mixed methods study in which 626 patients from hospice day care units in the north-west region of England were actively recruited to investigate the prevalence, aetiology, and natural history of depression and demoralization in patients with advanced cancer. A number of challenges relating to the recruitment of patients with advanced cancer to a research study, and gaining access/collecting data within hospice day care were identified. The paper also considers whether

challenges faced by researchers in this study reflect those recorded in the literature.

Following description of our research methodology, we reflect upon a number of issues identified by researchers in this study. We begin with a discussion of some of the ethical considerations and dilemmas that arise for researchers, in particular, the 'gatekeeping' of this group of patients, and the resulting relationships with hospice day care staff. We then consider the emotional impact of the research upon the researcher; the emotional 'threats' that this particular study may potentially have posed to members of the research team.[1] Finally, we discuss dilemmas relating to the setting and maintenance of role boundaries and the difficulties that some researchers may experience in determining the necessary levels of emotional connection required to establish relationships of trust and rapport with participants. The implications that the blurring of those boundaries might have in relation

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to imbalances in power and status between researchers and participants is also considered.

Undertaking research in palliative care and hospices is known to be challenging in a plethora of ways; ethically, practically, morally, and emotionally. The care of people with advanced cancer may be enhanced by examining the challenges that arise for researchers within hospice day care; for example, through an exploration of the emotional relationship that is established between researcher and participant. The practical and emotional involvement of researchers in patients' lives, sometimes for a prolonged period of time, may also possess implications for the data that are collected and the subsequent analysis of studies. It is hoped that other researchers engaging in the design and conduct of similar forms of research can learn from the challenges and solutions that have been identified in this paper, and that this may contribute to more effective ways of working in the future.

Aim

This paper considers whether challenges faced by researchers in this study reflect those recorded in the literature. The overall aim is to identify the ethical, practical, moral, and emotional challenges relating to the recruitment of patients with advanced cancer to a research study, to gaining access/collecting data within hospice day care, and highlighting lessons for the design and conduct of future research.

Method of main study

This paper draws upon the experiences of the researchers employed on a 3-year mixed methods study conducted between 2007 and 2010. During the study, 626 participants were recruited from 25 hospice day care units across the north-west region of England. Initially, managers at the selected services were invited to participate by a letter, which was then followed up by detailed discussion (by telephone and in person) about the purpose of the study, the data collection requirements, access to the services, and ethical issues. The researchers collected data using a number

of structured screening tools, containing questions on worthlessness, subjective sadness, and suicidal thoughts as well as questions about symptoms and pain. This prospective study required participants to complete an initial baseline assessment with a researcher and three further shorter follow up questionnaires (completed either face to face, by post, or by phone) at eight weekly intervals. This led to contact being maintained with some participants for a period of up to 6 months after initial recruitment to the study. In addition, 27 patients were invited to take part in in-depth qualitative assessments.

At the start of the study, researchers were encouraged to keep a research diary of thoughts, feelings, and interpretations, and how they coped with the emotional reactions that were evoked while listening to participants' accounts. These diaries, together with baseline assessments, emails, notes from research meetings, and informal discussion between researchers inform the discussion presented in this paper.

Disciplinary backgrounds between researchers varied, and it was considered that this multi-disciplinarity was beneficial to the study. Researcher experience of recruitment to palliative care studies ranged from highly experienced to relatively inexperienced, although all had previously conducted assessments (Table 1).

Results

The rest of this paper highlights the practical and ethical challenges relating to gaining access, the collection of data, and the recruitment of patients with advanced cancer within hospice day care. It considers whether challenges faced by researchers in this study reflect those recorded in the literature.

Ethical considerations and dilemmas

For some researchers, the collection of data within hospice day care presented a number of ethical considerations and dilemmas: for example, some researchers expressed concern that questions in the standardized measures may cause distress among

Table 1 Researcher gender/experience/background

	Gender	Research experience	Background
Researcher A	Female	Clinical trials – quality of life and experimental therapies for people with advanced cancer	Health psychology/oncology nursing
Researcher B	Female	Enhanced relapse prevention for bipolar patients/patients with medically unexplained symptoms	Administration
Researcher C	Female	Working with people with mild–moderate mental health problems	Psychology
Researcher D	Female	Acceptance and commitment therapy	Clinical psychology
Researcher E	Female	Working with children whose parents had terminal cancer	Psychology
Researcher F	Female	Health sciences/social housing research	Health sciences/social housing
Researcher G	Female	Community development project/end-of-life storytelling project	Community development/mental health
Researcher H	Male	Narratives of those caring for a person approaching death	Palliative/end-of-life care research

participants. This sometimes resulted in researchers conducting the assessment too quickly in order to minimize their own distress, being reluctant to discuss issues that they perceived to be potentially upsetting to the participant, or even omitting certain questions altogether. However, the ability to respond to such ethical dilemmas often appeared to be influenced by the background and training of the researcher; for example, researchers with training in 'risk management' reported that their previous experience had informed their practice when carrying out the research, and that this had made it easier to deal with patients presenting with suicidal ideation. For other researchers, although asking about suicide and self-harm ideation did not pose a particular problem, the fact that such questions were within a number of questionnaires and had to be repeated several times proved somewhat difficult.

Patients may have felt pressured to 'produce the right answer'[2] to questions asked of them in the study, or, as Batchelor and Briggs[3] have argued, felt 'morally bound' to continue in the study even when they experienced it as painful or stressful. A further ethical issue for some researchers was the uncomfortable feeling that they had only been able to collect the data after 'befriending' patients, and that they may have inadvertently exploited them by doing so; as de Raeve[4] argues, this has profound implications for the concept of informed consent.

Because the potential for research to cause distress with patients approaching the end of life is possible, their gatekeeping must be both protective and rigorous, and any other potential implications of their participation in a research study must also be carefully considered.[5,6] Even though managerial and ethical approval may have been granted to the study, researchers may still experience barriers to accessing hospice and palliative care environments due to the sensitivities of clinical 'gatekeepers'.[7] This was the experience of a number of researchers in this study.

In order to collect data effectively, a close working collaboration with hospice staff was crucial in achieving the aims and objectives of the study. This necessarily involved continuous negotiation with hospice 'gatekeepers'. Even though ethical approval for the study had been secured, some researchers felt that a continuous process of flexible negotiation and renegotiation was still required from those 'lower down' the hospice hierarchy.

Younger researchers employed in the study often faced difficulty in establishing 'credibility' within the hospice environment due to their age, with comments such as: 'how are you getting on with your course?' serving to undermine them. Researchers also reported feeling undermined on occasion when day care staff

questioned their legitimacy to be in the hospice at all, due to their 'not being from a healthcare background'. A small number of other difficulties in relationships with hospice staff were reported by some members of the research team, particularly in the way in which their presence in the hospice was construed by day care staff. For example, initially at least, there were suspicions about the role of 'academics' as 'observers' and their assumed motives. Tensions were particularly pronounced during busy periods of the day when day care staff would contrast their heightened activity with the perceived inactivity of the researcher with comments such as: 'You've a good job – all you do is sit around all day talking to people and drinking tea!'

Some researchers reported that hospice staff appeared rather reluctant at times to allow patients to be assessed; this often related to concern over how long the assessment may last with comments such as: 'Now you won't keep him/her too long will you?' Tensions surrounding the sharing of limited hospice space occasionally surfaced, in particular with difficulties in finding a quiet room to conduct assessments. There were also some instances of understandable irritation on the part of hospice staff when researchers requested use of their office space for prolonged periods of time. It was crucial, therefore, to maintain goodwill and co-operation with key members of day care staff.

Emotional impact of the research

For researchers working on sensitive topics, critical self-analysis of the interrelationship between their emotions and research procedures, process, and analysis can be highly productive and considerably enhance the value of a study.[8–10] Research into highly sensitive topics may possess an unknown and unpredictable quality;[11] for example, Hochschild[12] notes in her study of emotions that there exists a narrow division between the questions 'what do I feel' and 'what should I feel'.

Because of the highly sensitive nature of this particular study, and the potential emotional response of participants, reflection on the emotional impact of the research was considered to be absolutely vital. However, it should be acknowledged that the task of critical reflection proved to be a rather problematic experience for some researchers; this may have been due to unfamiliarity with the process of reflection itself which is very much a perspective espoused within the social sciences and qualitative research methodology, and was less familiar to those from other backgrounds.

Researching topics in sensitive areas may also have a detrimental emotional effect on the researcher; for example, continuous exposure to the suffering of

people at the end of life may prove to be mentally distressing.[13] Yet a number of authors suggest that relatively little consideration of the emotional and psychological problems that may arise through exploring sensitive issues has been afforded to the qualitative researcher.[14–16] Researchers working in areas such as the hospice environment may also be particularly prone to experiencing feelings of isolation.[17]

Consistent with the literature, while participating in the study was often described as an interesting, satisfying, and rewarding experience, a number of researchers stressed that there were times when recruitment and being in the hospices had proved difficult for them. The assessments were described as 'demanding', 'stressful', and 'exhausting', with some researchers feeling 'disturbed' by the interaction between themselves and patients. In some instances, being immersed in the hospice environment for a prolonged and sustained period of time with patients who had a life-limiting illness had affected the researcher's outlook on life. They suggested that this exposure had '[…] taken over everything', and that this had resulted in an imbalance in their outlook, with them often focusing solely on the '[…] dark side of life'. The data collection process was often described as highly 'emotional', and a number of researchers reported the difficulty they had relating to the management of their own emotions during assessments. One researcher felt 'emotionally overwhelmed' on occasion, finding it very difficult to contain feelings during some assessments and crying privately afterwards in order to resolve distress; this was reported as occurring 'out of the blue', sometimes happening in public places. Another researcher suggested that they had underestimated the intense emotional impact that close personal interaction with patients within the hospice day care environment would evoke, and was therefore unprepared for some of the distressing experiences that were encountered. These experiences often produced responses such as feelings of sadness and loss, distress, personal anxiety or fear, and even, on occasion, depression.

A further dilemma sometimes reported by researchers was that they ran the risk of experiencing 'burnout'. Some researchers reported that continuous exposure to death, dying, and human suffering had made them feel 'totally overwhelmed', emotionally 'drained' and, on occasion, feeling helpless, vulnerable, angry, and frustrated by the '[…] sheer hopelessness of it all'. Researchers often chose to discuss these feelings and emotions with other members of the research team who were conducting assessments with patients with advanced cancer, and this 'peer support' was described as 'invaluable' in helping them to successfully deal with difficult issues that arose. Other researchers reported that although certain assessments could be

emotionally charged, they did not impact upon them personally due to their extensive background, training, and experience in this area; although it is highly unlikely that these researchers did not react to some particularly sensitive or distressing situations at some stage of the study. As Jaggar[18] suggests, the concept of an 'unemotional' researcher simply does not exist.

It is therefore necessary to ensure that support is provided for the qualitative researcher in the form of regular supervision.[19] De Raeve[4] suggests that systems of support need to be established for the researcher, to enable them to cope with their own grief and to help them maintain the tenacity and resilience required in order to return to distressing issues. In order to combat distressing feelings while working away from their organizational base and assure emotional safety, researchers were provided with access to support in the form of confidential and professional research supervision. Sensitive and experienced support was provided throughout the duration of the study, including regular debriefing sessions with project supervisors – forums where they were able to process and discharge their feelings and emotions. In addition to those working 'in the field', other members of the research team (for example, transcribers and office staff who input and processed the data) were provided with regular supervision where they were able to discuss any emotional difficulties or potential distress. Researchers were also offered clinical supervision with the option of independent psychological counselling if they felt affected by some of the potentially traumatic experiences to which they were exposed. However, this proved difficult for some members of the research team as they perceived it as displaying a 'weakness' or personal 'inadequacy' of some sort; it also caused concern that they may be considered unsuitable for employment on similar studies in the future. The majority of researchers reported that they did not require a great deal of supervision or support either due to their previous background, experience, training, etc. or because their needs had been fulfilled through conversations with day care staff or, as previously mentioned, through engaging in informal mutual peer support with colleagues.

Finally, Atkinson et al.[20] argue that if researchers experience difficulty in 'leaving the field' it indicates that they have become both physically and emotionally immersed in the research, and while their relationships with patients are only of a transient nature, this does not '[…] prevent their ending from signifying a loss' (p. 55). A number of researchers highlighted the emotional difficulties in leaving the day care environment and 'letting go' of the highly dependent relationships that they had built up with both hospice staff and

patients; feelings of obligation, 'torn loyalties', and 'abandoning' patients were sometimes referred to.

The blurring of role boundaries within the research process

We now turn to examine how complex ethical dilemmas are inherent in the setting and maintenance of role boundaries between researcher and participant. Researchers may be faced with 'moral choices' during the research process, including the degree of emotional involvement with, or detachment from, research participants – 'being in' versus 'being out' of the research process.[21,22] Researchers who choose to be fully immersed 'in' the research process may 'compromise their professional detachment',[23] while researchers who opt 'out' may experience difficulty in 'getting below the surface' in order to share deeply personal issues.[24] As opposed to the rather rigid dichotomy of being either enmeshed 'in' the research relationship or being detached and 'out' of it, some authors have highlighted the concept of researchers 'being with' the participant, or 'alongside' them, on a 'co-journey'.[25,26]

A small number of researchers involved in the study considered dilemmas relating to the setting and maintenance of role boundaries as a challenge, in particular the complex moral interface between the 'professional' and the 'personal' self.[27] Determining the level of emotional connection that was required in order to establish a relationship of trust and rapport with participants was referred to, and some researchers reported conflict and tension involving relationships. Lee[1] suggests that researchers often become involved in '[…] a growing closeness which creates a blurred line between the role of friend and that of research participant' (p. 107). Some researchers were unclear about the limits of their involvement with patients; for example, they often felt confused about the dichotomy between their role as researcher, and the need to behave as a 'friend' or 'helper' to patients. However, this also appears to be age-related, as younger members of the research team did not consider 'befriending' patients due to the difference in age between them.

Some researchers in the study chose to maintain a rigid, detached, and objective distance from participants so that they did not forego 'their academic role'[28] or influence/contaminate the data through revelation of their personal feelings. This was also reported to be a strategy of 'self-protection'; researchers were able to 'screen themselves out' of a form of research that represented personal and emotional 'danger' to them.[23] Researchers who maintained high levels of objectivity during data collection (typical of a positive, quantitative approach) that minimized emotion (what Goffman[29] referred to as

'distancing'), reflected that this may have resulted in them appearing as cold, unfeeling, or insensitive.

Kellehear[30] suggests that a failure to acknowledge emotional interaction within the research process may underscore the imbalance in power and status between researchers and participants. Adopting a mechanistic stance may have proved to be a dilemma for some researchers in the study if the binary dichotomy in which one category is perceived as dominant to the other (such as the rigid positions of 'researcher' and 'researched') was further reinforced.

Hawthorne and Yurkovich[25] argue that nowhere is relationship more important than in situations involving terminal illness, which requires individuals to deeply engage with each other in a trusting environment based on shared humanity. Letherby[31] and Hesse-Biber *et al.*[32] reject the idea that a researcher should be detached from their research, insisting that this subjective element in research should be acknowledged, even welcomed. Within our context, some researchers felt that because of the intimate and highly sensitive nature of this particular research topic, it was inconceivable that they would not develop emotional connections and 'open up' to participants.

Huberman and Miles[33] argue that sharing experience and insights more fully makes researchers more accountable. The interview situation gave participants an opportunity to seek information from the interviewer, and some researchers revealed their 'personhood'[34] – a factor that may have revealed avenues of discussion that might not have otherwise emerged. Lee and Renzetti[35] suggest that researchers need to discover ways of coping with issues raised by research on sensitive topics that are intrusive of private and personal matters. One researcher could readily identify with certain aspects of life-threatening illness and death due to recent related losses; the researcher's father and mother had died during the course of data collection and certain aspects of the research process served as a reminder and re-awakened feelings and emotions about these losses. On occasion, this researcher felt able to empathize with participants by sharing personal details about this sad event with them. For other researchers within the study, personal losses not only served to give them a greater sense of empathy with participants, but also provided them with a deeper understanding of the contextual aspects of patients' lives. However, as Sque[13] observes, by disclosing painful personal experiences, the researcher has the potential to invade, distort, or destroy the private world of both the participants and themselves; resulting in what Goffman[36] termed a 'mortification of self'. Any researchers affected by personal loss reported compassionate and caring support from members of day care staff at their

respective hospices in relation to such loss. A further interesting area of study would be the cumulative effect that external factors (such as personal loss) may have on the researcher working within hospice-based studies.

By recognizing the differential in power relations between participants and sharing personal insights and beliefs, some researchers acknowledged that they were potentially as 'fallible' or 'vulnerable' as participants; this may have served to even up the imbalance of power between 'researcher' and 'researched'.[37] Wasserfall[38] suggests that the active deconstruction of the researcher's authority in this manner may lead to a dissolution of power differentials and '[...] mute the distance and alienation built into conventional notions of objectivity' (p. 152). Some researchers felt that by establishing non-hierarchical forms of relationship between themselves and participants,[39,40] more equal power relationships were created, and this enabled them to view the world through the 'eyes of the participant'.[41,42] Yet researchers in the study remained acutely aware of the risk that 'sharing' power with the researched may possess[21] – revelation of their personal experience may have interfered with or become intertwined and entangled with the experience of the participant.

Kvale[43] suggests that, in some instances, it may be difficult to separate a 'research' assessment from a 'therapeutic' assessment. A dilemma reported by some researchers who engaged emotionally with participants was that the trusting 'research relationship' they had established between themselves and participants may have occasionally shaded into becoming 'therapeutic' and thereby ran the risk of distorting the study aims and objectives.[44] As Duncombe and Jessop[45] suggest, '[...] even skilled researchers may find it difficult to draw neat boundaries around "rapport," "friendship," and "intimacy," in order to avoid the depths of "counselling" and "therapy"' (p. 112).

Some researchers reported the need to consciously blur the boundaries between 'researcher' and 'researched' and inject a 'third-ness'[46] into the process by negotiating an interactive identity that combined aspects of both. Entering into co-research with patients may be perceived by some as a problematic dual relationship that challenges 'traditional' research assumptions,[47,48] yet it may serve to enhance both the assessment experience and the quality of data collection.

Discussion

Insights into the experiences of researchers working in the field of hospice and palliative care may provide a vital perspective on the emotional connections that researchers establish with participants, and this may serve to enhance the care of people with advanced cancer. The practical and emotional involvement of researchers in patients' lives, sometimes for a prolonged period of time, may also possess implications for the data that are collected and the subsequent analysis of studies. Many of the challenges faced by researchers to recruit patients with advanced cancer from hospice day care to participate in a research study were similar to those described in the literature. For example (i) data collection sometimes presented researchers with ethical dilemmas, although the ability to respond appeared to be influenced by disciplinary background and training, (ii) emotional impact of the research may force researchers to face a variety of emotional responses, and (iii) dilemmas relating to the setting and maintenance of role boundaries included determining levels of emotional connection required to establish relationships of trust between researchers and participants, and imbalances in power and status.

Conclusion

This paper has shared the experiences of a group of researchers working in the field of palliative care, and considered some of the challenges relating to the recruitment of patients with advanced cancer to a research study within hospice day care. In conclusion, the vast majority of researchers involved in the study stressed that while there had been occasions when being in the hospice had proved demanding, these were isolated instances and that overall the experience had been a positive one. However, researchers also reported a number of moral and ethical dilemmas that required ongoing reflection and continuing support and supervision to resolve. It is hoped that other researchers engaging in similar forms of research can learn from the challenges and solutions that have been identified.

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