Journeys into end of life research:
some methodological considerations

ANA PATRÍCIA HILÁRIO

Ana Patrícia Hilário holds a degree in Sociology and Planning from Lisbon University Institute. She is currently taking her PhD in Sociology at Royal Holloway, University of London, and is carrying out research as a doctoral fellow at the Centre for Research and Studies in Sociology. Her main research interests focus on the sociology of health and illness, sociology of the body and sociology of death and dying. E-mail: patriciahilario@gmail.com

Abstract

This working paper is concerned with the research design and ethical aspects connected with conducting research with terminally ill patients, their family members and palliative care professionals. The first section describes the design of the research for this study. The strengths and weaknesses of employing observation and interviewing techniques are discussed. The second section explores the ethical issues of conducting research with terminally ill patients and those who care for them in the last weeks and days of their lives. The difficulties of gaining informed consent from these research participants are highlighted. The third section examines the process of qualitative data analysis. Attention is drawn to the grounded theory method. The purpose of this working paper is to offer guidance on how to conduct research with sensitive topics such as the end of life.

Keywords: ethnography, observation, interviews, ethics

Resumo

O presente working paper pretende discutir alguns dos aspectos metodológicos e éticos da investigação em torno dos doentes terminais, dos seus familiares e dos profissionais de cuidados paliativos. A primeira secção descreve a metodologia do estudo a ser desenvolvido. As forças e as fraquezas da utilização de técnicas de observação e de entrevistas são discutidas. A segunda secção explora as questões éticas de conduzir investigação com os doentes terminais e com os seus cuidadores nas suas últimas semanas e dias de vida. As dificuldades em obter consentimento informado por parte dos sujeitos participantes no estudo são sublinhadas. A terceira secção examina o processo de análise qualitativa. Uma particular atenção é dada ao método grounded theory. A proposta deste working paper é de oferecer linhas orientadoras sobre como conduzir investigação sobre tópicos sensíveis tais como o fim da vida.

Palavras-chave: etnografia, observação, entrevistas, ética

Introduction

Much of the literature associated with the body has been principally concerned with the unproblematic body. The body in these writings is portrayed as a project that is to be worked on and a marker of social distinction (Shilling, 1993; Bourdieu, 1984). However in the case of sick, elderly or dying people the body is the symbol of the separation between self and identity (Howarth, 2007). It is noteworthy that within sociology very few studies have succeeded in eliciting the perceptions and experiences of the very ill and those at the end of life. This field has been under researched since the observation by Lawton (2000) that self-identity in contemporary western society is dependent on the possession of a bounded, sealed, isolated body. As Bradburn and Maher (2005) argued, and Rier (2000) demonstrated, in his experience as an intensive unit patient, sociological research has failed to capture patients' experience of critical illness. The general aim of this working paper is to offer guidance, in the light of the preparation of an actual case, on how to conduct a qualitative study on sensitive topics such as the end of life.

In a broader sense, then, this working paper is concerned with the research design and ethical aspects connected with conducting research with terminally ill patients, their family members and palliative care professionals. The first section describes the research design of this study: the data will be obtained by ethnographic research strategies. Intensive fieldwork will be carried out over a seven month period in an in-patient hospice unit for terminally ill patients. Interviewing techniques will be complemented by participant and non-participant observation. The second section discusses the ethical issues of conducting research with terminally ill patients, their family members and palliative care professionals. The major challenge here is to balance the ethical requirements of consent, anonymity, confidentiality and privacy. The third section examines the process of qualitatively analysing the data. Since the research attempts to build new theories to explain the phenomena, the grounded theory method is highlighted. After presenting the guidelines of this working paper we will now turn to the methodology of the study.

2. Ethnography

2.1. Research design

A number of studies have reported on the success of ethnographic techniques to address the complexities and challenges in the lives of individuals who face chronic illness, disability and death (Glaser and Strauss, 1965; Sudnow, 1967; Strauss, 1975). Charmaz and Oleson (2007) pointed out that ethnography has become one of the most widely accepted methods of data collection within the field of medical sociology. This is because ethnographic research has moved away from a medicalised view of pain, suffering, and even death, to one that focuses on patients' perspectives and their everyday life contexts. This research study intends to explore the extent to which the self-identity of terminally ill patients in Portugal is affected when they lose control over the physical boundaries of their bodies and, if it is affected, how and why. Though this study is based on a number of techniques, it is primarily formulated within the ethnographic method. Ethnography provides many fruitful opportunities to learn about the experiences of terminally ill patients and those who care for them in the last weeks and days of their lives. Lawton's (2000) study, unlike McNamara's (2001), underlined the idea that ethnography provides an in-depth understanding of the daily lives of terminally ill patients, their family members and palliative care professionals.

Through an ethnographic approach the researcher will have the opportunity to record certain aspects of the daily lives of terminally ill patients in a detailed way (Seymour, 2007) and, thereby, make analytical observations without making excessive emotional demands on terminally ill patients (Lawton, 2001). It is also notable that ethnography involves a flexible design and highlights the contexts within which the viewpoints of terminally ill patients, their relatives and palliative care professionals are expressed (Seymour, 2007). A case study approach will be used to allow a detailed examination and representation of a group of patients, relatives and health care professionals. This approach will limit the researcher's observational range to events concerning a selected palliative care unit near Lisbon, Portugal, for people dying from cancer and non-cancer conditions. This setting was chosen because it is the place where the process of bodily deterioration and decay become highly visible. Indeed, Lawton (2000) has identified the existence of a sub-group of terminally ill patients, whose bodies become unbounded due to disease symptoms and are, therefore, sequestrated in

hospices from public view. The case study method has been described as appropriate for use when researchers need to: 1) define research topics broadly; 2) cover complex and multivariable conditions; and 3) rely on multiple sources of data (Yin, 2003: xi). These circumstances apply to this research. Indeed the aim of this case study is to collect a large amount of information about the interaction established between terminally ill patients, family members and health care professionals within a specific palliative care unit in Portugal.

It should be noted that the case study method offers opportunities for triangulation (Clark, 2001). This involves the use of multiple data sources to explore the same phenomena (Ingleton and Davies, 2007). So for the purpose of this study there will be two stages of data collection: 1) observation of the interaction between terminally ill patients, their relatives and palliative care professionals; 2) a series of informal interviews with terminally ill patients as well as a series of formal interviews with the relatives of terminally ill patients and with palliative care professionals. It should be noted that observation and interviewing techniques will be used for ethical reasons. These techniques will allow the researcher to conduct the study in an unobtrusive and non-invasive way. Indeed, Lee (1993) has convincingly demonstrated that research on sensitive topics such as the process of bodily deterioration and decay often draws upon ethnographic techniques. This is because researchers are more able to gain access to sensitive populations without disturbing the internal dynamics of the place where the research study is being conducted (Lawton, 2001).

We can now consider some of the aspects of the method in greater detail.

2.2. Observation

The data for this research study will be primarily obtained by observation techniques. Observation techniques have been suggested as an appropriate means of capturing the discrepancy between what people say they do and what they actually do (Payne, 1997). Through participant and non-participant observation techniques the researcher will become directly involved in people's daily lives and will thus gain access to the world of meaning from the standpoint of an insider (Jorgensen, 1989). She will be integrated into the palliative care team as a volunteer and, in this way, participant observation techniques will be used. In the case of terminally ill patients and

their relatives, non-participant observation techniques will be used since the researcher will remain on the outside of the group as an observer (Stacey, 1969). As a member of the palliative care unit, the researcher will be able to use direct observation to capture the reality and complexity of the research participants' thoughts and actions (Lawton, 2001).

Data will be gained by her becoming a participant in the hands of care in the palliative care unit, over a seven-month period. Three days per week will be devoted to helping staff by serving patients refreshments, assisting with eating, or sitting and talking with patients who feel lonely. By becoming a volunteer, long periods of time will be spent with terminally ill patients in the wards and communal areas of the palliative care unit without disturbing the internal dynamics of the place or making terminally ill patients feel under scrutiny. In her ethnographic study of hospice patients Lawton (2000) demonstrated that participant observation has the potential to be a non-invasive and unobtrusive method of data collection. As an in-house hospice volunteer, Lawton (2001) was able to spend considerable amounts of time with terminally ill patients and thereby to learn about their views and experiences without making excessive demands on patients' time or a negative contribution to the emotional situation. As Lawton noted, participant observation provides the most viable means of gaining insights into the perspectives of terminally ill patients.

The observational data will be documented by means of fieldnotes. These fieldnotes will describe the details of certain events, actions and interactions and will be complemented by a fieldwork diary (Clark, 2001; Emerson et al, 2001; Gilbert, 2008). Because research participants may feel uncomfortable with the recording of fieldnotes, observational data will be recorded discreetly in the staff room of the palliative care unit (Seymour, 2007). So, in order to make observation manageable, the researcher will need to make condensed notes that can then be expanded at the end of each day. An important point to stress here is that, as data will be reconstructed retrospectively, the researcher will not be able to collect long quotes from research participants (Lawton, 2001). In its broader sense, observation is time-consuming and involves many hours of hard work (McNamara, 2001; Seymour, 2008).

Lawton (2001) also alluded to the emotional effects on the researcher of spending considerable periods of time with terminally ill patients. This type of involvement may lead to detachment problems during the period of data collection. A similar observation was made by Cannon (1989), who, in her study of social research in

stressful events, argued that the broad methodological issues of involvement, detachment and personal responsibility had an added significance when studying topics of an emotive nature. In this research study, then, the researcher will need to spend a considerable time away from the fieldwork setting in order to interpret the data in a detached manner. Clark et al (2000) also pointed out that prolonged contact with the subject of a life-threatening illness may raise personal mortality-related fears for oneself and one's family and closest friends. The point to stress here is that the researcher will need to reflect and think about such issues before entering the field. In addition, the supervisor relationship may be seen as a source of emotional support and one possible way in which this difficulty may be overcome (Seymour, 2007). Thus, methodological triangulation will be used to achieve an in-depth understanding of the phenomena studied (Ingleton and Davies, 2007) and the observation will be complemented by interviewing techniques.

We can now turn to a more detailed consideration of this research technique.

2.3. Interviews

Interviews will allow the researcher to incorporate the views of research participants into the analysis of observational data. In this research study, then, interviews will be held during the observational phase of the fieldwork. In their broadest sense, interviews will provide opportunities to understand if the self-identity of chronically ill patients in Portugal is affected when they lose control over the physical boundaries of their bodies in the last weeks and days of life. Interviews have been one of the most widely used methods of generating data within the field of health research (Clark, 1997; Gilbert, 2008; Sandelowski, 2004). Compared with other research methods such as questionnaires, interviews are likely to generate a high response rate (Payne, 2007), which may be due to the relationship established between researcher and interview respondent (Lee, 1993). Indeed, as Cannon (1998) demonstrated, talking to and sharing feelings with respondents are vital to maintaining rapport and interest. Of particular note is the fact that such interviews may be emotionally demanding for both interviewer and respondent. Indeed, some studies have pointed out that interview respondents may feel embarrassed or experience substantial levels of distress (Lee, 1993; Murphy and Dingwall, 2001). Payne (1997) also argued that interviews may be

very invasive and, thereby, may lead people to think about painful issues. Yet, despite these negative aspects, interviews may also have a therapeutic effect on respondents. For example, Dickson-Swift et al (2006) suggested that, because respondents have the opportunity to tell their story, they are likely to feel that interview participation is therapeutic.

Interviews are likely to offer an appropriate approach to capture the views and experiences of those who are very ill and at the end of their lives (Thomas et al, 2009). To illustrate this point it is helpful to establish a distinction between formal and informal interviews. So, in the former case, the wording of questions and the order in which they are asked is the same for all interview respondents, whereas, in the latter case, the researcher is free to ask respondents questions in any order that seems sensible at the time (Gilbert, 2007). Since informal interviews are open-ended and allow a fluid interaction between the researcher and respondent they will offer opportunities to understand the extent to which the self-identity of terminally ill patients in Portugal is dependent on the possession of a bounded, sealed, isolated body (Marvast, 2004; Payne, 2007; Swain et al, 1998). Because informal interviews do not require advanced arrangement and do not make significant demands on patients' time, they will provide an unobtrusive way of observing and listening to the views and experiences of terminally ill patients (Jorgensen, 1989). Informal interviews will take place as casual conversations during the day-to-day interaction with patients in the unit. Through these interviews the researcher will also be able to gather information systematically. Nonetheless, it is important to stress that such interviews will require that a considerable rapport has been established between interviewer and respondent (Stalker, 1998). Indeed, before having an informal interview with terminally ill patients, the researcher needs to understand the amount of information that respondents may have about their clinical condition, in particular, if they know that they are dying. Conversations with patients' relatives and palliative care professionals may help to clarify this situation.

Formal interviews will additionally be conducted with the patients' relatives and palliative care professionals. Interviews with the relatives will give indications about the ways in which the patients' terminally ill status affects their sense of self per se in relation to significant others. These interviews will offer insights into the impact that terminal illness has on patients' everyday lives and their relationship with significant others. On other hand, interviews with palliative care professionals will provide details on the ways in which the process of bodily deterioration and decay in terminally ill

patients is interpreted and managed. This will provide opportunities to understand whether chronically ill patients experience a state of physical dependency and a loss of awareness of themselves and their environment in their last weeks and days of life. Through a structured schedule of questions the researcher will be able to ask interview respondents specific questions (Jorgensen, 1989). Interview questions will be as open ended as possible in order to obtain spontaneous information. Indeed, interview questions will encourage respondents to communicate honestly about their opinions and ideas (Gilbert, 2008). As outlined above, such interviews will be conducted during the later stages of fieldwork. This is because the researcher needs to establish a sufficiently close rapport with respondents to request a formal interview with them (Jorgensen, 1989).

Interviews with terminally ill patients, family members and palliative care professionals will be tape-recorded, with the participants' permission, and last around 60 to 90 minutes. This form of recording will be very effective in capturing the nuances of conversations like pauses and/or interruptions (Marvast, 2004). The data will be stored by sex, age and status for research purposes in the researcher's office and, after being transcribed, will be destroyed (Wilkie, 2007). The use of Computer Assisted Qualitative Data Analysis Software (CAQDAS) such as Atlas.ti5 will be considered (Payne, 2007). This CADQDAS software will help the researcher to organise textual data, in particular the transcripts of interviews and fieldnotes. It should be noted that, in terms of exploring data, Atlas.ti5 provides many different ways of annotating, including attaching comments to quotations. In addition, coding in Atlas.ti5 is very flexible and interactive, since it allows the researcher to see how codes are building up at the document level as she proceeds (Lewis and Silver, 2007).

Now it is time to discuss the research sample of this study.

2.4. Research sample

As a case study, the observations and subsequent themes developed in this research will be drawn from the entire population of the palliative care unit, with the exception of those who have asked to be excluded. The sample will not be numerically representative of the whole population of terminally ill patients: instead, it will be able to identify a range of experiences. Therefore a distinction will not be drawn between

patients who suffer from cancer and non-cancer conditions. In a broader sense, however, those who are mentally confused, unable to express themselves and too unwell to complete data collection will not be included in the interview study (Payne et al, 1996). Once a referral is made by the doctor or chief nurse, the researcher will contact the patient to establish willingness to participate in the study. Only patients who have been in palliative care for more than 48 hours can be referred. Interviews with terminally ill patients will be conducted by the researcher at their bedside or in another private area after they have given written or verbal informed consent.

In order not to make excessive demands on terminally ill patients the researcher will only interview twenty patients. Ten men and ten women will be encouraged to reflect on their deteriorating and debilitating bodily experiences, thus allowing us a total of twenty informal interviews. This is because the gender of terminally ill patients may affect their image of their body (Charmaz, 1995) and their relationship with others (McNamara, 2001). Previous research has suggested that physical changes in the body caused by the onset of a chronic illness may affect the sense of identity and social status as adults in men and women alike (Clark and Griffin, 2008; Chapple and Ziebland, 2002; Crouch and McZenzie, 2000; Oliffe, 2006). Furthermore, interview respondents will be aged from 25 to 35 yeard old and from 75 to 85 years old. This will allow the researcher to look at two different age groups: a group of relatively young women and men and a group of men and women in an older age group. Whereas, for those who are very old, the onset of a chronic and terminal illness might be seen as a normal and integral part of life (Sanders et al, 2002; Pound et al, 1998; Sinding and Wierrnikowski, 2008), for those who are relatively young their perspectives must surely be very different. That is, it may be understood as a traumatic and disruptive event (Bury, 1982).

Examining the discourses of family members and palliative care professionals will also provide opportunities to identify similarities and differences in ideas about the unbounded body and dirty dying. Indeed the literature has recently suggested that family members and palliative care professionals may have similar ideas and beliefs concerning the characteristics of a good death (McNamara, 2004; Long, 2004). Hence the doctor and nurse chiefs will be asked for a list of family members that they consider able to talk freely about their relative's experience and willing to participate in the research. Twenty family members of terminally ill patients, such as spouses or the next of kin, will be sampled from this list, which will result in ten formal interviews. In

doing so, the researcher will try to achieve a reasonable balance and representation by age and sex. Interviews will also be conducted with ten palliative care professionals. This group may include nurses, doctors, psychologists, social workers and chaplains, with the researcher also trying to achieve a reasonable balance and representation between these professional categories. Thus issues of gender and age will not be considered crucial in this sample group. Interviews with the relatives of terminally ill patients and their palliative care professionals will be conducted in a private area in the palliative care unit, after they have given written informed consent. Having outlined this, we will now focus on the ethical issues of conducting research with terminally ill patients and those who care for them.

3. Ethical considerations

3.1. Ethical issues

Attempts to investigate terminally ill patients' experience of bodily deterioration and decay raise methodological and ethical challenges. These challenges relate to the ways in which research is introduced and explained to terminally ill patients, their family members and palliative care professionals (Entwistle et al, 2002; Ryen, 2004). Research participants have the right to be informed of the aims, methods, benefits, and risks of the study (Seymour and Skilbeck, 2002). Additionally, informed consent is obtained from terminally ill patients, their family members and palliative care professionals on the understanding that participation is voluntary (Casarett et al, 2000) and that it can be discontinued at any time (Tee and Lathlean, 2004). Informed consent, on the one hand, protects the rights of participants but, on the other hand, highlights the responsibilities of researchers (Swain et al, 1998: 28). In a broader sense, although the research study will not benefit respondents themselves, it may help to improve the care of future patients. It should be noted that a short report will be sent to respondents and/or to their relatives informing them of the study results.

Another point to stress is that the consent procedure has a major impact on the way in which the researcher is seen by participants. Indeed the consent procedure influences the rapport that is developed between researcher and participants (Seymour, 2001: 25). A requirement for interviewing terminally ill patients, their family members

and palliative care professionals will be that written consent is given by the research participant after he or she has been informed verbally and/or in writing (Richards and Schwartz, 2002). Because of its formalized nature, the presentation of a written consent form may cause concern to some participants (Sheldon and Sargeant, 2007). The researcher will need to protect their right to anonymity, privacy and confidentiality during and after the fieldwork (Boman and Jevne, 2000; Jorgensen, 1989; Lee and Renzetti, 1993; Ramcharan and Cutcliffe, 2001; Marvast, 2004).

Another concern that will be briefly considered here is the ethical approval of an official research ethics committee. An ethics form will be sent for approval to the Research Ethics Committee of Royal Holloway, University of London. However, there is no need to request official ethical approval to conduct research on palliative care in Portugal. This is because of the non-existence of an official research ethics committee in the health care system in Portugal. It is worth mentioning that professional associations such as the British Sociological Association and the Portuguese Sociological Association offer a set of ethical guidelines that the researcher should unfailingly take into consideration. (Associação Portuguesa de Sociologia, 2009; British Sociological Association, 2002).

A formal letter will be send to the managers of the in-patient hospice unit explaining the study and inviting them to discuss any concerns they might have and, under these conditions, access to fieldwork will be negotiated with the team leaders of the palliative care unit. Conversations will be conducted with the doctor and nurse chiefs explaining the aims, methods and ethical aspects of the study. Indeed the process of negotiating access can be extremely difficult and time-consuming. Interestingly, this process can highlight aspects of the research setting and thereby it can become part of the data collection process (Seymour, 2007). Lawton (2001) in her ethnographic research on terminally ill patients examined her role as a researcher. Specifically, she noted that during her day-to-day interactions many patients appeared to forget that she was a researcher. Hence, although patients had given consent on their admission to the hospice, this could not be taken for granted in subsequent encounters with them. This issue needs to be addressed in this research study, perhaps by obtaining specific consent for observing agreed episodes of care (Sheldon and Sargeant, 2007). The procedure of continuously reminding patients and their relatives that data is being collected for research purposes seems to be problematic, precisely because an agreement has been made that research will be conducted in an unobtrusive way (Lawton, 2001).

Although researchers may take measures to protect their research subjects from harm it is impossible to anticipate every risk (Seymour, 2001). Indeed, the research process might affect individuals in different and complex ways (Marvast, 2004; Murphy and Dingwall, 2001). For example, data gathering about the process of bodily deterioration and decay might upset terminally ill patients. In these circumstances, the respondent is clearly free to discontinue the interview and specialist counselling will be offered by the palliative care unit psychologist. Additionally, respondents will be informed that if they decide to discontinue the interview and withdraw from the study this will not affect their care, the care of their relatives or the work of health care professionals in the palliative care unit in any way. The researcher will also give them the option of omitting questions that they do not want to answer. It is to be noted that, because terminally ill participants may make decisions on whether to participate in the study based on their current circumstances, further issues may arise due their deteriorating condition (Addington-Hall, 2002).

A similar observation was made by Lawton (2001) in her study of the difficulties involved in obtaining informed consent from terminally ill patients. Specifically, she questioned if consent remained valid when participants began to deteriorate physically and mentally. While informed consent from terminally ill patients was obtained on their admission to the hospice, it was difficult to establish the extent to which this consent could be taken for granted during the process of bodily deterioration and decay. Indeed, concerns have been raised about the vulnerability of terminally ill patients: their impaired decision-making capacity and their need for special ethical protection in the case of participation in research (Hewitt, 2007). To protect the rights of terminally ill patients in circumstances of impaired decision-making capacities, informed consent will be verbally obtained from family members such as a spouse or the next of kin (Casarett, 2005; Sugarman et al, 2001; Stocking et al, 2004). It is worth mentioning that observation for research purposes will not be conducted during episodes of acute physical illness or emotional distress (Payne et al, 1996). Furthermore, the researcher will need to ensure that participants feel comfortable with the use of tape recording and understand the procedures that follow (Wilkie, 2007). In a broader sense, however, the presence of a tape recorder may make the interview respondent self-conscious and, thus, raise fears about the purpose of the material recorded (Marvast, 2004). Hence the informed consent protocol will explain the purpose of the research and how the material

will be used. Indeed, respondents will be informed that interviews will be transcribed and coded, which brings us to the process of qualitative data analysis.

4. Qualitative data analysis

4.1. Data credibility

A significant amount of work has been written on the credibility of data in qualitative research. Generally speaking, there has been a move towards greater theoretical sophistication and methodological rigour (Silverman, 2005). This methodological awareness is established under the headings of 'validity' and 'reliability'. In this respect, 'validity' means the truth value and generability of the study, whereas 'reliability' refers to its degree of consistency (Seale, 1999). In a broader sense, then, the researcher will need to pay attention to the stability, trustworthiness and scope of her research findings (Elliot, 2005). In practice, the researcher will need to: refute initial assumptions about data and test evidence; constantly compare all data fragments; incorporate all cases of data into the analysis; address anomalies and deviant cases; and use quantitative measures such as simple counting techniques. In this study triangulation will also be used to generate more valid findings. This means that the researcher will take different sources of data into account and, in doing so, attempt to demonstrate that the study methods are reliable and the conclusions valid (Silverman, 2005).

Generalising claims will be based upon a theoretical understanding of other similar phenomenon. Indeed, the quality of qualitative research is closely dependent on the ability to provide an in-depth description and exploration of the phenomena under study. It should be noted that the search for reliability will lie in the assumption that it is possible to produce objective knowledge that is independent of the researcher and independent of the time and location in which the research is undertaken (Crossley, 2007). Therefore the researcher should keep in mind that certain factors such as gender, racial origin and background (in this case, female, white and middle class) may affect interaction with the research participants (Hewitt, 2007). Furthermore, as McNamara (2001) stressed, one of the biggest challenges in ethnographic research is to address issues of data legitimation. This is because the data collected may be a product of

participation in the field rather than a reflection of the phenomena studied. In many ways the attitudes and behaviours of researchers may affect the credibility of their propositions (Wray et al, 2007). The point to stress here is that despite all these challenges the researcher will need to pursue objectivity alongside the process of data collection and analysis (Social Research Association, 2003).

The next topic to be described will be the grounded theory method.

4.2. Grounded theory analysis

The grounded theory method owes its origins to Glaser and Strauss who challenged the assumption that qualitative research could not generate theory. In their book *The Discovery of Grounded Theory*, Glaser and Strauss (1967) suggested that theory may be generated by comparative analysis. As Payne (2007) argued, and Seale (1999) demonstrated, the grounded theory method aims to build up an inductive theory that is based on data. A grounded theory approach allows the researcher to compare data from the beginning of the research; to compare data with the categories constructed; and to demonstrate the relationship/s between concepts and categories (Charmaz and Mitchell, 2001). In a broader sense, then, this method involves a systematic and flexible strategy for collecting and analysing qualitative data. Thus, one of the major advantages of grounded theory is that it may help researchers to maintain control over the research process (Charmaz, 2006). Indeed, as Strauss and Corbin point out:

"Its procedures are designed so that, if they are carefully carried out, the method meets the criterion for doing 'good' science: significance, theory-observation compatibility, generability, reproducibility, precision, rigor and verification." (1990: 27)

As a grounded theorist, the researcher for this work will begin by studying the data collected and raising questions about it. Next, she will separate the data through coding and labelling, which will make comparisons with other segments of data easier. Then, the researcher will start to write preliminary notes about codes and comparisons, a stage called memo writing that will help her define ideas about the construction of analytic categories. Coding is the next analytical step: it involves naming/identifying each piece of data with a label. Through coding the researcher will be able to make analytical interpretations (Charmaz, 2006). So, the researcher will first code her fieldnotes and interview transcripts, which will provide opportunities to make

comparisons and thereby to gain awareness of similarities and differences among research participants and events. Then, through memo-writing, she will elaborate the relationships within these comparisons and address their meanings. Secondly, she will divide the categories into properties, subcategories and dimensions. Through constant comparative coding, a link will be established between categories and their ingredients and, finally, the researcher will be able to construct a conceptual framework for her research study (Charmaz and Mitchell, 2001).

In a broader sense, however, one could argue that the researcher will only partially use a grounded theory approach, for two reasons in particular. The first and most obvious is that a literature review will have been carried out before she conducts the data analysis. According to grounded theorists, the literature review should only be conducted after the development of an independent analysis. The second reason is linked to the fact that the research sampling framework has been formulated prior to data collection. From a grounded theory perspective, sampling is aimed at theory construction. It should be noted that simultaneous data collection and analysis, the construction of analytical codes and categories from data, the constant comparative method and memo-writing to elaborate categories are some of the strategies of the grounded theory approach employed in this research study. It has been suggested that engagement in such practices will help the researcher to control the research process and increase the analytical power of her work. Hence, it could be argued that one of the major advantages of the grounded theory method is that it offers systematic strategies for qualitative research practice (Charmaz, 2006).

5. Final remarks

This working paper has described methodological and ethical issues in research conducted with terminally ill patients, their family members and palliative care professionals. In the research planned, data gathering will be obtained by participant observation and interviewing techniques. This working paper provides a discussion on the strengths and weakness of these techniques in research among palliative care populations. Concerns about the protection of research subjects have been highlighted. This includes the difficulties of gaining informed consent from patients who are very ill and at the end of their lives. Furthermore this working paper provides a series of

reflections on the process of data collection and analysis. Indeed attention has been devoted to qualitative methods of analysing data, in particular the grounded theory method. In a broader sense, this research study attempts to give a voice to terminally ill patients and those who care for them in their last weeks and days of life. The data resulting from the implementation of the research will illustrate the everyday realities of terminally ill patients, their family members, and palliative care professionals. Ultimately, what is under analysis is the nature of real life situations, in which the human, the scientific and the ethical are inseparably intertwined.

References

Addington-Hall, J. (2002) Research sensitivities to palliative care patients, *European Journal of Cancer Care*, 11, 220-224.

Associação Portuguesa de Sociologia (1992) *Código Deontológico*. Lisbon: Associação Portuguesa de Sociologia. Accessed at: http://www.aps.pt/?area=000&marea=001& PHPSESSID=bb83c497cb3d696e0680c90388d5fc2c

Boman, J. and Jevne, R. (2000) Ethical evaluation in qualitative research, *Qualitative Health Research*, 10, 4, 547-554.

Bradburn, J. and Maher, J. (2005) User and carer participation in research in palliative care, *Palliative Medicine*, 19, 91-92.

British Sociological Association (2002) *Statement of Ethical Practice for the British Sociological Association*. Durham: The British Sociological Association. Accessed at: http://www.britsoc.co.uk/NR/rdonlyres/468F236C-FFD9-4791A0BD4D F73F10BA43/0/

Cannon, S. (1989) Social research in stressful settings: difficulties for the sociologist studying the treatment of breast cancer, *Sociology of Health and Illness*, 11, 1, 62-77.

Casarett, D. and Karlawish, J. (2000) Are special ethical guidelines needed for palliative care research?, *Journal of Pain and Symptom Management*, 20, 2, 130-139.

Casarett, D. (2005) Ethical considerations in end-of-life care and research, *Journal of Palliative Care Medicine*, 8, 1, 148-160.

Chapple, A. and Ziebland, S. (2002) Prostate cancer: embodied experience and perceptions of masculinity, *Sociology of Health and Illness*, 24, 6, 820-841.

Charmaz, K. and Oleson, V. (1997) Ethnographic research in medical sociology: its foci and distinct contributions, *Sociological Methods Research*, 25, 4, 452-494.

Charmaz, K. and Mitchell, R. (2001) Grounded theory in ethnography. In Atkinson, P. (eds) *Handbook of Ethnography*. London: Sage.

Charmaz, K. (2006) *Constructing Grounded Theory*. London: Sage.

Clark, D. (1997) What is qualitative research and what can it contribute to palliative care?, *Palliative Medicine*, 11, 159-166.

Clark, D. (2001) What is qualitative research and what can it contribute to palliative care?. In Field, D. et al. (eds) *Researching Palliative Care*. Buckingham: Open University Press.

Clark, D. Ingleton, C. and Seymour, J. (2000) Support and supervision in palliative care research, *Palliative Medicine*, 14, 441-446.

Crossley, M (2007) Evaluating qualitative research. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

Delamont, S. (2004) Ethnography and participant observation. In Seale, C. et al. (ed) *Qualitative Research Practice*. London: Sage.

Dickson-Swift, V. et al. (2006) Blurring boundaries in qualitative health research on sensitive topics, *Qualitative Health Research*, 16, 6, 853-871.

Elliott, J. (2005) *Using Narrative in Social Research*. London: Sage.

Emerson, et al. (2001) Participant Observation and Fieldnotes. In Atkinson, P. (ed) *Handbook of Ethnography*. London: Sage.

Entwistle, V., Tritter, J.Q. and Calnan, M. (2002) Researching experiences of cancer: the importance of the methodology, *European Journal of Cancer Care*, 11, 232-237.

Gilbert, N. (2008) *Researching Social Life*. London: Sage.
Glaser, B. and Strauss, A. (1967) *The Discovery of the Grounded Theory*. New Jersey: Aldine Transaction.

Hewitt, J. (2007) Ethical components of researcher researched relationships in qualitative interviewing, *Qualitative Health Research*, 17, 8, 1149-1159.

Hyman, H. (1954) *Interviewing in Social Research*. Chicago: The University of Chicago Press.

Ingleton, C. and Davies, S. (2007) Mixed methods for evaluation research. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

Jorgensen, D. (1989) *Participant Observation*. London: Sage.

Lawton, J. (2001) Gaining and maintaining ethical concerns raised in a study of dying patients, *Qualitative Health Research*, 11, 5, 693-705.

Lee, R. (1993) *Doing Research on Sensitive Topics*. London: Sage.

Lewis, A. and Silver, C. (2007) Using Software in Qualitative Research. Sage: London.

Ramcharan, P. and Cutcliffe, J. (2001) Judging the ethics of qualitative research: considering the ethics as process model, *Health and Social Care in the Community*, 9, 6, 358-366.

Renzetti, C. and Lee, R. (1993) *Researching Sensitive Topics*. London: Sage.

Rier, D. (2000) The missing voice of the critically ill: a medical sociologist's first-person account, *Sociology of Health and Illness*, 22, 1, 68-93.

Ryen, A. (2004) Ethical issues. In Seale, C. et al. (ed) *Qualitative Research Practice*. London: Sage.

Marvast, A. (2004) *Qualitative Research in Sociology*. London: Sage.

Murphy, E. and Dingwall, R. (2001) The ethics of ethnography. In Atkinson, P. (ed) *Handbook of Ethnography*. London: Sage.

Nunkoosing, K. (2005) The problems with interviews, *Qualitative Health Research*, 15, 5, 698-706.

Oliffe, J. (2006) Embodied masculinity and androgen deprivation therapy, *Sociology of Health and Illness*, 28, 4, 410-432.

Payne, S. (1997) Selecting an approach and design in qualitative research. *Palliative Medicine*, 11, 249-252.

Payne, S. (2007) Qualitative methods of data collection and analysis. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

Richards, H.M. and Schwartz, L.J. (2002) Ethics of qualitative research: are there special issues for health services research?, *Family Practice*, 19, 135-139.

Sandelowski, M. (2004) Using qualitative research, *Qualitative Health Research*, 14, 10, 1366-1386.

Seale, C. (1999) *Quality of Qualitative Research*. London: Sage.

Seymour, J. and Skilbeck, J. (2002) Ethical considerations in researching user views, *European Journal of Cancer Care*, 11, 215-219.

Seymour, J. (2001) *Critical Moments – Death and Dying in Intensive Care.* Buckingham: Open University Press.

Seymour, J. (2007) Ethnography. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

Silverman, D. (2005) *Doing Qualitative Research*. London: Sage.

Stephen, R. and Lathlean, J. (2004) The ethics of conducting a co-operative inquiry with vulnerable people, *Philosophical and ethical issues*, 47, 5, 536-543.

Stacey, M. (1969) *Methods of Social Research*. London: Pergamon Press.

Stalker, K. (1998) Some ethical and methodological issues in research with people with learning difficulties, *Disability and Society*, 13, 1, 5-19.

Sheldon, F. and Sargeant, A. (2007) Ethical and practice issues in qualitative research. In Addington-Hall, J. (ed) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

Social Research Association. (2003) *Ethical Guidelines*. Scotland: Social Research Association.

Stocking, C. et al. (2004) Ethics reporting in publications about research with Alzheimer's disease patients, *Ethics, public policy and medical economics*, 52, 2, 305-310.

Strauss, A. and Corbin, J. (1991) *Basics of Qualitative Research*. London: Sage.

Sugarman, J. et al. (2001) How proxies make decisions about research for patients with Alzheimer's disease, *Ethics, public policy and medical economics*, 49, 8, 1110-1119.

Swain, J., Heyman, B. and Gillman, M. (1998) Public research, private concerns: ethical issues in the use of open-ended interviews with people who have learning difficulties. *Disability and Society*, 13, 1, 21-36.

Thomas, C. et al. (2009) Narrative research methods in palliative care contexts: two case studies, *Journal of Pain and Symptom Management*, 37, 5, 788-796.

Wray, N., Markovic, M. and Manderson, L. (2007) Researcher saturation: impact of data triangulation and intensive-research practices on the researcher and qualitative research process, *Qualitative Health Research*, 17, 10, 1392-1402.

Williams, S.J. (1995) Theorising class, health and lifestyles: can Bourdieu help us?, *Sociology of Health and Illness*, 17, 5, 577-604.

Wilkie, P. (2001) Ethical issues in qualitative research in palliative care. In Field, D. et al. (ed) *Researching Palliative Care*. Buckingham: Open University Press.

Yin, R. (2003) *Applications of Case Study Research*. Sage: London.