

Title: “Conducting Qualitative Research with Patients Receiving Palliative Care: The Application of Hammick’s Research Ethics Wheel (1996)”

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Conducting Qualitative Research with Patients Receiving Palliative Care: The Application of Hammick's Research Ethics Wheel (1996)

Key Phrases:

- Factors that influence the vulnerability of patients receiving palliative care are highlighted in relation to research.
- The Research Ethics Wheel (Hammick, 1996) is introduced and proposed as a means of scrutinising ethical principles within a research study.
- The ethical issues that underpin qualitative research undertaken with participants who are receiving palliative care are examined
- Protection and valuing of the patient participating in research is crucial and practical suggestions are made throughout the article to facilitate this
- It is recognised that research with patients receiving palliative care is not without its ethical challenges, but such research is crucial to the enhancement of future nursing practice

Key Words:

- **Ethics**
- **Palliative care**
- **Qualitative Research**
- **Research Ethics Wheel (Hammick, 1996)**

Introduction.

The ethical aspects of all research must be thoroughly considered in order to establish the implications of the study and to ensure safety (Morse & Field, 1996; Haber, 2002) – in research that seeks the participation of people receiving palliative care, this is particularly crucial. This article will examine the ethical issues that should be considered before undertaking research with this vulnerable group of individuals. Initially, key factors will be highlighted; this will be followed by an introduction and discussion of the Research Ethics Wheel (Hammick, 1996) – a comprehensive tool that facilitates the researcher's scrutinisation of underpinning ethical considerations.

Ethical issues became a prominent focus for us when two years ago we were commissioned to undertake a qualitative research study that considered the needs of adults with cancer, and their families, who were accessing palliative care services in an area in the East of England; this was undertaken by means of semi-structured interviews. It has been suggested that the undertaking of research within palliative care is challenging (Arraf et al, 2004; Hopkinson et al, 2005; Keeley, 2008) and that it has a specific moral dimension (Janssens et al. 1999, Hermsen & ten Have 2001). Polit & Hungler (2002) point out that conducting research with people who are dying is problematical because their vulnerability results from the fact that they may be at high risk of unforeseen and unintended side-effects because of their particular circumstances. Consequently, Polit & Hungler (2002) feel that these patients need a higher degree of protection than is given by the general framework and ethical research guidelines.

Karim (2000) highlights seven particular concerns:

1. Patients often experience complex symptoms as well as mental and physical exhaustion; they may not be in any condition to be participants in a research study.
2. The research, particularly if it raises potentially painful issues surrounding death, may result in patients experiencing psychological distress (Aranda 1995).
3. Although willing to take part in the research, patients might find it increasingly difficult to do what is being asked of them. Karim (2000) points out that there may well be cognitive and physical deterioration that could affect their ability to complete questionnaires, quality of life scales, or even to be interviewed. Cognitive deterioration may also lead to a reduced decision-making capacity (Pereira et al, 1997), this is particularly crucial in terms of giving informed consent.
4. Patients who have not yet reached the terminal phase of their illness could have other demands on their time, for example multiple outpatient appointments, as well as regularly moving between home, hospital and hospice. This may mean that trying to find time for interviews or to complete questionnaires could be problematic.

5. Patients who are relatively well may not find it easy or convenient to spend their valuable remaining time participating in a research study. In addition, family members may raise objections since they themselves want to spend time with their relative. Addington-Hall (2002) points out that questions have been raised about whether it is ethically sound to ask patients accessing palliative care to participate in research, as this could risk depriving them of energy and time. Conversely, it is important from a research perspective to involve this group of patients in order to enhance future nursing practice.

6. Patients may be trying to distract themselves from their symptoms and involving them in research could focus them back on their illness and thoughts of dying.

7. Finally, patients might sign a consent form but only because they fear that refusing to do so may have implications for the care they are receiving. As Randall & Downie (1999) point out, this does raise the question as to whether any patient participation in health research can ever be voluntary, because there will always be a potential fear that by not taking part, the patient may be penalised in some way.

Hammick (1996) comments that researchers have an 'obligation' to assess the ethical implications of studies, and to aid this process she devised "The Research Ethics Wheel" (REW). This all-inclusive tool facilitates self-scrutiny of personal

ethical principles and will now be used as a framework to analyse and evaluate the diversity of ethical issues and how they pertain to patients receiving palliative care.

The wheel is comprised of four quarters each containing four segments (Figure 1), none of which assume more importance than any other (Hammick, 1996). The four key aspects of the wheel will be addressed in turn:

- *Principles* of research using people.
- *Duties* of a researcher.
- *Nature* of the outcome of the research.
- *Practicalities* of the research process.

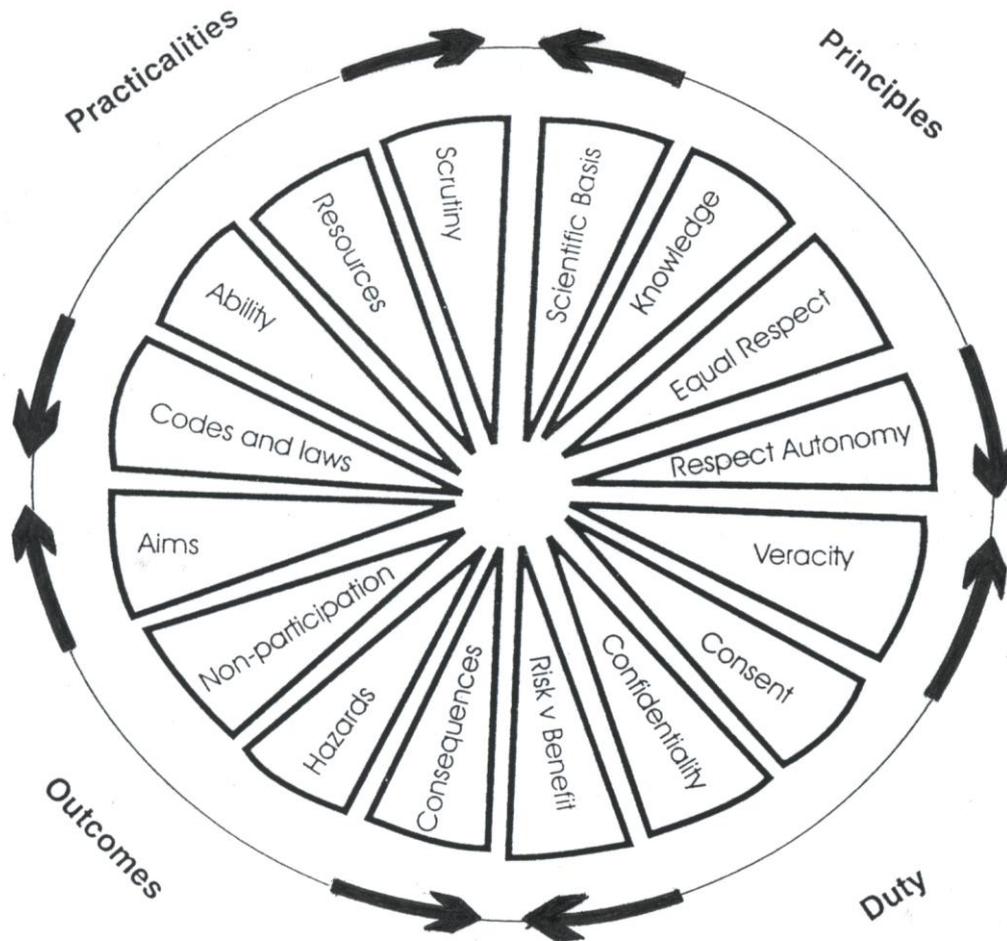


Figure 1: The Research Ethics Wheel (Hammick, 1996)

Principles of research using people

The first quarter of the Research Ethics Wheel is concerned with the principles pertaining to the use of people as participants. It covers four main areas which are addressed below:

Scientific basis

According to the Declaration of Helsinki (World Medical Assembly, 1989), research should 'conform to generally accepted scientific principles'. Although authors such as Hammick (1996) have discussed the value of studies conducted within the natural sciences, she suggests that these researchers must be able to "defend the scientific principles of their investigative work" (page, 41) particularly when faced with ethics committee approval. It is therefore crucial that, prior to the commencement of a study, researchers fully consider the methodological approach that will be utilised; this study drew upon a hermeneutical phenomenological approach (Heidegger (1962); phenomenological research is underpinned by the idea that the reality of any situation is that experienced by the participants – hence it was felt to be very appropriate for the identification of the perceived needs of patients (and their families) who were receiving palliative care. Semi-structured interviews were conducted with both patients and carers - it was thought that these methods would:

- Yield the richest and most valuable data
- Allow the participants to explore, identify and express their needs

Knowledge

The Research Ethics Wheel (1996) suggests that a study should only be conducted if it aims to increase the body of knowledge for a particular discipline. Although Hammick (1996) acknowledges that replication studies are appropriate in certain circumstances, the researcher should still be aiming to uncover new knowledge. She emphasises the necessity of carrying out a comprehensive literature search, prior to the commencement of a study to identify the scope of previous investigations – considerable time was invested in our searching process, this yielded a range of pertinent literature (for example, Ingleton et al, 2003; Soothill et al, 2003; National Institute for Clinical Excellence, 2004; Slater & Freeman, 2004; Andershed, 2006). Despite this, it became clear that the practical, physical and psychosocial needs of adults (and their families) who were receiving palliative care warranted further examination within the unique geographical area within which the research was to take place.

Equal respect

This segment of the Research Ethics Wheel states that everyone should receive equal respect and treatment, a view supported by Beauchamp and Childress (2001). Burns and Grove (2005) say that in any research, the selection and treatment of all participants throughout the study must be fair. They suggest that a number of points be taken into consideration (Table 1):

Points for consideration	Degree of achievement for this study
<ul style="list-style-type: none"> The participants should only be selected for reasons that are directly related to the issue being studied. 	<ul style="list-style-type: none"> Achieved. Clear inclusion and exclusion criteria were formulated – all participants were adults.
<ul style="list-style-type: none"> The researcher and participant should have a specific agreement about the degree of participation that is involved. This should be respected and not changed during the study unless consent is obtained from individual participants. 	<ul style="list-style-type: none"> Achieved. No alterations were made to the degree of participation.
<ul style="list-style-type: none"> The researcher has a responsibility to be on time for interviews and not to keep the participants waiting. 	<ul style="list-style-type: none"> Achieved. The researchers arrived approximately 10 minutes prior to each interview.
<ul style="list-style-type: none"> Any benefits that are promised such as a copy of the findings must be provided. 	<ul style="list-style-type: none"> Achieved. Summaries of the final report have been distributed to those who requested a copy.

Table 1: The right to fair treatment (adapted from Burns and Grove, 2005)

The conduct of studies frequently prompts researchers to consider whether small gifts should be given to participants as a token of respect and thanks. Interestingly, Gysels et al (2008: 347) investigated the motivation of patients receiving palliative care to participate in research studies; the findings revealed that there were four key influential factors:

- 'Altruism'
- 'Gratitude and concerns about care'
- 'The need to have somebody to talk to'
- 'The need for information or access to services'

An affinity was certainly felt with the above points; the participants and their carers all made it clear that they wanted to contribute to the development of new knowledge and were certainly not expecting a 'reward'. In fact the provision of a gift could have felt uncomfortable and inappropriate for this group of participants; each person was, however, sent a 'thank you' letter and a summary of the final report.

Respect autonomy

Hammick (1996) states that the respect of people's autonomy is a fundamental principle of research. She suggests that it is closely linked to the issue of informed consent (a separate segment of the REW) and relates to the researcher allowing participants to decide of their own free-will whether or not to become involved in the study – this is particularly important for those receiving palliative care as their time is so precious. In our research, patients were randomly selected from a database; they were then initially approached by their nurse who discussed the study with them and provided written information; if the patient/family wished to participate, they were able to consider this at their leisure and contact the principal researcher via a self addressed envelope. The specialist palliative care team did not know which patients/families were taking part in the study – an important factor as this has the potential to impact upon care and management.

The duties of the researcher

The second quarter of the Research Ethics Wheel focuses upon the responsibilities of the professional conducting the study towards the people who are invited to participate. The four issues raised will be considered.

Veracity and consent

Hammick (1996) discusses veracity and consent together. She says that although they are both closely related to the segment of the wheel entitled 'Respect Autonomy', this encourages the researcher to think about the ethics of a study from

differing angles. Veracity is concerned with the telling of truth, and unless participants are provided with all the facts about a study, it is impossible for them to make an informed consent (Hammick, 1996). Additionally, truthfulness links with the principle of fidelity, or developing trust, necessary for obtaining accurate data (Parahoo, 2006); consequently, every effort should be made to build a rapport with the participants – in our study, this was done via the telephone and in the patient's home prior to the interviews being conducted.

Parahoo (2006, page 469) describes informed consent as:

“The process of agreeing to take part in a study based on access to all relevant and easily digestible information about what participation means, in particular, in terms of harms and benefits.”

Gaining of informed consent of participants is essential (Locke et al., 2000; McHaffie, 2000) and has particular significance when those receiving palliative care are participating in a study (Arraf et al, 2004; Parkes, 2006). Burns and Grove (2005) suggest that certain details should be given to each person, prior to consent being obtained (Table 2). In our study, the consent process was an ongoing, dynamic process with written consent being obtained some weeks prior to the interview and verbal consent being ascertained the day before the interview, immediately before the interview commenced, and at stages during the interview.

Information to be given to participants	Degree of achievement for this study
<ul style="list-style-type: none"> Introduction of research activities. This should clearly indicate how the study is to be conducted. 	<ul style="list-style-type: none"> Achieved. Written and verbal information was provided. In addition, the participants had the researchers' contact details, should they wish to clarify any issues.
<ul style="list-style-type: none"> Statement of research purpose. This should include both immediate and long term goals. 	<ul style="list-style-type: none"> Achieved, both verbally and in writing (the latter via the provision of an information sheet).
<ul style="list-style-type: none"> Selection of research participants. Details need to be included explaining how and why the participants have been chosen. 	<ul style="list-style-type: none"> Achieved, both verbally and in writing (the latter via the provision of an information sheet).
<ul style="list-style-type: none"> Explanation of procedures. Information concerning how and when these are to be carried out, and in what setting, should be given. 	<ul style="list-style-type: none"> Achieved, both verbally and in writing (the latter via the provision of an information sheet).
<ul style="list-style-type: none"> Description of potential benefits and risks to the individual participants. 	<ul style="list-style-type: none"> Achieved, both verbally and in writing (the latter via the provision of an information sheet).
<ul style="list-style-type: none"> Disclosure of alternative procedures or treatment. 	<ul style="list-style-type: none"> Not applicable to this study.
<ul style="list-style-type: none"> Assurance of confidentiality. 	<ul style="list-style-type: none"> Achieved, both verbally and in writing (the latter via the provision of an information sheet).
<ul style="list-style-type: none"> Offer to answer questions. The researcher must make it clear how he/she can be contacted. 	<ul style="list-style-type: none"> Achieved. There was an opportunity to ask questions, initially with the nurse, then with the researchers, both via telephone contact and prior to the conduction of the interview. In addition, the participants had the researchers' contact details, should they wish to clarify any issues.
<ul style="list-style-type: none"> Noncoercive disclaimer. This should state that participation is voluntary. However, the completion of a questionnaire can be taken as consent. 	<ul style="list-style-type: none"> Achieved. Written consent was obtained from each participant.
<ul style="list-style-type: none"> Option to withdraw. 	<ul style="list-style-type: none"> Achieved. This was verbally expressed as well as being included within the participant information sheet.
<ul style="list-style-type: none"> Consent to incomplete disclosure. This is only relevant if participants are not to be totally informed about the study as it may influence their behaviour. 	<ul style="list-style-type: none"> This issue was not applicable to the study.

Table 2: Informed consent: Information to be given to participants (adapted from Burns and Grove, 2005).

It is also important to remember that veracity extends further than informed consent, for example, Locke et al (2000) point out the importance of reporting the findings truthfully and completely – we have produced a final research for the study.

Confidentiality

This segment of the Research Ethics Wheel is concerned with the issues of anonymity and confidentiality.

Parahoo (2006, page 466) describes confidentiality as the:

“assurance given by researchers that data collected from participants will not be revealed to others who are not connected with the study.”

Whilst Burns and Grove (2005) state that all participants have the right to privacy, anonymity and confidentiality, they do say that true anonymity only exists if the participant's identity cannot be linked, even by the researcher – clearly this is not feasible in an interview. Parkes (2006) states that any information that may mean that a participant could be recognised, should be changed; as a result, pseudonyms were used in the writing of the research report.

Guaranteeing confidentiality means ensuring that only the researcher is aware of the source of the information; the wishes of the participants were respected throughout the study with care being taken to ensure that all data was securely stored.

Risk versus benefit

This section of the Research Ethics Wheel relates to the researcher's duty to ensure that the participants are not involved in an investigation which will either benefit them or anyone else. In addition, it considers the need to minimise the risks associated with the study, so protecting the participants from unnecessary harm or discomfort.

Richards and Schwartz (2002) identified four areas of possible risk for participants in qualitative research: distress and anxiety; exploitation; misrepresentation and identification of the participant in publications. Whilst care was taken to avoid all of these potential dangers, there was particular concern that distress may be caused to the patients, not just because of the nature of the research, but because the very effort of talking to an interviewer may exacerbate their physical condition – Fitzsimmons and McAloon (2004) suggest that researchers should be cognisant of the fact that they may need to intervene. Some patients did become visibly tired, but none to the extent that the interview needed to be terminated, although they were given the option of ending the interview at any time. In addition, we occasionally cut short an interview if we felt that the patient was becoming weary.

It is important to remember that all research should benefit the participants to some extent. However with many palliative care patients, this may not be the case, and in some instances, they may die before any actions as a result of the research can take place – as occurred with our study. Janssens & Gordijn (2000) have suggested that it is possible that research in palliative care may therefore be unethical as patients will not have the opportunity to benefit from the study. However Addington-Hall (2002) points out this is not unique to patients accessing palliative care; many people who take part in research do not actually derive any personal benefit from it. Similarly many other patients could experience psychological distress as a result of research and may be fragile and exhausted as a result of their illness. In view of this, Casarett & Karlawish (2000) consider that there is no reason why palliative care should be a special case if ethical principles and guidelines are adhered to.

Outcomes of research

The third quarter of the Research Ethics Wheel pertains to the effects which the study may have, once it is completed.

It is acknowledged that studies involving patients receiving palliative care could promote anxiety. However, Lee and Kristjanson (2003) stress that without research taking place, there is a risk that nothing new is attempted and that there could be a failure to scrutinise how the profession cares for dying people. In addition they point out that without the use of research to demonstrate and justify the value of palliative care services, then palliative care providers may find it increasingly difficult to attract funding. From a social justice perspective, as Rawles (1971) suggests, all members of the community could have an interest in the provision of good healthcare because they have the potential for needing it in the future. However in terms of palliative care, as Seymour & Skilbeck (2002, page 219) state, "this requires striking a fine balance between the ethical duties of providing caring support, nurturing independence and autonomy, and achieving research outcomes that are rigorous while also being accessible and meaningful to users." Following the completion of our study and the writing of the report, the commissioners of the study did agree to discuss the findings with us and to consider the recommendations made.

Consequences

This segment acknowledges that there will be unknown facts associated with any research and that the study should be stopped if hazards are found to be greater than the advantages. Streubert Speziale and Carpenter (2006) suggest that a study may provide the only opportunity for the participant to discuss the identified topic.

This is clearly a vital factor for consideration in palliative care as particularly sensitive issues may be being addressed (for example, dying). Streubert Speziale and Carpenter (2006) advocate that time be made available at the end of the interview in case help or advice is required; this may be in the form of a discussion or by the provision of a contact name and telephone number . Whilst relevant details were given to participants, no-one became unduly distressed by the interviews; in addition, it was evident that there were already established support mechanisms for patients as their diagnoses were not new, although we did also put in place mechanisms for the support of patients that were external to their carers within the palliative care services, if that was what was desired.

Researchers themselves may find the whole experience of conducting the research stressful and they also may require psychological support; interestingly, we both commented that we had not found the actual interviews too distressing, but transcribing and reflecting upon the experience was far more emotionally challenging than had been anticipated. We were able to share these feelings and this was certainly beneficial.

Hazards

This section shares similarities with 'risk versus benefit'. The researcher clearly has a duty to ensure that the study does not carry undue risk; this study did not involve an alteration to the management of care, so there were no additional concerns over and above those already highlighted.

Non-participation

It is essential that participants feel able to refuse to participate in a study and that the issue is dealt with in a sensitive manner (Hammick, 1996). The building of a rapport with the participants is important and will help them to feel confident to say 'no', should they so wish; in addition, the opportunity to withdraw from the research should be reiterated at each stage so that participants feel that they have 'permission' to do so. This was fully adhered to; however it is interesting to note that the three participants who did leave our study, did so prior to the conducting of the interview – in all cases, they left a message on the researcher's work telephone at a time when no-one would normally be available (for example, late on a Sunday evening); it was assumed from this that the person did not wish to speak to someone and this choice was respected.

Aims

This segment of the model serves to emphasise that the aims of the research project should be realistic and achievable; the objectives of this study were carefully considered and identified - failure to do so could be perceived as being unethical.

Practicalities of the research process

The fourth and final quarter of the Research Ethics Wheel is concerned with the external environment.

Codes and laws

This segment of the model stresses that researchers must adhere to codes of practice, legal obligations and regulations (Hammick, 1996); both researchers were Registered Nurses and therefore a range of policies as well as nursing and research rules needed to be adhered to (McHaffie, 2000) in order to practice ethically; this included the Nursing and Midwifery Code of Professional Conduct (NMC, 2008) and relevant NHS Trust policies from where the sample of participants were drawn.

Ability

In order to meet many of the requirements mentioned in earlier segments of the Research Ethics Wheel, it is important to identify that the researcher is suitably qualified and possesses the ability to undertake the study (Hammick, 1996).

It is imperative that researchers acknowledge their limitations and bias and that they strive to achieve the knowledge and skills that are required for the investigation. Both researchers had been involved in previous studies, one having undertaken research with vulnerable groups of patients and their families; whilst additional training was not undertaken in relation to the development of interviewing skills, time was spent discussing and planning the format of the interviews.

Resources

Consideration must be given to the effect which the research may have on other work commitments as well as the availability of time and materials which may be required. This aspect should not be underestimated – the sense of responsibility towards the participants is very powerful; at the same time, other tasks do need to be accomplished.

Scrutiny

The final segment of the fourth quarter relates to scrutiny of the study. It is imperative that the research is considered by independent sources; this is usually the relevant Ethics and Research Governance Committees. This was duly undertaken, as well as internal and external reviews of the research proposal; the procedure went smoothly without any alterations to the research proposal being necessary – nevertheless the whole process took eighteen months as the researchers required honorary contracts and updated Criminal Record Bureau checks.

Within this segment of the model, Hammick (1996) also emphasises the obligation which researchers have to publish findings in an unbiased manner, so facilitating the sharing of knowledge; without this she argues, health care cannot progress. Locke et al (2000) concur that the dissemination of results is a central part of the research process; this should be undertaken in a thorough manner to facilitate the potential implementation of findings (Nieswiadomy, 2002). Two of the key strategies that are commonly utilised are conference presentations and publication via journals (Polit &

Beck, 2006). Conference presentations (either via a poster or an oral report) have the advantage of providing immediate communication of research as well as encouraging dialogue amongst conference attendees and generating further understanding through the answering of questions (Nieswiadomy, 2002; Polit & Beck, 2006); in addition, networking with other researchers may result in useful suggestions regarding further study (Macnee, 2004). Nevertheless, the largest number of professionals will be reached via a journal publication (Nieswiadomy, 2002). It is anticipated that both of these approaches will be used to disseminate the findings from our research.

Finally, and perhaps most importantly, it is advisable to report findings to participants (Macnee, 2004; Nieswiadomy, 2002). Therefore, everyone who took part in the study has been provided with a summary of the findings.

Conclusion

This paper has utilised an established framework in order to provide a systematic analysis of the ethical issues that should be considered when conducting research with participants who are receiving palliative care. Sound ethical principles must underpin any research; their exploration is of fundamental importance in establishing the veracity, rigour and ethical basis for research.

Researchers must acknowledge and honour the rights of palliative care patients who choose to be participants as it is only through research that clinicians will be able to better understand the needs of the community and improve the quality of palliative care in future (Lee & Kristjanson 2003).

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