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MORAL SILENCE?

Nurses' experience of ethical decision-making at the end of life

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DEDICATION

The thesis is dedicated to the nurses on the ward, now in many different contexts, who shared with integrity their commitment and struggle.

It is also dedicated to the patients and their families who generously allowed the presence of an observer during times of great personal upheaval.

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ABSTRACT

The ethics literature to date has suffered from an inadequate empirical base on which to support discussion about practice, policy and education. Research in the area of ethical decision-making has been inconclusive because of unclear conceptualisations of moral problems, and different methods to investigate the extent to which nurses are confronted with them. In particular, the contextual influences on the formation of moral conflicts and nurses' responses to them have not been explored. In cancer care, there is anecdotal evidence that such influences have a powerful effect on the interaction between individual nurses and perceived moral problems.

The study aims to redress previous inadequacies by exploring individual nurses' engagement with perceived moral problems as they occur on an acute cancer unit. The surrounding influences and effects on patient care are studied as part of a fieldwork analysis involving 18 months of participant observation. The researcher worked alongside individual nurses in order to deepen understanding of their perception of moral conflicts.

Findings involve the central concern that ethical decisions are not made, and that this can, in part, be attributed to nurses' evident pattern of emotional distancing. The function of emotion in enabling moral engagement is a central argument of this thesis. The lack of a credible ethical language in practice and the effects of hierarchical decision-making are also explored. Against a backdrop of the frequently mismanaged border between acute and palliative care, these issues

appear to combine to leave patients and their relatives unsupported as death approaches.

By studying ethical decision-making in the context of its application, this study can reliably suggest ways forward in practice. The implications are far-reaching and offer recommendations which improve on those contained in recent policy literature. They will be of direct relevance to those involved in pre- and post registration, and to those responsible for acute cancer services in the UK.

GENERAL INTRODUCTION

The answer to the question of how nurses perceive and react to moral problems is far from clear cut in current nursing ethics (Georges and Grypdonck, 2002). This study represents an empirical response to some aspects of this concern. In particular, the study has been driven by the need to counter a twin deficit in the literature. Firstly, the lack of empirical research in the area of nurses' ethical decision-making in clinical practice; particularly in cancer care. Secondly, the lack of contextual application demonstrated by many studies in the area to date, and the subsequent lack of insight into the encounter between the nurse and a moral problem.

I.1 Relation of thesis to previous work

The attention paid to the ethical issues faced by nurses when caring for cancer patients on the cusp of curative treatment and palliative care has recently grown, but has not been systematically addressed. Research to date reflects the use of unclear conceptualisations of moral problems, and different methods to investigate the extent to which nurses are confronted with them. There is little clarity in the links between the various issues discovered, and therefore little coherence in recommendations for improvement. The lack of progress in building a picture of nurses' ethical decision-making in cancer care appears to be due to a lack of understanding of the workings of the moral actors themselves. The current study aims to explore cancer nurses' own perceptions of ethical issues. This avoids prejudging the concepts to be investigated. The study draws back from debates as to how best to measure moral reasoning, or to evaluate moral sensitivity with different outcome measures, because of the failure of these

studies to build a systematic and rigorous base of evidence. The focus, instead, has been on the more fundamental issue of how nurses' perceive the moral dimension of their work.

Studies in the past have demonstrated the need for a new research approach in nursing ethics. It is possible to conclude from published studies that moral problems in clinical practice are substantially affected by organisational issues, such as a lack of involvement in the decision-making process and feelings of powerlessness. Nurses in cancer care seem to experience difficulty in influencing the ethical decision-making process and in resolving moral problems. Many studies indicate that nurses experience familiar ethical problems in the care of patients with a cancer diagnosis, such as honest communication, genuine symptom management and inappropriately aggressive medical treatment.

Despite the contextual elements attendant to nurses' experiences in these areas, studies consistently demonstrate a tendency to abstract the moral problems from their different environments, in order to study their nature and explore nurses' responses. In the course of their answers, nurses hint at elements of constraint, feeling forced to betray their own values, and professional disillusionment. Conclusions are reached about nurses' victim status within the organisation without analysis of the environments in question. Similarly, the moral problems are listed rather than analysed, and described without the contours of dynamic engagement in clinical practice. By doing so, the important implications for patient care of nurses' approach to moral problems are not assessed.

The literature further suggests that ethical issues are implicit rather than explicit, in that they are likely to be embedded in individual practice and perception rather than overt. The involvement of individual values and beliefs is also indicated. The methodological impetus for the current study drew on the need to explore how individual nurses understood the notion of ethical or moral, and how this was incorporated into their work. A second and related line of enquiry was to observe the clinical situations in which the issues took place, particularly in order to evaluate subsequent decision-making about patient care. In this way, the study of ethical decision-making could be made contextually relevant, and individually focused so as to enable the values and beliefs involved in decision-making to become accessible.

I.2 Outline of intentions

The study aims to faithfully reflect the interaction between individual nurses and the moral problems they encounter when caring for patients with a cancer diagnosis. This will be achieved by exploring nurses' perceptions of moral problems, both by their expressed values and by observing the attendant cultural and organisational issues that effect their engagement with the issues in practice. The original intention to study the process of nurses' ethical decision-making in practice evolved during the course of fieldwork. An unexpected finding that ethical decisions were systematically avoided led to a change in the focus of the study, away from the process of decision-making.

The findings rather reflect the study of barriers to ethical decision-making, as articulated by nurses in their interviews and also demonstrated in practice.

Within this analysis, nurses' awareness of internal constraints operating as barriers to taking action on ethical concerns are explored. Their perceptions of the culture of care, including interprofessional relationships on the ward, are also presented. The multifactoral nature of barriers to ethical decision-making are linked to patient outcomes by virtue of observational data.

The aims of research are consistent with the interpretivist philosophical tradition of Heidegger and others, emphasising the *emic* perspective. The study design rests on participatory fieldwork with interviews of nurses, and subsequently doctors, in an acute cancer unit. This enabled close study of the barriers to nurses' ethical decision-making. The researcher became familiar with individual nurses' perceptions of moral problems and their translation into action. The flexibility of methodological tools used also provided insight into wider organisational concerns, which nurses articulated to influence their practice.

I.3 New discoveries

Given the limits on generalisability in fieldwork, care has to be exercised in evaluating the impact of the findings involved. However, both the length of fieldwork and depth of penetration into the informal networks of decision-making mean that the applicability of these findings can be established by comparing the details of the settings.

This study shows that ethical issues are not readily discussed or actively managed in clinical practice. This is the first observational study to demonstrate, over time, a consistent lack of active decision-making surrounding ethical

conflicts. Contributing factors to this phenomenon include both nurses' and doctors' lack of confidence in the subject matter of ethical debate. There appears to be no clinically accepted language in which to discuss ethical concerns, and so many practitioners do not feel confident to voice genuine moral doubts about the care in which they participate.

The effects of hierarchical decision-making contribute to a culture of care which does not support the asking of questions, and not merely for those with traditionally low status within the system. This is linked to the formation of coping strategies by nurses, over time in the environment, which involve emotional suppression. These promote a lack of engagement with patients and ethical conflicts surrounding their care. The concentration of these conflicts around the transition from acute to palliative care, combined with the problems in articulating ethical concerns, leads to poor decision-making during times when patients are vulnerable and dependent on strong multiprofessional communication. It can be said that, due to the processes outlined by the findings, the lack of management of ethical conflicts directly gave rise to patients experiencing poor deaths, and their relatives a difficult beginning to the grieving process.

Many of these issues have been empirically demonstrated in isolation. This study is able to shed some light on processes which operate to link a range of factors, and contribute to an unhealthy environment for both patients and their health care professionals.

The implications for ethical theory include the role of emotion in perceiving and acting on moral problems. This role has traditionally been devalued and understated, but the findings indicate a more powerful influence than has previously been accepted. A central argument of this thesis is that it is probable that emotion has a critical function in enabling moral engagement. Without supporting nurses and other health care professionals in an area that has been neglected to date, ethical decision-making may continue to be a dormant discipline. The potential implications for patients should press the issue to policy makers, nurse leaders and researchers.

I.4 Structure of the thesis

The thesis begins with a review of the literature in nursing ethics research, examining the philosophical trends that have influenced developing themes. The research amongst cancer nurses is reviewed and central questions for the study are articulated in this context. Chapter 2 sets the theoretical context of the research and explores the methodological approach chosen. Details of the ethical issues encountered in the research, analysis technique and nature of the fieldwork site are also presented.

The length of fieldwork gave rise to a large body of data, and the presentation of findings represent a prioritisation in favour of certain key aspects. The impact on patient care of patterns of ethical decision-making was given a high priority in designing the structure of the findings chapters. Although all the interviews and field note observations were undertaken with a focus on individual values and beliefs, and practitioner perceptions of patients' situations, these lost some

contextual detail in order to highlight the joint effect on patient care. The views elicited and presented in quotes were themselves the product of consistent effort in fieldwork to gain an insider view of the way in which nurses attach significance to certain aspects of patient care. The impact of background training and experience for each nurse was sought as part of this and separately presented in chapter 3.

The findings chapters could rather have involved compiled portraits of each nurse and drawn together conclusions about the impact on ethical decision-making of the interplay of values and beliefs operating. However, the large dataset required choices to be made in order to preserve clarity and the primary messages of the thesis. The interview and fieldnote excerpts were therefore organised to represent a developing argument about the identification of moral problems by the nurses; subsequent patterns of decision-making, and the internal dynamic shared between nurses which served as a barrier to their engagement with ethical issues.

Chapter 3 therefore deals with the nature of the ethical issues identified by nurses on the ward, and the way in which judgements were formed about them. Chapter 4 explores patterns of decision-making in patients' care where nurses identified issues of ethical concern. Chapter 5 identifies barriers to ethical decision-making created by a process taking place within nurses themselves. The three chapters therefore describe what the issues were defined to be, how they were dealt with, and finally explains why. All names of patients and health care professionals

given in the chapters are pseudonyms in order to protect their confidentiality and anonymity.

Discussion of the findings in chapter 6 draws on ethical theory and some theoretical constructs from other disciplines in order to assess the findings presented. Recommendations for practice in chapter 7 give insight into how the findings could be acted on in practice. They also critique the recommendations from a major recent policy document that addresses similar concerns.

1.5 Summary

In summary, this study is an attempt to explore individual nurses' engagement with perceived moral problems as they occur in context. The surrounding influences and effects on patient care are studied as part of a fieldwork analysis involving 18 months of participant observation. Findings suggest that ethical decisions are not made, and that this can, in part, be attributed to nurses' evident pattern of emotional distancing. It argues that the effects are damaging both to nurses and to patient care.

CHAPTER 1: LITERATURE REVIEW

Into the jungle

Introduction

This chapter reviews the literature concerning ethical decision-making in clinical nursing practice. It increases in specificity, beginning by examining broad trends in the discipline of moral philosophy and ethics since 1950, and how these trends have been mirrored in nursing ethics. Assessment is made of the available empirical evidence for the type of ethical decisions faced by nurses and factors influencing the deliberation involved. This culminates in the examination of central studies in cancer care that helped to generate the research questions for this study, and illustrated a gap in the published literature indicating the need for a different approach for research in ethics. It is important to note that the nursing ethics literature is vast and poorly delineated, in that terminology does not have discrete application and abstracts do not always accurately describe the studies that follow. As a result, search terms were necessarily broad. The focus of the review was on empirical studies of ethical decision-making in specific situations of nursing practice.

1.1 Broad trends in moral philosophy and ethics since 1950

Throughout this chapter the terms ethics and moral philosophy will be used interchangeably to refer to the discipline of philosophy associated with moral practice, typically conceived as making distinctions between types of human behaviour that are virtuous or otherwise. Nursing ethics will refer to the rapidly expanding literature in nursing about the ethical implications of clinical practice.

Ethics has typically been conceived of as the search for a theory that systematically applies universal principles to particular cases (Foot 1967). Recently, this approach has generated criticism, and there has been a movement from abstract principle to focusing on common practice. This section will examine the traditional methods of analysis in moral theory, and the opposing approaches that have subsequently become more mainstream. Similar patterns in nursing ethics will be shown in order to give background to current debates in the literature.

1.1.1 Orthodoxy in moral theory

In this section, the traditional approach to moral theory will be located within wider philosophical trends, in order to establish how certain features of the theories were hallmarks of a particular historical period. Conventional ethical theory served to ultimately justify certain moral judgements, and so acted as the final arbiter (Degrazia 1992). It did this by having an overarching, abstract principle that defined what is good, and thus what should be aimed for in ethical behaviour. For example, the ethical theory of 'utilitarianism' seeks to place ultimate value on maximising the greatest good for the greatest number in any situation of conflict (Singer 1993). Kantian 'deontology', as another example, dictates that decisions should be made on the basis of their capacity for universalisation (Paton 1989). Although such ethical theories differ in the requirements of the overarching principle, they share a common approach to the application of the theory to practical situations. This is the rationalist thesis that universally binding fundamental truths govern rational persons and the situations they create. Practical solutions are therefore rationally and logically deduced

from the justifying principle. This methodology itself was consistent with wider philosophical trends at the time, such as the long-standing 'foundationalism' in the philosophy of science (Hospers 1989).

1.1.1.1 Foundationalism

Foundationalism suggests that all enquiry begins from first principles and proceeds to application in practice; moving from a 'rock bottom of basic tenets and hard knowledge' to the everyday (Degrazia 1992). It assumes, therefore, that decision-making can be predicated on *a priori* truths, established without reference to any particular (subjective) standpoint and so revealing the world's pure facts. The objectivity of particular judgements can be asserted by virtue of their deduction from first, factual principles. The criterion of inter-subjective testability (Popper 1968) for scientific credibility is an example of this. According to Popper, facts must be established across individual subjectivities and thus be demonstrated to be independent, in order to eliminate all possible bias from having a particular perspective.

Moral theory has therefore reflected the widespread foundationalist theme, being characterised by a computational approach to deducing norms from justifying principles. It suggests that what moral agents need is an awareness of the principles and the ability to reason in order to apply them in specific circumstances (van Hooft 1990). The field of bioethics has been largely dominated by a principle-based approach, shown by the popularity of Beauchamp and Childress' famous book entitled *Principles of Biomedical Ethics*, first published in 1979. Professionals welcomed this approach at the time

because of the attractive simplicity of the principles and the coherent statement they made about the aims and standards of professional practice (Stoffell 1994). Many of the concepts laid out in the book were used to inform codes of conduct drawn up both by the regulatory bodies for nursing and medicine, and later the Colleges of Surgeons and Physicians (UKCC 1997; General Medical Council 2001; Royal College of Physicians 1997; Royal College of Surgeons 1997). Again, the attraction with codes is of simplicity, clarity and direction; clearly stating to the public, and within the profession, that standards of ethical practice are integral to the overall endeavour. However, this analytical, rule-based approach has become increasingly criticised.

1.1.2 Decline of the orthodoxy

One of the first chinks in the armour of rule-based ethical theory came with the publication in 1958 of an influential paper by Elizabeth Anscombe in the journal *Philosophy*. She argued that ethical theories had not adequately demonstrated their claim for moral authority. She suggested that the imperative to act morally in accordance with the various principles espoused had no greater weight than other, non-moral commands. This was, she felt, due to the abandonment of Judeo-Christian divine law, whereby moral acts had their ultimate justification and compelling nature in God's sovereignty. Without this ultimate backdrop, the moral 'ought' was without power. The reasons for acting morally therefore have an infinite regression, always leaving the possibility of asking 'why not?' when justifying reasons are given. Anscombe suggests that we should return to the use of words such as 'unjust' or 'untruthful,' and avoid terms like 'right' and 'wrong', associated with 'ought' and 'ought not' in their absolute sense. She

asserts that the process of ethics could manage well without them, with less confusion. She also argues that the impartiality of traditional ethical theory renders any kind of action morally acceptable as long as its expected consequences are good enough. Her objection to this is that the motivation for moral action is as important as the action considered alone. It is not absolutely clear from her argument why there can not be notions of right and wrong applied to actions according to their effect on human flourishing, rather than adherence to a universal law. However, Anscombe's criticisms of traditional theory sparked interest in looking for descriptions of how human flourishing could be furthered through moral discourse and action, rather than by the justification of laws and deducing acts from them (MacIntyre 1989).

Many moral philosophers have since claimed that normative or rule-governed ethical theory is unnecessary and also impossible. The issues concerned fall in four central areas: the criticisms from principles; virtue; conflict and abstraction.

1.1.2.1 The criticism from principles

MacIntyre (1989) and others argue that deducing norms from overarching principles does not work in practice because they have different roles. Principles function as a premise in a deductive argument, whereas norms are socially constructed standards that guide behaviour. Principles must be definite in meaning, whilst norms need to be vague in order to have practical application. Many contemporary moral philosophers reject rule-based moral theory for this reason (Baier 1985; Williams 1985; Hampshire 1983).

The same problems with rule-governed approaches to ethical decision-making have been found with codes of conduct (Dawson 1994). Although they may be useful in making a public declaration of intent, their use in arbitrating clinical decision-making in situations of conflict is limited, because of the gap between applying a deductive principle to very particular and complicated situations in which many different factors are operating (Oberle 1993). In order to apply the principle, one would either have to have endless caveats and permutations, or meet each situation's specific circumstances, or be so overarching as to be useless in guiding action. This sense of misfit between principles and norms is noticeable in the nursing and medical ethical literature, especially over the last twenty years. Authors such as Norveldt (1998), Crowden (1994), Lutzen (1997) and van Hooft (1990) have written extensively about the inadequacy of a solely principle-based approach to describe and be useful in dealing with moral dilemmas in clinical nursing practice. Some authors have argued that nursing is so relational and inherently complex that a separate account of moral decision-making is required (Fry 1989). Research in ethical decision-making, although inconclusive, gives a more complex picture than that dictated by a justice or principle-based ethic (Smith 1996). The desire for a separate account shows something of the dissatisfaction with existing moral theory and the lack of authenticity it offers nurses.

1.1.2.2 The criticism from virtue

Rationalistic moral theory has also been criticised for the lack of value attributed to virtues and aspects of moral motivation (Baier 1985). With the emphasis upon independently justified moral principles, virtues become mere aspects of

personality. They may pave the way for behaviour directed by principles, but are necessarily secondary. The moral person is then simply the one who knows and follows rules, and this, to many philosophers, is counter-intuitive (Williams 1985; Elliott 1993). They argue that behaving rightly for the wrong reasons must surely have moral significance. They also argue that beliefs about rules are not enough to motivate action. The role of emotion, character and sensitivity to the vulnerability of others are unaccounted for in rule-based theories. Similarly, virtues that are unrelated to specific principles are left without any merit whatever. For example, honesty and justice can be couched in universalistic terms, as requirements of moral laws. However, virtues such as kindness, generosity and gentleness resist this identification and consequently are not considered appropriate terms of moral assessment. Annette Baier (1985) in *Postures of the Mind* argues that to be intelligently gentle, one takes an experimental stance, attending to the details of the other's response in case of a need to retreat or amend the approach. Behaviour is revised according to the response it receives, rather than rigidly applying principles known in advance. She concludes that there are virtuous practices that are not explicable in terms of principles and thus not accommodated by rationalist requirements. These traits are morally praiseworthy, in spite of this, and excluding them is to take the requirements of rationalism as absolute, when in fact they are far from obvious.

1.1.2.3 The criticism from conflict

Stuart Hampshire (1983), in his book *Morality and Conflict* further criticises rationalism for having too simple an attitude to conflict. Given the methodology of calculation and deduction from abstract principles, it is theoretically possible

for every moral conflict to be resolved. Hampshire argues that because conflict is linked to the conventional status of morality, it cannot be resolved by rational principles alone. He argues that the plurality of conventions in any society means that some obligations and loyalties will always conflict. Rationalists counter-claim that conflict among customs is not important, because they are not shaped by reason. However, simply because some customs have no basis in abstract moral principles does not mean that they are amoral. Many norms and customs are acknowledged by their adherents to be moral, having attitudes of respect and guilt attached to them. Conflict between them is therefore not resoluble by abstract principles. Very often it is necessary to take the approach of Annette Baier and negotiate resolutions which involve the least compromise to each loyalty. This is not to be sceptical about rationality, or about the possibility of truth in morality. However, imposing abstract frameworks to deduce by computation the correct action in any given circumstance, masks the complexity of issues which itself leads to further problems (Mordacci 1996). Thinking there is only one correct answer prevents the search for alternatives that could effectively resolve the conflict with as small a compromise as possible.

1.1.2.4 The criticism from abstraction

Bernard Williams feels that the use of abstract theoretical frameworks employing universal principles drives us to somehow get beyond humanity (Williams 1985). He questions the persuasive pressure toward theoretical structures, asking whether it might have stemmed from the view that the world is as it really is, only when we see it from the outside. Although this might be a proper ambition for some areas of science, Williams asserts that ethical thought cannot similarly

strive towards it. Instead, ethical thought should concentrate more on the realities of being human and some of these alternatives to rule-based theories will now be examined.

1.1.3 Alternatives to the orthodoxy

This intellectual trend away from rationalism has coincided with corresponding developments in the philosophy of science and hence research methodology (Sandelowski 1995), feminist theory (Oakley 1998), literary criticism (Hirsch 1967) and even mathematics (Dummett 1978). The philosophers proposing alternatives are by no means in one mind as to what should replace the previous orthodoxy (Clarke 1989). They differ on which aspects of moral motivation ethical 'accounts' should emphasise. Approaches have centred mainly on those areas that were criticised in previous accounts, and will be reviewed under some of the same themes.

1.1.3.1 The answer from virtue

Many call for some account of human flourishing and virtue, in order to answer questions such as 'why refrain from injustice?' For example, Ethical Naturalism, proposed by Williams (1985), does not suggest that moral notions refer to facts or properties that are distinctively moral. Rather, he sees moral terms as capable of truth or falsity depending on whether human flourishing is promoted by them. The theory accounts for normal experience, whereby most agree that human beings do need structures and standards in order to maintain the welfare of everyone.

Other proponents have argued that more is required when making moral decisions than applying the right principles. In order to establish the relevant moral aspects of a situation, certain virtues are required. Many authors refer to Aristotle, who discussed in *Nicomachean Ethics* the interdependence of practical reasoning and the virtues of character. Although inconclusive about the way in which virtues ought to be accommodated in considering ethical decision-making, these theories have led to an increasing interest in individual character, and those qualities that promote ethical behaviour (Scott 1995a). Van Hooft for example, recommends the Aristotelian view that the task of moral education is to develop the sensitivity to caring that would motivate good behaviour. This education would proceed by three steps; the training of habits, the development of attitudes, and reflection upon one's attitudes (Van Hooft 1990). This is not just a process of 'values clarification,' but of instilling certain values that are agreed upon.

In the nursing literature there is an increasing concern with individual nurses' character, and the way in which they separately encounter ethical concerns (Bowden 1995). This has led to the consideration of how nurses perceive their surroundings and bring their own values and beliefs to bear on situations in clinical practice (Oberle 1995). It is possible to see therefore, how philosophical perspectives have shifted and led to an emerging body of literature calling for empirical studies in ethics to examine the context in which nurses operate.

The inevitable criticism of theories about virtues is that of pluralism. Without certain principles and norms, surely there is no basis for choosing certain values

to instil above others. Having the desire to care at the centre of moral thought does not tell us what to care about and which to put first (Allmark 1995). In this case, the theory is as little able to arbitrate in ethical conflicts as the computational varieties it seeks to replace. Responses have pointed to the possibility of achieving, by empirical research, a moral consensus about which values to espouse (Benoliel 1993). However, little work has been done in this area to date.

1.1.3.2 The answer from abstraction

In answer to the abstract theoretical formulas of the past, other theorists have paid increasing attention to the area of emotion in moral reasoning (Krishnasamy 1999; Glen 1998). They have done so by demonstrating that emotion has a distinct function in ethical responsiveness, a vital feature of ethical behaviour. They argue that the bulk of moral work is done in the assessment of situations, in choosing what is significant, because this determines the action chosen as a result. In nursing research, this difference in emphasis has led to an increasing interest in the way in which nurses actually make decisions in practice, rather than the formulation and testing of ethical protocols which dominated the literature until fairly recently (Bergum 1994).

However, the criticism of this is that the theories concerned are undeveloped and so not useful, and proponents agree that more work needs to be done to clarify exactly what mechanisms operate. However, these theories support the need for more to be known about moral action than mere rule-following, as recommended by Anscombe in 1958.

1.2 Evidence base in nursing ethics

Given these changes in direction, the available empirical evidence for the kind of ethical decisions faced by nurses and the deliberation involved will be reviewed. The trends so far demonstrated are apparent in the changing style and focus of nursing ethics research over time. The review will have a dual purpose of displaying the trend, and also assessing the evidence in terms of what is known to date in three key areas. These are moral reasoning, ethical decision-making and ethical issues in practice.

1.2.1 Moral reasoning

Early research in nursing ethics until mid-1987 was mainly influenced by a positivistic account of morality, and involved attempts to define and measure ethical constructs such as moral reasoning and ethical practice (Liaschenko 1995). For example, in a review of the published research literature and doctoral dissertations between 1983 and 1987 by Ketefian and Ormond (1988), there were 37 studies of which 95% used structured instruments. These studies were attempting to find correlations between reason and action, or to explore reasoning about action, and many used mixed methodologies with the qualitative component being limited to open-ended questions appended to questionnaires. It is unclear how such kinds of methodology allow for the necessary manipulation of behavioural variables. It is well known in anthropology, psychology and other fields that intended action is not a reliable predictor of responses to actual stimuli (Burgess 1989). The validity of the findings of these early studies can therefore be called into question. On further examination, the lack of contextualisation can

be related to the type of theory underpinning the studies (Nokes 1989), and this will be briefly explored.

Ketefian and Ormond (1988) noted that the ethical construct of moral reasoning was generally poorly defined, but that it referred to the cognitive process involved in thinking about 'moral choice.' Many researchers studying moral reasoning were influenced by the work of Kohlberg (1976). He claimed that moral development was sequential and dependent on the individual's level of cognitive development (Kohlberg 1976). He hypothesised that principled thought was the highest level of moral development; meaning, for example, that those adhering to the laws of justice would be more advanced than those appealing to notions of caring. Kohlberg derived his theory from a 20-year longitudinal study of 28 males and their responses to hypothetical moral dilemmas. He maintained that moral reasoning was unaffected by the content or context of a moral dilemma, such as the individuals involved, how they were related, their relative power and where the situation took place.

Studies attempting to apply Kohlberg's theory used tools such as the Defining Issues Test (DIT) (Nokes 1989). This measure takes justice as the central core of morality, and is self-administered, involving stage-related responses to a hypothetical scenario. It therefore continues to reflect a positivistic and abstracted notion of moral judgement. Findings from studies using this test suggest that nurses have inferior scores for moral reasoning as compared with the gold standard of principled rather than pragmatic reasoning (Mahoney 1991). Duckett et al (1992) have raised numerous questions about how the DIT scores

have been used and interpreted in nursing studies. Among their concerns were the use of statistically inappropriate comparisons between raw scores and percentile scores in the analysis, and the comparison of data sets which are not equivalent. They point to the consistently low sample sizes, poor use of comparative groups and subsequent overgeneralization of findings from these studies. For example, Duckett et al (1992) found that DIT scores consistently showed even graduate nursing students to be using principled, or the highest level of, moral reasoning in decision-making less than 30 per cent of the time, which was on a par with junior high school students. Duckett et al (1992) conclude that such findings are unfounded because the groups compared are not similar in experience, educational preparation or gender.

The Nursing Dilemma Test (NDT) is a similar measure to the DIT, and results in principled thinking scores. These again reflected poor moral development in nurses, in fact decreasing with experience and seniority (Lawrence and Helm, 1987). Corley and Selig (1992) found that the NDT instrument had low internal consistency and used vignettes developed in 1979, without any recognition of the changes in US or UK health care in the subsequent 13 years. Again, this might be a reflection of Kohlberg's thesis that logical constructs rather than context are the highest level of moral reasoning, and so the age of the vignettes would not matter. Oddi and Cassidy (1995) further questioned the validity of predetermining responses to questions of what a nurse would actually do when confronted with an ethical dilemma, and felt that the situations included in the instrument were not representative of likely current experience. In fact, it seems plausible to suggest that nurses' scores on these tests were artefacts of an

underlying, prescriptive version of moral development that was not sufficiently sensitive to evaluate other forms of moral development, or to assess the value they may hold. Comparing the findings within and between the NDT and DIT, conflicts emerge as to whether or not there is a positive linear correlation between educational level and scores; about the effects of demographic and personality characteristics on moral judgements; and the positive or negative effect of years of experience on scores of principled thinking. The consistent finding was that of low scores for nurses, but as described earlier this may be due to the influence of Kohlberg's model of moral development rather than the absence of moral worth from nurses' judgements.

Other criticisms of Kohlberg came from studies examining situational factors in moral dilemmas. Rothbart, Hanley and Albert (1986) found that, far from being irrelevent, even the slightest changes in context strongly influenced moral reasoning (cited in Parker 1990). Other studies did not support universal, invariant staging in moral development, and reported shifting stages throughout childhood development.

Authors such as Gilligan gave a feminist critique of the application of Kohlberg's research to women (Millette 1994; Sharpe 1992). Studies attempting to apply Kohlberg consistently concluded that women developed slower than their male counterparts and were less likely to reach moral maturity (that is, the adherence to universal principles of justice over all others). These theorists were criticised for establishing men's experience and competence as a baseline against which human development is judged, leading to a misreading of women (Nokes

1989). Given the largely female workforce in nursing, studies examining nurses' moral reasoning found a similar pattern, in that many 'scored' higher on care rather than justice measures, and conclusions were drawn about the inadequacy of nurses' moral abilities and the implications for nursing education as a result (Yarling and McElmurry 1986). Nurse education journals reflected alarm at these findings, and also at scores that showed experienced nurses to be less morally competent than those nearer their training.

It was not until Gilligan and colleagues pointed to the influence of context, and the more pragmatic decision-making (given low rank in Kohlberg's theory) that is apparent when it is studied, that articles in nursing journals began to query the validity of Kohlberg's model to nursing research in ethics, and to wonder if the right questions had been asked all along (Liaschenko 1995).

Since then the notion that morality is largely a cognitive activity, taking place independently of our daily lives, has been thoroughly rejected by the nursing literature (Scott 1995a). Such abstraction, it is argued, does not describe moral experience, and suffers from the same criticisms levelled at traditional ethical theory (Glen 1998). However, studies as late as the early 1990s still reflect a positivistic, staged approach to moral reasoning in nursing practice (Duckett et al 1992). Even more enduring seems to be the desire to measure and test nurses' responses on the basis of questionnaires, and interviews using hypothetical situations or retrospective analysis that are all removed from practical situations (Stoffell 1994). The problem with this approach is that it divests nurses of their individual history and psychology, and removes the moral problem from the

social contingencies in which it may have occurred. However, most persuasively, results of these studies have been ambiguous at best. Ketefian and Ormond (1988) concluded that no clear trends have surfaced to guide nursing practice or education and Oberle (1995) demonstrated again that little consistency emerges from tests using theoretical constructs dependent on staging and measurement. She concludes that a new theory is still needed, based on narrative and context. Many other authors and researchers now share this opinion (Scott 1997; de Raeve 1998; per Norveldt 1998). The more qualitative studies examining the cognitive processes involved in thinking about moral choice have focused on ethical decision-making.

1.2.2 Ethical decision-making

Early studies such as that by DeWolf (1989) and Ketefian (1981) represented decision-making processes as logically interconnected cognitive process that began with problem identification and progressed to efforts to evaluate the course of action chosen. These studies led to the formulation of decision-making models. For example, Grundstein-Amado (1993) interviewed nine nurses and nine doctors, using in-depth semi-structured interviews, and analysed the transcripts for value statements and the process used to arrive at a chosen course of action. She found that in response to a hypothetical case put to participants there was a five-stage model apparent: information processing; gathering medical information; seeking other sources of information; listing the alternatives and anticipating the consequences. However, when asked to report on situations in their own practice, few of these stages were mentioned in accounts of how resolution was achieved. The general picture that emerged was

that decisions were made in a habitual manner, often eliminating the most demanding aspects of the process. Grundstein-Amado also found that the 'ethical approach' or value system of the individual practitioner had a significant impact on their processing of the situation. The limitation of the study is that self-reporting does not give adequate insight into real behaviour (Seale and Silverman 1997). Simply because certain actions were not mentioned does not merit the conclusion that they did not take place. However, it is interesting to note the difference between responses to the hypothetical scenario and accounts of practice. In this regard, the paper concluded that there may be significant differences between abstract moral processes and decision-making in practice. It suggested that research should focus on the subjective realities of individuals involved in actual decision-making processes, and the value and meaning ascribed to their choices (Grundstein-Amado 1993).

Subsequent studies found veiled hints in narratives that decisions were not acted upon in line with any model or process known to the staff, and that sometimes nurses felt unable to be part of the process at all (Liaschenko, J. 1995; Gold et al 1995). They also suggested that ethical decision-making needed to be studied in context. This section of the literature indicated that there were unclear processes of ethical decision-making, and confusion as to how to deal with perceived issues as they arose in practice (Smith 1996). The findings, taken together, give a sense of the need to study issues in practice connected with professional conflict, power hierarchies and individual reasons for action. Again, this area of research in ethics highlights the need for a different approach to that of soley interviewing or administering questionnaires, because of the lack of data these tools can

provide about the genesis of moral problems, their definition and resolution in patient care.

1.2.3 Ethical issues in practice

'Ethical practice' has been another dominant construct in nursing ethics research. The focus of this is on practical situations, but early researchers attempted to define the construct, and measure it across nurses with different educational preparation and experience, solely by responses to written vignettes. The conclusions of statistical tests in this area were inconclusive, perhaps not only due to poor construct definition, but also because, as exemplified earlier, self-reported reasoning removed from personal involvement can not account for all the variables involved in actual situations (Burgess 1989).

Studies after 1987 began to investigate the way in which practising nurses responded to the actual ethical circumstances in their practice. Work continued to try and measure nurses' judgements using tools based on Kohlberg, but some researchers began to reflect a greater awareness of the formulation of ethical judgements as a process rather than in any single event. In this way studies began to examine different elements of the process, including nurses' initial sensitivity to the moral components of a situation.

1.2.3.1 Moral sensitivity

Many studies have reflected a desire to quantify and measure rather than explore situational or contextual factors. Such methodologies employed researcher-developed instruments and, in published accounts, give little detail on the

psychometric properties of the tests, or procedures to establish content validity. They also reflect a continuing predetermination of nurses' responses, an earlier criticism of tools measuring moral judgements. For example, Raines (1994) gave 331 neonatal nurses a series of hypothetical vignettes and analysed responses by asking respondents to choose from a series of values which would most apply to their response to the dilemma. The values listed reflected commonly held moral principles such as beneficence, or 'doing good,' and autonomy or 'self-rule.' In doing so, she hoped to establish a ranking for the principles and to show which was most commonly held and acted upon by neonatal nurses. However, by listing the values from which they could choose, the nurses' responses were inevitably framed in a certain way. It is possible that nurses may have chosen the values they thought perhaps they should choose, or had to make an approximation to the nearest value to their own response. Given the chance, nurses may not have ascribed their reaction to any one value, but to a combination of many, or indeed without links to any currently recognisable principle at all. They may have introduced other influencing factors which they would need to assess before responding. In addition to the issue of predetermining responses, the problem of absence of context threatens the cogency of the findings. No indication was given as to the length or nature of the clinical and educational experience of the nurses, age, gender or nature of unit on which they were working. This emphasis continues to reflect an abstracted and purely cognitive perception of moral action. In this way, the shadow of Kohlberg's pyramid of moral reasoning, explained earlier, continued long after it's central thesis was rejected by developmental psychologists, feminists and nurses alike. Raines (1994) found that neonatal nurses ranked beneficence and

'doing right' as the highest values in their practice. However, in the second half of the study she asked them to report on behaviours they employed in order to effect resolutions to unspecified dilemmas. Again, the approach decontextualised moral action, but gave at least the freedom to describe behaviours in respondents' own words. No indication is given of how this was translated into the list of behaviours given in the results, but interestingly there was a lack of congruence between the values chosen and the self-reports of behaviours that were implemented in practice. The study leaves us with little to conclude about nurses' moral sensitivity, because it was not itself sensitive to the subtle and involved phenomenon in question.

Studies based on similar attempts to rank moral principles in order to explain how nurses perceive moral dilemmas report different findings. Miya et al (1991) reported that autonomy was the highest value held by nurses, dentists and pharmacists. Garritson (1988) found that beneficence was the basis of responses to case vignettes in her study of psychiatric nurses, but reported that responses were not consistent within subjects or across situations, and speculated about the influence of situational factors. Oddi, Cassidy and Fisher (1995) in their study of 125 registered nurses took a different approach, and attempted to measure ethical sensitivity by presenting nurses with a series of items reflecting situations in nursing practice, for which they were to identify the major type of issue involved. They were interested to see which situations nurses would define as ethical, and which would be allocated to the other options of clinical judgement, communication, institutional policy, or interpersonal relations. They had designed the items so that they should have all been categorised by the ethics

response option. Instead, they found that the highest percentage of respondents selecting this option for any item was 40%. They conclude that this shows a low level of ethical sensitivity amongst the nurses studied. There was a particularly strong overlap of responses to clinical judgement and ethics, whereby items depicting violations of ethical principles were wrongly allocated. Oddi et al (1995) conclude that nurses use a narrow conceptualisation of ethics, and focus on aspects of situations that obscure their ethical dimensions, such as conflict among co-workers, or the need to be professionally autonomous. Although this is an interesting finding, it may be explained in a number of ways other than the suggestions given. Ethics education and, particularly, the continually endorsed focus on principles and deductive moral theory (Scott 1998b), fosters a narrow conceptualisation of ethics. The content of ethics teaching has tended to focus on the very noticeable ethical issues such as euthanasia and resource allocation, rather than the everyday encounters with which nurses also have to deal (Gold, Chambers and Dvorak 1995). It is understandable in these circumstances that nurses should identify only the bigger issues with an ethical dimension. However, the tool used in the study might itself have confounded the findings by not allowing for the allocation of a situation to more than one category. Many communication, clinical judgement and interpersonal difficulties do have an ethical dimension and vice versa. Nurses were not given an opportunity to explore this. Having to make a choice between themes in each situation would force them to choose what they saw as the most overriding feature, and this does not entitle the researchers to conclude that the ethical dimension in each was not seen or accounted for. It may simply be a reflection of the ward culture, for example, whereby communication conflicts and interpersonal issues may receive

greater attention than the ethical dimension. Again, the study reflects an approach to moral sensitivity and action which isolates it from the rest of practice and personality, seeing it as a cognitive ability based on deducing right action from a knowledge of principles.

Davis (1989) concluded from the inconsistency of the available findings about ethical sensitivity that other factors, such as the complexity and uncertainty of clinical practice, may be the most profound influence on nurses' sensitivity to ethics of their practice. Although there have been very few observational studies, it is interesting to note that findings from these have shown a much greater degree of consensus about the factors affecting ethical practice (Oberle 1995; Krishnasamy 1999).

Many authors conclude that a new approach is needed in order to assess these factors (Stoffell, 1994; Gold, Chambers and Dvorak, 1995; Krishnasamy, 1999). Melia (2000), for example, suggests that attention to the 'data' of everyday nursing practice would make a significant contribution to the wider debate about nurses' interaction with the ethical aspects of care.

1.3 Selective studies in cancer care

There is a great deal of empirical evidence to suggest that cancer nurses find many aspects of their work ethically problematic and difficult to resolve (Asch et al. 1997; Scanlon 1998). The complex needs of cancer patients as they approach death, with issues of when to discontinue treatment and how to maintain the patient as the central decision-maker about issues of risk and uncertainty, make

the environment complex and challenging (Greipp 1996). The close involvement of cancer nurses with their patients is highlighted by many authors as significant in this (Ferrell and Rivera 1995). There is evidence of nurses' frustration that they have a limited role in end-of-life decision-making, particularly given the unique and essential perspective they feel able to offer (Asch et al. 1997). There is also evidence that nurses experience confusion as to acceptable goals and processes involved in caring for patients near the end of life (Asch et al. 1997). Studies reveal little social consensus between nurses about these aspects.

A large American study published in 1995 known as the SUPPORT study, documented deficiencies in communication, frequency of aggressive treatments and other aspects of negative hospital deaths (Greipp 1996). The 'Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments' was a controlled trial to improve care for seriously ill hospitalised patients. The observational phase lasted two years and involved 4,301 patients. 50% of conscious patients reported having moderate to severe pain prior to death; 46% of resuscitation orders were written within 48 hours of death (Principal Investigators, 1995). Discussions and decisions relative to death and dying rarely took place significantly before the time of death. Communication difficulties between professionals, and professionals and patients, were identified to contribute to prolonged, painful deaths. Many nursing authors in cancer care regarded the findings as a spur to action to find out and improve the role of nurses in these situations (Greipp 1996).

A recent small-scale but very sensitive study by Krishnasamy (1999) into nurses' views of the moral dimension of their work in caring for patients receiving phase I and phase II clinical trials for cancer, revealed that nurses were working in an environment suffused with moral conflict. They indicated a conflict between caring in a climate of scientific research, between a focus on clinical outcome as opposed to caring for the needs of patients, and a frustration with their lack of ability to influence patient care decisions. The issues designated as priority ethical issues in cancer nursing by nurses in survey research reflect these conflicts (Ferrell and Rivera 1995). The consequences for patients are largely unknown (Krishnasamy 1999) but have been suggested to link to experiences of poor hospital deaths. However, the evidence rests on interviews and surveys which means that the nature of the moral conflicts remain lacking in contextual clarity. The way in which nurses engage with the conflicts is unclear, as are the factors which affect their decision-making. The link between moral conflicts and patient care is also not clearly understood, with many opinions and insights given but little empirical investigation.

1.4 Summary

Trends in moral philosophy and ethics away from the rationalistic paradigm of moral frameworks have been mirrored in recent nursing ethics research. There has been increasing interest in the non-cognitive aspects of responses to moral issues, such as factors affecting nurses' ethical sensitivity. The need to assess the influence of context, rather than to simply measure ethical responses, has been emphasised. However, there has been a continued reliance on methods which abstract moral problems from the environment in which they occur. Little

research to date has attempted to explore the live interaction between a nurse, and a perceived moral problem. As a result, little is known about the factors which affect this crucial relationship.

CHAPTER 2: METHODS AND THEORETICAL CONTEXT

Walking the tightrope

Introduction

'In practice [nurses] have to span a staggering array of things: the physical and existential concerns of the people around us; the unpredicted and the unpredictable…at the academic level, where the discipline is supposed to be articulated and extended for posterity, we face a similarly staggering array of concerns – straddling multiple paradigms and methodologies; diverse and rapidly expanding knowledge bases; and research questions which may have no established trails to guide us.'
Lawler, (1998)

The link made by Lawler between the actual work of nurses and subsequent

nursing research had great pertinence in this project. In order to investigate

ethical decision-making in cancer nursing practice, the research approach needed

to negotiate methodological issues which were similarly multifactoral in nature.

There were indeed few established trails to follow, and little agreement in the

existing literature as to how to proceed in the exploration of ethical behaviour.

The lack of consensus in research design is traceable to current paradigm shifts

within epistemology and hence research methodology, and to the complexity of

the phenomenon in question. These will be explored in the chapter. Research

tools were chosen and adapted in order to balance conflicting needs. These

changed throughout the project, and gave rise to the evolutionary nature of the

approach taken. However, there remained a constant tension throughout the

project. This was the need for individuals to remain the focus of data collection

and analysis, in order to investigate their decision-making, whilst at the same

time acknowledging the dominant social constructs within which the nurses and

doctors were operating. The primacy of the individual versus the collective sits

on the cusp of phenomenological philosophy and social science (Draper 1996b; Soloman 1972). It was here that the greatest struggle of balancing needs was encountered, and this will also be explored in the chapter.

The chapter begins with an account of the way in which the research questions were developed from the literature, and subsequently directed methodological choices. It then falls in two sections. The first outlines the theoretical context of the methods employed in the study. The philosophical backdrop of interpretivism will be explored and key tenets of Heidegger's phenomenology described. Adaptation and application of these to suit the research questions and hence study design will be outlined. The second section describes the research tools chosen and their employment in the research setting. Although the tools are presented as they were used, it is difficult to incorporate the evolutionary nature of their development. They were in fact the result of the way in which the participant-observer role of nurse as researcher developed, and did not take effect immediately in the manner described. This is explored in section 2.9.

2.1 Development of research questions

The literature reviewed in the previous chapter confirms that there is a significant aspect of cancer nursing that is uncharted, unrecognised and ethically problematic. Various questions emerged from reading the literature. Firstly, what do cancer nurses think ethical issues are? And what effect do they have on patients? How are they then dealt with? In this way the focus of the study was the need to explore cancer nurses' own perceptions of ethical issues, and what and how they describe them to be in their clinical situation. The opportunity to

observe the clinical situations in which the issues took place was also indicated, particularly in order to evaluate subsequent decision-making about patient care. The literature suggests that ethical issues are implicit rather than explicit, in that they are likely to be embedded in individual practice and perception rather than overt (Oberle 1995). It became clear that the moral domain of cancer nursing needed to be identified *in situ*, in order to access situation-specific meanings. This is in contrast to approaches which foster an external, quasi-objective perspective, which had been the style associated with the prescriptive, question-begging frameworks and moral reasoning measurement tools. In the past these methods had relied on a tradition of empirical work based on hypothetical rather than contextual scenarios, and a propensity to artificial measurement. They had yielded inconclusive statistics and lists of problematic situations. They had also failed to deal with the pressing issue of individual differences in values and beliefs in the area of ethical decision-making.

In addressing the questions raised, two related lines of enquiry emerged. The first was the need to become acquainted with the clinical situation in which nurses were operating. The second and related line was to explore how individual nurses understood the notion of ethical or moral, and how this was incorporated into their work. In this way, the study of ethical decision-making could be made contextually relevant, and individually focused so as to enable belief-orientated decision-making to become accessible.

2.2 Choice of method

Qualitative approaches allow for the exploration of individual and social attribution of meaning, and are particularly suitable for examining the way in which different people experience, interpret and structure their lives (Burgess 1989). Within this, an interpretive, participatory approach was chosen, because of the need for flexibility in order to explore individual perception as a basis for analysis, and at the same time to witness those perceptions at work in the moral conflicts occurring in the clinical situation. The aim of this was to see how nurses construed their work and the decisions that presented, rather than to measure what the nurses said against what they actually did. In order to ensure cultural and related aspects of the work would be included in the account, participating in the environment in which nurses were working was essential. This was a key requirement given the suggestion in the literature that accounts of ethical decision-making lacked substantiality and relevance because of their removal from the situation causing concern.

I wanted to be able to have access to non-verbal, day to day working forms of communication, because others had found them to be rich sources of insight into nurses' knowledge of patients and situations. For example, Reed found that nurses find it difficult to articulate many aspects of their work (Reed, 1994). There is evidence too that nurses work with their thoughts and emotions (Savage 1995) and in their nursing actions 'speak' their concern and values. Similarly, research in the broad area of nursing epistemology has highlighted the issue of 'embodied knowledge' (Lawler 1991). This is the idea that nurses combine knowledge of the physical body with an appreciation of what it is to live in them.

Savage (1995) argues that this knowledge is shown in various types of communication:

> '...nurses' use of forms of communication (such as touch or forms of rhetoric) helps to reveal the embodied knowledge on which much of their practice rests.'
> Savage (1995)

Without being able to witness nurses' actual practice it would not be possible to ascertain the role and affect of such knowledge and communication on ethical decision-making.

There is a related theoretical issue about the best means to access individual perception. Traditionally, this has been by the open-ended qualitative interview (Mishler 1986; Packer 1991; Riessman 1993) with the assumption that the 'life-world' is told in narrative discourse. This method has almost exclusively dominated social research aiming to explore the *emic* perspective (Lincoln and Guba 1985). Atkinson and Silverman have recently criticised this as a romantic trend of:

> '...celebrating the interview and the narrative data it produces as an especially authentic mode of social representation...[which] reflect a more general Zeitgeist...cultural phenomena that constitute an interview society.'
> (Atkinson and Silverman, 1997: 312, 313)

Their concern is that researchers have endorsed the values of our contemporary 'confessional' culture without scrutinising the special significance attributed to narrative. They argue that narratives construct rather than reveal selves, and we

should be looking to see how they do this, rather than assuming they provide privileged access to the inner self. However, in fairness, many researchers have been willing to openly consider the constructed nature of an interview. For example Mishler (1986) acknowledges that interviews are an artificial environment and not a guarantee of access to the inner world of the respondent. In fact, current methods of narrative analysis assume the construction of narratives both by the researcher and the participant (Paget 1983) and use the evolving dialogue as the base for analysis. However, there is little justification for arguing a special access delivered only by the interview. This suggests a mind/body split in which the real self is found in thought and verbal expression, whilst action is simply the place where this is worked out.

Although many qualitative research methods detailed both verbal and participatory tools for data gathering, several would not give the flexibility to explore individual perception as a basis for analysis. Methods drawing on symbolic interactionism and social realism (Strauss and Corbin 1990; Miles and Huberman 1994) relied on ideas of construction which I felt would not provide an adequate backdrop to the study of individual values and beliefs. Problems in dealing with ethical issues were identified in the literature starting with differences at this level, rather than being mainly defined by social boundaries.

2.3 Interpretive design and philosophical background

Looking at the broad area of interpretivism revealed a more integrated approach to the study of values, background practices and thought in action. Interpretivism is often represented as a particular set of techniques for gathering and analysing

data, but the focus is not so much on methods *per se* but on epistemological assumptions about the nature of knowing and being (Wolcott 1994). Rather than aiming to identify the problem in isolation from its context, such as in critical reflection (Denzin and Lincoln 1994), the broad emphasis of methods under this umbrella is the need to explore phenomena of experience as lived, from the point of view of those who live in it. They share a goal of understanding lived reality and situation-specific meanings (Schwandt 1994). Attendant to this is the requirement to understand how the meanings are embodied in the language and actions of participants, by a process of interpretation. In this sense research becomes a construction of the constructed realities studied. I found these concepts useful because of the emphasis on the derivation of meaning from individuals within specific situations, acknowledging that the two shape and form each other. I felt that the study of ethical issues in clinical practice had suffered from a lack of emphasis specifically in this area.

Within the interpretive movement itself there are different theoretical orientations, many of which reflect a tension between celebrating the priority of first-person, subjective experience and then disengaging and objectifying the experience. For example, in their desire to be objective about people's subjectivities, LeCompte and Preissle (1993) argue for a 'middle ground' of methodology, whereby judicious use of method helps to avoid the subjectivity of inquiry. In this way, they assert, studies can be assessed for their objectivity and thus credibility. It is strange to note the desire to retain the scientific notion of objectivity, whilst rejecting the methods of natural sciences as capable of human inquiry. Having acknowledged that individuals occupy a particular standpoint

within the world, they and others (Omery 1983, Benner 1994) proceed to investigate this using a concept of objectivity which is reliant on the accumulation of knowledge by removing particular standpoints, in order to assess what is real about the world (McDowell 1978). The aims of this notion of objectivity and human inquiry will therefore conflict. This is not to suggest that the rigour or value of studies can be overlooked in interpretive inquiry. It is simply that traditional objectivity cannot apply when researching individual experience, because this objectivity is committed to eradicating the particular nature of experience in order to get at the real facts. I found that there were philosophers, notably Martin Heidegger, who denied the opposition of subjectivity and objectivity by looking at the very nature of 'being'. In his account, and in work that drew on it, I found a backdrop for the study of individuals and environments without the dualism that had affected so much prior work.

The clues I took from Heidegger's approach are centred around his analysis of how we understand and interpret ourselves in the world in which we find ourselves. The term *'being in the world'* is a central concept representing the unity between ourselves and the 'world' (Soloman 1972). World in this sense is constituted by things that have significance for us, pointing back to our being, our *Dasein.* In this way existential phenomenology is not merely concerned with interiority, but with people as 'situated,' in the world. For Heidegger, existential meaning is to do with temporality: choosing possible ways-to-be in relation to the way one-has-been. The choosing of 'how to be' is unique to each person and raises the interesting notion of authentic and inauthentic voice. Heidegger means

by this the choice facing each person either in 'taking hold' of their future possibilities; or following cultural norms and fulfilling societal expectations. The latter is, according to Heidegger, inauthentic being, where the genuine voice of the person is not heard. Nurses' lack of voice is a frequent and recurring theme in nursing literature (Rodney and Starzomski 1993). Constraints are often mentioned in anecdotal reporting of ethical dilemmas (Rayfield 1998; Smith 1997). Heidegger's theoretical framework offered a structure in order to approach these issues.

I was interested both in Heidegger's subject matter, that of existential meaning and significance, and also his approach to analysing this. Broadly speaking, it is a hermeneutic exercise to interpret the meaning given to things. This is in contrast to methods isolating social relations without taking note of subjective concerns. Heidegger argues that it is by studying the involved practical viewpoint of people in situations that meaning and significance can be examined. He therefore insists that we return to the phenomenon of everyday human activity.

According to Heidegger, there is no such thing as an investigative process which takes nothing for granted. We must already have some understanding of something in order to question it. In Heidegger's account, all comprehension relies on pre-conception, and so interpretation is an essential business (Dreyfus 1991). Finding in these concepts a powerful analysis and focus for researching perception, I began to look around for a methodological application.

Reading the work of researchers such as Tina Koch (Koch, Webb, and Williams 1995) and Peter Draper (1994) were convincing in their application of a methodology from Heidegger's phenomenology of Being. The methods used by these researchers had provided a platform for a richer analysis of multiple perspectives, compared to other researchers in their field employing methods with less emphasis on individual perception. The voices of participants were clearly apparent even in the final analysis, and understanding was gained of these people's situations which was not merely descriptive. Having seen the benefits of the approach, I further examined the use of methods drawing on phenomenology in the nursing and psychotherapeutic research literature. In agreement with others, (Cash 1995; Paley 1998) the review was disappointing in the way in which many of the studies had, far from offering a more penetrating analysis than other methods, seemed to offer no analysis whatsoever. There were often exhaustive descriptions of particular experiences without any interpretive commentary or background context to give the reader a handle on the narrative extracts.

However, rather than reject the method itself, it was important to explore how the philosophy could be applied more usefully, as in the work of Koch (1995) and Kaufman (1988). I decided to begin by addressing the main criticisms of methods drawing on phenomenology, which were highlighting the weaknesses of published studies. There were three central areas of concern in the literature: the question of interpretation; the question of reading minds; and the question of culture, time and place in the research account. These will be addressed separately, along with the adaptation designed for the project.

2.3.1 The question of interpretation

Despite its interpretive claims, methodologically it is unclear in many phenomenological studies how the process of interpretation is to be done. In the literature this seems to be part of a bigger problem, in that researchers have often assumed an uncomplicated leap from philosophical claims to research practice. Very often there is no clear link made between the two. Philosophical phenomenology gives clues as to an approach to being-in-the-world but the method it proposes is not empirical. The problem is to translate these clues into a research design that carries them forward. Instead, many articles claiming to draw on Heidegger described their philosophical basis, and then immediately presented a version of textual analysis followed by the presentation of themes (Benner 1994). This is no different to simplified forms of narrative analysis (Riessman 1993). Often there was no account of the interpretation of meaning, as phenomenology would imply. There was also no account of how the philosophical nature of human *being* had influenced the process of data collection and analysis. The term phenomenology was just a label in these studies, and the findings rarely gave anything other than descriptions of sense experience (Grieder, 1998). There was little insight or genuine analysis to be gained from reading the reports.

I chose to approach this by using Heidegger's work as a series of clues rather than an entire philosophy which had to somehow be superimposed on the project. I adapted known research tools to fit this purpose. The notion of interpretation was used to highlight the need for and inevitability of researcher involvement, to come to understand personally the situation and environment of the participants.

The different elements of it were used to point to the various places where attention needs to be focused: on the participants' past experience and future aims, on how these shape their present perceptions, and on how they relate to group structures. Interpretations can be erroneous, and they were checked with participants on an ongoing basis for this reason (Clifford 1983).

A second and related feature was the way that interpretive work in phenomenological analysis was often obscured by the detailing of validation measures. An example of this is the use of external auditors to verify that findings represent participants' experiences (Benner 1994; Bowden 1995). However, if phenomenology is an interpreted account of understandings, an external authority cannot validate the subjective meaning attributed to events by participants. Forms of member-checking were adopted to address this more appropriately. This technique involves giving the members of the study from whom the data was collected the opportunity to react to developing analytic categories, interpretations and conclusions. This occurred both during the data collection as analysis was concurrent, and also at the conclusion of the fieldwork stage. According to Lincoln and Guba (1985), the process is essential for research which claims to describe individual experience:

'If the investigator is to be able to purport that his or her reconstructions are recognisable to audience members as adequate representations of their own (and multiple) realities, it is essential that they be given the opportunity to react to them.'
Lincoln and Guba (1985)

The process occurred both informally and formally in the study, with the majority taking place during the data collection. Validation was therefore sought from those whose views and experiences the project was aiming to represent, rather than an external authority. The procedures involved are discussed in section 2.6.2.

The problems with interpretation feed into a further critique of phenomenological methods in the literature known as descriptivism (Burrell and Morgan 1979). This states that because the accounts of experience are inherently 'respectful' to participants, subsequent reports lack critical purchase. Silverman (1993) suggests that the reason for the disappointing lack of analysis in the studies is a fear of distorting participants' views. As a result, nurse researchers present sense experience as inviolable truth, reasoning that because participants are giving an interpreted account of their understanding, it cannot be subject to external critique (Benner 1994). If a person said it, then that is all there is to say. It is easy to see the tension between cross-case analysis and the need to preserve the 'face' of the individual at the same time (Hallett 1998). I chose to deal with this by questioning whether the analysis had to be cross-case. Instead I analysed multiple perspectives for types of experiences which were first developed at the individual level. In the analysis, field notes from participant observation were used to ensure that relevant features of the research setting were used as context. This was a vital means of 'fleshing out' the meaning of colloquial terms and gaining understanding of participants' work situation. Known aspects of the research process were also used, such as the difference between public and private accounts (Cornwell 1984), in order to design and carry out the

interviewing and observation. Rather than jeopardising the individual

contribution, this was important to developing a critical analysis, given research

access to multiple perspectives and the social environment. This interpretive

effort was then given back to individual participants for validation purposes. In

the end, interpretive research would be self-defeating if the end product were not

a synthesis of both the researcher's interpreted analysis and participants'

feedback. This is because philosophical concepts about the way we experience

the world around us apply as much to researchers as to those taking part in the

research.

2.3.2 The question of reading minds

The second strand of criticism was a concern with the aim of phenomenology,

both as a philosophy and as a base for qualitative research, of laying out the

nature of a person's world – that is, how they have understood it. The criticism is

that, if the researcher always comes across things because of interpreted

significance, as Heidegger puts it, they cannot then claim to lay out the nature of

another's 'world,' and how they construe it. Schwandt replies to this problem by

turning the question on its head, asking if there is any qualitative research that

does not in fact rest on an interpreted account of the participants understanding

(Schwandt 1994). There can be no unmediated access to views and opinions,

experiences and values, and nor can they be excluded from responses. In that

sense I could only write with authority of my opinions and views. I concluded

that the end product can only be an approximation. Within that I took several

things into account. Using participant observation meant that the interpretation

was not based on verbal expression only, which has been highlighted earlier as a

difficulty when working with nurses who feel disempowered and unseen (Reed 1994). I explored ways of complementing this approach, such as entering the nurses' clinical situation and becoming part of it. This was used as another means of establishing a participant's worldview and having a sufficiently individualised context in order to do so (Burgess 1989). It also meant that multiple methods of data collection were employed, and links between them were formed in the analysis (Fielding and Fielding 1986). In this way a broader account of participants' understandings was achieved.

Having acknowledged that as a researcher I was far from being a blank slate for others' experiences, it became clear that having a nursing background was useful in developing trust and acceptance amongst the staff on the unit. This was because I could understand how to participate and help, signalled by wearing uniform. It was possible to identify with the work they were doing and the issues being faced, having been in similar situations myself. Access to the participants was therefore made easier by trust and a strong sense of identification. This has been documented as a positive feature in other research studies undertaken by nurses in hospitals (Savage 1995). The problems with over-familiarity are also well documented (Kleinman and Copp 1993). They are discussed in section 2.6.2.

2.3.3 The question of culture, time and place

The third strand of criticism was the concern over the way in which time, place and culture are not paid due attention in phenomenology, given the emphasis on the life-world (Latimer 1998a). This encapsulates the overriding problem stated in the introduction, which is the need for individuals to remain the focus of data

collection and analysis, whilst accounting for the social constructs within which they are operating. Looking at culture, time and place was essential in order to lay out the influences perceived by the individual nurse, and to examine how they established themselves in the 'everyday', or 'the they' as Heidegger puts it. However, the approach was different in focus to a study of social practices. The project aimed to look from the individual perspective out, and this is a complement to other approaches. In order to bring sociocultural issues to the analysis, the links between the field notes and interviews were explored and used to create a single text for each participant. However, the pervasive influence of such dominant constructs as ward hierarchy, coping with death and dying, and compliance, featured strongly in the field notes and interviews. It was difficult to avoid using these as the base for analysis rather than individuals' perception of them. In reality, the two were held in tension throughout the project. This was to acknowledge on the one hand that there are no 'anonymous structures' without people (Grieder 1998) and also that individuals perceive and are affected by communal or traditional ways of dealing with certain activities. Throughout, an attempt was made to approach the issue from the perspective of each participant before discussing wider application.

2.4 Research tools

Many of the data collection tools used in the study are employed in research approaches other than phenomenology. For example, observation-participation is commonly used to examine the generation of particular cultures, and their impact on the behaviours of members. The aim of involvement in the field, in these studies, is to become familiar with shared practices, and the social construction

of identities within societies. However, the approach of this study is influenced by a phenomenological commitment to the way in which individuals construct their situation, rather than the way in which the social environment constructs individual identity. This involves a reverse orientation: the source of data is the individual's perceptions as opposed to the constructed social environment.

In order to reflect this, the researcher aimed to participate in the work of the ward to gain familiarity with the everyday experiences of nurses, and also to develop trusting relationships. These aspects of integration into the ward facilitated access to nurses' expressed and enacted values, and particularly to the ways in which they attached ethical significance to certain aspects of patient care. Data collection was focussed on the way in which nurses made sense of their environment and responded to it. In practice, this meant active prioritisation on the ward in favour of time spent alongside individual nurses in the course of their work. Strategies to observe ethical decision-making were undertaken from this starting-point, progressing outwards to shared understandings of ward culture.

The methods used in the project were therefore designed by considering what I was trying to find out, and where attention was to be focused, directed by phenomenological concepts. This was done by reviewing the deficiencies of previous attempts and returning to the philosophical roots of the discipline in order to trace other possible routes of application. Tools were chosen which would fit the philosophical premise, that is, an overriding principle of understanding how participants interpret their experience. These were, broadly speaking, participant observation; including the shadowing of individual nurses,

and the tracking of patients whose care was identified to involve an ethical concern. Focused interviewing with cancer nurses and associated doctors was also employed. All of these methods fit into the broad category of field research (Burgess 1989). The joint focus in these approaches is on research strategies which allow the researcher to learn about the social world at first hand (Hammersley 1995). However, it is not merely the techniques of doing research but rather the cultural perspective with which it is undertaken which distinguishes the approach for this project from ethnography or social anthropology, although the overlaps are considerable. Each tool has its own theoretical history and has often been traditionally aligned within certain discourses, and I will show how they were used to support a phenomenological approach in the project design.

2.4.1 Participant observation

In accordance with the aim to study both non-verbal and verbal interchange, and by doing so to gain access to nurses' perception and experience of ethical issues in practice, I reasoned that it would be necessary to become involved in a personal way on the ward. Rather than merely observing, it was necessary to develop relationships with participants which would support the exploration of beliefs and perceptions of current events. Given that the subject matter in question could potentially involve issues of practitioner's standards of care and even personal morality, it seemed sensible to assume that as a stranger and outsider, accounts would be likely to reflect the public rather than private perspective (Cornwell 1984). By having access to practitioner's daily lives on the ward it would be possible to gather accounts of situations in their own language,

and hence to concepts used in the everyday (Burgess 1989). The participatory approach is also supported by notions of 'radical empiricism' (Mishler 1986) which suggest that knowledge gained by the researcher's participation is just as important as that gained by observation. It is based on the idea that using one's body as others do mediates a 'personal realisation of social values' and may lead to new understanding of their verbal statements and ethical views (Adler and Adler 1987).

In contrast, field methods were traditionally aligned with anthropology in the study of cultures to which the researcher was a stranger, and were a rite of passage for anthropologists, involving living in another culture, becoming a friendly stranger and participating in activities wherever possible. The aim was to live like the hosts as well as among them (Burgess 1989). Gradually, interchange between social anthropology and sociology led to the use of field methods in the study of cultures closer to home, shown famously in the study of inner-city Chicago in 1916 by the founders of the Chicago School of Sociology, where anthropological methods were used which had originally been developed to study North American Indians. However, many researchers were still 'outsiders' to the groups studied, in that the focus was on groups of whom the researcher had little or no experience, whether this be by virtue of class, profession or location. Considerable difficulties were encountered in crossing the gaps, and accounts were clearly from an outsider's perspective and could not claim to represent the experience of workers themselves. In the last two decades there has been increasing interest, particularly in the sociology of education, in the social processes and perspective of participants. Although this was from an

interactionist perspective, where people are seen as social actors, co-creating meaning, it is also conducive to a phenomenological standpoint. It represents a general move away from the researcher as an outsider, with the corresponding desire for an 'objective' account, to a focus on accessing the participants' view of reality by sharing the same language and sociopolitical context. Researchers researching their own culture has gained currency and many participant observations studies in nursing have exemplified this (Smith 1992; Savage 1995).

Participant observation continued for a period of eighteen months, during which time I became increasingly identified as a part of the ward team, and this was often explicitly stated by nursing staff. As the main research instrument, I have had to write myself into accounts of the research. This is a key feature of the reflexivity associated with participant observation (Savage 1995). It involves acknowledging that the relationship between researcher and researched is a vital source of information because the findings will be significantly affected by it (Ball 1990). Many texts suggest that making this relationship explicit helps to show how interpretations of the data are reasonable, and acts as a form of self-monitoring for the researcher, so that errors are minimised. By detailing the development of the field relationships it is also possible to make explicit the impact of the researcher on the field situation.

The gradual integration and my own identification with the nurses in the study is described in section 2.9. This 'research biography' is based on a journal kept

throughout the period of fieldwork, in which methodological choices and personal reflections were recorded.

2.4.1.1 Conducting the study

The hospital chosen for the study was familiar to me, from previous experience working as a Staff Nurse, although never on the ward where the research took place. I had support from senior staff within the School of Nursing and Midwifery, who put me in touch with the Trust's Director of Nursing Research. She was a guide through the initial stages of meeting the Lead Nurses for the Cancer Directorate, and preparing the submission of the study to the local Health Authority Ethics Committee. During these meetings, approval was gained for the aims of the study and intense discussion took place about the nature of my involvement on the ward. An honorary contract was arranged between the School and the Trust in order for my actions on the ward to be professionally indemnified.

One ward was chosen rather than two or three, or a multi-centre approach, because of the naturalistic ethos of the project. I wanted to be able to become immersed into the ward culture and to gain access to beliefs and values, and also to ascertain features of the ward that were consistent over time. In doing so, Burgess argues that field studies gain validity because the researcher is exposed to participants over a prolonged period, and is less likely to make erroneous and unsubstantiated assumptions (Burgess 1989).

The ward was chosen because it had a reputation within the hospital for high standards of patient care. I had gathered this from informal conversations during work as a Staff Nurse, and also from the School's audits of clinical areas to which I had access whilst preparing for data gathering. Given the aim to explore cancer nurses' perceptions of ethical issues, I did not want to study areas which involved poor standards of patient care because these would be immediately apparent, rather than the more enduring features of caring for dying patients. My focus would be drawn to lapses in clinical standards and the dilemma of whether to take action about them, rather than to the consistent moral concerns which the literature suggested (Benoliel 1993).

Although the Lead Nurses offered to approach the Ward Sister, I approached her myself as there are known dangers in field research of being associated with senior management figures at the outset. For example, Whyte (1989) describes how association with a senior figure led to accusations of being a spy and delayed access for many months. Instead, I sent the Ward Sister details of the study along with letters of approval from the lead nurses. During a phone call and then interview, she was welcoming and approved of the study aims. I attended ward meetings at her suggestion, and informally presented the project to nurses working on the ward. I did this at several meetings in order to accommodate shift patterns. There was a positive response, and gradually nurses began to ask when I was starting. They particularly seemed to welcome the idea of research which would come to them, rather than be 'removed' and alien, and also on a topic which was close to their practice and not about skill mix and competencies, which had been associated with staff cuts. At this point, I gave

nurses information sheets and consent forms and asked them to give their consent to my participation on the unit. Later I found that the Sister had been responsible for 'championing' the project through these early stages. She was a respected leadership figure and I found that she had spoken about the project informally and at team meetings, encouraging involvement in it as good for nursing and positive for the ward. As a result, there was a snowballing of approval for the study and my presence, as information about it was passed on by word of mouth. This proved to be an important clue for tracking decision-making processes in later work.

When I had received consent forms and had opportunities to discuss the research with each nurse individually, I attended lunchtime handovers to begin integration onto the ward. I took field notes during these meetings, which did not stand out as different as it was common practice for nurses to take notes during these meetings. I wore uniform whilst on the ward, with a 'Research Nurse' badge, and found that the dress had a currency which greatly facilitated relationships. Whatever else I might be, they knew that I was qualified as a nurse and this provided instant rapport.

After two months of attending handovers, I was spontaneously invited by the staff to join them for shifts. Burgess (1989) emphasises the need for the field research role to be flexible and responsive. He notes the way in which negotiating access may progress differently with different individuals within the setting. Research accounts are often presented as linear progressions from total stranger through to total participant, but Burgess asserts that this is an idealised

rather than genuine reflection of the case (Burgess 1989). My participation on the ward was a substantial step for the nurses concerned. For this reason, starting was delayed until the majority had accepted the project, shown by a group invitation to begin the next phase on the ward, with which they were familiar from earlier information given about the study. However, there were differing levels of acceptance across the team, and at times it was difficult to ascertain whether some nurses had given their genuine consent to my presence, or had rather complied with the general feeling of positive endorsement the project received. Resolution of this concern is further discussed in section 2.8.

Field note taking centred on a form of 'moral witnessing' (Fox, 1997). This involved noting resistances, impasses and problems relating to ethical concerns, such as the degree to which people can and do talk about them. It involved observing what happened when the issues were raised, and what is conceived as ethical. It allowed me to observe critical incidents from an inside view of the world of nurses. Field notes were recorded using Labov's (1972) approach to structuring personal narratives (appendix A.3). These have the aim of constructing a story from primary experience and interpreting the significance of events in embedded evaluation. He argues that narratives have formal structures which include an abstract or summary of the narrative, an orientation giving details of the situation and participants, the sequence of events, an evaluation of the significance and meaning of the action, a resolution, and a coda, which returned the perspective to the present, specifying implications for how to proceed with the research. I found that structuring my observations in this way

helped me to 'process' the day, to work out what I had interpreted from what, and to give a rationale for selective recording.

Another aim of early fieldwork was to learn about the organisation of care, nursing culture, leadership and type of care that was encouraged. It was also to literally share in the nurses' practice and everydayness, to gain background to their perspectives. I found that the nurses and doctors on the unit were welcoming and open, identifying that the issues I had come to study were pertinent and challenging. Throughout this period I was aware of a sense of having touched a 'raw nerve,' and interestingly this never eased.

After six months of working within teams, I began to work alongside an individual nurse each shift, to witness the practices involved, come to interpret his or her understanding of situations as they arose and also record what I perceived them to be. 18 nurses were shadowed in this way, for 2-3 hours at a time, on approximately 10 occasions for each nurse. This proved to be more demanding initially, as nurses felt they would have nothing to tell me and feared that I would see no significance in their work. The information sheets and informal conversations had stressed that the research was not designed to evaluate them against pre-determined criteria, but to share in their work and how they perceived it. However, nurses' fears of not being significant, which proved to be a key line of enquiry, were resistant to reassurance and in the first instance shadowing was kept to a few hours at a time. As the relationship with each nurse grew, shown by invitations to nights out and leaving parties, a sense of working together rather than shadowing took place. Nurses would then ask me to stay and

sometimes resented my attention being given to another activity in which they weren't involved. I found I was often used as moral support when meeting the doctors, and increasingly I was asked for an 'ethical opinion.' The process of gradual integration was fruitful in making the research (and researcher) less threatening, and in gaining access to the private world of nurses. The problems associated with becoming involved to the extent that I did are explored in section 2.9.

Another line of enquiry included during data collection was that of tracking patients whose care nurses had identified to involve an ethical dimension. The decision-making surrounding 15 patients was observed. The data collected was no different in nature to any other part of the field analysis, being mainly comprised of nurses' perceptions of the patient's care, and subsequent decisions. This enabled links to be made between individual perceptions, styles of decision-making and their effects on patient care. Observations were recorded in the field notes. It was therefore possible to 'track' decision-making across several days or weeks in the field notes, and build this into the overall data set.

2.4.2 Interviewing

Interviews took place with the same 18 nurses I had been shadowing. The purpose of this was to ensure they were familiar with me and felt able to discuss their feelings freely. I returned to shadowing them after the interview, so that contextual data would provide a commentary on what had been shared. The interviews provided an opportunity for nurses to talk further and explore areas of concern in their field of practice. Many texts on interviewing suggest that

meaning is jointly constructed between interviewer and respondent (Mishler 1986), and this came to have more and more pertinence for me. I found that unstructured interviews in the area of ethics, where language is such a problem anyway, were not empowering nurses to express their experiences. I found instead that questions and responses were developed and shaped by dialogue between us. I don't mean that I was sharing *my* experiences but that by listening to the answers to questions, it was possible to see their interpretation of the question, and to let this shade the meaning constructed. Questions became part of a circular process in this way. By recording details such as pauses and emphasis in the subsequent transcription, it is possible for this process and the developing meaning to become clearer. After the interview I would return to working alongside the nurses. In this way a broader understanding could be gained, and there was more opportunity for nurses to continue to speak about issues they had often considered openly for the first time in the interview.

The 18 taped interviews with nurses varied in length from 1 to 3 hours. They were taped, with permission, to allow for greater depth of analysis than written notes. The tape also meant that I could be free to engage with the participants, rather than be concentrating on recording their answers. The grades of nurses reflected the ward team, being two senior Sisters at grade G, two junior Sisters at grade F, six Staff Nurses at grade E and eight at grade D. There were 17 female nurses and one male nurse. Informal, untaped interviews took place with five doctors, where each grade was represented from House Officer to Consultant. There were three male and two female doctors. The interviews were not taped, because they were considered to be part of the background to nurses' experience,

rather than a key focus of analysis. The permission to tape had also not been obtained from the ethics committee.

2.5 Analysis

The data reflects approximately 156 full shifts of observation participation. In addition, there was observation at handovers prior to active participation, and attendance at ward meetings and other events in the period of withdrawal from the ward. In total, this approximates to 1230 hours of exposure to the research site. Narrative presentations of shifts, in the form of fieldnotes, were approximately 1,000 words in length for each shift, giving a body of data of 160,000 words. This includes the patient tracking data, and notes from shadowing individual nurses. The journal kept to record methodological decisions and personal reflections amounted to 50,000 words.

Interview transcripts ranged in length, and some of the longer ones could individually amount to 8,000 words of text. Together, the 18 transcribed interviews amounted to 77,000 words of data.

The data set was therefore large and unwieldy. A priority was to impose some form of order on it, and this was done by importing the documents into a computer software program designed to assist with qualitative analysis. NUD.IST, standing for non-numerical, unstructured data, indexing, searching and theorising, allows files to be stored and electronically linked to each other. In the first instance, it operated as a filing system where the raw data could be kept

in one place, rather than in many different files, and where parts of the data could be found by a variety of different search terms.

Hermeneutic analysis, which was originally a method of studying biblical texts, was used to analyse the transcripts and field notes. This draws on phenomenological concepts to focus the analysis on the way in which individuals construct their experiences. The primary goal is to work with data within the 'first horizon' of individual context, in order to control the way in which derived concepts are applied (Riessman 1993). This avoids the temptation to link superficial similarities between nurses, and generate conclusions that lack depth. The analysis involves a method of 'harmonisation' across different data sources with the aim of building as complete a picture as possible of the individual's perception of events.

In practice, this meant analysing the interviews separately, compiling fieldnotes and journal entries that applied to the individuals concerned in one place in the software program. The observational notes and details of informal conversations were used to add background and context to nurses' descriptions of ethical issues and the actions subsequently taken. Recurrent themes in individual nurses' accounts were first substantiated within the body of data for that individual. For instance, a key finding was that of nurses' feelings of inadequacy to express an ethical opinion. This was visible across many data sources for each nurse; directly in their interviews, indirectly in practice on the ward as they clearly held ethical opinions in certain instances yet felt unable to express them; and again in informal conversations during fieldwork. Harmonisation meant holding these

aspects of the data together to build a bigger picture than any one source could have provided. Once a finding of this type had been drawn from one individual, it was possible to link with other nurses' accounts to see if it was substantiated across individuals. The phenomenological emphasis on the individually constructed lifeworld therefore gave the analysis direction and consistent focus.

Riessman (1993) argues that analysis is not easily distinguished from transcription, and that arranging and rearranging texts in the light of our discoveries tests, clarifies and deepens our understanding of what is happening. Analysis involves asking questions of the data, such as how is it organised; why is it developed in this way; starting from meanings encoded in the talk and bringing to the interpretation the social, cultural and institutional discourses in which they are situated (Riessman 1993). Themes were developed from experiences that were common across nurses, but which had first been identified by exploring each nurse's individual understandings and behaviours.

This process initially involved reading and re-reading the entire data set, of interviews, field notes and journal. The data had already been organised to reflect nurses' experiences of ethical decision-making, with notes on shadowing nurses, and interviews asking them to explore areas of ethical concern in their work. The dangers of preconceived ideas are well-known in qualitative analysis, but as Dey (1993) argues, there is a difference between an open mind and an empty head. He argues that accumulated knowledge needs to be used in qualitative analysis, rather than dispensed with. The focus of analysis had developed during fieldwork itself, and so key themes, to which individual details of analysis could be related,

had already been formulated. Reading and annotating the data then involved a process of interpreting the meaning involved, integrating various parts of data with other parts, and to the data as a whole. This process was greatly assisted by the use of NUD.IST. The database allowed for copies of the data to be manipulated without changing the 'live' document. Coding took place by attaching each line or section of data to a 'node' or to various different nodes. Nodes represent lines of similarity in the data. These were initially descriptive, but allowed the data to begin to be grouped systematically.

However, an early problem with the database was the way in which it assumed that the best method of building an analysis was by developing a 'tree' structure for analytic nodes. In this system, each node is given a place in a hierarchical structure, which has a 'parent' node and several 'child' nodes. The 'child' nodes than become parents in themselves, and this mapping process is designed to build the analysis. However, this means that one needs to decide which finding is at the base, and how it linked to other findings, before analysis has progressed sufficiently to be able to discern the pattern of findings and any hierarchy of causation. It is then unclear how to proceed with analytic coding. In the current study, this problem was dealt with by making use of the section in the program entitled 'free nodes.' These are a repository for analytic nodes that have not yet been planned into a hierarchical structure. They are intended to be temporary, but in fact they were used throughout the analysis to store emerging themes. At the end of the period of fieldwork there were more than 80 free nodes. Linking the nodes together could then take place, when patterns had been observed in the

dataset. The descriptive and then more analytical nodes were clearly visible and labelled, ready for this process to take place.

The program has node memos that allow a record to be kept of the trail of thinking about each concept without searching through reams of text. There is also a resource of 'jump to source,' when viewing data extracts in analytic nodes, which immediately helps to contextualise the issue. Electronic cross-referencing enables viewing of text with the same coding. With the flexibility to go in and out of different sections of data, the researcher becomes very 'close' to the data and emerging ideas about it. This closeness is key to developing a data-focused analysis. The data analysis can become more analytical, without loosing the roots of actual data, because the analytic categories can be viewed at the same time as the data where they originated. The build-up of the analysis can therefore be seen at close hand.

An important aspect of minimising the effects of prematurely committing to a particular perspective, and so foreclosing the analysis, was in the formation of categories (appendix A.4). These are, according to Dey (1993), both a conceptual and empirical challenge. This is because they need both to relate to an appropriate analytic context, and be rooted in relevant empirical material. By having to meet these twin demands in the allocation of data to categories, prejudices had to be faced because data could not be made to say what it did not. Categories reflected distinctions made by the nurses and doctors in the study, but also distinctions that became apparent across the different types of data. Fielding and Fielding (1986) discuss this concept in terms of the 'interpenetration' of data

and text. It is a process of tightening the base from which a concept emerges, by bringing several different sources of data to bear on it. The field notes and journal acted as a commentary on the interviews, providing the background information to their expression of struggle and unease.

Categories were a fundamental means of imposing order on the material gathered during extensive fieldwork. Criteria lists for inclusion and exclusion were drawn up for each category. A process of 'splitting and splicing' categories then took place (Dey, 1993). This involved splitting categories in order to generate greater detail and accuracy in the naming of concepts in the data. Splicing involved joining categories in an attempt to achieve greater integration of categories. The aim was data reduction into fewer and more powerful categories. Again, the use of the software package prevented the need for cutting up sheets of paper and sorting and re-sorting them into piles. The process could be done electronically, by joining or dividing nodes, which are collection points for data of a similar nature. Where a node represented a category, the criteria for inclusion and exclusion could be attached to its' property list. Changes to nodes left an automatic trail of what had been done, so the process of analysis could be more easily tracked.

A process of data linkage then took place. Categories reflected the relation between bits of data in terms of their similarity or difference. Linking the data involved identifying interactive relationships (Sayer, 1992). In this way, the analysis moved to examine processes occurring within the data. The effects on

nurses, over time, of working in the ward were a crucial discovery from linking categories in this way.

2.6 Dependability, credibility and transferability

There is considerable divergence in opinion amongst qualitative researchers in their approach to reliability and validity. A fundamental area of difference involves the extent to which an assessment should be made of the quality of qualitative data. For example, Buchanan (1992) argues that there can be no mechanisms to assess the quality of data, because this lies in its descriptive power:

'...[quality] can not be determined by following prescribed formulas. Rather its quality lies in the power of its language to display a picture of the world in which we discover something about ourselves and our common humanity.' Buchanan (1992)

Authors such as Seale and Silverman (1997) disagree, arguing that this approach constitutes methodological anarchy. They point out that there is an implicit assumption that all knowledge and feelings are of equal value, whereas in everyday life they are evaluated and sorted. They also suggest that audiences of qualitative health research may read this as giving up all claims to validity.

It is clearly necessary to be able to critically evaluate qualitative methods. However, researchers agree that that there is no canon for assessing the reliability or validity of a qualitative study, whereby a set of formal rules or standardised technical procedures can be applied (Riessman, 1993). This is

particularly the case where methods have relied on observation participation in a fieldwork exercise, such as the current study. Ball (1990) argues that the data gathered will inevitably be the product of the interaction between the researcher and the researched:

> 'Data are a social construct of the research process itself, not just of the 'natives' under study. Data are a product of the skills and imagination of the researcher...what counts as data, what is seen and unnoticed, what is and what is not recorded, will depend on the interests, questions, and relationships that are brought to bear in a particular scene.'
> Ball (1990)

Ball (1990) continues that methodological rigour will not be ensured by pseudo-objectivity, but by the presentation of the instruments employed to collect the data, that is, the researcher him or herself. The procedures undertaken by the researcher should be clearly demonstrated. He suggests that one way of achieving this is to include a research biography, which is a reflexive account of the conduct of the research. This should recount the processes, problems, choices and errors which describe the fieldwork on which the research is based. The account included in the thesis is based on both fieldnotes and journal to accomplish this.

2.6.1 Dependability

Issues of reliability are more frequently known in the qualitative literature as dependability or auditability (Miles and Huberman 1994). This concerns the stability of the findings over time and over different researchers and methods. Critical to assessing the stability of findings, argue Miles and Huberman (1994),

is the clarity of the research report. The research questions need to be congruent with the research design, and the researcher's role and status explicitly described. Basic paradigms and analytic constructs need to be specified, and there should be evidence of data collection from the full range of appropriate settings, times and respondents suggested by the research questions. The research biography and account of field relationships during participant observation present these aspects of the study.

External replication of study findings in order to enhance reliability is difficult to achieve in qualitative research, because the whole aim of the process is to be sensitive to factors embedded in a specific time and place. Dey (1993) argues that the focus instead needs to be on internal replication, by which procedures can be replicated by others, using the same data to produce the same results. He also argues that the researcher can do this independently, by taking advantage of the ongoing nature of data analysis during the period of data collection. The results of a preliminary analysis with part of the data, can be replicated with the remainder. The 18 month period of fieldwork allowed for prolonged exposure to the site and participants, and this in itself is argued to increase reliability, because biased and unwarranted judgements are less likely to be made over an extended period (Burgess, 1989). It also enabled a form of internal replication to take place. Analytic categories from fieldwork data in the first three months were compared to those emerging from data in subsequent analysis. Although the categories increased in analytic depth, the dominant constructs remained the same. However, some coding of material in the initial period was changed due to subsequent greater understanding of the participants and their working

environment. Initial impressions were, at times, erroneous and an example of the need for prolonged exposure in order to generate more reliable analysis.

Several authors suggest that using computer software facilitates attempts to increase reliability (Seale and Silverman, 1997; Dey, 1993; Ball 1990). This is because the process of data analysis is more traceable, and therefore more transparent. The use of software in this way has been described in section 2.5. Computer aided analysis can also provide procedures for enumerating the degree of empirical support for the categories and connections identified in the analysis (Dey, 1993). Although numbers in qualitative research can not and do not reveal a complete picture, they can be a useful corrective to initial impressions. Measuring the amount of support there is for a particular category can help to ascertain whether significance attached to it early in the project is mirrored in later analysis. In this study, the empirical significance of a category was established by the frequency with which the category was assigned to data. However, the quality of the evidence and its conceptual significance was also part of the assessment. The central participants in the study were nurses and so greater weight was attached to data from them than, for example, other health care professionals. This reliability check is therefore not entirely mechanical.

Dominant constructs had data from every nurse participant and the majority of doctors. 'Major' themes in the analysis had data from approximately 80% of nurse participants. Concepts derived from observation alone, as opposed to corroborated interview data, were described as such rather than as analytic categories. In this way, checks on the quality of data included in the study were

applied throughout analysis. However, category formation was not overseen by an external reviewer, and so the analysis, and checks involved, remain solely the interpretive effort of one person.

The detraction of having a sole researcher responsible for data collection, analysis and internal stability is also seen as an enhancement to consistency by many authors, particularly in fieldwork. For example, Ball (1990) argues that the analysis and interpretation of data should not be separated from the social process which generated them. This means that the same person collecting data in the field should also carry out the data analysis, because only they will be aware of the choices and interactions which gave rise to the data in the first place. The isolation of carrying out the research alone therefore has simultaneous advantages and disadvantages for assessing the internal stability of conclusions drawn from the data analysis.

2.6.2 Credibility

Validity is also known as credibility or authenticity in the qualitative literature (Miles and Huberman, 1994). It refers to the trustworthiness of the findings, such as their credibility to participants and other readers. Riessman (1993) makes the point that assessing the validity of data based on individual narratives, such as interviews, is not merely a matter of ensuring historical truth. She argues that narratives always assume a point of view, and are not meant to be read as an exact record of what happened. Rather they are accounts of interpretations of events, which is pertinent to this study.

Lincoln and Guba (1985) suggest that one approach to validation in these circumstances is to take results back to those studied. If the categories, interpretations and conclusions are recognisable as adequate representations then the findings are more credible. This form of 'member check' was carried out in several stages in the current study. After the taped interviews, full transcripts were returned to participants for their opinion. As the analysis began to develop, interpretations were shared with the nurses in a series of planned feedback meetings. These continued throughout the study and also the process of writing up. The difficulties involved are discussed more fully in section 2.8, and centre around the discomfort nurses appeared to feel in reading their own words, and in facing an exploration of what was happening on the ward. Their defence strategies involved distancing techniques, and so receiving feedback was something many nurses tried to avoid. At the same time, they were very clear that they were happy to accept the findings, and very much wanted the research to continue in the hope that the issues may be addressed in the longer term. This made member checking very difficult.

Riessman (1993) questions whether credibility can be affirmed by member checks at all. She argues that the meaning of experiences shift as consciousness changes, and so may not be the same as when the interview was initially undertaken. She also argues that individuals cannot give opinions on concepts which have emerged from the analysis of a number of narratives. In the current study, many nurses were amazed at the similarity in findings across individuals and professions. They felt that they were not in a position to comment, because they did not know the opinions of those concerned.

However, it is possible to gain from participants an idea of the congruence to their experience of the broad brush strokes of analysis. Nurses agreed that they felt that they witnessed poorly managed deaths, for example. They also agreed that they carried a sense of guilt for not intervening. Most of this form of discussion happened out of the ward context, and when I was least expecting it. Even at these times, nurses expressed agreement only to go on to say that they did not wish to discuss further. The form of member checking undertaken in the study can therefore be said to be informal rather than formal, because of the difficulties experienced.

Another means of assessing credibility is that of deviant case analysis, suggested by Miles and Huberman (1994) and Seale and Silverman (1997). Both authors argue that the charge of anecdotalism and hence implausibility can be addressed by critically reviewing the selection of examples used to support the analysis. Deviant case analysis involves attempting to seek out instances in the data where events have taken place which do not support the dominant constructs of the analysis. It also involves actively considering rival interpretations to explain the analysis.

Deviant case analysis was employed at the level of assigning categories to the data, and with the central concepts to emerge from the analysis. It was an ongoing process rather than a subsequent analysis, and involved examining the data for examples which did not fit existing patterns. Analysis was ongoing throughout fieldwork, and where deviant cases were found, the nature of a possible rival interpretation for the pattern of events under scrutiny was

considered. Subsequent data collection changed to include the new possibilities raised. Fieldwork would then include a focus on the new factor isolated, until it had either been shown to be with or without empirical support. This was part of the mechanics of the study itself rather than an extra analysis. Constant searching for rival interpretation, and changing fieldwork priorities in the light of them, is an established part of observation participation itself (Burgess 1989). This check for credibility occurred simultaneously with data collection and analysis, and was enhanced by the length of time over which this occurred.

2.6.3 Transferability

Dey (1993) argues that there are two aspects of generalisation, or transferability, in qualitative research which are sometimes confused. The first involves inferred generalisations, whereby a general proposition is inferred from empirical observation. This is dependent on the theoretical process of developing concepts and connections. The second aspect of generalisation is the process of applying the theory to a wider population. This involves ascertaining the empirical circumstances in which the theory may hold true. The first is a general statement about the data, and the second is an application of the statement beyond the original data. Dey (1993) argues that qualitative studies often provide a better basis for inferred rather than applied generalisations.

The limited number of participants in the study provided the opportunity for a thorough analysis, and therefore a good basis for the inference of some theoretical propositions. However, the numbers involved and the non-random nature of sampling means that transfer to other contexts needs to be cautious.

Miles and Huberman (1994) argue that the presence of 'thick description' is the best means by which to facilitate comparison of qualitative findings. This involves giving a full description of the sample of persons, settings and processes observed. Readers may then be able to assess the potential transferability to their own settings.

Giving a clear research account of how findings have been derived from the data, and sufficient description of the time, place and context of the research setting therefore provides the best means of assessing transferability. The nature of the research site, research biography and details of the analysis have been included in accordance with these requirements.

2.7 Nature of the research site

The research took place in a London Teaching Hospital between 1997 and 1999. The hospital was at the time subject to many changes. There were regular announcements from the Chief Executive regarding a planned merger with a local hospital, and the impact this would have on staffing and the site of various services. It was known that the Cancer Directorate would remain primarily where it was, but feelings of instability were widespread. The merger had been dictated by a government report and reception in the hospital had been hostile. Senior members of staff were leaving in the wake of the merger proposals, and so there had been some recent changes to the Consultant team of the Cancer Directorate. However, the most senior Consultants remained. They were well-known in their field and had a long-standing reputation for excellence in chemotherapeutic trials of various kinds.

The study occurred at a time of decreasing public respect for the medical profession. This was evident in the media, and also in patients' attitudes towards the junior medical staff on the ward. However, the recent influential enquiry into paediatric cardiac services at the Bristol Royal Infirmary was not yet published, although towards the end of the study there was some media coverage of the whistleblowing issues involved. The need for cultural change that the report would herald, in terms of openness with patients, and health care professionals' joint responsibility for patient care, had not yet been pressed home.

The ward was designated to be for acute cancer treatment, with many ongoing research trials originating with the Consultants attached to the ward. Patients were admitted via tertiary referral, and had been through many stages of cancer treatment before arriving on the ward. They came from a wide range of places, and some patients had come from abroad to receive treatment. A small number of these were private patients, but many had come to stay with relatives and gain residency. There were 24 beds, which were hotly contested. The telephone rang every morning with patients asking whether there was a bed for them, so that their treatment could begin. At times, there could be as many as fifteen patients waiting to be admitted. However, because patients were very sick upon admission to the ward, many would become too ill to move over their period of treatment. Referrals to hospices were delayed because of a lack of availability, and also because it was difficult to move patients visibly approaching death. This resulted in delays in beds becoming available for patients waiting for acute treatment. Doctors often expressed frustration over this issue.

The ward was well-known throughout the hospital and School of Nursing and Midwifery to have very high standards of clinical nursing care. This was reflected in yearly nursing audits and also general reputation. There was a moderate nursing shortage throughout the duration of the study, worsening and becoming critical as the research concluded. For most of the study, there were two senior Sisters at grade G, two junior Sisters at grade F, approximately 6 Staff Nurses at grade E and 8 at grade D. Two long-standing health care assistants were also part of the team, along with a ward clerk who had a central function in arranging social events and interprofessional harmony. She was extremely popular with both doctors and nurses, and her approval was vital to enjoying working on the ward. By the end of the study, there were 4 E grade posts unfilled, and 4 D grade posts.

The ward was arranged in a Nightingale fashion, with a partition down the centre, and twelve beds either side. Some attempt had been made to ensure that the halves of the ward reflected gender separation, but in reality this had not been possible. The pressure on beds was so intense that the next patient went into the next empty bed. Attempts were made to cluster patients according to their preferences. There were two siderooms which were usually reserved for patients approaching death.

The ward had recently implemented team nursing, with a dedicated team leader each shift, for half of the ward. Nurses acknowledged that team nursing did not always work as intended, because in practice nurses shared each others' workload during the shift. The system that actually seemed to be operating was a

form of 'mucking in.' However, patients were always allocated to individual nurses, and often there was a degree of choice about how this was done. Nurses would request the patients they wanted to care for in handovers. Very often, this crossed the 'team' border, but allowances were made for the personal relationships that had developed between nurses and certain patients. This could operate in favour of popular patients, and militate against those who were less popular. There were fewer requests to care for patients with limited English, those who had given up fighting and wanted to die, and those who questioned authority. These patients were allocated to nurses on the basis of their other workload. The dominant impression was of a whole team of nurses caring for the patients, with some individual responsibility but a corporate emphasis.

The nurses on the ward developed exceptionally close relationships with each other, which accounted to some extent for their patterns of working. They socialised together, and wrote to each other when on holiday. In pub discussions they highlighted that the nature of work on the ward was so 'heavy' that they needed to be united in order to face it. The ward clerk described the nursing staff as a family, sharing the burdens of care.

The ward had had a series of attempts to implement counselling sessions run by the hospital counsellor. These had been open to both doctors and nurses, but poorly attended and poorly evaluated. They had been stopped as a result. The counsellor identified that she had only been able to support the nurses' defences, because she felt it would be irresponsible to break them down and leave them with no replacement. Clinical supervision was being implemented as the research

concluded, but only for the senior nursing grades due to financial constraints. There was some indication that the doctors similarly suffered from the emotional burden of caring for patients in the environment of the ward. Five years previously, a House Officer on the ward had left a note saying he could not cope and had committed suicide in his on-call room. At the time, senior doctors had tried to arrange more support for their juniors. If this transpired, it was no longer in place.

The system of nursing management in place at the time of the study was not respected by the Sisters or Staff Nurses on the ward. They perceived that the Lead Nurse for Cancer Services was not interested in the day to day functioning of the ward, or in their welfare. This was because they felt that she rarely came to the ward, did not help out in practice if they were short-staffed, and tended to take the side of the doctors in any interprofessional conflict. There was some feeling that she was a 'handmaiden' to the most senior Consultant Oncologist, who did not value the work of nurses. According to the Lead Nurse, there were financial constraints affecting the directorate, and her insistence that the ward regularly overspent its budget was also unpopular. All these issues generated a climate where nurses felt unsupported from all directions.

The study was therefore taking place in a time of considerable unrest for the hospital as a whole, and uncertainty for the Cancer Directorate. The climate of nursing was that of being unsupported from senior management, both from within nursing and also medicine. Nurses felt that they faced a considerable emotional burden from the care of patients who were often extremely sick. They

relied on each other for support. However, there was a strong commitment to high standards of clinical nursing care.

2.8 Ethical issues in the research process

When designing the study, the literature on ethical issues in research was consulted and plans made to provide for the ethical issues likely to arise. However, once fieldwork commenced, these issues became more and more of a pressing concern, and techniques to deal with them had to be developed 'on the run.' Initial methods to address ethical issues will be outlined, before exploring the responses made to ethical issues encountered whilst actually conducting fieldwork.

A major decision at the outset was whether or not to employ covert or overt participant observation. Covert observation was rejected, because over a long-term project of immersion into a cultural setting this was simply considered to be unethical and also impossible. Where nurses were going to be open to observation on a sustained basis, with their conversations in coffee rooms as well as on the ward overheard and possibly noted by a researcher, to do so without giving consent seemed to involve both deception and a violation of trust between the researcher as an individual and the staff. The benefits to the research process of observing nurses behaving naturally without the knowledge of being observed (Roth 1970) seemed to be outweighed by the infringements of privacy and social contracts involved (Merrell and Williams 1994).

However, even overt observation runs the risk of being secretive in some aspects, because the research question is continually evolving and therefore it is impossible to provide full information about the research process ahead of the event (Merrell and Williams 1994). This was addressed by giving nurses information about the research questions and also the methodology. The fact that the research questions might change was included in this initial information. Regular ward meetings were planned throughout the project to give an opportunity for changes in direction of the study to be shared with staff and discussed. These meetings were chaired by the project's clinical supervisor, and were also designed to allow nurses to share how they were experiencing the project and any difficulties they felt were involved.

Informed consent was sought by way of designated forms from the local area Research Ethics Committee. The information given at the point of signing the form was supplemented throughout the project, through meetings but also by individual negotiation prior to periods of shadowing. Informed consent was sought separately for both the observation participation, and then later for the taped interview. Both the forms and preliminary discussions about the research indicated to nurses that the information gained would be both confidential and anonymous. This meant that field notes did not use real names, and that interview transcripts and tapes were not linkable to the participant involved. Both were kept in a locked filing cabinet in the School of Nursing and Midwifery throughout the project. The local area Research Ethics Committee gave permission for the study to go ahead after clarification of the role of the researcher whilst in clinical practice (appendices A.1 and A.2). They raised the

issue of what would be done if poor practice was observed in the course of the research. The response they accepted was that nurse researchers always remain bound by their own Code of Conduct, and ethical sensibilities. If observed practices were felt to be harmful or neglectful to patients, then the role of observer would have to be subsumed to that of practitioner, given that both are held simultaneously. Active intervention would take place on these occasions, either directly or by consulting senior colleagues.

The issue of whether or not to gain the consent of patients was another major decision to be taken at the outset. Given that the focus of the research was on nurses and their experiences, there was an argument that patients need not be affected. However, the research approach of participatory fieldwork meant that patients would inevitably have some dealings with a member of staff they would perceive as in a clinical role, who would in fact be a researcher. The patients may divulge more information than they would otherwise, as a result. A solution was reached with the ethics committee that I would wear a name badge which clearly designated the role of researcher. Patients would not be asked to sign a consent form for the research because, as the committee indicated, it did not directly affect them and may contribute to further anxiety on their part. Instead, the process of continually negotiating informed consent throughout fieldwork (Whyte 1989) would apply to patients. If shadowing of a nurse involved witnessing the delivery of care of a particular set of patients, the nurse concerned would explain the research to them and ask their permission for this to take place. They would explain that the researcher was interested in the work of nurses and was observing for this reason. If any patient registered discomfort or

refusal, shadowing of that nurse would cease for the day. Attendance at information-giving sessions and other care planning meetings involving patients would only be by invitation from the patient.

In practice, the process of gaining consent was much more complex. Nurses seemed inclined to agree to the research without even hearing about what it involved. They eagerly signed consent forms for the fieldwork. However, when the research initially began on the ward, they would avoid my presence as far as possible. This gave rise to considerable concern, because active consent can never be reduced to a piece of paper. Nurses who avoided the research were not pursued, but in the ward environment it is difficult to avoid giving the impression of forcefulness, just by one's presence.

Ensuring nurses' implicit as well as explicit consent to participant observation involved continuous negotiation at the level of body language and non-verbal cues. This was particularly important given nurses' tendency to acquiesce to the research rather than overtly agree to it. If nurses seemed to be turning away from me and attempting to conduct conversations out of my earshot, for example, I would not attempt to shadow them in their work for that day even if they had agreed to this. If they later came to find me, and request my presence, the period of shadowing would resume. The same issues applied to my involvement in informal conversations, both on the ward and also in local bars on ward night outs, to which I was often invited. If the topic of conversation turned to patients on the ward, and aspects of their care which were causing concern, nurses were aware that I might be interested in their opinions for research purposes. It was

difficult in practice, however, to know when it was acceptable to note informal conversations afterwards, and when this transgressed borders of privacy to which I had access by virtue of a developing relationship rather than express consent.

I dealt with this by asking the nurses, at the time of conversations, if they would agree to me noting the essence of their opinions in my fieldnotes. I emphasised that their names would be changed and the patients not recognisable. I also suggested that nurses could read the fieldnotes at any time. Many of them wanted to do so, and each day I brought in a copy of the previous day's observations, which would be stored in a locked office in the ward. This reduced the fear of what I was writing, and particularly of nurses feeling judged by the research as they saw the style of the fieldnotes. Nurses often agreed to me noting informal conversations, but there were times when they asked me to listen as a friend rather than as a researcher. At these times, I would simply not record the issues discussed.

Helping with bedmaking and bedpans proved helpful to situations where nurses appeared to be unwilling for me to participate in their care of patients. After a period of concentrating on helping with these aspects of care, nurses began to ask further questions about the research. This allowed the process of gaining their implicit consent to begin. It continued throughout the project, and was synonymous with gaining their personal trust.

However, gaining this trust in time raised another ethical issue. As certain features of caring for dying patients became apparent, the role that nurses were

playing in these situations became harder to understand. Having to write honest

fieldnotes began to conflict with the trust vested in me by the nurses involved.

They consistently expressed their pleasure at 'having a person who was on their

side,' and someone interested in their perspective. However, it was increasingly

uncomfortable to have to work on the ongoing analysis when off the ward, and to

see that the care of dying patients was not being managed well. The regular

meetings chaired by a clinical supervisor to the project were the place in which

the conflicts were eventually faced. The findings, as they were emerging, were

described openly. However, nurses did not feel the need to attend the meetings.

They expressed that they were very much enjoying having my presence on the

ward, and whatever I found to be the case, they would be happy with it. In the

circumstances, I did not feel this situation could be left as it was. Informal

discussions in the coffee room, in the pub after work and in other settings were

the occasions where feedback was attempted. Nurses were very resistant to

talking about the issues. It later became apparent that this was part of their

coping strategy, confirmed by the hospital counsellor who had occasionally

visited the ward to do a group session. They did not feel they could examine their

situation on the ward, and found the feedback too threatening. At the same time,

their welcome to me had deepened to such an extent that any ethical issues which

occurred outside the times I was on the ward, were relayed to me and my

attention brought to interesting meetings or other aspects of the ward they

thought I might find useful. The tension experienced through not having their

explicit co-operation in feedback was never fully reconciled.

Another ethical issue encountered was the way in which nurses began to

associate me very closely with the research project itself. This is a well-known

concept in the fieldwork literature, known as double recognition (Barrett 1996). They began to treat me as a moral policeman, or custodian. My 'ethical opinion' was sought, despite numerous occasions where they had been informed of the research approach, which was to gain understanding of their approach to the issues. This became difficult when compromises in patient care were evident, and I was approached. To have made an explicit statement would have been an implied criticism of other health care professionals, but clearly the situation for the patient was unsatisfactory. At these times, responsibility for the situation was given back to the professional concerned, but followed up rather than merely observed. For example, if the situation had not been resolved, direct questions about what had been achieved for the patient would be put forward. At times, these prompts continued over several days until action had been taken. Clearly, this is not the role of a researcher, and were not recorded for analysis, but the priority of patient care took over. Knowing when to take action in this way, and when to observe, was extremely difficult and there were occasions where action was not taken which are the subject of regret.

Some of the same difficulties in obtaining consent to my presence on the ward also applied to patients. Patients were very willing to allow the presence of a researcher, but did so whilst it was clear that they did not understand the purpose of the research. The nurse caring for them would explain my presence, but the patient would often indicate that they felt they did not need to know in order to accept my involvement. On these occasions, I would explain the research again, and emphasise that they did not have to allow my presence. Again, discretion had

to be used to realise when they were genuinely happy for an observer to be present, and when they were not.

The participation of doctors in the study was not anticipated, and was prompted by their interest and subsequent request to be involved. All of the interviews with doctors were undertaken at their request. Given their willingness, the medical director of the unit felt that no further consultation was necessary.

The issue of anonymity was difficult to maintain subsequent to completion of the project. This applied to nurses, doctors, patients and the research site itself. Many of the situations and circumstances necessary to understanding the findings in their proper context, are recognisable as particular individuals or a certain ward situation in a specific hospital. Details of patient care necessary to understanding the ethical issue itself often disclose the identity of the patient, by virtue of the events in their care. Practitioners would then be able to discern the clinicians involved, and so then be able to work out who had said what. The anonymity of participants and patients would begin to unravel. Whyte (1989) argues that there is no effective resolution to this except to work with the people involve to reach a compromise in wording that they are happy with. In this situation, however, many of the patients have died and the professionals moved on to other areas. The resolution agreed with the ward was that patient care details would always be amended in such a way that they were not recognisable, without compromising the ethical aspect of their care. Similarly, with nurses and doctors, issues of recognisable personality and professional conflict would be amended without changing the veracity of events and conversations as they related to the

ethical issue. This created a lot of extra ongoing fieldwork notation, as events were recorded and then immediately amended in a suitable way. Undoubtedly, some of the contextual richness of the data was lost in doing so. As with the decision between overt and covert research, the benefits to the research were outweighed by the potential harms to the privacy and trust of the participants concerned.

2.9 Research biography – reflections on the process

'How will I direct the whole thing? Do I just wait for the situation to do this? Must ask someone.'
Journal May 1997 14-15

This beginning to the first day of field notes reflects the feeling of isolation and lack of clear role that characterised the initial phases of the study. Having read numerous research books and articles about participant observation, and long-term field studies, I was aware of the distinctive nature of negotiating access and conducting research in situational analyses. However, I was not prepared for the experience of being on the ward as a researcher, rather than as a Staff Nurse with explicit patient care responsibilities. The need to 'collect' data from the hectic environment surrounding me was daunting. Research texts had emphasised the need to identify emergent themes in the initial phases of research, and to then focus data collection accordingly. The surroundings were to mould the study. In practice it was difficult to see how to achieve this. I did not know whether I was to choose a focus, or whether this would be considered to be prejudicial to the study. An even more fundamental problem became evident very quickly. This

was the issue of negotiating access to the real world of nurses and the care they provided.

2.9.1 Difficulty in negotiating access

I came to the ward with the explicit aim of becoming a participant, and entering a dialogue with the nurses on the ward about their practice. This was a middle course between remaining at the margins, being detached and removed; and becoming totally immersed, so as to become like the participants (Burawoy 1991). It made necessary allowance for the fact that it is never entirely possible to remove all personal bias by throwing off one's beliefs and becoming one of the participants. It also dealt with the problem of detachment. Remaining uninvolved risks leaving the researcher's own biases unrevealed, and also missing what remains implicit to the participants. Burawoy (1991) argues that the 'practical consciousness' of everyday life contains a great deal that is tacit and not explicitly articulated. This, he argues, calls for active participation but not total immersion.

I was not prepared for the difficulty in negotiating this border in practice. Nurses had readily signed consent forms following information-giving meetings and the period of attendance at ward handovers and meetings. However, when I was on the ward, nurses would avoid my presence. Although very friendly and courteous, I was aware of being politely excluded from nurses' conversations and the delivery of care. I decided to take recourse to familiar jobs on the ward which did not require specialist knowledge, such as making beds, delivering meals, running to pharmacy and delivering commodes or bedpans. After a few

days of participating in this way, the ward bedpan washer broke. I spent the whole shift ferrying a series of bedpans to the next ward's washer. During this time, I had more questions about the research from nurses as they handed me the next bedpan, than I had had in the entire period of attempted integration. This proved to be a catalyst for my acceptance. Nurses began to be more searching in their questions about what I was trying to achieve. They registered amazement that anyone could be interested in doing a study which involved watching them at work. They continually asked if I wanted to go and listen to the ward round, or to the doctors' discussions, rather than simply watch them give a bedbath and talk to the patient. They suggested that I came to work at weekends, as this was when the doctors were not in evidence and so the nurses made real decisions. In this way, I made the first discovery about their perception of their environment and local power networks.

However, gaining access had required me to become involved and absorbed in the work of the ward. It subsequently proved difficult to disengage from these jobs. They provided a clear means of further access, as nurses came to appreciate the extra help and were more happy to discuss their perception of events when I was involved in this way. Increasing acceptance over the next few months meant that I began to have a welcome place in informal coffee room discussions, and a place in care planning meetings for patients. Nurses would actively seek me out if they thought I should be attending a particular event. Very often, it was interesting just to see what they thought was important for me to hear. Individual nurses began to discuss with me their reactions to medical decisions with which they disagreed. They also began to share more private feelings about patients and

their relatives. At the same time, the pattern of my involvement in the ward began to affect my ability to remain a researcher, as well as a participant.

2.9.2 Emotional involvement

It had become clear by this stage that nurses were exposed to multiple griefs, and were often taking part in care which they did not privately endorse. My feelings were very similar. In very short spaces of time, I found myself attached to particular patients and then very distressed when they suddenly died. The fact that relatives were often not psychologically prepared for deaths made these situations even more difficult. The relentless pattern of curative treatments despite obvious impending death seemed to be an oppressive ceiling to critical thinking. I had realised that ethical issues were not discussed, and that decisions about them did not appear to get made. However, I was not asking critical questions about this, and so not following crucial lines of enquiry. I was particularly avoiding the issue of why nurses were involved in care with which they genuinely disagreed. Instead, there was some temptation to abandon all pretence at research in order to be totally involved and just help out.

Writing and reviewing journal entries and field notes during this time proved to be a crucial means by which I realised what was happening. I saw that I was becoming too immersed in the surroundings in order to function effectively as a researcher:

'...the nightmare of role and involvement is like trying to determine where a cloud ends and begins; you have to be far enough away to do so. And I'm not.'
Journal, January 98: 167-169

I had heard and read about the benefits of clinical supervision, and as a result sought to find an appropriate mentor. Fortunately there was a senior researcher within the University who had significant clinical experience in oncology, and was not intimately involved with either the research or the site. This meant that she could remain impartial whilst understanding the nature of patient care on the unit. She had prior experience in clinical supervision and was willing to provide an environment in which I could reflect on my research role. Her knowledge of the clinical environment was invaluable in discussion of events on the ward. She was familiar with the provision of care to dying patients in an acute environment, and so readily understood the tensions being articulated. She also understood the emotional impact of working with very sick patients. Her involvement was different to that of my academic research supervisor. Clinical supervision was based on integrating understanding of the research process in participant observation with the clinical area in question. It involved the exploration of my emotional coping mechanisms, and their impact on the research role. Academic research supervision monitored the analytic development of the study. The empirical substantiation for emerging themes were the focus of this period.

The clinical supervisor listened to my accounts of events on the ward, and reflected with me on my responses to them. This strategy proved to be very effective in regaining a participant stance as opposed to one of total and unquestioning involvement. It enabled me to plan the focus of data collection more clearly, having seen the elements of the data in need of further investigation. Clinical supervision continued once a week, not only for the duration of participant observation, but also until the end of analysis. This was

because I found the possibility of overinvolvement remained an issue even when

I was not on the ward itself, but working with the field notes and transcripts. The

emotions they raised, and memories they elicited, were able to dampen critical

engagement with the underlying issues:

> 'Like the way that the internet holds 'previously cached sites' in its memory
> even though you are not now connected, so the memories seem so vivid. I
> come to write up sketchy field notes and I'm back with Maisie Wilkins
> [patient] at the end of the ward, in all that clarity, with the colour and texture
> of her skin. I did not expect to have this recall, with clearness. It is
> disturbing.'
> Journal, July 1998: 56-62

I found that without support, I began to avoid the issues altogether. In the light of

subsequent analysis of nurses' experiences, it seems that I had experienced to

some extent the processes they described.

2.9.3 Finding the main focus

Through clinical supervision and review of field notes I had realised that the

central issues of the study were about the discussion and management of ethical

issues. I also knew that there was some aspect of nurses' emotional responses

which was acting to prevent them from taking action on situations which they

perceived to involve compromised patient care. These areas now gave focus to

the project. I could plan my time more carefully and be in control of what I

wanted to observe, rather than feeling I had to be everywhere and hear

everything. I made it a priority to attend as many handovers as possible, both the

formal exchange at the beginning of shifts and also subsequent bedside

conversations between individual nurses. These occasions proved to be

opportunities to observe the prioritisation of information, and the rank which ethical issues attracted. Comparing the formal and informal exchanges of information gave important clues as to perceptions of ethical issues, such as when, where, and with whom they could be discussed.

However, it was also vital to have a wide-ranging facility to observe the developing ethical issues between handovers. Shadowing individual nurses began at this time, after considerable participation on the ward. The degree of acceptance achieved meant that most of the nurses were open and chatted informally throughout the periods of observation. I continued to help with non-specialised jobs in order to maintain this. Access to nurses' perceptions enabled greater understanding of how ethical issues were identified and perceived. The opportunity to observe what nurses then felt able to do about their concerns was critical to understanding the links between individual action, teamwork and resulting patient care.

Tracking of patients whose care was seen to involve an ethical dimension took place across several areas of observation. Nurses' individual concerns about the patient, and their subsequent action; discussion amongst teams of nurses, if any; handover exchanges; interprofessional discussion in ward rounds, and finally, what actually happened to the patient. These observations were recorded in the field notes and decisions could be traced in the data over several weeks.

2.9.4 Expanding lines of enquiry

This was the period of greatest involvement in the ward, where I was party to informal discussions and privileged information. It had become evident that

ethical issues seemed to operate only in the informal networks of the ward, and so this is where I used my acceptance by the staff to the greatest effect. However, in doing so considerable dilemmas were raised for me as a researcher. The tracking of patients often involved witnessing the result of decisions that should have been made several days or weeks ago, such as starting opiate analgesia. I was aware at times that a patient was about to die, and yet neither the patient nor their relatives appreciated the severity of the situation. It was difficult to know when to 'break cover' and intervene.

As agreed with the ethics committee, I did intervene when the patient was actively suffering through lack of action. In these situations, I directly approached the nurse responsible for the patient and quietly mentioned the issues. This was often sufficient stimulus to prompt a change in direction, because in many cases the nurse needed extra support in order to voice the opinion they already held. However, it led to a new problem for the fieldwork. This was the way in which nurses came to want me to represent their ethical opinions to others, such as the doctors. I continually resisted this, and explained that I was interested in how they usually dealt with the issues. It was interesting, nevertheless, to see the need that nurses felt they had for additional support and validation in raising ethical concerns.

The doctors on the ward initially ignored my presence. Gradually this changed, particularly as I became accepted by the staff and was therefore present more frequently. At the same time I began shadowing nurses, and tracking patients, one Senior House Officer (SHO) approached me and asked if she could be

interviewed about her perspective on ethical concerns. She felt that it was important for the doctors' views to be included in the study. This contact, along with the subsequent interview, acted as a catalyst for other doctors on the ward such as the House Officer, Registrar, Senior Registrar and Consultant. It became apparent that they had 'recommended' me to each other. Nurses on the ward felt that the study had achieved greater status because of these interviews, and they were very keen to know what the doctors had said about them. The doctors were also interested in what the nurses felt about their decision-making, and about what each other had said. I emphasised that all data remained confidential and anonymous to each participant, and had to be careful in what I said in order to achieve this. The interviews were therefore useful in gaining further insight into interprofessional relationships, decision-making and power dynamics.

Managing the different lines of enquiry meant that the majority of the week and some weekends were spent on the ward. This proved to be physically and mentally exhausting, as I had to return after shifts and write field notes and journal, and plan the next day's focus. Negotiating relationships and continuing consent meant having to be constantly vigilant. It was difficult to manage the entire project alone, and I had a strong sense of personal responsibility for the events I witnessed. My acceptance on the ward had taken a long time, and had been personally costly, and I felt that the data elicited was relevant and significant. I did not want to stop. I realised after eighteen months that I needed to leave, but I did not know how to pull out of a situation in which I had become so involved.

2.9.5 Leaving the ward

Ongoing review of the developing analysis helped to see that there were recurring themes in the fieldwork and interviews. I realised that central findings were already in place in the form of dominant analytic categories. Further data collection was consistently falling into the categories identified, and established links between categories were confirmed by further analysis of new data. I came to see that data analysis was providing a satisfactory structure for new data, and that saturation had been achieved. I also realised that more data collection would make the amount to be analysed untenable. The decision to leave the ward was prompted by these reflections.

My clinical supervisor further helped me to see that my role as a researcher was to systematically analyse, write up and disseminate the findings rather than to try to 'mend' this particular ward, and the nurses I had become close to. After leaving the ward, I was able to liase with a researcher within the trust, who wished to investigate the effects of supporting nurses working with cancer patients. The supportive strategies instigated on the ward as a result enabled some feeling of closure to take place. Representing the findings to key decision-makers in the trust is ongoing.

At the time, staff on the ward were harder to convince that I had to leave. They had appreciated the support and extra help, and I was aware that this was not going to be completely replaced. It was with very mixed feelings that I gave feedback and set a day on which to leave. I knew that ultimately I would have to present some difficult issues about care of the dying. There were many

complexities and ambiguities to be held in tension in order to concentrate on developing a convincing analysis, which would be recognisable to the staff, truthful, and also helpful in future planning of patient care and staff support.

2.10 Summary

Consistent with a philosophical position which emphasises the *emic* perspective, the study design rested on participatory field work with interviews of nurses and associated doctors in an acute cancer unit. Structured field notes were taken over a period of 18 months, with interviewing and shadowing of individual nurses taking place ten months into the project. Tracking data of inter-professional decision-making about the care of 15 cancer patients was recorded within field notes. Whilst individuals remained key to the project, wider organisational concerns were also explored, taking advantage of the flexibility of the methodological tools used.

CHAPTER 3: FINDINGS

Examining ethical issues in cancer nursing

'Among other things, CPR [cardiopulmonary resuscitation] is our culture's desperate dance around the bed of a dying loved one…CPR does a lot of work even when it is futile.'
Lantos (1995)

Introduction

This chapter deals with the nature of the ethical issues identified by nurses on the

ward under study. These findings are drawn from 18 months of fieldwork,

involving 156 shifts of participant observation, allowing for sustained and

repeated observations, and in-depth interviewing of 18 ward staff, ongoing over

the period of study. This approach was taken in order to generate a contextual

approach to ethical decision-making, learning from earlier research which failed

to give practical accounts of moral behaviour, and focused on theoretical criteria

for the measurement of moral reasoning. Previous research had not mapped the

processes occurring in clinical practice, or described the influences which

mediated the encounter between an individual nurse and a perceived moral

problem. By exploring both verbal and observed behaviour over a sustained

period of time, this study aimed to redress the previous emphasis on the purely

cognitive aspects of decision-making.

The chapter will explore firstly the manner in which ethical issues were

identified by the nurses in the study, and secondly identify what kind of concepts

were perceived to be involved. Reference will be made to the effect of individual

background, current situation and future aspiration in the formation of judgements about ethical issues. Finally, key patients who repeatedly feature in nurses' dialogue will be used to outline commonly arising concerns. These reflect the nature of treatment decisions in transitional care.

Data extracts from interviews with nurses carry the code 'Intn' followed by the participant number. Informal interviews with doctors carry the code 'Int' followed by the initials of the professional grade of the participant. For instance, 'IntSR' refers to an interview with a senior Registrar. Data from fieldnotes are coded as 'FN' followed by the month and year in which they were recorded.

3.1 Identification of ethical issues
3.1.1 Embedded in practice

In the literature it has been common to find ethical issues discussed as isolated and momentous events, such as abortion, euthanasia, and withholding life-sustaining treatment (Ferrell, 1993). However, nurses working with cancer patients clearly saw ethical issues embedded in the fabric of providing nursing care. Whilst this may apply to other areas of nursing, many nurses felt that the specific nature of providing care to dying patients brought about a constant engagement with ethical issues:

> 'There's usually some kind of ethical issue... I would say a majority of the time there's usually something going on the ward that involves some sort of ethical issue...'
> Intn13 20-23

This theme was also consistent across the interviews with medical and administrative staff. It was linked with the sense of issues that are implicit in the smallest details of patient care, and so occurring on a continual basis:

'...so little things, they're constantly...every *minute* of it, you're making a decision. You have to make a decision that is right for you and the patient...you know, so I think it's hard...you're dealing with life and death and people's comfort...what priority you want to put...'
Intn7 277-284

Ethical issues were thus found to be ever-present in daily clinical practice.

3.1.2 Hidden and ignored

Nurses often spoke about ethical issues being hidden in their day-to-day practice. Intuitively, they knew ethical issues existed, but found it hard to articulate their concerns:

'I think a lot of the things we do have ethical, implications behind them, but when...as you're sort of going about your every day duty you don't always realise that. I think a lot of the time you don't realise that, it's just some intuitive or instinctive, thing that happens...'
Intn1 102-106

Many nurses reflected on the need to remove themselves from the immediacy of the situation in order to think about the issues more clearly and in more depth:

'...I think a lot of it is [ethical decision-making] sub con, subconsciously absorbed. Because you're doing it all the time, I think, you know....maybe it's something, we need to step back and think of a bit more. I think it's very much a day to day, run of the mill thing, that it's absorbed, and, you discuss it briefly at report, and sort of think things through...and then follow it up later if you've got time, sort of thing...'
Intn3 322-330

The existence of hidden ethical issues was confirmed in the observation field

notes. It was as if the research process itself caused staff to think more deeply

about their patients and in so doing, helped them to identify ethical concerns. The

following extract is taken from field notes where a senior staff nurse is giving

handover to the early shift:

> '..she came to a situation of a 93yr old lady who thinks that the diagnosis of
> 'tumour' is not cancer...the impression was given that it really would have
> taken too much effort, considering the lady's age, and maybe caused
> unnecessary pain, to tell her the truth. Jenny looked up suddenly at me and
> said, 'oh! that's an ethical one!!"
> FN 5/97 321-327

This type of startled 'double' recognition happened repeatedly over the period of

the study. Other members of the multiprofessional team also readily identified

the project with ethical issues. Hearing about the nature of the research prompted

discussion about current clinical concerns:

> '...the SHO and ward clerk both articulated that I had come at the right time,
> as in Sarah's (SHO) words 'there's a right corker' going on. This turned out
> to be to do with multidisciplinary care planning for a young lady with severe
> learning difficulties who had end stage cancer. She had also developed renal
> failure and they did not know whether to give dialysis or not. In the end they
> did, and they felt it turned out badly because she very quickly died anyway.
> There was a lot of feeling around this...'
> FN 04/97 311-333

Interestingly, issues identified during the research were not spontaneously

followed up in later discussion, and often remained unresolved. It was evident

from the character of nurses' dialogue, both in interviews and on the ward, that

ethical issues provoked both anxiety and, on occasion, considerable distress. At

times, delay in dealing with ethical concerns caused tension in itself.

3.1.3 Drawing on personal knowledge

When describing their reaction to a perceived ethical issue, nurses drew more

from their own personal experience rather than from their training or education.

Many nurses identified features of their personality, age or past experience to

highlight the way in which they approached the issues. The nurse in the

following extract was talking about truthtelling in a situation where she felt there

had been a failure of communication between medical staff and a patient

concerning their diagnosis:

> '...I do think that nurses are put in...so many situations where you, you're
> torn...I mean, I happen to be the kind of person, with my maturity in nursing,
> that I find it easier to actually deal with the person, on a psychological
> level...not divulging anything that comes into the head...I mean, experience
> does count...'
> Intn16 357-365

The influence of individual history featured strongly in nurses' accounts of their

response to ethical issues:

> 'Actually looking at why, you might be feeling something, it could easily be
> because of where you come from. I mean, I know that a lot of, my thoughts
> and feelings have come because I worked in a hospice, and I've seen very
> different care and so, unless I'd been there, I certainly wouldn't have felt,
> the way I do about a lot of stuff...'
> Intn2 221-226

There was often explicit reference to the need for the involvement of these

aspects of the self in ethical decision-making, as opposed to the attributes of a

purely professional role:

'...in this area of work, whether we're aware of it or not, you know, obviously we make a decision as a whole person, not just as a nurse, you know, not just in a specific role...and I think previous experience as well makes you, sort of, makes you who you are...'
Intn15 571-576

Other evidence of nurses' strong personal response was the fact that discussion of current ethical concerns would often be accompanied by reflection on past critical encounters. These could have taken place many years ago, but had made sufficient an impact to give rise to enduring memories:

'...you remember these things, up to two or three years later...I mean I remember very, clearly the whole sort of, event and basically you always have the memory going round...'
Intn6 120-124

It was interesting to note that these appeared to function as key influences to which nurses returned. This extract was a senior nurse describing memories of her work in a cancer unit and the ethical conflicts she encountered:

'I still have my own personal tapes, in my head, and I rerun them, and, you know I go through them...'
Intn16 59-62

Similarly, doctors clearly indicated a reliance on previous significant encounters with ethical issues when forming attitudes about current situations. These were more influential than formalised policies, and at times in clear conflict with them:

'With resus as our biggest issue, you've got these crap and naive policies that mention things to do with telling the patient their resus state. The people that design these policies have never met a patient. I once tried

telling a patient about their resus state one Sunday morning when I was a house officer and all my senior cover was away. It was absolutely dreadful. The man flipped and wanted me to track down a priest as he suddenly wanted a deathbed conversion. Can you imagine that, as a general medic for goodness sake? It was a nightmare. It was the worst thing that could possibly have happened. So I don't care, I'm never doing that again.'
IntSR2:567-577

However, it was noticeable that the deeply personal nature of response to the

issues seemed to function in their intrinsically complex and troubling nature.

Many nurses sought to define an ethical issue as that which had no consensus,

precisely because of this:

'I think having ethical issues are difficult anyway because a lot of it is on people's opinions, and different people can have very different opinions, and it is always hard to know what your actual ideas of what the ethical issue is and what is involved because your ideas are very different to somebody else's...and I think that makes it difficult.'
Intn13 33-39

3.1.4 Approached with uncertainty

Related to this was the sense of uncertainty many nurses expressed on dealing

with the issues. There was no sense of an ethical expert. In other areas of skill,

such as ward management, drug administration or other forms of clinical

decision-making, expertise was clearly linked to seniority. When discussing the

way in which she approached ethical issues, one senior nurse reflected:

'...although I may have had that extra experience, it doesn't necessarily mean that I'm going to...be able to make those decisions...um you know, make...make a better decision than say somebody who's...a more junior member. 'Cos as I said before, you know, quite often, it's other people anyway...that raise those issues, and I think, you know, 'why didn't I think of that?"
Intn9 201-222

These issues clearly involve a dimension which is difficult to articulate and in which to demonstrate competence. The lack of a senior reference-point was distinctively different to all other areas of care. Not only are the issues embedded in clinical practice and so perceived as 'hidden,' but identification of and response to the issues is affected by personal background, and so approached with uncertainty. As many of the patient care situations that were perceived as ethically problematic required teamwork rather than solely individual action, it is perhaps easy to see why many nurses found ethical decision-making complex and troubling.

3.1.5 In need of a catalyst

It further became noticeable that there were complex issues surrounding particular patients' treatment and care, and conflicting, polarised opinions surrounding them. These patients were often spontaneously mentioned in connection with the project. In this way, the research prompted nurses to think about ethical issues, where previously they had remained in the background.

In the early field notes, observations concentrated on the patient care scenarios identified by nurses in connection with the project. They were studied in order to understand the nature of the concerns, and also the useful information they provided about what was considered to be ethical. The patients in question caused concern to all levels of staff, and were often expressed independently. In nursing, medical and interprofessional documentation there was no trace of the kind of concerns expressed to me, and yet I was often sought out specifically to be told, commonly in whispers, about conflicts surrounding the care of these

patients. Related to this was the way in which the project received acceptance and therefore access to the informal networks of relationships and undercurrents of the ward. Many staff expressed, again independently, that the project was relevant because the issues were currently unaddressed. Nurses particularly articulated that they felt supported by a research project looking at these hidden problems, although this later became a problem in itself when I was expected to resolve the conflicts. All these factors led to a ready integration into the ward and rapid exposure to sensitive areas of patient care.

3.2 Nature of ethical issues identified

The chapter now turns to detailing commonly arising ethical concerns in patient care. These will first be described conceptually, using data extracts to illustrate perceptions of power, truthtelling, resuscitation, informed consent, futility of treatments, hierarchical conflict, confidentiality and patient advocacy in reduced competence. Similar data analysis and presentation has been accused of 'fracturing' the data (Benner 1994). However, data reduction and classification is essential in order to grasp the nature of the issues nurses identified. In the second part of the chapter the context within which the ethical decisions were made will be described.

This section will review a representative selection of problematic patient care episodes. These patients recurred in interview transcripts, and were the unacknowledged focus of informal discussion on the ward as a whole. Detailed observational notes were made of their care and treatment, as well as gathering the independent views of nursing and medical staff involved. Details relevant to

patients' clinical history and situation which are recognisable have been altered, whilst preserving the issues and tensions identified by the nurses involved. In many instances, perceived ethical issues did not occur in isolation, with one concern per patient. Instead, nurses were concerned about a number of issues in any one patient's care. Deciding which to address in limited time was in itself an ethical decision for them. This becomes clear in the context of ethical decision-making. All of the patients are now deceased.

3.2.1 Ownership of information
3.2.1.1 Confidentiality

Many nurses expressed a tension between the large amount of privileged information they frequently held about patients, and the fact that often they had little or no knowledge of the patient in the first instance:

> 'it's very easy once you, particularly if you've, you are a named nurse and you've admitted someone, it's very easy to get bogged down in, thinking you know them personally, where you still might only have known them for two weeks, and you're making big decisions, you know, life decisions...'
> Intn3 114-119

Nurses struggled with feeling that relatives in particular seemed to have a greater claim on the information by virtue of their relationship to the patient and knowledge of them. Many nurses felt that it was difficult to maintain patients' confidentiality in the ward situation, particularly because of this:

> 'a patient would tell me a little bit of their history and talk about death and that they are dying and then you would see the family, the spouse or the partner and you don't know whether to discuss it with them because the patient has said that *just to you* and haven't included their family in the discussion...'
> Intn4 72-76

In many instances patients' relatives would telephone or arrive on the ward wanting clarification of the patients' condition, and keen to know as much as possible. This became difficult for nurses to answer when the patient had explicitly asked for their relatives not to be informed. Nurses often expressed concern for these relatives, who they felt would not be able to appreciate the true nature of the situation and the arrangements they might need to make. However, nurses felt that their primary allegiance was to the patient:

> 'some patients will say to you, 'I don't want my relatives to know anything,'
> and then you, the relatives comes in and he says, 'listen, I wanna know all
> about my Mum, you've gotta tell me now' and the Mum has said don't you
> dare tell my son or daughter what I've, what I've got, they will worry silly,
> they won't have a life, they've got children to look after, I don't want them
> worrying...' and you don't, you don't know what to do, because you want
> so desperately to tell them she needs help, she's gonna need care, and, and
> the patient is saying, 'I don't want them to know' you know... you can't say
> anything because you know, obviously that's, you know, it's, it's
> confidential...'
> Intn16 329-357

Many nurses felt that it was difficult to remain honest with relatives, because in discussion it was necessary to avoid disclosing not only confidential information, but also the potentially hurtful fact that their relative had instructed that they should not be told. In this way, nurses felt that they became intimately involved in family dynamics whilst being a relative stranger.

In some ethical theory confidentiality has been linked with autonomy, and freedom of individual will. This is traceable to Kantian theory, where the will is given priority in assessing the moral worth of actions (Paton, 1989). Whatever is accomplished by a person's will is less important than their volition, which if

good, has its ultimate value in itself. The freedom of the will is Kant's supreme moral principle:

> 'Autonomy of the will is the property the will has of being a law to itself (independently of every property belonging to the object of volition.)'
> Kant cited in Paton (1989)

For Kant, violation of this autonomy limits a person's moral agency. Revealing information about a patient without their direction would be to infringe their ability to be a 'law unto themselves'.

In contrast, other ethical theorists such as Mill and Locke identified general welfare or utility to be the core value of morality. In this ethical structure telling the truth would be a conditional good, in so far as it maintains relationships which enable society to function for everyone, for example. However, if a group of people would generally benefit by one individual not receiving the truth, the priority would be to the group. In this way maximum utility is gained.

The two ethical positions effectively describe the tension which nurses articulate. They felt strongly that the patient should be in ownership of their own information, but also perceived that often the needs of close relatives were not served in doing so. However, in their transcripts nurses generally expressed that the patients' decisions about disclosure should take priority.

3.2.1.2 Truthtelling about diagnosis and prognosis

Nurses felt that patients did not always get told the truth regarding their

diagnosis, prognosis and hence the aims of their current treatment. This was

sometimes expressed obliquely rather than directly. For example, the following

extract from a senior nurse refers to the propensity of patients to ask searching

questions to junior rather than senior staff. In doing so, she implies that patients

may often feel they are not fully aware of their situation:

> '...and then patients will home in on those people they feel they trust, but
> inevitably they home in on more, junior staff and students to ask those
> important questions, yes, to a degree, until they've built up a relationship
> with you. Um, I think that's something they do quite a lot...particularly on
> the health care support workers. I'm sure that people will ask them, 'what
> have they been saying about so and so?', not in a horrid way but in a sort of,
> 'oh, they might tell me straight up what's going on.'
> Intn3 397-405

Other nurses referred directly to the way in which patients were not always

explicitly informed of their diagnosis and prognosis, because of the threatening

nature of such communication:

> 'you're usually torn between, um what the doctor should have said,
> sometimes, and *hasn't*, what the patient er, thinks is wrong with them
> sometimes, and *isn't*...'cos doctors hedge it, they go, 'we're gonna put you
> on this and put you on that, and we're gonna see '...but doctors don't, they,
> they're as scared as nurses, I think, certainly the junior doctors are as scared
> as nurses, when it comes to patients, especially nice patients, which are so
> easy to, to love and like and care for, they're as bad as nurses, I mean I think
> we're a team in this, as avoiding the issue...I think the young doctors on the
> ward, they're like us, they're not any different, but I think that the
> consultants don't pass on, this information to the doctors, and say 'look,
> when you get a situation like this, sit down with the lady, sit down with the
> man, and really map out what we're trying to achieve here.'
> Intn16 100-121

It was clear that nurses found patients' questions about future treatment plans ethically challenging, because they felt that patients may not have been fully informed in the first instance and should have been. They were also concerned that patients may have been informed but chosen to ignore this. This then raised another tension between the obligation to tell the truth in answer to questions about treatment, and the patient's decision to overlook the information given to them:

'you know, some of these people think that they're going to get better, no matter what the doctor said, I've had loads of those, they go into denial, and it's like, you know, 'after this treatment what other treatment can we try?' And you think, 'oh God, how do I answer this one?'
Intn16 329-357

Related to this, nurses expressed difficulty in knowing how to maintain a patient's sense of hope and yet tell them the truth about treatments at the same time. The questions asked by patients about treatment often incorporated a more substantial hidden question about prognosis. The efficacy of treatments became connected with the length of time remaining to the patient, and therefore their sense of hope. Advising patients on which to choose, if any, was identified by nurses to be a crucial issue:

'And sort of, 'cos, research has shown that, you know, people who have hope and, have that little bit extra, live longer, so, are you then....is it ethically sound to say, 'well ought, this isn't gonna do you any good but you know, we'll try it anyhow?' Or do you, should you say, 'um, this isn't gonna do you any good, it's gonna mean you, spend more time in hospital, why don't you go home, and, and get on with it?' But then you're destroying a sense of that hope...although you're not...yeah, no, it's very hard to, to verbalise. I think, um, but yeah, I think it is to do with, with truth, and how, how truthful the team you're involved with, is with the patient on the whole.'
Intn3 236-256

This extract also highlights the culture of medical dominance affecting the way in which nurses dealt with patients' questions. Nurses often referred to the fact that decisions to inform the patient were made by the 'team,' which usually referred to the medical team. Nurses articulated that when faced with explicit questions from patients about their prognosis, they felt that they were not in a position to redress lack of information:

'...because you don't *feel* that you're qualified to say without a doctor and a whole team of people, like a social worker, I mean the whole multidisciplinary team around you to say, 'this is when it'll happen' but they really wanna know from you, because you're the person that's with them 24 hours or most days of the week...'
Intn16 74-84

Talking frankly to patients about their prognosis and treatment was further complicated by a frequent mismatch between what the relatives were told and the information given to patients. Nurses indicated a general pattern of relatives being informed of patients' diagnoses prior to patients:

'...and it seems to be easier to talk to the relatives, for some reason, I don't know why...'
Intn9 334-335

This pattern was also indicated by nurses' frequent reporting of requests from the relatives themselves not to inform patients of distressing news. By necessity this implies that relatives were often informed ahead of patients. The following extract is from a senior nurse who is describing situations where relatives are requesting information about the patient's diagnosis:

'...and it really is difficult because you might be saying [to the relatives] something that the patient has a totally different idea about, he's thinking he's gonna live forever, he's gonna fight things, and you're telling the patient's relatives otherwise...'
Intn16 100-103

Nurses felt that because many of the families often appeared to be in crisis, it was difficult to then insist that the patient be told the truth, because it would add to the burden on the relatives at such a critical time. Nurses also felt that the relatives might be better able to judge the effect that the information would have on the patient, and therefore were more able to mediate the information given than the nurses. However, nurses continued to espouse an appreciation of the patients' right to know, which created the ethical dilemma:

'We had a young girl here over New Year who, um, she's got a brain tumour, and she basically nearly died, they thought she was gonna cone, thought her tumour was gonna sort of, she was gonna cone and die, and her, it was a great shock to her family, and her Dad, sort of, walked out in shock, and, um, but their one sort of, wish was that they didn't want her to know that she was potentially gonna die within a few days, or hours or whatever, and that, that's sort of happened before... and then you think, 'well, it's their [the patient's] *right* to know', and they [the relatives] sort of say, 'oh but we know that they wouldn't want to know', sort of thing, whether they know it would be too much for them sort of thing, and that's really so, so difficult.'
Intn15 490-495

The use of relatives as mediators between the health care team and the patient was particularly pertinent when they were acting as translators. There were situations where nurses felt that patients were not being adequately or correctly informed because relatives were trying to protect them or remain in control of decision-making. Nurses perceived this to be an ethical issue concerning, again, the patient's unique right to the information. However, many nurses felt that this

was very difficult to address in practice, because of the need to depend on the

relatives for translation:

'...with a patient who doesn't speak English and the family are controlling
what information they're getting... you can say to them this [information] is
right or this is wrong, but if you can't get them to sort of work with you then
it's very hard to get through that.'
Intn13 42-47

Situations where patients asked not to be informed of the results of tests to

diagnose their illness also raised ethical difficulties for nurses. They felt that the

need to make arrangements for future care, and to provide for the adjustment of

relatives were powerful tensions:

'what do you do if somebody who has very advanced cancer, who's saying,
'I don't want to know,' and it's happened very often, 'if things are that bad,
I don't want to know,' yet you know that they have a young family, you
know there, there are things that you need to do, you know, I think,
ethically, do you, take that, you know, to the letter, and just do not say
anything, tell them any information, or do you very very gently try and, put
that to them...?'
Intn6 34-42

Related to this, nurses often felt that relatives had not been informed

sufficiently to prepare for the death of the patient. Although they expressed no

sense of the absolute right of the relative to know, as with the patient, nurses

felt that the extreme grief reactions they often witnessed were due to this lack

of information. The following extract is from a junior nurse describing a

situation where she felt the relatives had been misinformed:

'...because Belinda was...um in a lot of ... well pain and...and the family
wasn't informed about her prognosis, but then, um actually she'd gone
downhill so quickly and the information that was given ...to the family was

like, 'don't worry, we, you know, get the bleeding under control and she'll be fine,' kind of thing and that was not the case... and um, yeah, so, it's like, that is not right really, because yesterday she went downhill so quickly and we had to tell the family...that were there...so...it was a shock to...to all the family...it doesn't come in as something that is right really.'
Intn7 16-30

These situations were particularly disturbing because relatives would sometimes become angry after the death, expressing their feeling that events had been poorly managed. Nurses were often in the front line of addressing their concerns as well as their immediate grief.

A central ethical tension that nurses articulated was the struggle to ensure that patients were the focal recipients of accurate and relevant information-giving about their diagnosis and prognosis. Throughout nurses' transcripts was the dominant theme of the need for the patient to be in primary ownership of their clinical information. Competing for priority were relatives, given their close relationship with and knowledge of the patient, and the pattern of prior divulging of information. Disclosing information to the patient was itself perceived to be challenging and often avoided. At times the decision of the patient to remain uninformed was perceived to be in direct tension with truthtelling.

Telling the truth has been a fundamental tenet of both nursing and medical codes of conduct for the past fifty years. Nursing codes do make provision for the fact that a nurse may not feel qualified to inform patients of their diagnosis (UKCC 1997). However, there are also clear statements that there should never be the need to actually lie. Ancient and middle-age medical codes did not wholeheartedly support the principle, largely because medical beneficence took

priority over patient choice. However, since the Nazi atrocities of the Second World War, the centrality of the patient in all clinical care has been firmly enshrined in both professional and public opinion. The nursing literature makes frequent reference to this issue as being of ethical concern, particularly in cancer care (Ersek et al 1995).

Modern ethical theory is broadly supportive of telling the truth, whether this be because of greater public utility such as social cohesiveness, or more fundamentally because of the value of a human being and their right, as autonomous agents, to information about themselves. Nursing textbooks refer to the need for truth in relationships with patients in order to promote trust and confidence, essential to a therapeutic relationship (Chinn and Kramer 1991). Nurses were clearly identifying an ethical issue which has received wide attention from moral philosophers and clinicians alike.

The current tensions and dilemmas involved for nurses in grounding the principle in reality are less well documented. Recent nursing literature has made frequent reference to the improvement in truthtelling practices since the findings of research from twenty years ago (Anderlik et al 2000). These studies made reference to the way in which there was often a 'silent conspiracy' between nurses and doctors in avoiding the issue of disclosing information to patients (Oken 1961; Knight and Field 1981). The most influential factor influencing the decision to withhold information was maintenance of hope. They concluded that dying patients had to work out their diagnosis from a series of cues and verbal slips, and that staff communication was poor. It was also concluded that junior

nurses received the impact of all this. Recent literature has assumed a more transparent approach, where the guidelines may not yet be consistent but the essential practice is a commitment to disclosure (Smith and Swisher 1998).

Nurses in the current study articulated that there remain several persistent barriers to the 'full and honest disclosure of information' at the appropriate level for the understanding of the patient, recommended by the famous biomedical authors Beauchamp and Childress (1983). According to the nurses interviewed, the very basic consideration of informing patients of their clinical condition and its implications remains a deeply contested area at the ward level.

3.2.2 Power in clinical decision-making

Closely related to the ownership of information were nurses' perceptions of the imbalance of power between patients and the health care team in clinical decision-making. Nurses felt that it was difficult to ensure that the patient remained in control of what was happening to them. This often related to the level of information given to patients in order to make informed and effective decisions. Because of their close relationship in the data, informed consent will be discussed within the context of autonomy, defined earlier as the individual's 'self-will' and therefore self-government.

Nurses felt that patients were under-informed because of fears that they might find the details overwhelming:

> 'I mean, around information giving, there's lots of things around that, are you giving people enough information um, to make a decision, um, you know, what we call informed decisions...you know, are we giving them the

information, and then, I found people will say, you know, 'they don't have the capacity to take in all the information, that you could give,' and therefore are they, they're making that decision without all the information, so that's, I think that's an ethical issue...'
Intn6 11-18

Nurses were not only concerned for the level of information given, but also for the way in which treatments were discussed. Many nurses felt that patients were sometimes pressurised into having treatment because the side-effects were not adequately explored. Nurses also articulated that they felt the patients' and families' fear of death was employed in the pressure to accept curative treatment:

'I think sometimes people are talked into having treatment, that might not be in their, probably in their best interests, it's very difficult to know...and you know, we've got young people who are, they are pretty much talked into, they're first instinct is, is, 'no, I don't want any more chemo, treatment,' and they're, 'no,' then, they're talking about their treatment, because, 'one more, if you don't have the treatment, you'll be dead in a few months, [but] if you have the treatment, it may be you will live for years,' so, you know, people with, young people with, you know, families will think, 'alright then, I'll go for it,' and yet, you know, they're dead in three months anyway...you know, sort of think...what if, if they'd had three months of, of sort of, fairly decent, perhaps, without the, you know, without all the, thinking more, sort of, um, side effects, and everything...'
Intn6 342-364

Doctors on the unit articulated a similar concern. All five of those interviewed felt that their position and use of power over patients was the most regular and persistent ethical issue encountered. This appeared to be compounded in many instances by the trusting attitudes of the patients themselves, despite their own preferences:

'The most common thing is the abuse of the power we have...like with old Parker, I'm doing things for his best interests, to get him into a place of safety, but he doesn't want it...but then, I mean he would lie down and die if I told him to...'
Intdr2 20-25

In both nurses' and doctors' transcripts there was an implicit understanding that doctors held this power rather than nurses. Some nurses felt that this in itself was to deny appropriate powers of decision-making to the patient and others around them:

> '...they [ethical dilemmas] raise issues as to whether, people, um, have a right to know, if no more, if they're not going to have any more treatment, um, and who is entitled to make decisions like that, um, I guess sometimes in the medical profession, people have to, make decisions that they probably should be discussed by, by everybody concerned...
> Intn14 26-31

In this way nurses articulated a culture of medical dominance, which they felt was exclusive and, with ethical decisions in particular, at times unmerited. However, nurses identified many occasions where they also struggled to act solely in the patient's best interests, protecting their autonomy. This seemed to be a function of their awareness of the needs of others, for whom they also felt responsible:

> 'It's difficult because you don't, you're wanting to act in so many people's best interests, sometimes it's yours, sometimes it's the pat, *ultimately*, it should be the patient's, and the relatives, um, there's so many different, sort of areas that you're trying to, well, people you're trying to please...'
> Intn1 62-69

This theme was particularly evident when patients were unconscious or had reduced competence to consent to investigations or treatment. Nurses frequently articulated that it was sometimes easier, on these occasions, to treat the anxiety and concerns of the relatives rather than the direct needs of the patient. The following extract is from a senior staff nurse reflecting on the administration of opiates to a patient in her care. These were prescribed on an 'as required' basis

because the patient had been in considerable pain with end-stage cancer. However, now she was unconscious her relatives were very anxious that her pain might be undetected. The nurse felt that extra pain relief would do little harm to the patient and be very reassuring to the relatives:

> '...and I gave one or two more injections, that, I don't really, in fact I'm quite sure I probably wouldn't have, had her family not been around, um, but I did, and, and I have, I have said that a few times, not, probably since that incident, that I have felt that I was treating more, the concerns of the family than the patient, and whether it's eth, ethically right to, give somebody, like two more stab, like injections, rather, um, if they're not needed, if I don't feel she's in pain...um, but, if somebody, I, I mean, I think you're, you're, I can't say you're pretending that the patient's in pain, but, you're giving, this little injection and you're thinking, 'well, it's not going to give them too much discomfort,' and, you know, and this particular woman had liver failure as well, I remember, and so that you knew that it was only a matter of time, the more injections that you would give, perhaps there might be a build-up in the system, and that she probably would die very quickly, and she did.'
> Intn14 97-106

Similar concerns were expressed about the need to act for patients perceived to be unable to make informed choices and so legally consent to treatment. Nurses articulated that relatives often had very strong opinions in these situations and that these tended to be respected by the medical team. This could be especially difficult when nurses perceived that relatives were making decisions that were not in the best interests of the patient. The following extract is from a senior Sister talking about a patient who had a severe learning difficulty, and who had been newly diagnosed with advanced metastatic cancer:

> ...'she's gone down to clinic to talk to Dr. X about um...well with...her *sister* had gone down to talk to the consultant about whether she can have treatment or not... it was the sister that insisted...that she went ahead with chemo, and this lady's got metastatic disease and liver mets and you think, 'well, it's buying her time, but it's not really giving her a fair deal,' in my

opinion...because she had been made really distressed, from the way she was on the ward....um....obviously this had really upset her normal pattern, of how she...you know spent her day and I think...you know I was really quite upset dunno, and shocked that the sister had...[insisted on chemotherapy]
Intn9 248-275

Nurses articulated that they knew that relatives could not consent in place of the patient, and yet frequently expressed concern that this did often appear to be the practice in situations where patients were not able to authorise treatment themselves.

Generally, nurses expressed an intense struggle to preserve the authority of the patient over their treatment. They clearly identified this to be of ethical importance, and prioritised in favour of patient autonomy in their transcripts. Among the barriers to achieving this was perceived to be the fear of overloading patients with bad news, meaning as a result that their consent was not on the basis of full information. Another barrier was the apparent power of doctors to persuade patients to choose curative treatment, especially when the side effects were not fully explored, and patients and families were apprehensive of death. Nurses themselves found it difficult to act solely in the patients' interests when relatives were highly anxious and insistent on certain treatments. The power given to relatives in decision-making was also identified to be of ethical concern when patients were not able to make decisions themselves. This was often because nurses felt relatives were unable, in their grief, to consider the present suffering of the patient as opposed to preserving extra months of life at any cost.

Medical and nursing ethics literature has increasingly reflected a shift from paternalism and beneficence to patient autonomy (Anderlik et al, 2000). This has

been attributed to increasing public knowledge, consumerism, and the legal status of informed consent. There is also a historic influence in the Nuremburg Code of 1953, which outlined the safeguards for humane medical experimentation following the atrocities committed by Nazi doctors during their research. The Code stipulates the essential nature of voluntary, informed consent:

> 'The person involved ...should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, over-reaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.'
> (GPO, 1953: The Nuremburg Code).

Informed consent clearly reflects the principle of autonomy, because the patient's self-determination is visible when making and acting on choices about what is going to happen to his or her own body. These principles are well established in current legal statute, and by the regulatory councils of the health care professions (UKCC 1997; GMC 2001). Nurses were identifying a recognised and established ethical concept.

The issue of decision-making entitlement in situations where patients have a reduced capacity to decide about treatment for themselves has been under recent discussion by the General Medical Council. Legally the entitlement falls to the medical team responsible for the patient, taking into account any of the known wishes of the patient:

> 'Where adult patients lack capacity to decide for themselves, an assessment of the benefits, burdens and risks, and the acceptability of proposed treatment must be made on their behalf by the doctor, taking account of their wishes.'
> (Standards Committee of the GMC, 2001)

Relatives do not have any legal authority to consent or act for the patient. Although the information they can provide should be respected, it can only be used in decision-making as far as it relates to what they know of the wishes of the patient:

> 'Relatives and others close to the patient should be assured that their views on what the patient would want will be taken into account in decision-making but they cannot insist on treatment or non-treatment. Their information is to help ascertain what the patient would have wanted, as opposed to what they would like for the patient.'
> (Joint statement by the BMA, Resuscitation Council (UK) and RCN, 2001)

This clarifies many of the situations nurses described as being ethically problematic, where relatives were given what was perceived as an inappropriate significance in discussing treatment options, and plans to disclose diagnosis and prognosis. However, many of the nurses knew these legal principles, and suggested that the problems in upholding them in practice concerned the fear of frank discussion with patients and the close relationships between the relatives and patients. Both these factors are enduring features of palliative care (Murray-Parkes, 1998), meaning that the situation is unlikely to change until they are addressed.

Recent debates in the literature about patient autonomy have explored the sociocultural context in which patients are making decisions. Some authors argue that, in the concern for patient empowerment, the vulnerability of the disease is underestimated (Scott, 1999). In making decisions near the end of life, a patient will always to some extent be acting for other members of the family (Anderlik et al, 2000). Nurses in the study clearly articulated the tensions of preserving

patients' self-determination in the context of an anxious and grieving family. What is more difficult to see in the literature are the needs and wishes of relatives in these situations, and the very real conflict between them and the physical well-being of the patient that can be created.

Further, implicit in the need to empower patients with their own decision-making ability is the sense that it was removed from them initially. By this argument it has been suggested that the debate about autonomy suffers from a practitioner rather than patient focus (Scott, 1999). Both nurses and doctors in the study highlighted the various pressures brought to bear on patients which limited their autonomy, even in the very basic need for information about treatment. Faced with this disempowerment, nurses often felt unable to redress the balance.

3.2.3 Beneficence during transitional care

Beneficence is the ethical principle of 'doing good' defined by Greek philosophers as essential to medicine. Although the shift from this to patient autonomy has changed the emphasis of recent ethics debates, it remains a central feature, particularly in oncology. Nurses identified many ethical issues connected with doing good rather than harm in the transition from acute to palliative care.

3.2.3.1 Inappropriate treatment

Nurses felt that dying patients did not always receive appropriate, compassionate care because of the prevailing ethos of curative treatment. They articulated a frequent sense of ambiguity about the long-term goals of treatment for patients whose clinical condition was on the cusp of curative and palliative care. This was

reflected in conflicting messages within patients' clinical care, such that some aspects were treated as if the patient were receiving curative treatment, and other aspects treated with palliative care in mind:

'...there was, that lady who, wasn't for resus, and was septic, er, I can't remember what and, but she wasn't for resus and yet she was gonna have an ITU assessment and she was gonna have this, that and the other, and she was having all that stuff shoved in her, dopamine, this that and the other, and, and I thought, well, I mean, and she actually died, with a lot of stuff in her, and I, and I thought 'ooh,' I mean, I, maybe I didn't know enough about it, she, and, yes, she probably wasn't dying of her cancer, she was dying of her sepsis, and that, and should you treat the sepsis, I mean it is that kind of, I mean...I, a lot of the time I, I don't feel I'm, I'm in a position, you know, position to say, 'I know a lot about this and therefore I can criticise the care.' I just get cross about anyway, regardless...'Ah, I'm right, everyone else is wrong!' but it's, I mean I remember sitting and looking at, that lady, and, and I think having just come from the hospice, thinking, 'just pull out.' I mean, if she doesn't die from this, she's gonna die from her cancer, fairly soon, you know, um, and certainly make a decision to treat her one way or the other. If she's gonna be for ITU assistance make her for resus, don't do one or the other, you know, um, but that was just my feeling...'
Intn2 287-310

As with the above extract from a senior nurse, these conflicting aims of care were often attributed by nurses to a lack of realistic assessment and decision-making about patients' conditions by the teams caring for them. Nurses felt that, as a result, patients received curative treatment after the point at which it was realistic or beneficial:

'I suppose, I don't think, I still don't think that we're completely honest, with people. I think some, I think it goes up to consultant level, I think, you know, a lot of that you can't change, but I don't, if you get people, if you get someone who comes in who's, I don't know, had chemo for, metastatic disease, who, is neutropoenic, who could, die, from the sepsis, and yet they're still planning a next cycle of chemo and you're still, trying to you know, buoy them up for that, I find that frustrating, I mean I've, we've had people like when it's quite clear when I first met them, I mean, I look at them and I just think, 'what are we, doing treating you with chemo that's nearly killing you, when you're, dying anyway?' I mean it's, it's a very grey

area of palliative care isn't it, and I don't, I sound very, I don't mean to sound this harsh as that, but I think, they're the things I get frustrated with, 'cos I think, 'where's that person's quality of life?'
Intn10 138-154

In fact, nurses felt that patients were sometimes actually harmed in the constant striving for the goal of cure. This was either by overtreatment, to the detriment of the patient's quality of life, as above, or by undertreating symptoms such as pain because the patient was technically classified as receiving curative treatment. For example, the oncology teams expressed caution about the use of opiate analgesia when patients were still for active resuscitation. Nurses repeatedly articulated the difficulty of caring for a patient who they felt was dying and yet was in pain:

'And her pain was ...really bad and when she goes on the bedpan...she's like in agony and the nursing staff...well...mentioned about pumps...probably it was my fault as well, I didn't push it too far...and insist them to do a pump... but it's just not permitted...she was crying her eyes out basically, not last night, the night before last and we turn her, and it's like...hard, pretty hard basically...time is just too precious...'
Intn7 37-50

Nurses felt that relatives were also keen to pursue curative treatment in situations where this was not a realistic aim. They felt that this resulted in a suspicion of analgesia which could be difficult to manage:

'They had a man, who was quite clearly dying, yet, the relatives were very keen, perhaps, he really, had minimal analgesia, they, you know, I'm not sure what, what I *think* it's about was they just hadn't accepted that he was dying, and, it was, oh, terribly difficult, because you had, um, on one hand you had, you had the palliative care team involved, but they're not around all the time, and if relatives come in the evening, they never ever meet them, you know, and then you've got the surgeons, who, you know, want somebody, you know, giving them sort of, post op care, but they don't really want to know, and they're not 'just palliative care...'
Intn6 86-88

Nurses articulated that it was difficult to address these aspects of patients' care and relatives' concerns with medical staff, because the teams actually on the wards when relatives were present were concerned with curative rather than palliative care.

Less commonly, nurses identified situations where patients did not receive adequate treatment for potentially resolvable symptoms because they were officially being treated palliatively. Nurses felt that because these patients no longer fitted the admission criteria of the ward, every effort was made to transfer them to hospices. Nurses felt that treatment for symptoms which could have impeded their discharge was unethically omitted:

> '...the bleeding ulcer could have been stopped...I'pose they needed the bed and I understand that he needed to be somewhere else...but it was really distressing for him and it could have been investigated...'
> Intn20 251-255

3.2.3.2 Inappropriate resuscitation decisions

Within this context, resuscitation decisions became the focus of confusion about the aims of treatment. Nurses felt that there was a contradiction in terms involved when patients who were not for active resuscitation were being given chemotherapy with a curative aim. This appeared to be because of the mixed messages involved, reflecting the competing interests of the decision-makers:

> 'What happened there was...um...a patient was dying and been given active treatment but at the same time was not for resuscitation. So you've got the contradiction of active treatment with a patient who's not for resuscitation. So of course you're completely confused. What is going on? Who is dealing with this? The doctors were dealing with this, the doctors were making a decision that's not right. On the other hand you've got to consider the

relatives who want active treatment, who have probably pushed for active treatment and the doctors are going along with their wishes as well. So really who are we thinking about here? The patient, the doctor or the relatives, which is a difficult one.'
Intn4 203-213

Nurses also identified situations where patients for active resuscitation were clearly dying. Nurses felt that the practical impact of these unresolved situations often fell unfairly on them:

'there are situations where, somebody's, um, for resuscitation that none of us feel should be, and it's us that are gonna have to deal with it, should that person arrest it, you know, and espec, especially on nights, I think it's very hard on night shift, um, because there may be only two or three of you around, and it's, I mean it, that's sort of, talking very selfishly, but it is very trau, you know, traumatic, and, and senseless...'
Intn15 331-431

Nurses also identified these situations as examples of poorly managed deaths. They felt that patients' quality of life had not been adequately considered and, at times, been neglected altogether. In every instance they described a lack of clear decision-making about the aims of treatment:

'...it's horrible to come back from days off and find the patient still in pain...still with everything up in the air...'
Intn21 250-253

Throughout nurses' descriptions of situations involving the distinction between acute and palliative care, nurses made reference to the difference in ethical values between doctors and themselves. They frequently articulated their appreciation of the different pressures on doctors, such as patients waiting at home for beds in order to commence treatment. However, nurses felt that their

closer relationship to and focus on the patients, made them more aware of quality

of life issues:

> '...we care what it's like for them [patients]...whereas the doctors have their
> drug trials...and think more about results...but we see what happens to the
> patient because we're here for 24 hours a day...they might be here for ten
> minutes a day and it's very different...'

Nurses were articulating a prevalent and current discussion in the oncology and

ethics literature, known as the care/cure debate (Krishnasamy, 1999). The ethical

principle of beneficence or 'doing good' has been a key feature of this. The harm

caused by chemotherapeutic drugs has been argued to outweigh the

comparatively small benefit in five-year survival (Braverman, 1991).

Oncologists remain divided in their opinion on the clinical effectiveness of

chemotherapy as the treatment of choice for metastatic cancer (Braverman,

1991). It has also been argued that lack of public acceptance of death, linked

with decreasing religious belief, has resulted in the search for 'miracle cures' and

so the pursuit of treatment at all costs (Corner, 1997). The value of palliative care

has been established, particularly within nursing, but is argued to remain a

'Cinderella discipline' within medicine (Saunders, 1999).

Nurses were identifying a tension between two modes of care, prevalent in wider

societal values, but also inherent within the care of patients whose condition

forces those caring for them to cross an uneasy border.

3.3 Contextual examples

Presentation of the majority of the findings necessarily involves some breakdown of the context in which the issues are embedded. This is to enable an understanding to be gained of the various elements compromising nurses' perception of the moral domain of cancer nursing. The chapter now turns to more detailed presentation of the context of ethical decision-making. Accounts of the decision-making affecting two patients are presented in narrative form. They are adapted from field notes which tracked conversations, care planning and care delivery over a course of several weeks in the first instance, and one intensive week in the second. In order to protect the identity of the patients, the accounts reflect amalgamated details rather than biographies. The details of the situations are based on two patients in the tracking data, but have been changed in key aspects, such as diagnosis and age. The accounts have been constructed to provide an exemplar of repeated patterns of decision-making within the text.

The situations exemplify many of the ethical concerns identified by nurses. Issues of the rightful ownership of power and information are highlighted in both accounts. The impact of conflicting clinical priorities on patient care are evident. The accounts are presented in order to enable these issues to be understood as part of a developing clinical scenario. They are intended to give a flavour of the environment within which nurses encounter ethical issues, and are presented without further comment.

References to field notes carry the code (FN) and are incorporated into the text for ease of interpretation. In order to protect the anonymity and confidentiality of

participants in the study, pseudonyms are used to replace the names of patients, and the health care professionals involved in their care.

3.3.1 Matthew Phillips

Matthew was a 72-year-old Jamaican man who had worked as a Charge Nurse in Mental Health. He had been diagnosed with prostate cancer, which had now metastasised to areas adjoining his spinal vertebrae, lymph and liver. He was well-known to the staff because of frequent in-patient admissions for cancer treatment. He was no longer being treated acutely with chemotherapy or radiotherapy because his tumours were not responding to even the most aggressive drug combinations. On this admission he had spent a number of weeks on flat bed rest with a neck collar in situ, due to unstable spinal cord compression risking neurological impairment and possibly paralysis. He needed frequent 'log rolling' where nurses would turn him to alleviate pressure but not cause any movement to his neck or spine. A urinary catheter had been inserted to conserve his movements, and he had great difficulty accepting the lack of freedom and dependence this necessitated. During his hospital stay Matthew was fitted with an upper body brace, designed to restrict movement and yet allow him to sit up. Despite his poor prognosis, the physiotherapists in multidisciplinary team meetings emphasised that he could be rehabilitated to the point of walking with the brace.

Matthew came to be perceived by most nurses as difficult and often offensive, because he regularly challenged nurses' knowledge whilst struggling to come to

terms with his condition. Nurses commonly dealt with this by avoidance. The

following extract from a senior staff nurse highlights the technique used:

> 'I found it easy on the ward, perfectly to start with, if I didn't like people, I,
> I could still perfectly just carry on, and, and, you know, keep my distance,
> when I could...'
> Intnl1 780-781

The distancing involved was often physical, observed in the amount of space

given to Matthew's bed as the nurses walked around the ward. It was also

reflected in their brevity of interaction with him.

Matthew was perceived to be a challenging patient because of his seniority and

yet his lack of familiarity with cancer treatment. This meant he would feel able to

query drug doses and other clinical decisions, and then not be easily reassured

about their accuracy. He had deep and unresolved spiritual questions about his

now terminal illness. He also occasionally made comments with sexual overtones

to the female nursing staff, which a number found threatening. With male nurses

he would at times attempt to joke inappropriately about these comments. He had

an alert and uncompromising mind, where he refused to accept false hope and,

progressively, any hope at all. Nurses found the combination of his emotional

and physical needs, and yet his intellectual confidence and intimate knowledge

of another NHS setting, very challenging. There were frequent discussions in

handover as to who would look after him, with apologies often made to me. It

was evident from their manner that they considered their approach to be open to

censure but also inevitable. The tension felt in caring for him therefore resulted

in very little continuity of nursing care. This phenomenon was not specific to Matthew.

Given Matthew's potential rehabilitation, there was difficulty in knowing where to discharge him. The surrounding hospices did not usually offer rehabilitation, and most rehabilitation centres expected to send a patient home rather than to a hospice. There were funding issues involved about the local authority's willingness to pay for rehabilitation in such circumstances. Many of the nurses considered the enforced inclusion of resource factors other than those directly related to the patient unethical:

'you always obviously want the best for your patients, and you don't always feel you're getting that, and it's sometimes, reasons, beyond your control, just, like, where they live, or, the consultant looking after them...it's just, it's very difficult sometimes, to rationalise that...'
Intn1 443-439

Alongside the complex resourcing issue about Matthew's rehabilitation was pressure from the medical staff to make a decision. Field note observations record how the Senior Registrar angrily explained to the Staff Nurse in charge of a shift during this period, that the ward was not designed to be taken up by people not receiving chemotherapy. He clearly identified the priority of getting Matthew into a hospice. This would allow the next person on the waiting list, whose tumours were growing and life expectancy thus diminishing, to be treated. He divulged that some patients and their relatives had his bleep number and would use it continually to inquire about the bed status on the ward. It was clear he felt a strong accountability to patients fitting the admission criteria of the

ward. The Sister, and most nurses, in contrast, felt that Matthew's needs should take priority over patients on the waiting list. This is an extract from a junior staff nurse reflecting on Matthew's care after he had been discharged:

> 'you know, there *are* other people waiting to come in, sometimes forget that…um, but again, you feel that the decision isn't always, necessarily the patients' or the families' best interest, it's, it's a rushed decision, it's because of another reason, not because of *him*, um, and that's quite hard, especially when you know that they're going to die, you obviously want them in the best place for them…
> Intn1: 393-400

During the period of uncertainty over Matthew's discharge, he seemed to become increasingly agitated. In the early evenings he would often call out loudly for sedation. He knew the name and dosage of the drug that he felt was required. This had been prescribed for him, but there were differences of opinion amongst nurses about whether he was addicted to the drug or whether he was increasingly suffering from a psychiatric disorder. There were also differences of opinion about whether this distinction mattered, given his condition.

Several nurses were concerned that the effect of the sedation was to make Matthew sleep heavily, and were worried that he simply wanted the drug in order to be unaware of the difficulties of his situation for a few hours. Other nurses felt that he should be able to choose whether or not to spend his remaining life in this way. There was no clear leadership on the issue, with conflicting opinions also amongst senior nursing staff (FN 8/97 250-375). Matthew began to scream in the evenings and appeared acutely distressed, saying that he had loud ringing in his ears which was unbearable. The nurse caring for him had a decision to make

every evening, between administering the drug or not, according to their judgement. There were discrepancies between the actions taken, which may have contributed further to Matthew's distress when the decision was to withhold the drug.

During a ward round, the nurse in charge, who was a fairly junior staff nurse, brought up Matthew's agitation and mentioned the possibility of a psychiatric review. The Consultant, Registrar and SHO all felt that the psychiatrists 'would not be interested.' In the Consultant's opinion, they would refuse to come to the ward for such a patient (FN 8/97 344-346). In a separate discussion with me later that day, the Senior Registrar mentioned that such a referral would lengthen the discharge process and so was unacceptable. Given the poor prognosis, he did not consider psychiatric treatment a necessity, but felt that effective sedation was the best course of action (FN 8/97 360-363).

The nurse on the ward round came to me to speak about her distress. She felt that Matthew was not being given adequate treatment for a condition that she felt was unrelated to his terminal prognosis. She considered, in conversation, whether she should override the doctors' decision and contact the psychiatrists herself. She felt however, that they would be unlikely to listen to her, and that the retaliation from the doctors on the ward would be humiliating for her (FN 8/97 371-382). The acute phase of Matthew's agitation had been ongoing for four days when a bed became available at a local hospice that had some occupational therapy support. However, most nurses felt that he was unlikely to receive there the rehabilitation he needed in order to maximise his walking. The issue of addiction

as opposed to psychiatric symptoms was not resolved when he was moved. Approximately two months later the ward heard from the hospice that he had died.

Matthew's care raised a number of concerns which nurses identified to be ethical in nature. His challenging behaviour and yet needy situation caused nurses to avoid him, which they then felt guilty for. The lack of provision for his rehabilitation need because of his diagnosis of cancer was perceived to be an unethical omission. The emphasis of some medical staff on the next patient on the waiting list rather than the patient presently in the bed, was considered by all the nurses to be unethical. The lack of a psychiatric review and Matthew's continued agitation was deeply distressing and most nurses felt that he had been poorly cared for. Many nurses expressed for several weeks afterwards that they were continuing to review the decisions they had made about giving or withholding the tranquilliser.

3.3.2 Belinda Foyle

Belinda was a 68 year old lady who was part of a very close-knit family. She had worked as a 'teacher's help' for many years and was extremely friendly. She expressed full trust in the doctors and nurses and passively accepted any intervention without question. Her diagnosis was squamous cell carcinoma of the lung with spinal metastases, and stable cord compression. The current in-patient stay was in order to receive radiotherapy to reduce the spinal tumour size, and to plan future care. An ongoing problem was that Belinda was experiencing large

amounts of malaena and had a very low haemoglobin level. This made her look extremely unwell and she reported feeling tired and ill. In handover on her first full day following admission to the ward, a staff nurse mentioned that she was not yet querying why she had malaena, which was due to further tumour invasion to her small bowel. There was a general consensus that her absence of questioning was a good thing and made life easier (FN 11/97 132-146). Her resuscitation state changed during the first day of her stay, as the Registrar observed her poor state of health and tumour invasion. During the next 48 hours, Belinda began to complain of increasing pain in her abdomen and her haemoglobin level continued to decline. She began to take breaths in gasps and her pallor was grey. Despite two units of transfused blood, her general condition did not improve. At this point, in the third morning handover following admission, the senior staff nurse outlining Belinda's care stated that she felt she was now clearly dying (FN 11/97 345-362). However, the medical handovers to the nurse in charge each day were not similarly emphatic, and reflected only a 'day-by-day' approach, managing symptoms as they arose.

Belinda continued to complain of increasingly serious pain and she began to refuse to move in bed because this exacerbated it. Several nurses involved in her care over the next two days mentioned in handovers that she should now have an analgesic pump rather than relying on regular oral medication. There was some resistance from the SHO over this, who felt that she had not been clearly labelled as dying, and that pumps were only applicable during the end stages of cancer. Although many of the nurses disagreed, there was no clear lead to address the

issue further. This in itself caused nurses concern, as the following extract from a senior staff nurse highlights:

> We didn't start the pump until yesterday afternoon...about evening time about six o'clock, which is...which is not right really. Well, I mean, I don't know....who should be the one that push it...or who should be the one that makes the decision? I don't know...'
> Intn7 37-50

Nurses clearly felt that the decision to not have a pump should have been challenged, but were unsure who should have done so.

During this time, Belinda's son and daughter were in fairly constant attendance, and her daughter Betty was keen to look after Belinda at home following her inpatient stay. Many of the nurses became concerned that the relatives did not appreciate the severity of Belinda's condition and the possibility that she may shortly die. They also felt that Belinda herself did not appreciate this. During the third day, Betty, her daughter, was looking through the nursing notes at the end of the bed, and asked the meaning of the word 'malaena.' She went on to ask if there anything was being hidden from them. The staff nurse answered that she would organise a care planning meeting for them to have their questions answered. This nurse later expressed to me that she was very relieved that something had happened to break the cycle of silence (FN 11/97 423-465).

During the ensuing care planning meeting, at which Belinda was unable to attend due to her pain, her son and daughter asked the Registrar the implications of her having malaena. He answered that this was due to a bleeding ulcer, which needed

to be treated. The staff nurse attending the meeting went on to inform them that it was unlikely they would be able to look after their mother at home, even with full-time support. She told me later that she had said this in an attempt to heighten their awareness of her dying condition (FN 11/97 556-578). The Registrar then went on to assure the relatives of the need for a day-by-day approach, to which they agreed.

Many nurses felt that the relatives had not been told the truth. The following day Belinda's condition had deteriorated markedly, and the relatives were told by the Registrar that she was going to die either overnight or in the next few days. They were very shocked. All of the nurses found the lack of accurate information-giving, alongside Belinda's sudden deterioration, distressing. This is an extract from a senior staff nurse reflecting on Belinda's care:

> '...because Belinda was...um in a lot of ... well pain and...and the family wasn't informed about her prognosis, but then, um actually she'd gone downhill so quickly and the information that was given ......to the family was like, 'don't worry, we, you know, get the bleeding under control and she'll be fine,' kind of thing and that was not the case.... and um, yeah, so, it's like, that is not right really, because yesterday she went downhill so quickly and had to tell the family...that were there...so...it was a shock to...to all the family...it doesn't come in as something that is right really.'
> Intn7 16-30

Belinda's care was complicated by the very short time span in which the events occurred. She was in the ward for less than one week before she died, and it was not possible to predict such a marked deterioration from her diagnosis at the outset. Many nurses felt that clinical decisions such as for pain relief were hampered by the lack of a medical consensus on her now palliative condition.

Many also identified a confusion in responsibility for challenging decisions not in the best interests of the patient. The lack of truthtelling to the relatives was considered to be unkind and unethical. No-one, however, identified Belinda's own need to know the reality of her condition.

3.4 Summary

Nurses identified that ethical issues were implicit in many aspects of their care of cancer patients. In spite of this, they lacked visibility in the clinical context. Nurses felt that the issues involved a personal response and were therefore approached with uncertainty.

The border between curative and palliative care provided the backdrop for many of the ethical issues identified. These involved maintaining the patient at the centre of care planning, in the ownership of information and allocation of power in decision-making. Issues of overtreatment in the palliative stages of patients' stay on the ward caused considerable distress. Nurses felt that dying patients were inadequately supported on the ward.

CHAPTER 4: FINDINGS

Discovering patterns of ethical decision-making

Introduction

This chapter explores patterns of decision-making in patients' care where nurses
identified issues of ethical concern. Observational and interview data are
presented in order to highlight common strategies used to address ethical issues,
both articulated by nurses and observed in fieldwork. The methodological
principle informing the dual data collection strategy was that of achieving a
contextual account of individual nurses' world view. This enabled the analysis to
draw on an integrated understanding of nurses' experiences, where different
types of data were interlinked rather than used to critically review the other.
Critics of the use of observational methods as well as interviewing in
phenomenological research have argued that the result is often to attribute
primacy to observational data in any contradiction with verbal accounts (Paley
1998). Observation was not perceived to be more 'real' than interviews, or used
to undermine nurses' verbal accounts. For example, it was possible to interpret
some apparent contradictions in nurses' accounts of ethical decision-making as
being a reflection of the contradiction between formal and informal accounts. In
everyday conversation on the ward, nurses expressed their opinions differently to
the replies that they gave during the opening of a taped interview. At a later point
in the interviews, nurses' accounts would often return to the more informal style
and content of day to day conversation. Linking fieldnotes and interviews
enabled conclusions to be reached about the private understandings of nurses,
and also the opinions they felt that they should have held. In many cases these

were different and gave insight into the kind of constraint nurses felt in voicing and acting on ethical opinions.

This chapter will describe the way in which many ethical decisions were avoided rather than actively managed. As a result, the chapter can not present an analysis of decision-making processes because the data rather illustrate the effects of not initiating and sustaining that process. Decisions were not made in any systematic or well-defined manner, but chaotically, changing in emphasis from practitioner to practitioner. In both data collection and analysis, it was difficult to trace decisions through relevant documentation or patient care meetings, because ethical issues were essentially kept in the informal networks of the ward and surrounding teams. Analysis has rather reflected thematic similarities in approach to the issues and in the barriers experienced to their resolution. There was also a consistent effect of these barriers on the patients concerned, even though the ethical concerns may have been very different in each case. The methodological focus on individuals' perceptions of events, as well as active observation of the setting, facilitated the study of these 'hidden decisions.' Insight was gained into each practitioner's personal approach, often directly as they were faced with ethical issues prompting a response. At the same time it was possible to witness the sequence of events and the eventual outcome for the patient.

The format of the chapter is therefore to first establish the way in which ethical decisions were avoided by all staff, at all levels of responsibility. In some of the nurses' and doctors' discussion about these issues, contributory factors were

evident. The chapter then explores those factors which inhibit ethical decision-making, with reference to field notes and interviews. Finally, the avoidance of decision-making will be shown to lead to nurses' unwilling involvement in compromised patient care. These situations typically occur at the interface between acute and palliative care.

4.1 Absence of ethical decision-making

Nurses privately identified ethical concerns about aspects of the transition from acute to palliative care in the ward. These have been described in chapter 3 and include truthtelling, resuscitation, informed consent, futility of treatments, hierarchical conflict, confidentiality and patient advocacy in reduced competence. Many nurses described the issues as being hidden and implicit rather than explicit in care. They were also described as being difficult to articulate, involving strong personal opinions and values. This section will show that ethical decisions did not get made because of a related lack of open discussion, combined with a lack of awareness that others shared ethical concerns.

4.1.1 Lack of open discussion

Strikingly consistent with the hidden nature of ethical concerns was the observation that they were not openly discussed on the ward. This observation was an enduring phenomenon over the 18 months of field work. The lack of open discussion was clearly reflected by many nurses when discussing possible improvements to current practice:

'...perhaps discussing, like making it a, regular thing, to discuss ethical situations on the ward, or something, and, er, yeah, I think just making it, more sort of a talked about thing, rather than, coming across a situation, and thinking, 'oh, you know, what do we do, here?' (if) you're so used to sort of thinking about it and debating it, and talking about it, it's sort of easier...'
Intn15:262-268

The implication was that the issues were not readily or easily discussed in everyday work. Field notes also confirmed that although ethical issues were identified in practice, they were not directly addressed and so not discussed. The following extract is from a handover of night to early shift, where a senior staff nurse was explaining that an elderly patient appeared not to understand that she had been diagnosed with cancer. The suggestion was made that as she was elderly, it might not be worth upsetting her with the truth. This was identified to be an ethical issue but then not pursued:

'I was trying to think how Michelle had dealt with the ethical issue. I kept thinking, in the ordinary way. So what is the ordinary way? She talked about the other practicalities. The way things were going ahead. But with no discussion of the actual ethical nature of the lady's misunderstanding, of whether it was significant in any way that she should have the right knowledge. The situation was acknowledged to be ethical, (because I was there as a prompt raising the issue?) and was then passed over. Not just because of lack of time, or not the right atmosphere to ask questions, both these were not unduly pressured. The issue was not taken up, or wrestled with but ignored.'
FN May97 22-32

This sense of issues being ignored and overlooked was difficult to equate with an environment where the standard of clinical care was acknowledged within the hospital and by other cancer units in the area to be very high. Few other details of patients' situations were overlooked and the approach to daily care was meticulous. As explained in chapter 3, nurses' motivation to care for

patients was strong, often arising from deep personal conviction. It seemed that ethical concerns raised such complex issues that a motivation to care, and a discerning attitude, were not sufficient to combat the obstacles involved.

4.1.2 Unaware of shared concerns

Nurses appeared to be unaware that others shared their concerns about ethical issues. In their interviews, many nurses made reference to the same patients and identified the same features of their situations as a cause for concern. These were spoken of as issues that were personally troubling, rather than as widely acknowledged problems of patient care. It was as if they felt that the concern had only occurred to them and was not immediately apparent. Where interviews occurred in the same period of time, the same two or three patients would consistently feature in participants' interviews. Summaries of the concerns raised about these patients are given at the end of chapter 3. However, nurses and doctors were clearly under the impression that in most instances their concerns were unique to themselves. Nurses often excused themselves when expressing opinions in interviews, frequently stating that they did not have sufficient knowledge or expertise to criticise. Yet many of their colleagues highlighted the same concerns about the same patients, whilst similarly pointing to their own inadequacy to judge the clinical situation.

There were rare incidences where nurses described having broken out of the pattern of not discussing concerns and frankly raised an ethical issue. In 18

months there were approximately three clinical incidents where this occurred[1].

In these situations nurses highlighted their surprise at finding that their

colleagues shared their conviction that the current situation was not in the best

interests of the patient:

> 'I remember one day actually um…saying, I think, I can't remember
> which Sister it was, one of the Sisters, I just, I said to her, 'what are we
> doing?' you know, actually, what are we doing, and I think she, at the time,
> she said, 'look, we've just got to get on and do this, the person is for resus,
> and we're gonna, for now,' but then afterwards, she actually said look,
> we're all finding this really difficult, you know, and I think, yeah, I wasn't
> aware that everyone else was, I assumed that I was the only one because
> maybe I, the background I come from. But the fact is that everybody else
> did, and, you know, it was good, because we could sit down, and we did all
> say 'yeah she should have been one or the other, but we don't..' I mean, that
> was I think the issue within that, you either treat someone actively or you
> don't, you don't make them not for resus and then, very actively treat them
> at the end.'
> Intn2 339-352

In these situations, nurses expressed a great sense of relief at being able to

discuss the scenario in question. Observation revealed how this resulted in a

decrease in tension between nurses and the patient, shown by more lengthy

interaction and less avoidance. It was also apparent that the discussions often

led to more direct action in the form of raising the topic in multidisciplinary

environments.

4.2 Barriers to decision-making

This section will explore the way in which nurses' lack of confidence in their

knowledge, combined with and affected by the culture of medical dominance

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[1] In any fieldwork there will have been periods of unobserved time and therefore instances which
have not been recorded and included in analysis. However, over a prolonged period of study

generated a sense of inability to deal with ethical issues. However, doctors also

expressed an inability to deal with the issues. The fact that no one felt able to

accept responsibility led to poor management of the issues.

4.2.1 Lack of confidence

Nurses often made reference to their assumption that their ethical concerns

could not be expressed because of their lack of qualification to raise the issues.

Every nurse interviewed expressed this to be a personal barrier to dialogue,

particularly with medical staff. In most instances, the perceived inadequacy

appeared to be related to knowledge:

> 'I mean...I, a lot of the time I, I don't feel I'm, I'm in a position, you know,
> position to say, 'I know a lot about this and therefore I can criticise the
> care.''
> Intn2: 299-301

However, it was further apparent from nurses' transcripts that their

underconfidence in expressing ethical judgements was not due to the absence

of knowledge, but rather from fears of having the wrong kind of knowledge.

Nurses felt that they were working from experiential knowledge, rather than

the objective, clinical knowledge of the doctors. In many cases, nurses linked

this with the status of nursing knowledge in the medical hierarchy:

> 'well you know...there's still that sort of feeling....doctors are up here and
> we're down here...and we know that we can't think that...you know we
> haven't got the knowledge and we haven't got the expertise to actually be
> saying, 'well, hang on, I disagree' um...and I suppose as well, you feel like
> you're not actually giving a valid argument. Because we're actually looking

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most field researchers agree that general patterns can be detected and abnormalities placed in that
context.

at it from a different perspective perhaps, well you know from experience in a sense...'
Intn9:241-246

Closely linked to the feelings of inadequacy because of the kind of knowledge nurses felt they possessed, was the perceived invalidity of ethical concerns themselves. Nurses felt that such concerns would not be well received by the medical staff because of the existing pattern of avoidance and disrespect for the issues themselves:

'you know quite often they're [ethical issues] ignored, or passed over or, you know, some sort of um flippant comment is made...to make it look like it isn't an important issue. And obviously they are avoided....again by...various members of the team...I think the coping strategies are involved...'
Intn9:260-264

There were therefore two undermining forces at work in nurses' decisions to not raise ethical concerns. There was the perception of having the wrong kind of knowledge, or at least not the kind of knowledge that was given weight in multidisciplinary patient care planning. There was also the anticipation of a poor reception for ethical concerns, including attempts to trivialise their nature and direct avoidance.

4.2.2 Inability to challenge decisions

Implied rather than spoken was the perception amongst nurses that raising ethical concerns would be seen to be a criticism, rather than a normal part of constructive, open dialogue. This can be seen from previous extracts where nurses discuss their hesitation to raise ethical concerns for fear of criticising

without due authority. On many occasions during observation it was clear that nurses felt that there was an official course of action which was not open to scrutiny. It was interesting to note that they often felt that the official treatment should continue despite being personally opposed to it. This sense of treatment plans that were not open to question, even in the face of private concern, was consistent throughout nurses' interviews. Junior doctors also spoke of established treatment plans as stipulations which they felt had to be followed without question, especially when these were seen to be consultant-led. The private concerns which were rarely discussed between nurses and equally rarely with even junior medical staff, were therefore seen to be subversive to the treatment occurring in the unit and to those authorising it. This created a culture where staff felt unable to challenge decisions.

When interviewed, one of the consultants attached to the ward felt that it was the particular environment of the cancer directorate which did not facilitate good decision-making. He felt that professional relationships between consultant teams was not collaborative. He mentioned the accumulation of professional resentments between particular consultants, and in particular the pattern of one powerful consultant setting treatment regimens without research evidence or dialogue. This led, he felt, to poor standardisation of chemotherapeutic treatments. Other consultants similarly felt that there were very poor relationships between teams and a lack of open dialogue about the often very aggressive treatments that they felt obliged to offer. It seemed that the culture of being unable to challenge decisions permeated to all levels of clinical responsibility.

4.2.3 Hierarchical referring

The lack of discussion of ethical concerns, and feelings of inadequacy to manage them, led to staff attempting to refer the issues on to others, usually their senior. This formed a pattern of hierarchical referring, where no-one felt able to address the issue. The junior staff nurse in the following extract felt that the Sister on the ward would be more able to deal with the ethical issue because of her greater seniority:

> 'And I think you have to be quite...up front to speak to the doctors, especially the Registrar. Some of them just don't want to know and they have a lot of pressures and they can take it out on you. And you don't want to be shouted at so you leave it to another person...so...maybe sister might be able to do something...you know what I mean? I don't mean pass the buck...but just feel...if you've got the blue dress on maybe that help with it a bit...it does help...'
> Intn7 110-114

Again, the fear of a poor reception for ethical issues can be seen here. The desire to pass on the issue was noticed by the senior nurses on the ward, who felt that this was inappropriate because they were often no better equipped to deal with it. They had often not been caring for the patient concerned, and felt that junior nurses expected them to be able to resolve the issue, when the same issues of confidence and fears of a poor reception applied:

> '...seeing me as a senior member on that um shift , that it's my duty to like, to actually then go and deal, *deal* with that situation and, and and, obviously discuss it with the people I feel it needs to be discussed with. And that's often not as easy, when it's not something that you've actually...you know, thought about yourself, you're know, they're getting...you know quite often they're [ethical issues] ignored, or passed over or, you know, some sort of um flippant comment is made...to make it look like it isn't an important issue. And obviously they are avoided....again by...various members of the team...I think the coping strategies... you know if they have me up against

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that then you've got to have experience and... confidence to be able to actually say to somebody ...'
Intn9 231-246

The junior doctors on the ward also recounted many occasions where they felt that unresolved concerns were suddenly presented to them by nurses, often when the situation had become more problematic because of delays in effective management. They clearly felt that they were made inappropriately responsible for these situations, and subsequently blamed by their seniors for the degenerating situations:

"These kinds of things [ethical issues] are dumped on me by the staff on the ward. They're not essentially my problem, they then become my problem, and then the team blame me for it...'
FNJ97:23-26

Again, each member of staff in the hierarchy did not appear to know that the others felt unable to deal with ethical concerns. The consultants on the unit felt that they were also presented with situations they were expected to resolve, even though they may not have had any personal dealings with the situation:

'There was a resus situation over this Afro-Caribbean man a few months ago. It ended up with me backing down in this office at 11pm one night. The family were up in arms over it and I was suddenly presented with this very difficult situation.'
IntCon1: 196-201

In this way, it becomes clear that the hierarchical pathway along which clinical decisions usually passed, was not operating effectively, but generated feelings of unease at each level. Ultimately, no-one felt able to take responsibility for ethically problematic situations.

4.3 Consequences of poor ethical decision-making

Related to the lack of discussion of ethical concerns, and the pattern of continuous referral, were admissions of a lack of management of patient care dilemmas. These unresolved or poorly managed situations were directly linked by many nurses to the lack of open and shared discussion:

> 'Probably, like with Niky (patient) now, probably we'd really have to get together have...talk about it. Discuss how we can actually....not identify why we wouldn't....not actually accusing people about why things aren't done, but identify why, why nurses didn't go...go to doctor and set up the pump or whatever, making that decision, and why...we...we didn't talk about it, the doctors didn't talk to the family more up front and identify that kind of issue around it but not blaming people...not...for not getting things done, because that's going to get everyone really wound up about it. But identify it, so properly, we can reflect on that next time actually we can actually tackle these kind of problems a bit more...different way...'
> Intn7:310-322

Lack of direct communication about the issues affected not only teamwork but also relationships with patients. In these situations, there was little or no agreement between teams about the best method of resolving the issue, and no understanding with the patient as to the nature of their situation and the best means of resolving it. In other aspects of clinical care there was good teamwork and patient involvement.

The lack of discussion and management of ethical issues led to a variety of situations where patients were not dealt with frankly and honestly, particularly in the trajectory approaching death. For example, it led to patients not receiving appropriate analgesia whilst dying of metastatic cancer, because the

deteriorating nature of the patient's health was in conflict with their curative treatment, and no one felt able to say this.

It also led to patients never being told of the nature of their diagnosis in a way they could understand and make sense of. This was because various team members became aware that the patient did not appreciate the nature of their condition, but felt unable to be the one to address it, or raise discussion about it. Consistent throughout nurses' accounts of these situations was the sense of no one person taking responsibility for what was happening:

> 'what happened was, was all this, chasing around, and nobody really wanted to take responsibility for what was going on... you know, we should have sat down, talked to him and his wife...you know, as I say, nobody was in control of the situation, at all, and you know, ethically, there was lots of things going on there, all about, trust, about giving more in[formation]...we were all sort of like, 'oh well, you know,' it was a typical avoidance thing...'
> Intn6 100-112

It can be seen here that the patient is lost as the focus of the dilemma, because the central issues are not addressed. The picture of staff 'chasing around' the situation was an accurate portrayal of what happened, during observation, to ethical situations which were receiving attention only because the issues had become too problematic to ignore. In recounting these situations, nurses often reflected that it was difficult even in retrospect to see who should have been the instigator of change in the situation:

> 'Well, I mean, I don't know....who should be the one that push it...or who should be the one that make the decision? I don't know...no one has even tried to undo the damage. No, I mean nobody actually trying to raise the

issue or push it, so that....you know...actually put it in the picture.'
Intn7 35-61

In discussing their own lack of involvement, nurses again looked to their lack of confidence to express ethical concerns, but also to the general pattern of avoidance of ethical issues on the ward:

'...I mean I think we're a team in this, as avoiding the issue, of not saying to the patient...'
Intn16

Ultimately, the lack of management of ethical dilemmas resulted in situations which were only resolved by the patient's death, or by having to deal with an 'explosion' of problems associated with the patient in question. Many nurses mentioned that ethical decisions were often made 'too late':

'thinking of Astrid for example, and I think, again, that was another decision I felt was probably managed inappropriately and wasn't, you know we weren't able...able to give our....I wasn't actually involved in that, but um, I never actually looked after Astrid, I know...and it was something that was never really brought up in hand over, until it was really too late.'
Intn9: 460-463

Situations that overtook ethical decision-making resulted in what many nurses perceived as compromised patient care. Observational data highlights situations where patients were at times left in acute suffering, either physical or mental, because decisions not been made earlier in care planning. This could result in extreme grief reactions on the part of unprepared relatives, for example, if they had not fully realised the extent of their relative's condition or witnessed a death following a painful descent. Nurses were left traumatised

following these events, even more so because they felt that they did shoulder some of the responsibility. The effect of both grief and guilt on nurses' coping strategies did not facilitate further open dialogue and was cumulative in effect.

4.4 Summary

Decisions about aspects of patient care which were perceived to involve an ethical dimension were regularly avoided by staff at all levels. Ethical issues were not discussed openly, and so shared concerns were not identified. Nurses felt inadequately equipped to express their ethical opinions, perceiving that to do so would receive disapproval and censure. There was a pattern of referring decisions to those in senior positions, who also felt inadequately equipped to deal with the issues.

The consequences for dying patients in particular involved poor teamwork in assessing developing needs. The provision of adequate pain relief and relevant information were the most seriously affected areas of patient care.

CHAPTER 5: FINDINGS

Determining aspects of moral agency

Introduction

Having identified some of the barriers to ethical decision-making in the last

chapter, this final findings chapter will describe a process operating amongst

nurses on the ward, which further impeded their response to compromised

patient care. There will be a greater level of interpretive analysis than in previous

chapters. Findings were regularly discussed with nurses during analysis, in order

to validate key aspects of the process identified. Nurses felt strongly that the

findings were congruent with their experience. Whilst they found the analysis

difficult to discuss, nurses expressed relief that the issues identified had been

unearthed. Some of the impediments to discussing and acting on ethical issues

involve a complex internal dynamic for nurses. Analysis has involved close

integration of field notes taken over the 18 month period, and interviews which

took place with individual nurses at different stages in their stay on the ward.

Data extracts and field notes will be used to highlight ways in which nurses view

themselves and their contribution to decision-making. Their moral values and

attitudes will be shown to be subject to change over time in the ward

environment. This is a stable finding across many nurses, and was unknowingly

attributed by them to the same process. The relationship between this process

and nurses' ethical decision-making will form the body of the chapter.

5.1 An eroded sense of control

In their interviews and in observation, nurses demonstrated that they did not

consider themselves to be personally in control of ethical decision-making and

patient care planning. There were both external and internal attributes of this

phenomenon. Internally, there were many indications over the period of

fieldwork and in interviews that nurses had an eroded sense of their personal

capacity to form valuable opinions or to effect change. This was highlighted by

nurses' consistent use of the plural rather than personal pronoun when referring

to their opinions on patient care, or interprofessional relationships. Nurses found

it difficult to express an opinion without knowing it was part of a more widely

agreed phenomenon. In interviews, nurses would often be expressing views that

the nursing team held, and would speak personally only after subtle

encouragement:

> '...but somehow we think as nurses, you know, well, I think, I'll talk about
> me now, I think, as a nurse, I can meet everyone's need...'
> Intn2:549-551

The same issue also applied to nurses making admissions of what they found

difficult about the ward. They would rarely express a personal struggle without

having first framed it in the context of a wider group, to authenticate it:

> 'I think it is an issue and I think it's something that, we struggle with as
> nurses, I think that I struggle with sometimes...to know people's, doctor's
> rationale behind their decision-making...'
> Intn15:381-383

Nurses also rarely felt able to initiate discussion independently. They readily

linked this to their fear of a lack of knowledge or simply of having the wrong

viewpoint. Their first reaction to noticing an ethical issue was to take soundings from others in order to gain enough confidence to take the issue further. Nurses needed reassurance that their opinion was valid in order to proceed with investigating the concern. The Senior Sister in the extract below has just been talking about her difficulties in personally raising concerns about patient care:

'[I often feel that] I don't have knowledge or um maybe the right viewpoint, and I suppose that maybe puts put me off. But then I'll actually...if there is something that bothers me that I feel I should bring up I might actually talk to a colleague and say that, 'I'm concerned about this, what do you feel?', and I just get a little bit of feeling on what someone else thinks about the matter and then perhaps that gives me enough...to talk about things...'
Intn9:418-428

In this way, nurses needed support and reassurance from others in order to begin discussion about ethical concerns. Despite regularly having serious concerns about aspects of patient care, nurses remained unable to challenge decisions alone. They also continued to participate in treatment plans which conflicted with their personal assessment of the patient and their needs. This again was related to nurses' need to avoid offering a personal opinion, because they did not appear to trust their capacity to make sound judgements. Nurses preferred to act as a group where the responsibility for the concern would be diffused:

'I suppose that you, um, I mean you wouldn't, I wouldn't anyway, sort of, challenge something, without, you know, without discussing it with my colleagues...not, not formally anyway, I might say, I might say, "what we doing treating this person when they look so ill?" in my usual, kind of, offhand way, but I wouldn't sort of formally approach someone without, seeing what other people, felt, and, approaching, maybe colleagues with a similar, level of knowledge and experience, who could make a...perhaps look at it with the same, not the same eyes, but look at it with a, with a similar background, professional background anyway, and I spose then, 'cos, then, if you have to take it to, um, I don't know, to other members of the

multidisciplinary team or to, you know, and or to, medical staff, you're then, saying, we, you know, we feel this as a, as a team.'
Intn10:301-316

Concerns would be raised in the informal networks of the ward, but action was slow to take place because opinions needed confirmation and group action. Nurses often felt a subsequent sense of guilt for having been involved in care which they felt was not in the patient's best interests. This was particularly intensified after the patient's death. They also felt responsible and therefore guilty for the lack of action which they had taken. These feelings proved to be destructive, and nurses became less and less sure of their ability to care for patients, given their silence in the face of patients' suffering. The nurse in the following extract was expressing concern over the fact that a dying patient in intractable pain had not received opiate pump-controlled analgesia for several days. She felt that this was because, although initially refused by the doctors, nurses did not query or insist on the need for the pump:

'...we need to discuss how we can actually....identify why, why nurses didn't go to doctor and set up the pump or whatever, making that decision...and why...we...we didn't talk about it...'
Intn6:311-317

In interviews themselves, nurses were also reluctant to offer any criticisms of the unit and management of care. Informal conversations and observation had highlighted their substantial concerns, but in interviews nurses needed permission and reassurance in order to express a dissenting view. For example, there were often two contradictory positions expressed in interviews. At the beginning, nurses would describe the better team relationships in oncology, and

the inclusive nature of the team on their particular ward. However, in the closing section of the interview where they were asked for recommendations for supporting ethical decision-making, nurses would reveal the absence of teamwork and resulting lapses in the standard of care, particularly with palliative treatments. Criticisms could therefore only be expressed when disguised as recommendations for practice. This again reflected nurses' need to avoid or distance themselves from offering a personal dissenting voice.

5.2 Medical domination of practice

Externally, nurses indicated that there were many instances where their opinions were not sought nor their contribution asked in care planning meetings. This made the delivery of care more labour intensive, as nurses had to seek out the latest decisions in order to implement them, and were then left in a dilemma if they felt that the decision was unsuitable. It was also then difficult to ascertain what patients had been told by different members of the team. The lack of involvement seemed to arise from the dominant culture of medical leadership in decision-making, where nurses had to struggle for information and co-operation:

'we weren't invited to that decision making process and um...maybe it would have made a difference...you need to be involved in [talking to patients and relatives] so you can actually do your job properly...but, again it's the pressure of time, doctors come onto the ward and they can't find us...and you know they come up and there's not the person they're looking for that's available, so therefore they'll go on barging in, and talk to this person without one of us being there, and um you know then they just go off the ward without telling us...so there are lots of complications...'
Intn9:501-509

More directly than being excluded from decision-making, nurses also felt that their opinions were not always respected or welcome. They felt that when they were trying to explain aspects of patients' conditions relevant to current decision-making, doctors did not value or act on their contribution:

'I think sometimes things happen and we're not involved, or we say things and the doctors don't listen or they don't believe what you're saying...there are times when that happens.'
Intn13:304-307

Nurses often described the dialogue between themselves and the medical staff as a power game. Many nurses articulated the way in which they would try and disguise their suggestions for changes to patient care as originating from the medical staff. In this way they felt that they could avoid directly offering an opinion which may not be well received. Nurses felt compelled to play the 'game' because they felt that the content of the information they were trying to transmit to the rest of the team was often crucial to the welfare of the patient. As a result, they did not feel content to leave it out of care planning:

'...sometimes it's difficult to say exactly how you do have influence on decisions, but, I mean, you've thought of things that you have to do, like, make people think they've made the decision, and to a certain extent, you know, I think, 'oh, I haven't got time for these games,' you know, um, sometimes you do it, and sometimes you just think, 'I can't be doing with this,' you know, sometimes you've, got the energy to expend on it, and sometimes you haven't, it's like, 'look, listen to me,' you know, I haven't got the time for this, and sometimes you go, 'you know, if you think about this,' you know, 'you can sort of see this'...[making decision originate from medical staff]
Intn6:301-313

Having to play a game in order to pass on relevant clinical information left nurses doubting their own contribution. Although they frequently acknowledged that oncology had greater teamworking than other disciplines, and that nurses were becoming more able to disagree with medical decisions, the dominant perception was that of nurses not being in control of decision-making:

'...when, um, talking about decision-making, I feel, ethically, that nurses are seen to be more, a carrier out, we carry out, things rather than, um, make the decisions. I feel that, ethically most of the decisions seem to be made from a medical team, um, but I think that probably, nurses have more of a say and I guess, if we don't, agree with decisions then, then I think, we'll say it now...'
Intn14:32-38

Nurses therefore felt that their ethical decision-making was subject to both internal and external constraint. Internal constraint involved nurses' concerns over their lack of knowledge and ability to form wise judgements, and their corresponding need to express opinions as a team rather than as individuals. However, ethical issues were not frequently discussed amongst nurses and so action was rarely taken on an ethical issue. External constraints were present on the ward not only in the sense that medical decisions were made by doctors, which nurses expected to a certain extent, but in that the nurses' opinions were actively discredited when offered and their contribution therefore not encouraged.

5.3 Cultural clash between acute and palliative care

There was some evidence from interviews and observation that the fear of dissent and the external constraints which hindered nurses' individual and corporate voice had at least part of their origin in a clash of cultures of care on

the unit. The ward was designated an acute treatment unit and yet care of the dying was a large proportion of nurses' daily work. This ethos meant that the observable reality of the condition of many of the patients was often at odds with the aggressive treatments being administered. The focus of practice was strongly pro-treatment and resistant to the involvement of the Palliative Care Team, or other agencies whose sole aim was to provide symptom management rather than increased survival. A senior doctor on the ward mentioned in her interview that there was significant peer pressure not to involve these agencies. This seemed to be because of the incompatibility of their ethos with perceptions of the more valued and heroic attempt to cure:

'I have to make a clear assumption of responsibility and give definite parameters for decision-making, and discussing it all with a palliative care nurse is just seen to be wet, completely wet...'
IntSR:608-609

Nurses were unsupported by medical colleagues in their care of patients with terminal illnesses. There was evidence that the clash of cultures did not only emanate from the medical hierarchy but also from the nursing leadership. There was a noticeable lack of targeted education in care of the dying. In 18 months, ward teaching did not include a session on issues relating to death and dying. The focus was rather on acute treatments and their side effects. Members of the palliative care team within the hospital spoke informally about their concerns that nurses on the ward were not supported in providing palliative care. They mentioned that when asked to lead a teaching session by senior nurses, the request was often to speak about 'a drug' rather than aspects of dying. The

unspoken aims of practice were at odds with the nature of care nurses were providing.

The curative culture of the ward made death seem to be a failure, which also served to decrease nurses' own value for their care for the dying. It was difficult for nurses to have a sense of achievement about the care of dying patients. There was no clear goal in mind for these patients, whereas for those undergoing curative treatment there was clearly marked treatment progression, such as the next chest x-ray to assess tumour response, or a further course of radiotherapy. These events gave structure and purpose to discussions about care, both for the patient and for the team involved. For clearly dying patients, discussion centred around the procurement of a suitable hospice bed for them to die. This gave an entirely different flavour to the planning of day to day activity. For example, in handovers, care of dying patients would often be prefixed by comments such as, 'we're not doing anything for this man.' However, in the summary of care then given, it was clear that many necessary and compassionate actions had been carried out. These would be acknowledged in lowered tones, and not affirmed or rewarded. The activities that had taken place were perceived as inconsequential because they were not part of an attempt to resolve the underlying disease. In this way, the greater bulk of nurses' work was not supported and valued. Nurses' own opinion of what they were doing was undermined, both within nursing culture and without. Simultaneously the emotional cost was overwhelming.

5.3.1 Adhering to the 'rules' despite personal disquiet

The cultural clash between acute and palliative care was heavily reinforced by a set of unwritten 'rules' of practice which nurses detected. The rules were about the pattern of care giving, and involved the medical curative model described. The dominant feature of the 'rules' on the ward was that planned treatment and ways of carrying it out, and patterns of disclosure to and involvement of patients, continued despite any disagreement. The staff nurse in the following extract had been asked about the kinds of support she used in order to guide her decisions:

> I suppose you go, I suppose most people go by what they feel in their heart...yeah, it doesn't mean that you can always do anything, about that, because you then also [have] your set way of doing things in medicine, or nursing or both, but it doesn't stop you from having a reaction; and it's quite interesting that you can kind of conform with, the rules, and...I mean, and you come to a point sometimes where it doesn't matter what I think or feel because we're going to do it this way, anyway...'
> Intn2:402-410

She clearly points to the reactions she continued to have despite conforming to the rules. She makes the point that conforming was the only thing to be done given the inevitability of the planned patterns of treatment and care. For example, decisions about cardiopulmonary resuscitation appeared to be made according to the preferences of the consultant concerned rather than the clinical indication of each patient. Nurses felt that there was a propensity to actively resuscitate despite an evidently poor prognosis for the patient. At times, nurses would be chastised by doctors from other departments in the hospital, responding to an emergency bleep following the cardiac arrest of such patients. The on-call doctors often refused to carry out resuscitation on seeing the condition of the

patient, and yet nurses remained unable to persuade the medical teams in charge

of patients on the oncology ward to make different decisions:

> 'because a lot of the consultants have got very strict, views on whether
> patients are for resus or not, um, and don't like bringing up those issues with
> the patient necessarily, so it's just a blanket statement that they are all for
> resus, and these patients are sometimes, you, you know the kind of people we
> get, have got widespread disease, very widespread, and they're still for resus,
> and you'll get another patient that's nothing like, as, ill, and the prognosis
> isn't as poor, that isn't for resus, because it's from a different consultant, and,
> it's very difficult...'
> Intn1:273-284

Similar patterns were seen throughout observation and interviews. In the

following extract, a staff nurse recounts how she once tried to question the

treatment being carried out, and was rebuked by a Sister. However, the Sister

later revealed that she too had felt uncomfortable about the care being given, but

had continued to feel that it should go ahead. This highlights the presence of

rules which nurses felt could not be questioned, despite private doubts:

> 'I remember one day actually um...saying, I think, I can't remember which
> Sister it was, one of the Sisters, I just, I said, 'what are we doing?' you know,
> actually, what are we doing, and I think she, at the time, she said, "look,
> we've just got to get on and do this, the person is for resus, and we're gonna
> [get on with it] for now," but then afterwards, she actually said look, we're all
> finding this really difficult, you know, and I think, yeah, I wasn't aware that
> everyone else was, I assumed that I was the only one [who thought the resus
> should have been decided differently] because maybe I, the background I
> come from. But the fact is that everybody else did...'
> Intn2:338-347

Nurses needed to subsume their own reaction to events in order to follow the

prescribed pattern of care. Discussion rarely took place and so these individual

reactions remained unexamined and unconfirmed, with many nurses feeling that

they might be alone in their response to patients' situations. The continual

pressure to conform to the 'rules' meant that nurses felt they were loosing sight

of their genuine motives:

> '...there is a real danger of actually then not being aware of what you're
> thinking and feeling, and making decisions not from your heart and what you
> see, but from policy, and from, what is the done thing, um, and you know,
> then I think that's when people start getting really stressed out because they
> then start losing touch with what they're feeling...somehow not being able to
> express it, because they, they're working from what's in their head about what
> they know they should be doing, thinking, feeling, does that make
> sense?...but when I was doing the said or done thing, I was aware there was a
> lot of stuff going on inside, but I didn't know what it was and I think it was
> because I couldn't fully be me and live out what I knew to be true, for me...'
> Intn2:410-447

In a similar way to the above extract, many nurses recognised over time the

danger of not being true to themselves. They were aware of not being able to be

genuinely themselves at work, and of some form of emotional debt accruing as a

result.

A culture of coping developed amongst nurses on the ward where competence

was linked with 'getting on', despite the challenges. This involved ignoring

emotion and adopting various coping mechanisms. An example of one of these

was the pattern of drinking alcohol after work, identified by nurses to occur

particularly after patients' deaths. Nurses often jokingly referred to these

episodes of drinking. They strongly condemned others who gave vent to

emotional distress in the context of the ward environment. Such lapses in

'professional behaviour' were seen to be examples of slipping competence.

5.4 Becoming two people

Nurses commonly described themselves becoming two people over time in the ward. The split seemed to mirror the difference between the reality of the situation on the ward, and the rules which applied. Nurses were observing curative treatment often being administered to evidently dying patients. In order to cope with the planned treatments, nurses had to deny their personal response. The nurse was then functionally two people: one with personal reactions, the other with an obedient task-orientated approach.

The effect of this split on nurses' emotional wellbeing was destructive. During the long period of fieldwork it was possible to observe the longitudinal effects on individual nurses. Initially, nurses were keen to contribute to the care of patients and expressed a sense of privilege in having so much contact with them during critical times of their lives. Slowly, nurses then became aware of the hidden complexities in providing compassionate care to patients. The mismatch between the overtly curative practice of the ward, and the actual reality of frequent cancer deaths, became more evident and destructive:

> 'I've been here two years now and at the beginning I wouldn't have even thought about things like that, but now I do, if you come across patients that are obviously very ill, obviously not going to get better, and, it just starts triggering things and you just think you know, 'what are we doing here, and, and why are we doing this' and it just, you become more aware of that, I think, I'm much more aware of that now, and you, you start questioning yourself how appropriate it is, a lot of the time...'
> Intn1: 44-53

Nurses began to have misgivings about the acute treatment of patients who were obviously dying, and found that questions about patients' treatment were not

welcomed, treated with interest or discussed. The tension between what nurses wanted to do and suggest, and what they felt able to change, given the culture of the unit, began to result in confusion of role and purpose. Nurses increasingly felt that their personal views were in conflict with the care they were involved in providing. This later translated into doubts over their ability to provide effective care, and guilt over the ways in which patients were treated.

Continued work in the ward further fed these doubts, and also propagated the need to deny emotion in order to survive:

> 'I saw Sandra rushing around, trying to stay cool, then having a chat with me to the effect that the work was rending her physically and mentally, being emotionally draining and exhausting, with constant interruptions and no clear ability to focus because of it. She went off saying 'oh well, off again I suppose, back into it with all this on our minds.' As she went, she set her face in a firm smile. It was as if she had momentarily taken off her protective raincoat, and was putting it on again as she went back into the downpour.'
> FN 12/97: 91-96

There was an absence of effective support at this point, either from senior nurses or from appropriate external sources. Nurses had no opportunity to talk about their involvement in situations they found to be unbearable, both in terms of their perception of the patient's needless suffering, and their own lack of ability to prevent death or even to make it more comfortable.

The coping strategy of suppressing emotional responses to the situations on the ward led nurses to face an intense sense of personal instability. The split between personal beliefs and public action meant that nurses felt they were one person at

home, and another at work. This involved, over time, a kind of deliberate personal alienation from self.

Nurses' attitudes to talking about death with each other and with patients were an example of this. Although most daily clinical care centred around death and dying, nurses avoided discussing death with each other and with patients. Nurses frequently expressed awareness of this, and felt that the pressure of task orientated jobs connected with daily care prevented such discussions. However, they also perceived that their adherence to these jobs rather than to deeper discussion with patients was a distancing strategy:

> 'At the end of the day people can not talk about death in a ward like this...where they've got task oriented jobs to do...so you're dealing with...it's like a blind spot lot of the time...because the patient is going to remind them [the nurse]of their immortality and how they deal with it. And if they don't want to deal with it, they won't. So they'll cut off and keep doing tasks oriented jobs to hide behind it.'
> Intn4:107-118

Attending to task orientated jobs therefore presented an opportunity for nurses to maintain their public role when presented with a powerful personal challenge. It was evident that nurses considered the boundary between their private beliefs and values, and their professional values, an important survival tactic which had to be closely guarded.

Nurses became less motivated to act on their moral instincts as the process of emotional distancing became more entrenched. As nurses' emotional responses were suppressed, so were their ethical concerns and their willingness to act on

them. Earlier discussion has explored the high level of personal response nurses felt was involved in responding to ethical tensions. They frequently referred to past experience, personal beliefs and character traits as influential factors in responding to aspects of patients care which caused ethical concern. These personal responses were suppressed along with emotional reactions to the overwhelming suffering of the patients. Nurses then became increasingly submissive to the perceived inevitability of unethical treatments, rather than their initial practice of questioning and attempting to tactfully offer suggestions for improvement. The staff nurse in the following extract had been working on the ward for 18 months, and expresses her sense of the futility of trying to change the pattern of hierarchical decision-making in resuscitation decisions:

'...we have got protocols, not everyone goes by them, guidelines rather, um, that's the consultant's decision, if they choose to ignore them, there's very little we can do about that. If they choose to ignore them because they don't want to bring it up with the patient, there's nothing we can do about that either, really, um, they do have more power, and they know that, and um, sometimes it just comes to taking a step back and thinking there's only so much you can do, you can bring up these issues, and, that's where you have to sort of, almost end, you know, you can't, do, so, much more than that, you can bring it to people's attention.'
Intn1:492-506

This was a distinctively different position to that she had originally held when approaching patient care, by her own admission and by observation. Many nurses experienced this increasing sense of the futility of attempting to act on ethical concerns. This did not reflect a change in the external constraints to their actions, although they remained present and oppressive. The change was also an internal dynamic, occurring as nurses divided themselves between the personal and the

public, avoiding conflict and personal unease by denying intuitive responses in order to comply with the stipulated patient care.

5.4.1 Personal crisis

After a period of time, which varied between nurses but approximated to one year, nurses began to realise that a personal crisis was approaching, and that action needed to be taken. Many nurses expressed that they were leaving the ward because they did not like the person they had become at work. They felt that they did not want to expose patients to that person any more, and they expressed an urgency to leave in order to avoid becoming entirely subsumed by the other character. Several nurses felt that the decision to leave was the most crucial ethical decision they had made on the ward. Nurses gave similar accounts of the need to leave in order to preserve moral integrity:

> 'It's very difficult...maybe you sort of blame, you know, blame the patient, 'cos you're running around and you're mad, and you're angry, and you know, you've hardly got time for your break, you're up here, you feel stressed, but you know, I'm trying not to say it, but, there was times, well I will, there was times when I, I couldn't be bothered, I couldn't be bothered, I didn't want to look after these people any more you know, they were, they were doing my head in, and I, I've, I, I, I mean that's awful, and that is awful, and that's why I've, I'm, I've, I've, you know, I don't wanna go back, onto that ward, 'cos I know that would be a wrong thing to do...'cos I don't wanna be like that, I couldn't continue like that, but I just didn't know I was getting fed up...'
> Intn11:545-569

Nurses were consciously suppressing their personal reactions to patient care, and then becoming detached from them over time, because of the presence of a prescriptive curative model of care. Initially in control of this process, nurses left the ward when they found they were now unable to maintain their integrity as a

person and also in ethical conduct. Evidence of nurses being increasingly divided between a personal and a public role has an interesting bearing on the eroded sense of moral agency that they demonstrated. Given that nurses grew progressively more detached from their personal responses and feelings, it is likely that the same effect was carried over into ethical decision-making in general. Many of nurses' ethical concerns were about the very divide between acute and palliative care that formed part of the dominant pattern of care on the ward. If nurses were not making personal responses to these situations, but rather following the 'rules,' then authentic ethical decisions would not be easily made. These require acting on personal beliefs, which is precisely where nurses were disabled.

5.5 Summary

This chapter has shown that nurses were seriously disabled by the processes taking place on the ward at the time. Of primary relevance to ethical decision-making is the finding that nurses had an eroded sense of their control over decision-making and action. There were both external and internal aspects to this phenomenon, which were illustrated by both observation notes and interviews. Part of the cause for this was evident in the dominant culture of curative treatment and denial of death on the ward. Nurses felt that there was a set of unwritten rules which could not be questioned. They felt inadequate and poorly equipped to raise concerns. Nurses continued to participate in treatments which conflicted with their personal response to the situation. As a coping strategy, nurses subsumed their personal responses in order to carry out the required care. This coping strategy, developed in the absence of any meaningful support,

directly eroded nurses' moral agency or sense of personal efficacy in ethical dilemmas, and therefore their ethical decision-making. It also meant that palliative care was compromised. It further led to nurses' increasing sense of the need to leave in order to regain moral integrity. This may help to explain the 'boom and bust' cyclical phenomenon of acute cancer wards, where staff turnover is very high despite the higher level of personal commitment to patient care expressed (Corner, 1997).

5.6 General summary of findings

We have seen that both nurses and doctors in the study felt that ethical issues were embedded in the fabric of providing care to patients suffering from cancer, both those with treatable conditions and those in a palliative phase of care, and also those in transition between the two. The culture on the ward where the research took place was predominantly curative, where the explicit aim of treatment was tumour reduction and increase in life expectancy. Palliative care was not given priority, being seen as what took over when everything else had failed.

In discussing their ethical concerns, nurses and doctors emphasised the constant prioritisation necessary in adjudicating between patients and relatives, in terms of the ownership of information and the allocation of power in clinical decision-making. Nurses particularly perceived ethical significance in the dynamic between a realistic prognosis and the level of curative treatment attempted. A consistent struggle for both nurses and doctors was to accord to the patient the

primacy in decision-making and care which they clearly attributed to them in theory.

According to the nurses in the study, encountering ethical issues involved a personal response to the patient's situation that concerned past experience and individual history, age and personality. This meant that the issues did not have a consistently credible basis for practice, reflected in nurses' view of ethical issues as without consensus because of the private values and beliefs involved. It is also reflected in nurses' sense of there being no ethical expert; where nurses in senior positions felt as poorly equipped to offer an ethical opinion as those in more junior positions. Nurses seemed unclear as to what counted for knowledge in ethics. They did not feel that their values and beliefs were an adequate basis for expressing opinions on ethical concerns in practice.

Nurses indicated that ethical issues were hidden and ignored in daily practice. They were identified to be intuitively recognised but not overtly discussed. This led to ethical concerns that were mentioned in whispers in the informal networks of communication on the ward, but not formalised in actual discussions of patient management. Both nurses and doctors expressed ethical concerns about the same patients in their interviews, unaware that their concerns were shared: in one case by all six members of a decision-making hierarchy, yet without discussion. This culture of silence about ethical issues inevitably led to a lack of management of the ethical aspects of patient care. These were concentrated mainly on the transitional period between curative, acute treatment and palliative care. In many cases, the lack of discussion led to decisions not being made, such as whether or

not to terminate active treatment and rigorously attend to symptom control. It was clear that patients received less than adequate care in such situations; and occasionally experienced intensification of their suffering due to lack of discussion about pain relief during transitional care. The nurses and doctors involved in these scenarios experienced great distress, but the culture of silence surrounding the decisions persisted.

The nurses in this study felt that their ethical decision-making was subject to both external and internal constraint. The external constraints involved a powerful medical hierarchy endorsing curative rather than palliative treatment despite the reservations of both junior medical staff and the nursing body. Although the focus of the research was on nurses' experiences, interviewing doctors provided insight on the constraining nature of hierarchical decision-making for them as well as for nurses. The ability to question decisions and voice independent concerns was not related solely to issues of status.

Internal constraints affecting nurses involved their eroded sense of personal capacity to form valuable opinions or to effect change. This was further complicated by the need to consistently suppress their personal response to aspects of patient care management which they felt to be inappropriate. The perceived inevitability of certain patterns of care led to nurses' increasing unwillingness to risk voicing an ethical concern solely on the basis of a private opinion. As discussions were rarely initiated, nurses did not have the opportunity to discover shared opinions and draw strength from consensus. Being involved in

situations with which they were in private disagreement led nurses to distance themselves by emotional withdrawal.

Given that we saw that engaging with ethical issues seemed to involve a personal response for nurses, it is understandable that the coping strategy of emotional withdrawal was damaging to nurses' ethical decision-making. Over time, nurses became less and less able to make personal responses to patients and so became less and less likely to respond compassionately to ethical concerns. The means by which they engaged with the ethical concern became disabled; that is, their ability to be moved by a patient's distress was reduced because they had removed their personal self from their professional role, in self-protection.

The silence and lack of management of ethical issues therefore drew on three main areas of cause: the nature of the issues themselves, being without a clinical language and established credibility; the hierarchical nature of patient management, leaving many practitioners without the opportunity to invest in discussions about care which involved them; and the coping strategies implicit in surviving in such an environment.

CHAPTER 6: DISCUSSION

Divided we fall

Introduction

This chapter will explore the findings in relation to two main areas of research interest. The first is patterns of care on acute cancer units where palliative care is also delivered. It is argued that dying patients do not appear to be adequately supported in environments where there is a curative paradigm. The second area is current debates in nursing ethics, including moral agency and moral distress, moral autonomy, and the role of emotion in the moral life. In both areas, the significance of the findings from the study will be interpreted with reference to previous published research. Findings will also be discussed in relation to the wider theoretical literature, in order to assess the contribution made by the current study.

The central argument of the thesis is that nurses' emotional engagement with the care of patients may have a crucial role in enabling subsequent moral engagement with ethical concerns. However, the claim is not that emotion has a directly causative effect on ethical decision-making. There are many factors involved in providing ethically competent care, which could not be reduced to the presence of one quality or feature. However, where nurses suffer emotional disengagement, many other aspects of their work appear to be compromised. The links made in this study, emerging from the data, suggest that emotional engagement with patients could have a crucial impact on nurses' reactions to ethical concerns. The chapter begins with an analysis of the strengths and weaknesses of the study.

6.1 Acknowledging the limitations

The strength of the study is in its contextual depth. Previous studies have identified nurses' ethical concerns in cancer care but have not been able to explore their interaction with the issues in practice. Ethical decision-making has been studied by self-report and by measured responses to hypothetical scenarios. This leaves out the vital component of active engagement. This study was able to use observational techniques over a sustained period of time to study nurses' identification of and subsequent response to ethical concerns in practice. It was also able to explore the experiences of doctors and therefore some of the interprofessional issues involved in caring for dying patients. As well as maintaining a focus on individual experience, the extensive fieldwork and patient tracking data allowed the process of decision-making itself to be closely followed. The reality of ethical decisions not being made, and the effects on patients, could be established as a result. In this way, a synthesis was achieved between the experience and perceptions of heath care professionals, the prevailing conditions affecting them, patterns of decision-making and patient outcomes. Study of any of these factors in isolation is inadequate, given the strong interdependence suggested by the findings.

The weaknesses of the study lie in its small scale case approach. The issue of generalisability needs to approached cautiously as a result. Fielding and Fielding (1986) suggest that findings from case study fieldwork can be applied to other areas where the microcosmic details are similar. They argue that visible similarity is not sufficient to establish this. Before the findings could be more widely applied, care would have to be taken that the settings were substantially

similar, in detail as well as in wider issues. Another weakness of the study is the fact that the research was conducted by an isolated and, at times, overinvolved researcher. The responsibility for the overall synthesis of information gathered was located with one person. Although this is the same in most fieldwork, it remains a limitation. The findings were found to have coherence with the research participants, but it could be argued that this was merely a reflection of their esteem for a willing and free helper on the ward.

6.2 Palliative care in the hospital environment

Research into the acute hospital environment as a place to deliver palliative care has not been extensively researched, but isolated studies make disturbing reading about the shortcomings involved (Addington-Hall et al. 1991; Cartwright 1991; Dunne and Sullivan 2000; Mills, Davies, and Macrae 1994). The patient approaching death requires close attention and privacy, and good communication between their health care team and relatives. They need to be given systematic pain relief and have their symptoms closely monitored:

> 'As death approaches meticulous attention to detail is essential and communication between nurses and doctors in the monitoring of symptoms and responses to medication is of even greater importance than usual. It is important to plan for the provision of support and care for the family, partner and friends as they grieve in anticipation and as they watch at the bedside. Plans should also be made to ensure that, if at all possible, the patient is not left alone at any time.'
> (Sims and Moss 1991)

Studies examining the experiences of family members show that privacy in hospital is difficult to ensure; that communication is often fragmented and unclear (Georges and Grypdonck 2002); and that pain relief is perceived to be

inadequate (Dunne and Sullivan 2000). Family views of pain relief can often be inaccurate (Madison and Wilkie 1995), and such discrepancies between perceptions of pain ratings are also possible between nurses and patients. However, the administration of analgesia on the unit in this study often fell short of patient's needs, by their own estimation. Continuous opiate pain relief was only prescribed to those patients for whom a definite decision had been made to commence explicitly palliative care and to discontinue curative attempts. The difficulties experienced by the ward teams in making this decision meant that many patients were effectively caught between the two categories. Privacy was difficult to provide, with the limited availability of side rooms and medical consultations taking place at the bedside within earshot of others. There was often a disparity in knowledge of diagnosis and prognosis between patients, relatives and the medical team; with observation indicating that the patient often knew the least, or the least accurate account. In this way, the palliative care ethic was not operational on the cancer unit, because of the disparity between the ideals involved and the established curative paradigm.

Palliative care provision in the context of cancer services in acute hospitals was advocated by a number of influential reports in the mid-1990s, such as the Calman-Hine report, the Campbell report and the report of the National Council for Hospice and Specialist Palliative Care Services (Campbell, 1996; Department of Health, 1995; NCH-SPCS, 1996). The hospital is till the most common place of death from cancer, although this is reducing (Higginson 1998). The reports recommended that palliative care should be an integral feature of all clinical practice available to all patients within the hospital setting. This posed a major

clinical and cultural challenge, in the context of which hospital support teams were developed to enable staff without palliative care training to improve the care given to dying patients (Bircumshaw 1993).

However, there is evidence that the ideals involved in a palliative care approach can sharply contrast with the philosophy of care that prevails in the acute hospital setting (Andershed and Ternestedt 1997). Palliative care teams (PCTeams) depend on ward-based staff for referrals and so rely on their acceptance and trust. There is empirical evidence to suggest that these teams often have difficulty persuading colleagues of the value of their clinical expertise. They find that their role can be reduced to that of finding hospice beds for dying patients in order to maintain the throughput of patients being treated acutely (Dunlop 1989). This study indicates that nurses on the ward were at times actively prevented from enlisting the advice of the PCTeam for particular patients. Observation notes record difficult scenes where members of the team wrote recommendations for dying patients in their medical notes, and returned to find that their advice had not been implemented. There was a lack of communication between the oncology teams and the PCTeam which led to nurses being unsure of when it was acceptable to ask for advice.

In 1994 a controversial paper by Mills, Davies, and Macrae was published in the British Medical Journal. It reported the situation of dying patients on an acute hospital ward in a Scottish Hospital. The study had used observational methods and the researcher had witnessed the strategies used by health care staff to distance themselves from dying patients. This meant that far from being

supported and nurtured as death approached, these patients were isolated and poorly informed. In one instance, the provision of water and food was inadequate as assistance was not given to access it. Considerable reaction was in evidence in the letters written to the journal over the following year. Criticism was made that as the data had in actuality been gathered 8 years prior to publication, the subsequent emergence of Palliative Care Teams meant that such findings were no longer applicable. Some respondents were in agreement with the findings, but the majority were hostile and claimed that the study was out of date.

The current study shows many similarities with the findings of Mills et al (1994). A difference was that on this ward there was generally a very high standard of clinical care, and lapses in the provision of basic care were extremely rare. However, the lack of discussion about and management of ethical issues led to examples of poor palliative care in the areas of pain relief, overtreatment, information giving and support at the end of life. Nurses felt underconfident and unable to advocate for these patients. Their sense of guilt for this, along with an existing coping strategy of emotional withdrawal, led them to unwittingly remove themselves from dying patients, leaving some to die isolated and confused. The discussion of other findings that follows gives further explanation for how this could have happened. The fact remains that despite the advances in palliative care over the last two decades, the situation of dying patients in hospitals indicates that the setting may not have made sufficient changes to provide for this most difficult and vulnerable stage of life with cancer.

It is interesting to note that the areas needing further work are those that are seen as ethically sensitive. A recent literature review examining moral problems

experienced by nurses when caring for terminally ill people highlight these same areas (Georges and Grypdonck 2002). Until the hidden problems associated with the management of ethical issues are addressed, I suggest that it is unlikely the situation will radically alter.

Aspects of the findings will now be discussed in relation to more theoretical constructs. Firstly, the finding that nurses experienced a divided self, increasingly over time in the unit, will be explored in relation to theories from social psychology and existential philosophy. Although social psychology does not reflect the theoretical basis of the study, aspects of the findings have great pertinence to the concepts discussed. The links will be explored and then followed by a more central examination of the extent to which nurses can be morally autonomous, and the implications for whether or not they can be held responsible for their actions.

6.3 Divided nurses
6.3.1 Cognitive dissonance theory

The finding that nurses were aware of an increasing division between their personal self, with responses to patients based on their individual history and character, and a professional self, carrying out prescriptive care regimens without questioning, can be related to cognitive dissonance theory in social psychology. The premise of this theory is that when individuals act contrary to a belief or attitude, they experience negative emotions, or dissonance. This precipitates a search for a reduction in the negative affect, by changing the attitude or belief to be more consistent with their behaviour. In the original statement of this theory, Festinger (1957) proposed that,

'the existence of dissonance, being psychologically uncomfortable, will motivate the person to try to reduce the dissonance and achieve consonance.' (Festinger 1957)

Festinger and Carlsmith (1959, cited in Harman-Jones 2000) tested this hypothesis by the induced compliance paradigm. Participants were induced to act contrary to a belief or attitude. They found that if the justification for acting was sufficient to induce the behaviour, then persons were likely to experience dissonance. This motivated them to reduce it, by changing their attitude or belief to be more consistent with their behaviour. However, critics argued that the results were skewed, because experimental settings were designed to ensure that the behaviour was more resistant to change than the attitude, and because the attitude change opportunity was highly salient – making the attitude more likely to change to reduce the dissonance. In this way, it was not the dissonance that was causing the attitude change but the aversive consequences of not changing it. Harmon-Jones (2000) carried out further research which tested the hypothesis that sufficient cognitive discrepancy alone, rather than aversive consequences, could cause dissonance. He found that negative emotion could indeed be aroused by a sheer discrepancy between cognitions. This work has been used to investigate the formation, maintenance and change of attitudes, beliefs and values.

Nurses clearly experienced emotion that could be labelled as dissonance when acting in ways that contradicted sincerely held values and beliefs. The increasing division they experienced between a private and public self could therefore be explained as a means of reducing dissonance, and increasing consonance.

Although there was no evidence of nurses changing their attitudes and beliefs regarding the value of palliative care, for example, they were aware of deliberately removing themselves from a situation of conflict by suppressing their emotional response to it. There then ensued changes in attitude over time, in that nurses' emotional responses became less and less apparent and therefore the cause of less emotional discomfort. The conflicting cognitions involved in taking part in some aspects of care on the ward led nurses to find ways of suppressing their attitudes in order to reduce the negative impact of the conflict. However, what is left unexplained by this theory is the personal crisis that nurses subsequently encountered. Leaving the ward was often precipitated by an awareness that they had lost their integrity, both in terms of the division between their private and public self, and in their ethical actions. This crisis of realisation broke the pattern of emotional suppression to such a degree that nurses were able to think clearly, and choose to leave in order to regain their ability to function in a way that was consonant with their values and beliefs.

6.3.2 Inauthentic and authentic being

The divided self that nurses articulated also has pertinence within Heidegger's notion of inauthentic and authentic being. The interpretive approach to data collection and analysis adapted from Heidegger, also sheds interesting light on these findings. Heidegger and his associates were keen to make the practical world of individuals the subject of philosophical exploration and research rather than any abstracted form of human existence. A key aspect of Heidegger's ontological thesis is that the human 'way of being' has various possibilities for conducting itself. Given that we share everyday patterns of living, and cultural

norms and values, one possible way of being is to be absorbed by this and to find

one's meaning within it. This is the paradigm that Heidegger terms

'inauthenticity.' Being inauthentic is to follow the dictates of the everyday

pattern of life, fulfilling its endless necessities. In this way the individual is lost

within it:

> '...none of his values are his own, not even his conception of himself is his
> own.'
> (Soloman 1972)

According to Heidegger, conforming to everydayness is to be subject to the

anonymous levelling of standards. Authentic being, on the other hand, is the

possibility of taking hold of one's own way of doing things. Meaning is

attributed purposefully, rather than being dictated by prevailing cultural attitudes:

> 'The Self of everyday...which we distinguish from the authentic Self – that is,
> from the self which has taken hold of in its own way.'
> (Heidegger 1962)

The absorption in everyday practice, and acting on values which are not

personally held but rather culturally endorsed, has strong resonance with the

current findings. For Heidegger, the ultimate form of inauthentic being was

where the individual lost even their own conception of themselves. Nurses

described precisely this sense of divorce from their true self. What is interesting

is that Heidegger argued that the human 'way of being' starts by being

inauthentic and may or may not progress towards authenticity, particularly as

they appreciate or fail to recognise their own mortality. These nurses, however,

began on the ward with a clear sense of their own purpose and contribution. By

the time of leaving, they were identifying with a set of cultural values which

downplayed and disallowed the role of palliative care, and so their most substantial contribution and area of greatest personal investment. Nurses felt they had lost hold of themselves. Heidegger does not comment on or allow for the effect of surrounding conditions on the self-awareness and authenticity of people in these kinds of situations.

However, the exit interviews conducted with nurses as they were leaving did not reveal nurses still trapped in Heideggarian inauthenticity. It is clear that this analysis would have applied while they were practising on the ward. At the time of leaving, however, a kind of spontaneous crisis within nurses prompted them to take radical action, and to leave an environment where in most instances they had gained promotion and seniority, with expertise in a wide range of cancer treatments. This is very different to taking meaning solely from within a defined role. Nurses were acting from personal motivation and a strong belief that to continue on the ward would damage themselves and their patients. This action would fit Heidegger's notion of authentic being, but is a sobering fact to consider in the light of their trajectory on the ward. To have to leave in order to regain an authentic grasp of one's self and actions highlights the hidden dangers of dominant cultures. It also prompts questions about the health of the processes taking place in an environment where patients are necessarily even more vulnerable than nurses.

6.4 Eroded moral agency?

The relationship between individual action and the surrounding influences in ethics has been the subject of much philosophical discussion, and is reflected in

the nursing ethics literature in the notion of moral agency, or moral autonomy. The notion usually entails a commitment to the person being the genuine originator of their own moral actions. These actions are not seen to be the inevitable product of social or other conditions prior to the choices made, otherwise the person would not be an agent, but only the vehicle through which a causal chain took place (Hospers, 1989). Features of nurses' experience of ethical decision-making in this study have some similarities with previous studies. The nurses in this study clearly shared with others what might initially seem to be an eroded sense of moral agency, whereby they felt that the surrounding environment was predominantly in control of their decision-making and action. They also appeared to doubt that they had the capacity to make effective moral judgements. For any model of ethical decision-making this would be extremely problematic, because a basic premise in ethical theory is that of the moral agency of the individuals concerned.

Many authors assert that nurses are compromised by the repressive nature of their workplace and their subordinate position within the health care team (Erlen, 2001; Tiedje, 2000; Wilkinson, 1988). For example, Yarling and McElmurry (1986) in the United States asserted that nurses working in hospital settings were often not free to be moral because they were deprived of the free exercise of moral agency. They advocated that nursing ethics become the basis for social reform, freeing nursing from the hegemony of the hospital as a morally culpable social institution. Rodney and Starzomski (1993) identify many situational constraints in nursing practice, and link the phenomenon of moral distress to these findings (Rodney and Starzomski 1993). Where nurses' perceptions of

constraint deterred them from acting on their moral choices, they experienced great distress. Rodney and Starzomski conclude that nurses need to be empowered to participate as full interdisciplinary team members. They argue that the institutional environment needs to change in order to be more supportive of nursing practice.

The role of social influence on moral identity is discussed by Kelly (1998a) in her research following up new graduate nurses two years after graduation. She argues that the maintenance of professional values is greatly affected by social forces such as the pressure to fit in with a focus on tasks rather than patient care, for example. She observed that nurses often perceive a disparity between what they expect of themselves, and what they experience in everyday practice. This leads not only to distress but also to impaired performance. Kelly concludes that the environment in which nurses are working needs to become more supportive in order to avoid this 'circular web of causation' (Kelly 1998a). Oberle and Davies (1993) argue that nurses often have styles of caring which are different to the technology and task orientated hospital system. The superior strength of the latter means that nurses are often carrying out care in ways which contradict their personal ideals (Oberle and Davies 1993).

However, the majority of research papers in nursing ethics examining nurses' moral agency employ a notion of moral autonomy which will be shown to be underanalysed. This will be shown both empirically and theoretically. It can be seen from the above accounts that nurses' lack of moral autonomy is primarily identified by the presence of external constraint. The culture in which nurses find

themselves working is described as repressive, putting a large amount of pressure on nurses to conform, in many instances against their moral values. There is considerable evidence for these external pressures. This study adds insight into what these can be in an acute cancer unit where patients are also making the uncomfortable transition to palliative care. The nurses clearly had dominant cultural influences to contend with when advocating for dying patients in a curative paradigm. However, this is only half the story.

Describing the external pressures on nurses does not fully account for the silence surrounding ethical concerns. If moral autonomy were solely a matter of external freedom, then a young child with the freedom to run about at will could be said to be fully autonomous. Since the Nuremburg war trials of 1946-9, codes of ethical practice have accepted that a person remains accountable for their actions even when under orders, with sanctions attached for disobedience. It is clear from this that, even though external constraints have an important part to play, moral autonomy must have some internal as well as external aspects (Young 1986).

This is also clear when considering the nature of ethical action. In the study, nurses themselves described ethical concerns as embedded in the fabric of providing care to patients, rather than in isolated, momentous episodes. The way in which they interacted with patients was part of an ethical response, as well as their ability to change, or not change, the pattern of treatment for a particular patient. The external constraints on nurses would not be sufficient explanation for the ways that nurses cared for and interacted with patients. This requires an

account of an internal dynamic, whereby some account is made of nurses' own conception of how they are choosing to live their lives in this context.

Discussion in the nursing ethics literature seems to link the forcible limitation of nurses' moral autonomy with their status or rank within the organisation (Rodney and Starzomski 1993). However, doctors interviewed as part of the study indicated a similar experience to that of nurses when voicing dissenting opinions to the curative paradigm. The individuals concerned ranged from Senior Registrars to House Officers. They all expressed a feeling of being trapped in a pattern of care from which it was difficult to disentangle. The pervasive influence of hierarchical decision-making rather than specific issues of status may be a more fruitful focus of attention, as nurses were not the sole sufferers of external constraint.

In fact the study showed clearly that there was an internal dynamic to the experience of constraint. Ethical issues did not clearly translate into an accepted clinical language. Nurses felt that there was not an accepted body of knowledge in ethics in order to justify voicing a dissenting opinion. Admittedly, the environment was not conducive to open discussion, and especially not to criticism, but nevertheless the fear of lack of knowledge was an antecedent factor to the lack of discussion. Added to this, was nurses' lack of confidence in their own ability to form valuable opinions. Various studies have suggested that this is due to socialising influences within nursing itself (Dartington 1997), where nurses are systematically encouraged not to think and question. They argue that historically, nursing education has not been carried out in a spirit of mutual

enquiry, so that teachers do not welcome questions and are uninterested in the answers. Certainly, nurses in the study did not seem to believe that they had the ability or right to question surrounding treatment plans.

The effect of not questioning, and of continuing to carry out the prescribed care despite their reservations became a destructive process for nurses, as we have seen. It resulted in nurses becoming psychologically disabled through a process of emotional suppression and withdrawal. This greatly reduced their ability to identify with patients and perceive their suffering in a genuine manner. Nurses identified that they were eventually acting in ways contrary to their wishes and expectations. This internal dynamic therefore impinged on their internal motivations. These internal motivations are a crucial element of personal autonomy (Young, 1986).

There is considerable theoretical debate about the wider notion of autonomy as part of ongoing processes rather than one-off decisions, as the experience of nurses in the study suggest. For example, Thomasma (1995) uses the example of research examining patients' response to illness to demonstrate that a crisis can evoke a wide range of coping behaviours relating to personal survival and integrity. Not everyone had a clear picture of their future life plans, with the risks and opportunities likely to be encountered. Some showed a lack of future planning; some had a lack of appreciation of risk; others lived always in fear of a crisis and so did not form strategies. Thomasma argues that rather than autonomy being analysed in one-off decisions, the concept should account for the way in which individuals struggle throughout their lives to develop their primary values.

He argues that autonomy is part of ongoing moral identity, being continually developed in response to current situations and environments.

If autonomy is part of a self-conscious moral identity, it cannot be an abstract notion that is somehow absorbed by each individual. Rorty, cited in Thomasma (1995) argues that one's moral identity is not founded on a world beyond time, but on a chain of associations and highly idiosyncratic memories. Thomasma goes on to argue that moral identity and autonomy must in fact be shaped by personal experience (Thomasma 1995). Given that decisions are made in the context of relationships with family, workplace, and culture, a person is not acting as an autonomous decision-maker but as 'bound' by these relationships in way previously unexplored by ethics:

> '...autonomy cannot be properly understood, either conceptually or operationally, without an understanding of cultural experiences, personal history, expectations...family and personal values...[it] is thus an essential function of personal moral identity in the particular circumstances of life.' Thomasma (1995)

This notion of autonomy as a developing aspect of character, negotiated in particular circumstances, would far better explain the findings of the current study than a conception which is defined purely by the presence or absence of external constraint. Such a conception would appear to be too simplistic given the complexity of both the nurses' circumstances and their responses to it.

In this way, the assumption behind many of the research papers that a person is capable of full autonomy is rejected. Living in a social context means that interdependence is a part of existence (Downie and Telfer 1971). MacDonald

(2002) argues that the study of nurse autonomy could be more usefully explored by employing the notion of 'relational autonomy' rather than simply stressing independence. Living a fully autonomous, independent and entirely self-caused moral life in the ward context is not compatible with nurses' role as belonging to a health care team. Instead, he argues that supportive social conditions foster autonomous action. This means more than freedom from interference, such that relationships with others foster genuine opportunities for choice:

> '...increasing professional autonomy must mean finding ways to facilitate meaningful self-direction within the context of an interdependent health care team.'
> MacDonald (2002)

However, as Scott (1998a) points out, autonomous practice is not the same as moral autonomy. As we have seen, it is not possible to argue that practitioners can be deprived of their moral agency by the removal of external freedom. Scott (1998a) argues that because health care practice is essentially a moral activity, health care workers cannot be prevented from being moral agents. This increases the responsibility of practitioners to respond to the moral domain of practice.

Moral autonomy is therefore both more restrictive and more powerful a concept than the nursing ethics literature in this area has accounted for. It is more restrictive because common usage assumes an absolute autonomy of the will which is philosophically unfeasible. It is more influential because moral choices cannot be said to be entirely dependant on external freedoms. The constraints under which nurses work are not sufficient to remove responsibility for actions:

'The moral life is human affection and behaviour determined, not by nature, but by art. It is conduct to which there is an alternative. This alternative need not be consciously before the mind...nor does it require that each occasion shall find a man without a disposition, or even without predetermination, to act in a certain way...the freedom without which moral conduct is impossible is freedom from a natural necessity which binds all men to act alike.'
(Oakeshott 1989)

The only way in which moral responsibility for actions could have been absolved is if nurses were somehow bound by nature to respond as they did. There were still alternatives at every stage, and nurses themselves felt that they were, in fact, responsible for maintaining silence in the face of compromised patient care. There are very pressing reasons for their silence, involving both internal and external constraint. Nevertheless, it is not possible to conclude that their actions were devoid of personal responsibility.

The implications of the findings for moral theory will now be explored, with a particular focus on the role of emotion in ethical decision-making. This aspect of moral life has been traditionally avoided by ethical theories, and I suggest that this is the reason for their poor transition into the realities of clinical practice, and the resultant scepticism of practitioners for ethical codes and policies (Stoffell 1994). The implications for improving the translation of ethical concepts into practice are considered at the end.

6.5 Emotion and moral theory

Although nurses did not overtly describe their concerns in terms of ethical principles, the issues described as problematic fell thematically into normative ethical principles. Patient autonomy was a central ethical theme which permeated discussions about information-giving during the transition from acute to

palliative care, informed consent to chemotherapeutic treatments, and disclosure of information to relatives. Considerations of beneficence were evident in discussions about adequate symptom control, and negotiating the wishes of relatives in patient care planning, such as in resuscitation decisions.

However, the findings clearly demonstrate that nurses did not operate solely on the basis of a cognitive application of accepted ethical principles. Recognition of the issues as of ethical significance and personal concern were not sufficient to motivate action in ethical dilemmas. In reality, ethical decisions were avoided by nurses who referred, deferred or delayed acting on relevant information in a patient care dilemma. The lack of visibility of the issues in clinical practice was clearly a considerable impediment, leading to a lack of discussion and of teamwork. However, favourable external conditions, such as the facility for open dialogue, can not be the only factor affecting ethical action. Nurses themselves indicated that the gradual process of suppressing emotional responses to patient care problems, as a coping mechanism, increasingly inhibited their actions when faced with an ethical issue. This indicates the need for nursing ethics to account more closely for the links between moral belief, motivation and action. It also indicates some of the reasons why the application to clinical practice of moral frameworks, codes of conduct and ethical principles alone are not sufficient to motivate ethically competent care. These findings can be related to current debates in ethical theory and particularly nursing ethics.

The 'belief-desire' hypothesis in moral theory asserts that any explanation giving reasons for action must cite a cognitive state, that is a belief of the agent, and a

motivating force such as desires, emotions or attitudes. Beliefs provide information and channel the desire in appropriate directions. Proponents of this theory, for example (Hare 1963; Ayer 1946) argue that only desires, rather than beliefs, are motivational. In their account, moral conviction must entail an element of desire, otherwise there would be no motivation and so an incomplete reason for action. Moral judgements cannot therefore be solely expressions of belief because these do not give adequate reason for action. An underlying philosophical issue at stake here is the status of moral knowledge itself. For philosophers such as Hare, the problem with this theory of motivation is that it renders moral beliefs purely affective in nature. This means that moral judgements become statements of opinion or evaluation, rather than cognition.

It is possible, however, to argue that a theory of moral action must include a motivational aspect as well as asserting that moral judgements are statements of belief rather than purely affective in nature. This is made possible by having the view of morality as founded in human welfare, whereby everyone can see that moral requirements stem from the realisation that actions guided by mutual love and respect generate harmonious societies. The beliefs themselves do not provide the reason for action, which is achieved by the desire to promote harmony and human flourishing. The desire to promote this may also be absent and hence moral considerations may leave people unmoved.

Various positions attempt to refute the point that an explanation of moral action must include an account of desires as well as beliefs. For example, McNaughton suggests that to be aware of a moral requirement is to have a conception of a

situation as demanding a response, asserting that the belief that a particular state prevails may be of itself motivation to act (McNaughton, 1988). In this sense, action is not conditional upon desire, or emotion. The findings from this study indicate that such a conclusion has inadequate explanation for situations where an agent may appreciate salient aspects of a person's suffering, for example, and yet not feel motivated to overcome certain external constraints in order to ameliorate the situation. Nurses crucially felt divorced from their emotions, which eventually led to lack of action.

There has been increasing frustration with accounts of moral action which rely exclusively on the action-guiding power of beliefs. These moral theories seem narrow and impersonal when faced with the complexity of the ethical dimension of health care practice. Increasingly, questions about personal character have come to occupy a central place in ethics (Pence, 1993). A concern driving this interest is that aspects of character are a feature of ordinary moral life. Pence (1993) highlights this by examining the situation of Dorothea Brooke in *Middlemarch* by George Eliot. Dorothea marries Reverend Casaubon, whom she finds to be insecure and uninteresting. Much of the novel depicts Dorothea's struggle with herself as she battles with questions about what kind of person she would be if she left him, and if she stayed. Her husband and children will be hurt if she leaves, and yet she is extremely unhappy in the marriage. The question becomes how a good person in her situation should prioritise between loyalty and autonomy. Merely looking to the salient features of the situation does not reduce the ethical choice to be made. There is nothing in a theory which leaves out the motivational aspect of desire or emotion to connect the decision-maker with the

judgements at hand. Kupperman makes this point in relation to traditional ethical theory:

> 'Despite the opposition between the Kantians and the consequentialists, it is easy for someone who is reading the works of either school to get the picture of an essentially faceless ethical agent who is equipped by theory to make moral choices that lack psychological connection with either the agent's past or future.'
> (Kupperman, 1988)

Similarly in the nursing ethics literature, numbers of authors have questioned the value of concentrating on the beliefs of practitioners at the expense of other motivational aspects:

> '...in order to have the type of respect for [persons as ends]...this type of ability to relate, seems to demand a sympathy and fellow feeling that is not established or ensured by merely stating to the health care practitioner that she has a duty to respect her patients.'
> (Scott 1995c).

Nortvedt (1998) argues that emotions are central to grasping a patient's experience of illness, and that this emotional understanding of patient realities is essential to ethical practice in nursing. Apprehension of a patient's discomfort requires emotional interpretation, he argues, and this has great personal impact on the patient. For example, making an imaginative leap to understand what it is like to be aware of the whispers between doctors on a ward round, knowing that your own future is at the centre of the debate and you are not being involved in it, is critical to understanding the patient's reality and engaging with it. He therefore argues for a distinct motivational addition to ethical beliefs or principles:

> 'To understand what suffering is for a person is an affective understanding of what has normative value.'

(Nortvedt 1998)

Emotional understanding enables pain to be understood as suffering, and as a moral reality. For Nortvedt, being affected by a patient's suffering is to encounter moral responsibility. Professional observation in nursing does not merely discover pathophysiological phenomena of merely factual or neutral value. The pain is seen and then evaluated as a kind of suffering or discomfort for the person. Emotions are therefore the way in which value is invested in surrounding situations; they enable an 'inner understanding' of the conditions of others, establishing contact with their human experiences.

Other accounts of sensitivity to patients' moral reality also imply a personal investment similar to Nortvedt's analysis of the role of emotion. Scott (1995b) refers to the skills central to using the self as an instrument of care and healing in heath care. She asserts that these skills are manifest in the general approach of a practitioner to a patient, in their depth of humaneness, sensitivity and compassion. Analysed under the notion of constructive care, the patient and the patient's needs are the focus of attention. This assumes, Scott argues, that the practitioner begins with a point of respect and compassion. In order to ensure that these are employed, the practitioner needs to be able to attend to the patient as a person as well as to clinical procedures. The distinction is made between merely attending to the patient as a driver does to gear changes, and the 'agent attention' of loosing a sense of self because of the degree of focus on the other (Scott 1995b). Perceiving accurately the needs or vulnerabilities of another person requires the boundaries of the self to be crossed. This requires, argues Scott, an imaginative leap, even to see the need to do this. The ability to imaginatively

identify is central to the way in which the practitioner carries out their publicly

defined role, or 'role enactment.' There is a considerable difference to the patient

between the person who merely carries out various duties, and the person whose

attitude is concerned and courteous. Similarly, imaginative identification in

ethical decision-making is vital, she argues, because the strategy with which a

moral decision is implemented can often be as important as the action itself. For

example, the way in which a patient is informed of their diagnosis is as important

to their adjustment as the fact that the information has been disclosed.

In a similar notion, Iris Murdoch (1989) described moral imagination as a 'way

of seeing.' It is this ability to identify with the patient's suffering, in order to

appreciate their reality and experience, which touches on the area of personal

investment in the patient and situation. Merely apprehending the salient features

of the situation does not account for ethical motivation as the above accounts

demonstrate. An account has to be made of the affective component of our moral

psychology.

The area of nurses' ethical decision-making that seemed to be preventing them

from taking action despite acute awareness of the dilemmas and strong

inclination to help, was their personal interaction with the patients and their

situations. Because nurses were emotionally distanced from the events around

them, as a coping mechanism, they felt that they did not engage with the

dilemmas as themselves. It is precisely this engagement which authors such as

Nortvedt, Scott and Murdoch emphasise as a crucial element of ethical action. It

is also the area most unaccounted for in established moral theory, and in most of

the ethical protocols and frameworks in place in ward environments. The findings of this study highlight the moral significance of emotion. New work in moral theory has examined this and will be reviewed with reference to Justin Oakley's account of virtue ethics and the role of emotion within it.

6.5.1 Emotion and virtue ethics

The moral significance of emotion depends not only on its nature and function, but also on the conception of morality which employs it. A central question in ethics has recently been whether moral value should be attributed solely to actions, or whether the motive behind them should also be included in evaluating the moral action. Questions of character and emotion only become significant if the motives for and means of carrying out moral action are considered important.

Justin Oakley (1992) examines emotions within an account of morality based on an ethics of virtue. Strongly featured in this are not only doing good acts, but carrying them out as a result of good motives and for the sake of good reasons (Oakley 1992). He draws on the Aristotelian notion of a good life, whereby the ethical focus is on a broad spectrum of contributory factors:

> '...acting well is only one aspect of living a good life, for living well perhaps more importantly involves the development of a certain good character as an enduring way of being which underlies and informs the actions we perform on particular occasions.'
> (Oakley 1992)

Oakley argues that the fundamental place occupied by emotion in the moral life has been obscured by recent ethicists' preoccupation with action. Other philosophers have focused on the significance of particular emotions, such as

compassion. Oakley argues for a wider interpretation; asserting that the true

significance of emotions can only be apprehended by an evaluation of their three

components. He argues that these are cognition, desire or motive and affect.

The justification for this tripartite composition of emotion is made by evaluating

the impact of leaving out one of the given elements. For example, philosophers

such as Jerome Shaffer and A.C. Ewing argue that the moral status of an emotion

is merely a matter of the moral status of the causative beliefs and desires. This

would mean, argues Oakley, that there is no moral difference between having a

pair combination of cognition, desire or affect, and actually having the emotion

itself. Believing that another person is suffering, and wanting to promote their

welfare, is not the same as actually having compassion for the person. If a person

is not moved affectively by the suffering of another, they may fail to act on their

beliefs and desires when it is appropriate to do so. Similarly, just having the

affective desire to be compassionate to a person in distress is inadequate without

a level of cognitive understanding of that suffering. As Haldane puts it,

'intuitions on their own are blind' (Haldane 1997). Oakley criticises Blum at this

level, who gives an account of the moral value of emotion depending on whether

or not it is grounded in the 'weal and woe' of another (Blum, 1988). Oakley

argues justifiably that if only the motive is judged then there is no ability to

discern between acts. Feeling compassion for a thief on a failed attempt to rob a

bank cannot be considered morally good, even if the emotion is fixed on the

suffering of the thief. Similarly, a friend might prefer visits in hospital from a

motive of sympathy rather then obligation, but equally a wealthy neighbour

might enjoy the envy of others without making envy a morally valuable emotion. The point is that other features of the emotion need to be considered.

The third component of emotion, namely desire, is equally vital, argues Oakley. The moral goodness of an emotion rests not only on being pained at an understanding of another's distress, but also on an altruistic desire for their recovery. In this way, the three components of desire, or motive, cognition and affect need to be considered in the moral evaluation of emotion. Reducing the evaluation to one or two of the components means that the actual emotion itself is not properly analysed.

Oakley deals with a traditional argument against the involvement of emotion in an analysis of moral action, proposed by Kant and the Stoics. This is the accusation from analytic moral theory that emotions are nothing but an impairment of perceptual and cognitive faculties, reducing our appreciation of reality. Oakley argues rather that emotions deepen and enlarge our perception and understanding. Having care and interest in features of our surroundings motivates us to learn about them, and may in fact be necessary to appreciate them. He argues that a compassionate person is more likely to perceive situations that require beneficent intervention, than a person lacking this quality. Having an emotional response to another's distress enables an understanding of what the suffering involves and what needs the person is likely to have. He makes a point similar to that of Scott (1995b) in asserting that the emotions enable a person to 'see through another's eyes,' enlarging insight.

Oakley strengthens his argument by asserting that a person lacking emotion is less likely to be motivated by what they believe to be good. This is because, he argues, various emotions are morally significant in the transformation of values into action. Although it is possible for a person to pursue what they believe to be good without caring for it personally, emotions play an important part in preserving commitment to values. For example, having courage would help a person acting alone against a hostile team to maintain their commitment to integrity in business dealings.

Emotions can then be judged morally good or bad depending on the value which is being pursued. The ability to discern between emotions is vital to preserving this kind of moral theory from a criticism often made by traditional ethical theory. By investing moral value in virtue and emotion, the criticism runs that virtue theories are rendered useless in discerning good from bad moral action. However, if emotions are considered in their complement of cognition, desire and affect then this attack is defended. Emotions are not judged solely on the basis of the feeling of the person in question, but on the motive and aim of their actions.

Oakley follows Aristotle in claiming that harmonisation between a person's actions and their emotional motivation indicate that the values acted on are truly held. This makes the action ethically superior to a person who does the right thing but does not feel like doing so. In this case, he may be undertaking the action for some other reason that that of his own genuine values. Oakley uses the example of love. Here motives and reasons for action are in harmony, because if

they conflict the action is by definition not done out of love. The goal of another person's welfare is the motivating force of good action. This example shows that where emotions accord with values, the values are more easily transformed into action. Their moral significance is thus demonstrated.

Oakley argues that emotions differ in their degree of moral significance according to their relation to human virtues and vices, and so human flourishing. Care, compassion and envy have moral significance because they help either constitute or undermine one of the 'goods' central to human flourishing. Emotions such as embarrassment are not morally significant, according to this account. However, Oakley adds a further distinction by asserting that emotions are not universalisable. For example, sympathy may be characteristically good but can also be badly employed when helping a thief. He insists that the moral arbiter is linked with his broadly Aristotelian account of the virtues. If goodness and badness are to be found in terms of what helps or hinders a flourishing life, then an emotional response is right if it is directed at what is good, and vice versa.

The Aristotelian notion of '*phronesis,*' or practical reason, is the means by which a person deliberates about the right goals, and therefore right emotional responses, in particular situations. Oakley refers to Aristotle's *Nicomachean Ethics* to describe *phronesis* as the capacity to discern what is generally useful for human flourishing and then to see what this entails in the current situation:

> '...it is a capacity to deliberate well such that one realises virtuous ends in
> one's responses to particular situations...[it] is a capacity which integrates

these perceptual, deliberative, affective and practical faculties so that they operate well together.'
(Oakley 1992)

This is different from intellectually understanding what is virtuous without seeing the personal implications; and also different from doing the 'right' thing without having deliberated. It co-ordinates perception of and response to a situation with what should be felt and done in the situation given the virtues and vices inherent in it. Through the use of practical reason in this way, sensitivity to ethically salient features of situations develops. Over time, the recognition of these features becomes more practised and the decisions made more practically wise.

The notion of habituation in Oakley's use of *phronesis* is also discussed by other authors in the nursing ethics literature who have written about virtue ethics. Sellman (1997) and Scott (1995a) both write about the Aristotelian notion of developing a good character by practising virtuous habits. The developmental process by which this occurs is dependent on observing others with virtuous characters and habits, and developing habits as they do. This implies a focus on the individual and their private values and beliefs. Sellman (1997) makes the valuable point that nursing students have traditionally suffered from a lack of attention paid to this area:

As the situation stands, nursing education tends to disabuse students about the value of their own inclinations...this may result from organisational structures rather than educational strategies, but the latter have some part to play.'
Sellman, 1997

He argues that the teaching of health care ethics has been centred mainly upon rules and principles, separate from real patients and real nurses making decisions in real contexts. By using this approach, Sellman continues, student nurses' own values become less clear, making them vulnerable to persuasion about the morality of certain acts before their own opinions are firmly made. In an attempt to redress this imbalance, the teaching of nursing ethics and also other forms of professional ethics teaching have encouraged the use of clinical scenarios and narratives to heighten the contextual element of ethical decision-making (Durgahee 1997; Vitz 1990). However, the point remains uncontested in clinical practice itself, where, as Scott (1995c) argues, there has been a general failure to identify role models in order to provide students with the ideals of practice involved in giving morally sensitive, humane and compassionate care. She asserts that the traditional view of medical ethics teaching that learning best takes place from seniors at the bedside, has considerable weight from an Aristotelian perspective, but omits a valuable caution. This is that good practice can only be learnt from some seniors at some bedsides. In other words, considerable differentiation needs to be made between ethically good practice and the bad practice that can also be easily learnt and developed.

6.6 Links to practice

The Aristotelian notion of developing good character and habits by observing role models in practice has clear links to clinical supervision in nursing practice. Identifying role models who are sensitive to the ethical dimension of health care practice would not be without difficulty, but as Scott suggests, is vital to producing practitioners who are developed in their moral character as well as in

other clinical competencies. This emphasis on practice which Aristotelian ethics brings to bear would meet the expressed needs of health care professionals who look for ethical guidelines which will help them in practice. Whilst ethical principles and guidelines remain useful, their application to practice in a role model, perhaps the clinical supervisor, would remove from them the legalistic abstraction which caused previous dissatisfaction (Beresford 1996).

de Raeve (1998) argues that clinical supervision can have a role in maintaining the moral integrity of practitioners by exploring the emotional impact of caring for sick patients. She asserts that by recounting experiences in a trusted context, nurses have the opportunity to reflect on their reactions to patients, mistakes they feel they may have made, and to talk through different ways of approaching situations. In this way, feelings can be processed creatively and the link between emotional response and service delivery be more clearly understood (de Raeve 1998). Her point links with the Aristotelian emphasis on the need for aspects of individual character to be the focus of development in the moral virtues. By allowing nurses to think about their experiences and reactions, the focus is on their unique interaction with patients rather than on the fulfilment of protocols. The possibility of learning about how to take compassionate action, and how to speak out for patients, would therefore be more greatly facilitated.

Durgahee (1997) argues similarly that his experience of providing a 'holding environment' for conducting reflective analysis with student nurses was that it enabled emotions to be discussed and explored, and attitudes, stereotypes,

prejudices, preconceptions, frames of reference, and cultural influences to be

uncovered (Durgahee 1997).

6.7 Summary

The hospital environment is known not be an ideal setting for patients to die.

However, with the introduction of Palliative Care Teams, attempts have been

made to adapt hospital culture for the provision of palliative care. The findings of

this study link with older studies to suggest that the transition has not yet been

fully achieved.

The study suggests a potential link between nurses' deployment of emotion and

subsequent engagement with moral problems. This link emerged directly from

the data, in a series of key findings. Nurses defined ethical issues to be moral

questions that were not capable of consensus. They felt that ethical opinions were

expressions of personal values and beliefs, which could conflict between people.

As a result, they felt that the issues were not sufficiently credible to raise with

each other or in interprofessional dialogue. In addition, nurses felt that there was

a set of prescriptive rules in place which could not be questioned. They felt

inadequate and poorly equipped to raise concerns. Nurses continued to

participate in treatments which conflicted with their personal response to the

situation. As a coping strategy, nurses subsumed their personal responses in

order to carry out the required care. Given that engaging with ethical issues

seemed to involve a personal response for nurses, it is understandable that the

coping strategy of emotional withdrawal also caused disengagement from ethical

concerns. Their ability to be moved by patients' distress was reduced because

they had removed their personal self from their professional role, in self-protection. Both cognitive dissonance and the existential notion of inauthenticity explain aspects of this phenomenon. They fail to account for why nurses experienced a personal crisis that prompted them to leave.

Recent literature in moral philosophy on the analysis of emotion supports the potential link demonstrated in this study between nurses' emotions and their subsequent engagement with moral problems. The combined empirical and theoretical basis for this link would suggest that nurses in clinical practice need to be supported in maintaining a personal response to their environment, in order to secure more effective ethical decision-making.

CHAPTER 7: RECOMMENDATIONS

Introduction

The study has some interesting similarities with conditions surrounding the events highlighted in a recent report into the paediatric cardiac service at the Bristol Royal Infirmary. The report has been seen as a major landmark in awareness of the need for cultural change in the NHS concerning whistleblowing, honesty with patients and teamworking between heath care professionals (General Medical Council, 2001). It is likely to impact policy change and professional regulation in the near future. Recommendations made in the light of the findings of the current study will be situated in the context of this influential report.

The Bristol report was occasioned by a higher than average death rate in open-heart surgery for children under the age of one. The report concluded that around one-third of all children undergoing open-heart surgery between 1991 and 1995 received less than adequate care (Bristol Royal Infirmary Inquiry (BRII), 2001). The nature of care and type of patient involved at Bristol is different to that of the current study. However, both were acute environments where procedures associated with risk and uncertainty were undertaken in an attempt to save lives. The Bristol report highlighted several factors which caused and maintained instances of poor standards of care. These were managerial and ethical failings as opposed to straightforward clinical error, and have similar patterns to the current study.

Because the Bristol Report was necessarily large in scale, the findings and recommendations reflect broad themes. The advantage of the current study is that it can offer insight into the inner workings of larger processes that give rise to compromised patient care, and poor staff morale. Recommendations for nurses' ethical decision-making in acute units which also provide palliative care will make reference to the Bristol report as a basis for discussion. The suggestions made will reflect the argument that greater detail is necessary in order for change to be effective. Discussion will take place under the common areas of concern for both settings. To conclude, implications for research, practice and education will be presented.

7.1 Links with existing policy recommendations
7.1.1 Communication between health care professionals

There is some evidence in the Bristol Report of competing ideologies amongst teams of clinicians. This led to conflicting decisions where it was never really clear who was in charge (BRII, 2001, synopsis 29). Health care professionals failed to communicate with each other, and to work together effectively for the interests of their patients (BRII, 2001, synopsis points 3 & 4). This led to an environment where there was a lack of leadership, and of teamwork. Of a similar nature is the competing values of teams of medical oncologists and the Palliative Care Team in the current study, where divergent practices were confusing to those carrying out care at the bedside. A critical failure of teamwork in both institutions was the way in which certain aspects of care went unchallenged despite there being considerable evidence that these were not in the best interests of patients.

Recommendations made by the Bristol report involve giving greater priority to non-clinical areas of competence such as interprofessional communication and teamwork. The ability to understand and respect the views of other health care professionals, and to engage with patients on an emotional level, are suggested to be critical to this. Further suggestions are that there should be more opportunities for clinicians to learn, train and practice together (BRII, 2001, recommendations 58-62). Feasibility studies to develop and evaluate a system of joint undergraduate education in the first year are recommended, as are university initiatives to facilitate closer links between medical and nursing education in general. Communication skills should be assessed as part of any professional qualification in healthcare (BRII, 2001, recommendation 58).

The current study also highlights the significance of communication, and the deleterious effects on patient care of inadequacies in interprofessional dialogue. However, the findings indicate that the contributing factors to poor communication are complex and subtle. Joint education, and opportunities to develop together, will undoubtedly generate greater understanding of the role and value of other professionals. However, it will not tackle the ongoing pressures of working in units where there are conflicting ideologies of care between senior medical figures. It will also not address the issue of cultures of prescriptive care, to which professionals feel they must adhere despite personal unease. Both these factors were shown to adversely affect communication in the current study.

The Bristol report treated communication in isolation, and made recommendations on this basis, targeting the specific issue of encouraging professionals to talk to each other, and to patients. The current study shows that communication is dependent on a number of interrelated other factors and cannot be addressed in isolation. The Bristol report highlighted some of these other factors, and again made recommendations specific to them, without seeing their interdependence.

7.1.2 Reporting areas of concern

The report notes that staff felt unable to share their concerns about patient care, or to speak openly. Those who tried to do so found it difficult to have their voice heard (BRII, 2001, synopsis 26). The report mentions the need for a different 'mindset' on the part of professionals for the necessary interventions to have been made. The existing attitude was one of 'carrying on' (BRII, 2001, synopsis 24). This is the area of greatest overlap between the two environments. Nurses and doctors in the study indicated that discussions did not take place about areas of concern that later proved to be shared. They felt unable to raise concerns, even when there were clear compromises in pain relief for dying patients, for example. They felt obliged to carry on with prescribed treatment without asking questions.

The recommendations made by the Bristol report focus on the reporting of 'sentinel events.' Such an event is described as 'any unexplained occurrence involving death or serious physical or psychological injury, or the risk thereof.' The incentives to encourage reporting of these events are to provide confidentiality and immunity from disciplinary action within a specified time

frame. The process of reporting should be included in induction and other staff training. The clinical negligence system, by which patients are compensated for proved lapses in standards, should be abolished, according to the report. Other systems of compensating patients should be found, because at present, the system poses a barrier to the open reporting of sentinel events. A national confidential database should be in place, representing a single and accessible system for reporting events.

The ability to report concerns in confidence and freedom from fear of reprisal is an essential intervention given the current climate of professionals feeling unable to share doubts over aspects of patient care. What is concerning is that this would not change the underlying pattern of a lack of honesty in teamwork. The report also makes no provision for the internal dynamic shown by the current study to affect communication. In the area of ethical issues, such as intervening over perceived compromises in patient care, nurses particularly felt that they did not have the knowledge to offer a suggestion for improvement, or even to register a concern. They may be unlikely to feel that their concern would constitute a 'sentinel event.' Doctors also felt that ethical issues were a 'no-man's land' and that they did not have the resources to deal with them. Without dealing with this most basic issue of feeling qualified to have an opinion on the ethical aspects of care, discussion amongst professionals will not take place, leaving the culture unchanged. In addition, the coping mechanism of emotional suppression made genuine engagement with patients and their care less and less possible the longer a professional worked in the unit. This would be another factor mitigating against the reporting of sentinel events, even with the provision of confidentiality. The

Bristol recommendations have a tendency to dwell on the institutional and

governing aspects of management without attending to cultural and personal

change.

7.1.3 Hierarchical decision-making

The report identifies that consultants have a relationship with the trust that

employs them which secures them a 'job for life' (BRII, 2001, synopsis 16). This

makes change more difficult to bring about. The consultants had no contractual

obligation for keeping their skills and knowledge up to date, and still do not

(BRII, 2001, synopsis 15). They were able to introduce new techniques without

any formal system of notification. There was too much power in the hands of too

few, with no clearly defined accountability.

Similarly, in the current study, care was consultant-led and yet instructions for

care were rarely given first-hand. Actual practice on the ward was often on the

basis of the rumoured opinions of the patient's consultant. Junior medical staff

were dependent on their consultant for a good reference, and were anxious to be

seen to be competent. This made them more likely to carry out prescribed

patterns of care despite any doubt.

However, when consultants were interviewed as part of the project, they

identified a political structure operating within the hospital which left their

decision-making also subject to hierarchical constraint. The medical director of

the cancer directorate set the clinical standards for the treatment of cancers

within the trust. Even when the accepted protocols differed from nationally

agreed standards, they were enforced either by the director or by consultants amenable to his powerful position. The accumulation of power with attendant lack of accountability to national standards and external review is clearly a threat to clinical safety, but also damaging to health care professionals at all levels.

The report recommends that consultants should be subject to appraisal, continuing professional development and revalidation. Their terms of employment should be similar to those of junior doctors and nurses, with clear lines of accountability. These changes would ease the sense of absolute power being invested in the clinical lead. However, they would not change the system of patronage spoken of by the junior doctors in the study. Their need for a good reference would remain the same, and so the power and authority invested in consultants would remain unchanged.

The hidden power relationships at senior levels within Trusts seem entrenched, and changing terms of employment may not permeate to this level of power politics. Critically, the sense of treatment plans not open to scrutiny may not be addressed. Nurses on the ward, witnessing in most detail the effects on patients, would still be without a forum for the discussion of concerns.

7.1.4 Culture of protecting patients from information

The Bristol report identifies that patients were not openly informed of the issues surrounding risk and uncertainty in the procedures being undertaken. Information was not given freely, honestly or regularly (BRII, 2001, summary 62). It was regarded as a one-off event rather than as a process. Nurses at Bristol told the

enquiry that they were concerned when sitting in on information-giving sessions

with relatives that the recoveries predicted were too optimistic. However, they

did not mention their concerns, or take any action following the sessions.

Similarly, nurses in the current study felt that information relating to patients'

diagnosis and prognosis was often not truthfully conveyed to the patients

themselves. They also did not feel able to follow up any of their concerns.

The report recommends a variety of measures to tackle these issues. Information

given should be tailored to the situation of the patient, with summaries of the

available evidence given in comprehensible format. Various modes of conveying

information should be piloted with patients, such as different types of literature

and videos. An agency to monitor the quality of information given to patients

should be established. The facility to tape record information-giving sessions

should be offered, along with the presence of a chosen person to accompany the

patient (BRII, 2001, recommendations 1-19). These measures would tackle the

mechanics of honest communication with patients, and may operate as incentives

to facing the difficult task of conveying what can be bad news.

However, the overriding problem to honest communication with patients shown

in the current study was attitudinal. Individual concerns about patients' lack of

knowledge were not discussed. Essentially, the emotional task of facing a

distressed patient meant that professionals withdrew from the task and 'hid'

behind euphemisms and day to day management plans. Again, the underlying

reasons why certain features of patient care are inadequate are not addressed in

the report. The following recommendations attempt to address these more

underlying issues. They reflect the way in which interconnected issues caused compromises in patient care. The combination of an absent language for ethical concerns, hierarchical decision-making and coping strategies on the ward are addressed.

7.2 Recommendations for practice

The integration of palliative care into acute ward contexts clearly needs to be addressed. The clash in ideology between the two paradigms could be improved by a greater number of both nurses and doctors with hospice experience working on the ward. Ongoing ward teaching about caring for dying patients could also raise the profile of and need for palliative care in the acute context. Hierarchical decision-making needs to become more collaborative, so that care plans are no longer specified by the wishes of a consultant rather than the clinically indicated needs of the patient. Regular clinical meetings to establish the stage of each patient in the transition between acute and palliative care may enable junior medical staff to take appropriate decisions in the absence of a consultant. In these meetings, nurses need to have a pre-defined role and expectation to contribute. The issue of senior medics refusing to allow patients access to the Palliative Care Team needs corrective attention from senior members of the trust who are not subordinate in power to the clinical directors of individual directorates.

The use of ethically sensitive role models mentioned in the discussion could be employed to heighten the awareness and validity of ethical concerns in the ward. With appropriate training, these role models could also use teaching sessions on the ward to give names to the ethical concepts nurses discern in practice. Role

models in medicine could work in conjunction with those in nursing, perhaps with joint teaching sessions on the ward, to raise the interdisciplinary profile and clinical language associated with ethical concerns.

Nurses urgently need emotional support in contexts where they are exposed to multiple griefs, and environments where they feel unable to raise concerns about patient care. It was apparent in interviews that the same issue applied to doctors at all levels, but the focus of the study remains on nurses and so most recommendations will reflect this. Hierarchical decision-making may well take time to change, and in the meantime it is essential that there is some forum where nurses can remain genuine. They need to be able to speak honestly about the conflicts they experience in caring for dying patients, about the difficult questions encountered and about the effects of emotional exhaustion. They need to be able to discuss these issues with the same person over time, to build up trust and confidence, and to do so in work time. In this way, the organisation could belatedly relay to nurses that their opinions and gifts are important enough to warrant special attention. The time needs to be regarded as essential maintenance, rather than as luxury. The person chosen to provide this forum for nurses needs to be sufficiently clinically knowledgeable in order to understand quickly and clearly the situations nurses are likely to be encountering. The meetings need to be regular and often, out of earshot of others on the ward, and free from interruption. Nurses at all levels require this support, rather than those purely at senior levels, as was the pattern with clinical supervision on the ward as the research drew to a close. Having the evidence from this study and from others of nurses' distress in comparable situations, means that not providing

additional support would be a serious omission and a failure to protect nurses from a known danger. It would also be to inadequately protect patients from nurses who have disengaged from their care to the extent that they no longer make efforts to intervene in situations of compromise.

7.3 Recommendations for education

The themes addressed in practice are also reflected in this section. Crucial to the preparation of nurses and doctors for clinical practice is to appreciate the significance of and language for ethical concerns. In order to prevent previous problems of scepticism resulting from an over-emphasis on teaching principles, codes and frameworks (Degrazia 1992), the translatability of ethical concepts into clinical practice needs to be demonstrated. This means that nurse teachers also need to be role models for ethical sensitivity. There needs to be sufficient time for these teachers to spend on the ward with individual students, to enable them to encourage and assess the ability of students to identify ethical concerns, give them a name, and offer appropriate suggestions for discussion. There can simply be no replacement for this kind of apprentice-like teaching, crucial to early habit formation as Aristotelian philosophy would imply.

Studies examining the use of role models in nurse teaching have shown that it is effective as a means of learning for the students (Parathian and Taylor 1993; Wiseman 1994). These studies describe modelling processes based on structured activities, in order to bring salient characteristics to the students' attention. However, other studies indicate the powerful influence of the 'workload' version of nursing in acquiring various competencies (Melia 1987b). Pang and Wong

(1998) argue that role models who do not actively and fully engage in clinical practice will impede students from going beyond these workload versions of nursing to see the moral dimension involved. Due to the constraints of clinical practice and the present invisibility of ethical concepts amongst health professionals, the current study would suggest that role models should, in fact, invest teaching time on the ward in considerable blocks, rather than isolated visits. The resourcing implications of this would be considerable, and evaluative studies would need to be conducted to demonstrate the benefits involved.

Liaison between nurse teachers, role models for practitioners working on the ward, and their medical counterparts would be essential. In effect, discussion taking place on the ward, between these professionals, could also role model interprofessional teamworking. Ethical concepts need to be shown to be the valid remit of all members of staff, for the protection of patients.

In their education, nurses need to realise that whilst there is a distinct evaluative role in making ethical decisions, this does not mean that the ethical issue itself does not exist or is incapable of resolution. In raising the profile of ethical issues, nurse teachers in collaboration with role models on the ward could generate discussions on the ward and in teaching sessions which reveal that many practitioners hold the same concerns. Even where divergent attitudes are in evidence, the value of discussion could be shown to be of great significance to the resolution of the concern, especially for the patient. Crucially, each student nurse needs to realise their own capability of and personal responsibility for making ethical opinions and choices. This needs to be shown to be an inevitable

feature of working with vulnerable patients, rather than as an ability or responsibility for which special qualifications are required.

7.4 Recommendations for further research

Being a case study, the findings need to be strengthened by further research in different environments, but at a similar observational depth. The multiprofessional focus could be widened, to further explore the way in which doctors form ethical judgements, and to examine the impediments to their open discussion.

There are a number of questions raised by the study findings. One is the issue of nurses who are able to maintain their ethical integrity despite similar pressures to those described. It would be very interesting and instructive to know whether their ability to do so draws on aspects of personal character, external support, a different type of education or some combination of any of these. The related issue of long-term ethical sensitivity and implications for selection criteria would also be a useful field of further enquiry. Analysing nurses' reasons for leaving wards, particularly in the oncology context, could also be a useful area to investigate.

Evaluating the use of ethically sensitive role models in education and practice would be an essential follow-up to this study. The evaluative methods involved would need considerable sensitivity to capture the outcomes in question, which might even require long-term study of individuals, including observation of their practice and records of their length of stay in nursing.

Care of dying patients in acute contexts needs to be the focus of widespread examination. The information given to these patients, and provision of support for them and their families as they approach death, needs to be assessed and deficiencies made known. The emotional support of nurses in these environments also needs to be assessed and improved accordingly. The amount of evidence available to show the deleterious effects of not providing this resource for nurses is sufficiently large to make further study unnecessary. The task ahead is to establish areas where provision is lacking, and implement mechanisms to address this.

EAST LONDON & THE CITY HEALTH AUTHORITY RESEARCH ETHICS COMMITTEE

1. GENERAL DESCRIPTION OF RESEARCH PROPOSAL

(Answers should be as simple as an accurate description of your research will permit)

1.1   Title of project: **The value systems held by cancer nurses and other health care professionals, and their influence on ethical decision-making**

1.2   Name and address and qualifications of Consultant/Principal Investigators(s) responsible for the project.

    a) Name: **Dawn Elizabeth Hobson**
    b) Address: **St Bartholomew School of Nursing and Midwifery,**
                             City University, Philpot Street, Whitechapel, London E1 2EA
    c) Qualifications: **M.Litt. Moral Philosophy (St Andrews University, Fife);**
                             B.Sc.(Hons.) Nursing and Human Sciences, classification
                             upper second; R.G.N (St Bartholomew's School of Nursing
                             and Midwifery and City University)
    d) Post: **Research student with JRB funded scholarship,**
                             St Bartholomew School of Nursing and Midwifery
    e) Telephone/Fax: **0171-505-5815; 0171-505-5811 (fax)**

1.3   If subjects are patients who is the clinical contact responsible for their care?

The subjects will not be patients. The main focus of the study is oncology nurses, with other health care professionals included in so far as their approach to care has an impact on the work of nurses. Patients will not be interviewed or involved in a formal capacity, but may be observed by the researcher as nursing care is provided. Permission has been obtained from the Senior Nurse Manager to the Cancer Services Directorate, ward Sister and lecturer to the ward from the School of Nursing and Midwifery. The Oncology Consultant to Heath Harrison ward has also been informed.

1.4   To whom should correspondence from the Committee about this study be addressed?

    a) Name: **Dawn Hobson**
    b) Address: **AS ABOVE**
    c) Qualifications:
    d) Post:
    e) Telephone/Fax:

1.5   Referenced background of study, including a short bibliography of relevant research papers

Contemporary literature reflects the many competing theories regarding the application of ethical principles in decision-making (shown by authors such as Stoffell, 1994; Elliott, 1993; Dawson, 1994) with no means of discerning between them (*ibid.*). There is disagreement as to the purpose of such theory and little research evidence to give weight to any particular variety. Stoffell (1994) and Scott

(1996) argue that this has brought about a theory-practice gap in ethics. There is also little research into current decision-making practice in the clinical environment, in order to evaluate the effects of values and beliefs on patient care.

It is frequently documented in the nursing literature that the application of ethical thinking in clinical practice is essential to meeting the needs and serving the interests of the patient (Benoliel, J.Q., 1993; Leavitt, F.J., 1996; Tschudin, V., 1993; Scott, P.A., 1996; Winters *et al*, 1993; Wros, P., 1994), as required by the UKCC in its recent document, 'Guidelines for professional practice' (1996). Nurses regularly take part in implementing decisions made in areas of uncertainty (Astrom, G. *et al*, 1993). In order to be clear in their position as advocates to clients, there is a need to be aware of the suitability of a decision, and to be satisfied that it is genuinely in the best interests of the patient (Benoliel, 1993). Similarly, to be fully accountable to the patient nursing involvement needs to be justifiable, seeking to protect the right of the patient to personal autonomy on the basis of accurate information (Thompson, *et al*, 1994). For these reasons, decision-making practice needs to be rigorous, patient-centred and free from other influencing factors (Elliott, 1993)

Given this background, it is anticipated that an exploratory study into the value systems held by oncology nurses and related health care professionals would clarify and give insight into current methods of decision-making. This would be examined with reference to developing a model of decision-making which could enhance nursing practice in all specialities.

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Jansson, L., & Norberg, A (1989)   'Ethical reasoning concerning the feeding
                                   of terminally ill cancer patients
                                   Cancer Nursing, 12(6):352-358

Lutzen, K., Nordstrom, G.,   'Moral Sensitivity in Nursing Practice'
        & Evertzon, M (1995)   *Scandinavian Journal of Caring Sciences*,
                                   9:131-138

Wros, P. (1994)   'The ethical context of Nursing Care of
                                   Dying Patients in Critical Care'
                                   in Benner, P (1994) *Interpretive
                                   phenomenology*, SAGE publications

1.6   What questions will be addressed by your study?

       1. What value systems do nurses hold in ethical decision-making?
       2. What value systems do other health care professionals hold?
       3. What are the relationships between these value systems?
       4. How do these value systems influence the patient care that nurses give?

1.7   Methods/design of study

Qualitative methods drawing on interpretive phenomenology described by Benner (1994) will be used to analyse taped interviews and non-taped group discussions with oncology nurses and other health care professionals. Phenomenology concentrates on lived experience, believing that personal understandings of the world cannot be separated from objective events in the qualitative research process. It is therefore a useful perspective in the study of personal values and motivation. The goal is to analyse individual understandings in order to reveal commonalities and differences between participants, to use in making recommendations for practice and education (Benner, 1994).

The interviews will be audio taped and semi-structured, asking participants to reflect on situations in which they consider an ethical decision to have been made (see topic guide, appendix three, p13). The interview would be of approximately 30 minutes duration, at a location of the participant's choice. Participation in the delivery of care will take place at the beginning of the research, before and during the period of interviewing, to provide contextual background to the experience of participants (see statement on potential stress, appendix four, and expectation of time, appendix five, both p14). Notes from this will be used in conjunction with the interview transcripts.

Textual analysis will be used to process transcripts of the recordings and notes from group discussions. Coding takes place according to qualitative distinctions within the text - such as recurrent concerns, and repeated similarities between individual participants. Notes from participation in the clinical environment will provide contextual background at this point. Continued thematic analysis incorporates the critical opinion of the participants, and conceptual categories or sets are developed which describe the main findings of the study. Paradigm cases are extracted which demonstrate the central distinctions and similarities in narrative form. In this way, the actual experience of oncology nurses can be preserved and examined to gain understanding of their techniques of ethical decision-making. The data is examined with continued reference to the participants themselves, who are asked to comment on and criticise the conceptual categories developed.

SUMMARY

Stage 1 - Participation in the delivery of care
Stage 2 - Interviews undertaken with ward staff and continued participation
Stage 3 - Initial textual analysis of data and critical review from participants
Stage 4 - Development of exemplars for practice, used to disseminate findings

1.8   Duration of study

Approximately ten – eighteen months will be spent in the clinical area for data collection. The analysis and formulation of the thesis will take one further year.

1.9   Justification of Sample Size - including formal statistical advice, if any

Phenomenological research holds no formal sample size for reliability because the aim of the study is to be faithful to the data collected and the experience of the participants. However, it is anticipated that no more than twenty interviews will be undertaken. The cited study by Astrom *et al* (1993), for example, used 14 key informants to yield a common experience amongst nurses of confusion regarding the interaction of values, tasks and relationships in situations they saw as being ethically significant. The researchers recommended further analysis of decision-making to clarify current methods and the problems faced.

1.10   If this is a multi-centred study, which others are involved?

This is not a multi-centred study.

2. RECRUITMENT OF SUBJECTS
(If this section is not relevant to your application, state why and delete what follows)

2.1   How will subjects be recruited?   **Convenience sampling**

2.2   What will be the age group of the subjects?   **Working age**

2.3   What inclusion and exclusion criteria will be used?
              (If women of childbearing age are excluded then justify this
              See Section 3 - Notes For Guidance)

Inclusion criteria will be registered nurses in at least their third month of employment in the area, and other health care professionals working within the oncology directorate of the Royal Hospitals Trust.

2.4   Will the subjects include healthy volunteers?
              (staff)

2.5   Will any of the subjects be medical or nursing students?

                                                           No

              If **Yes**, please provide evidence that the Dean approves their participation.

2.6   Will your subjects include:

              a) persons under 18?

                                                           No

              b) psychiatric patients detained under the Mental Health Act?

                                                         No

              c) mentally disabled patients unable to give informed consent?

                                                           No

              d) unconscious patients?

                                                           No

              If **Yes**, please provide clinical justification

3. DISCOMFORT AND POTENTIAL HAZARDS FOR SUBJECTS
(If this section is not relevant to your application, state why and delete what follows)

The research tools for the study are interviews and participation in clinical care. It is expected that there will be no physical discomfort or hazard attendant to the study, other than potential emotional stress (see appendix five, p14).

4. PAYMENT/FINANCE
(If this section is not relevant to your application then state why and what follows)

No payment will be offered for participation in the research.

5. RADIATION
(If this section is not relevant to your application, state why and delete what follows)

The research will not involve the use of radiation.

6. MEDICATIONS/ DEVICES USED IN THE INVESTIGATION
(If this section is not relevant to your application, state why and delete what follows)

Medication or other invasive devices will not be employed in the research.

7. INSURANCE
(If this section is not relevant to your application, state why and delete what follows)
Please provide written evidence of how you and any others conducting the research will be indemnified. (See Section 9 - Notes for Guidance)

If the Medical College, Trust, University or commercial sponsor is unwilling to provide suitable indemnity then the responsibility for ensuring such provision falls on the principal investigator. If appropriate cover is unobtainable then subjects must be told this on the information sheet.

7.6   For studies initiated by *Universities*, have you enclosed written confirmation that suitable indemnity is being provided?

Written documentation to this effect is being forwarded to the committee by the Academic Registrar's Office at City University.

8. CONFIDENTIALITY
(See Section 6 - Notes for Guidance)

8.1   Will your research include a) named subjects, b) subjects whose names have been separately coded or c) un-named subjects?

c) un-named coded subjects

8.2   Where will locked files of research materials be stored?

In the postgraduate office locked filing cabinet, at City University St Bartholomew School of Nursing and Midwifery, Philpot Street, Whitechapel, E1 2EA

8.3   Does the research involves storage of personal computerised data?
       If **Yes**, how will confidentiality be maintained?
       Have you registered your research with the local Data Protection Registrar?

       **Storage of information will be coded and not traceable to any participant in the
       study. Information held on the 'U' drive of City University's networked computers is
       inaccessible except by user name and identification, and research at the University is
       registered with the local Data Protection Registrar.**

8.4   Does the study entail the use of photographs or videos?
       No

8.5   If research does not involve contact with patients but includes access
       to medical records, will consent from patients be obtained?
       If **No**, how can this be justified?

       Access to the medical records of patients is not part of the research

9. CONSENT

(If this section is not relevant to your application, state why and delete what follows)
In the case of patients, researchers should ordinarily make contact through the clinician
most active in the patient's treatment. If your research involves children, you must provide
a separate information sheet for them which is written in language which they can
understand. Where appropriate, justify the inclusion of incompetent adult patients and say
how their interests will be protected. You must as a matter of courtesy provide an
information sheet for their relatives and seek their assent. All research involving the use of
foetal tissue must have the general consent of the mother. All research involving genetic
screening should include appropriate counselling before consent is obtained. **Please read
Section 2 - Notes for Guidance**

9.1   What type of consent will you seek?
       If **verbal** only, please justify.

       **Written consent will be obtained from oncology nurses, and any other health care
       professional interviewed.**

9.2   By whom will consent be sought?

       (a) The investigator responsible for the research.
           Give name(s): **Dawn Elizabeth Hobson**

9.3   How and where will the researcher make contact with the patients or
       healthy volunteers for the purposes of obtaining consent?

       **Nurses and other health care professionals working in the clinical area will be given
       an information sheet and verbal clarification at a ward meeting. This will be prior to
       the period of participation in the delivery of care. On a separate occasion their
       consent will be sought for the participation. A further information sheet and consent
       form relating to the interview will subsequently be given to nurses and other staff,
       and time provided for questions to be addressed. The rationale behind a second
       meeting in each instance is to give the participant time to think over the proposal,
       and to have a further opportunity to ask any questions. Patients will receive an**

introduction to the researcher by the nurse caring for them as participation takes place. It will be explained that the researcher is interested in the work of the nurses and is participating in order to study this.

9.4   If your research involves patients who have been detained under the
       Mental Health Act, how will you decide which subjects are and are
       not able to give informed consent for participation?
           N/A

9.5   If your research is a clinical drugs trial and includes women of
       childbearing age, then in ordinary circumstances they should have a
       pregnancy test and give their consent for it. They should also be told
       to employ a method of barrier contraception and to inform you
       immediately if they suspect that they may be pregnant. Has this been done?

                                                                            N/A

9.6   If your research involves subjects whose first language is not English,
       has formal provision been made for translation or advocacy?
       If **No,** how can this be justified?

       As registered practitioners members of staff are required to be fluent in English, so that translation and advocacy will not be required.

9.7   You must now formulate an information sheet and a consent form. **This document must be attached to each submitted application form.** The information sheet should be attached to the written consent form on Page 9 below. These should always be kept together as one document in the patients' notes or healthy volunteers' files after they have given their consent. You should make it clear on both the information sheet and the consent form whether or not they are for patients, healthy volunteers, children or relatives. In the case of relatives of adults, assent rather than consent should be sought. **(See Section 2a, Notes for Guidance).**

A.1.1 INFORMATION SHEET FOR PARTICIPANT OBSERVATION
'The value systems held by nurses and other health care professionals, and their influence on the care provided by nurses in an oncology setting'.
EAST LONDON AND THE CITY HEALTH AUTHORITY
Information to Staff to Participate in a Research Project

We invite you to take part in a research study which we think may be important. The information which follows tells you about it. It is important that you understand what is in this leaflet. It says what will happen if you take part and what the risks might be. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is entirely your choice. Please ask any questions you want to about the research and we will try our best to answer them.

You have been invited to take part in this study because you are a registered nurse working within the Cancer Services Directorate of the Royal Hospitals NHS Trust, having been in the area for more than three months. Previous research suggests that you may face ethical issues in the care of your patients. I am interested in your experience of having to make ethical decisions in practice. The research approach being taken is not designed to be critical, or to test, but to develop a broader picture than currently exists of what goes on when ethical decisions are made.

The study is qualitative and focuses on your perceptions as a practitioner. To do this I would like to work alongside you in your role as a practitioner. I will be seeking to gain understanding of the situations in which you work and the issues you may face in decision-making. Your name will not be recorded at any stage to protect your right to confidentiality and anonymity. I will not be involved in appraising standards, and my supervisor and myself will be the only persons to have access to the observations. Findings from the study will not disclose your identity. They will be used for the purposes of research only.

You don't have to join the study. You are free to decide not to be in this study or to drop out at any time. If you decide not to be in the study, or to drop out, this will result in no penalty whatsoever.

What happens if you get worried ? You will always be able to contact me to discuss your concerns and/or to get help:

Name: Dawn E. Hobson
Address: Room 1.3,
         St Bartholomew School of Nursing and Midwifery,
         City University,
         Philpot street, Whitechapel, London E12EA
Telephone number: 0171-505-5815 (direct)
                  0181-518-2695 (home)

A.1.2 WRITTEN CONSENT FORM FOR PARTICIPANT OBSERVATION

Title of research proposal: 'The value systems held by nurses and other health care professionals, and their influence on the care provided by nurses in an oncology setting'

REC Number:

- The study organisers have invited me to take part in this research. ☐

- I understand what is in the leaflet about the research. I have a ☐
copy of the leaflet to keep.

- I have had the chance to talk and ask questions about the study. ☐

- I know what my part will be in the study and I know how long it will take. ☐

- I know that the local East London and The City Health Authority ☐
Research Ethics Committee has seen and agreed to this study.

- I understand that personal information is strictly confidential: I know the ☐
only people who may see information about my part in the study are the research
team or an official representative of the organisation which funded the research.

- I freely consent to be a subject in the study. No-one has put pressure on me. ☐

- I know that I can stop taking part in the study at any time. ☐

- I know if I do not take part I will not suffer any penalty ☐

- I know that if there are any problems, I can contact:

Ms. **Dawn Hobson**
Tel. No. **0171-505-5815 (work - direct)**
0181-518-2695 (home)

Volunteer's: Signature ....

Witness's Name ....

Witness's Signature: ....

Date ....

The following should be signed by the Clinician/Investigator responsible for obtaining consent

As the Investigator responsible for this research or a designated deputy, I confirm that I have explained to the patient/volunteer named above the nature and purpose of the research to be undertaken.

Investigator's Name: ....
　　　　　　　　　　Investigator's Signature: .... Date:
　　　　　　　　　　　　　　...................................

A.1.3 INFORMATION SHEET FOR INTERVIEW
'The value systems held by nurses and other health care professionals, and their influence on the care provided by nurses in an oncology setting'.
EAST LONDON AND THE CITY HEALTH AUTHORITY
Information to Staff to Participate in a Research Project

I invite you to take part in a research study which I think may be important. The information which follows tells you about it. It is important that you understand what is in this leaflet. It says what will happen if you take part and what the risks might be. Try to make sure you know what will happen to you if you decide to take part. Whether or not you do take part is entirely your choice. Please ask any questions you want to about the research and I will try my best to answer them.

You have been invited to take part in this study because you are a registered nurse working within the Cancer Services Directorate of the Royal Hospitals NHS Trust, having been in the area for more than three months. Previous research suggests that you may face ethical issues in the care of your patients. I am interested in your experience of having to make ethical decisions in practice. The research approach being taken is not designed to be critical, or to test, but to develop a broader picture than currently exists of what goes on when ethical decisions are made.

The study is qualitative and focuses on your perceptions as a practitioner. To do this I shall invite you to participate in an interview which will be taped, during which I will ask you to reflect on any situations in which you feel an ethical decision has been made. It will be of approximately thirty minutes duration and will not have your name recorded to protect your right to confidentiality and anonymity. The transcript will be coded and stored in a locked cupboard in the research office of the School of Nursing. I will be the only person to listen to the recording and findings from this study will not disclose your identity. The interview will provide a confidential forum in which I hope you will feel free to discuss your experiences. It will be tape recorded in order that I do not loose the essence of what you say. It can take place at a location of your choice, and you are free to terminate it at any point. The findings from the study will be used for the purposes of research only.

You don't have to join the study. You are free to decide not to be in this study or to drop out at any time. If you decide not to be in the study, or to drop out, this will result in no penalty whatsoever.

What happens if you get worried ? You will always be able to contact me to discuss your concerns and/or to get help:

Name: Dawn E. Hobson
Address: Room 1.3,
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         City University,
         Philpot street, Whitechapel, London E12EA
Telephone number: 0171-505-5815 (direct)
                  0181-518-2695 (home)

A.1.4 WRITTEN CONSENT FORM FOR INTERVIEW

Title of research proposal: **'The value systems held by nurses and other health care professionals, and their influence on the care provided by nurses in an oncology setting'**

REC Number:

- The study organisers have invited me to take part in this research. ☐

- I understand what is in the leaflet about the research. I have a ☐
copy of the leaflet to keep.

- I have had the chance to talk and ask questions about the study. ☐

- I know what my part will be in the study and I know how long it will take. ☐

- I know that the local East London and The City Health Authority ☐
Research Ethics Committee has seen and agreed to this study.

- I understand that personal information is strictly confidential: I know the ☐
only people who may see information about my part in the study are the research
team or an official representative of the organisation which funded the research.

- I freely consent to be a subject in the study. No-one has put pressure on me. ☐

- I know that I can stop taking part in the study at any time. ☐

- I know if I do not take part I will not suffer any penalty ☐

- I know that if there are any problems, I can contact:

  Ms. **Dawn Hobson**
  Tel. No. **0171-505-5815 (work - direct)**
  0181-518-2695 (home)

Volunteer's: Signature ....

Witness's Name ....

Witness's Signature: ....

Date ....

The following should be signed by the Clinician/Investigator responsible for obtaining consent

As the Investigator responsible for this research or a designated deputy, I confirm that I have explained to the patient/volunteer named above the nature and purpose of the research to be undertaken.

Investigator's Name: ....
                     Investigator's Signature: .... Date:
                          ....

A.1.5 INTERVIEW TOPIC GUIDE

An introduction and information sheet prior to each interview will have outlined:

> The interviewer's background
> The length of time the interview will take
> The subject area to be discussed
> The purpose of the interview and the use of the results
> The confidentiality and anonymity of the data generated
> The taped nature of the interview
> The right to withdraw without penalty and not to participate

A further opportunity will also have been provided to answer any queries before consent is requested.
As the interview is designed to be informal and to gain insight into the perspective of the practitioner, the following questions may be rephrased, and the direction of the conversation may focus on one area more than others. Following the pilot study a reworked schedule will be submitted to the committee.

Initial questions will seek to gain a focus on the subject of decision-making in the interviewee's field of practice:

> As a practitioner do you consider that you have to make decisions that have ethical implications?
> If so, what kind of issues do they raise?
> Can you give an example of ethical decision-making in your practice? (previous cited research has shown that narrative examples are the most effective tool in making ethical issues explicit)

Depending on the development of the interview, the following areas will be used to prompt the participant to explore their involvement in the decision-making process:

> In the example you have given, was there a protocol, ward policy or theory which helped you?
> Did you rely on your past experience to help to guide you? If so, how did it do that?
> Did you discuss the situation with others? If so, who were they?
> Did you feel that your personal values were involved? If so, how?
> Can you give any more examples of situations where you have felt that your own values have been involved?

The interview will conclude with the participant being asked if they feel supported in this area of practice by any particular facilities, and if they have any recommendations for the future.

Potential stress

The interviewee will be aware that they are not being tested or formally appraised in their decision-making practice, and that their taped interview will remain confidential and anonymous at all times. This will have been emphasised through ward meetings, information sheets, personal communication and at the time of obtaining consent for both participation and interview. In participating in the delivery of care, practitioners will have been made aware that the researcher is not in a position to critically assess standards, but will be gaining background to their experience of practice.

The interview may cause the participant to recall issues that they have found difficult, or that they feel are unresolved. There will be the opportunity to discuss these issues further at the end of the interview, with assurance of confidentiality. This dialogue will not be used for research purposes. The participant will also be aware that they can withdraw from the research without any penalty.

The findings of the study will be given to the participants at each stage of analysis for critical review, as part of the reliability of the study. They will be kept informed of progress and this involvement will hopefully decrease possible stress.

Expectation of time required from participants

Participation in the delivery of care will involve the researcher working alongside the practitioner, and conversations relating to the research will be at their discretion. This section therefore has no formal requirement of time. However, having a person extra to ward numbers may slow the participant initially, as they introduce the researcher to each patient. Interview length is also at the discretion of the participant.

DECLARATION BY THE CONSULTANT OR PRINCIPAL INVESTIGATOR IN CHARGE OF PROPOSED RESEARCH: REC No.....

I ACCEPT RESPONSIBILITY:

1. To inform all relevant medical and nursing staff at each location where a patient/volunteer may be treated, that a subject is enrolled in a trial or experiment, what drugs (if any) or invasive procedures will be used (or not as may be) and what precautions they should take, if any. In some cases it will be necessary to give special training to nurses or junior staff to prepare them to undertake procedures. Finally, with the patient's consent, the GP should be informed about the trial in which the subject is enrolled, including information concerning any adverse findings.

2. To ensure that details of each procedure to be done or drug to be given are entered in the clinical notes and that the date and time when the procedure was done and/or drug given are subsequently noted.

3. To make three copies of the "Written Explanation to be Given to Potential Subjects" and the signed "Written Consent Form", including the signed "The Declaration by the Consultant or Principal Investigator in Charge of the Proposed Research". **One copy of each should be kept by the patient/volunteer, one copy should be included in the patient's clinical notes and one copy should be kept by the Senior Consultant/Chief Investigator responsible for the Research.**

4. To ensure that each subject is verbally warned not to take part in more than one study at any time.

5. To inform the Committee of any adverse or unforeseen circumstances arising out of this research.

6. For clinical research, to provide the Committee with one brief report of progress half way through the project and another at its completion.

7. To make every effort to tell the participants about the results of the study.

Principal Investigator ....
Signature ....

The original signed copy of "The Declaration ..." should be attached to the application form when it is submitted.

Ms D Hobson
St Bartholomew's School of Nursing & Midwifery
City University
Philpot Street
London, E1 2EA

Our ref: RS/sb/p97057s   25 March 1997

Dear Ms Hobson

Re: P/97/057s - The value systems held by nurses and other health care professionals, and their influence on the care provided by nurses in an oncology setting.

Thank you for your letter of 13th March 1997, addressing the points of the Committee's earlier letter. I am happy to tell you that I am now able to approve this study on Chairman's action with a view to ratification at future meeting of the Committee.

Please note the following conditions to the approval:

1.   The Committee's approval is for the length of time specified in your application. If you expect your project to take longer to complete (i.e. collection of data), a letter from the principal investigator to the Chairman will be required to further extend the research. This will help the Committee to maintain comprehensive records.

2.   Any changes to the protocol must be notified to the Committee. Such changes may not be implemented without the Committee or Chairman's approval.

3.   The Committee should be notified immediately of any serious adverse events or if the study is terminated prematurely.

4.   You are responsible for consulting with colleagues and/or other groups who may be involved or affected by the research, such as extra work for laboratories.

5.   You must ensure that, where appropriate, nursing and other staff are made aware that research in progress on patients with whom they are concerned has been approved by the Committee.

6.   The Committee should be sent one copy of any publication arising from your study, or a summary if there is to be no publication.

I should be grateful if you would inform all concerned with the study of the above decision.

Your application has been approved on the understanding that you comply with Good Clinical Practice and that all raw data is retained and available for inspection for 15 years.

Please quote the above study number in any future related correspondence.

Yours sincerely

Mr Richard Smith
Vice Chairman
ELCHA Research Ethics Committee

A.3 Exemplar of daily field notes
Names of patients and staff are pseudonyms

07.08.97

Abstract:
Staff are incredibly strained and there are three sick, so Sister Elizabeth has to try and re-organise shift patterns to accommodate. This means Miriam might not be able to have a 'life away from this place' as she puts it, and agency nurses are relied on. The day is heavy and with a very heavy work load; the ward feels heavy on our shoulders. The day involves dilemmas for me as a researcher; and for the negotiation of consent with one of the nurses.

Orientation
Miriam, Alison, Michael, course nurses Sarah and David, Celia, who is an agency, very good but slightly difficult interpersonally, Sisters Charlotte and Elizabeth in the morning. 25 patients, one death on the early, 4 or 5 patients nursed in bed, needing two nurses to mobilise, student nurses Louise and Sarah. Alison and David don't get on.

Sequence of events
I worked with Alison who became extremely stressed, and was explaining nursing actions to me so I felt she didn't really understand why I was there. As well, there was no time to do this, explain further. I decided not to press her until I have had further opportunity to discuss the project.

Rose tells me half way through the morning there's, 'an ethical one for me.' This is Molly Trendall, who thinks she is cured as she is being sent home for palliative treatment, when her prognosis is but two to three months. Rose thinks this is 'naughty', but is not sure of what her role should be. She tried to approach the subject via Molly needing the Macmillan nurses, which is something that Tzah did with another patient. But, Molly feels this is unnecessary. Miriam's action is to call up Mo, the SR, and get an earlier family meeting. The relatives have come to an appreciation of the time scale, Rose feels, after a telephone call. They do not want to discuss this with Molly. The nurses feel they are hanging on to straws. Molly is thinking of returning to full time work. Mo mentions to the son, in the meeting, that 'this might tire her a bit,' and I thought that this was an inadequately direct comment. He was actually asking to be told at this point, and by a very gentle circumnavigation she avoided telling him directly. An unresolved situation with haphazard communication, where Rose feels something is wrong and Miriam is not sure of what to do. Rose says, 'An ethical dilemma is where you don't know what to do', but it seemed to me that they both knew what to do or thought so, they knew what was wrong, that Molly herself didn't know her true prognosis and was mistakenly planning on the basis of being cured. But one wonders how Molly herself had suddenly come to this, when she clearly could not have been told in these terms – just she just want to avoid the subject? They just didn't know what to do about it, with the involvement of doctors.

Miriam does come up to me several times throughout the shift and for the first time acknowledges my area of interest and wants me involved. She is obviously thinking very deeply, and is disturbed by the fact that Molly does not know. She wants to intervene but does not know how. The members of the family are often ringing up, wanting clarification, and she is constantly in demand by them. She tries to be as frank as she can, and continues to try and raise with Molly the idea of Macmillan nurses. She then is approached by a relative who told Molly of another family meeting happening tomorrow, which was planned confidentially from Molly - although the doctor would ask Molly's permission for this. Molly was not aware yet and wondered what was happening. The relative then got very distressed and wanted to know what was going on. Then Mo, the doctor, Miriam and I happened on this in the ward office and talked to them. Mo said about not treating the extra lump they had found, that the brain scan had been metastases, that means she was in a poor category. They didn't actually 'hear' this. They wanted to know it wasn't in the next couple of days. 'Oh no, it's not like that at all,' Mo escaping. Miriam left to wonder what to do about that. Also she felt bad that the relatives were the ones getting the attention, and she said, 'What about Molly out there?' I then felt that I should ask Miriam if she was happy with the outcome. She said yes, because she had organised a meeting with the doctor. I asked if Molly's actual knowledge was any different. She said that well, no, it wasn't. She then became unhappy. After a while she came to me and said that she had had a conversation with Molly and that she had established with her more about the more real time scale of her prognosis. This seemed to make her feel very relieved. After that she said to me that day that she suddenly saw the reason for my presence. I wondered if the raising to the surface of me was actually the raising to the surface of the actual ethical issue. The dilemma for me was obviously in changing the whole situation by selective questioning. I felt and decided here that it was a situation that I was unhappy to leave, as a registered nurse myself. I also felt that the resulting situation was interesting, both as a dilemma for me, for Miriam, and for our developing relationship.

Another situation involving Patricia Hollwell. This is a 99 year old lady who is not to be taught any other swallowing techniques as she is 99. Miriam looks over at me deliberately in handover. The question raises in my mind of how we know how long she may have and as this method is minimally invasive, why not try? Sister Charlotte feels though, at 99, this is an understandable decision. Miriam, I don't think agrees. There is no nursing intervention on this as a result. Charlotte does not really acknowledge either dilemma.

Evaluation
Again, problems with ownership of information, confidence in opinion, lack of discussion together. Doctors fear and unwillingness to be frank, relatives wanting priority, relative wanting her to be cured and trying to believe she is. Patient alone.

Coda
Need to explain to Alison about the project more clearly. Need to disallow data on Molly as I intervened in the outcome. Need to build on relationship with

Miriam - note how the project raises her awareness of ethical issues and helps to give them a name.

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Appendix A.4 Exemplar of analysis

Section 1: Descriptive categories with definitions
Q.S.R. NUD.IST Power version, revision 4.0.
Licensee: Dawn Hobson.PROJECT: d2, User Dawn Hobson, 10:49 am, Sept 7, 2002.

(F 1)///decision not made
> Definition: Where a potential decision is identified, and is unresolved in the period of need.

(F 1 1)///decision not made/not taken up by senior
> Definition: issue mentioned by junior nurse or junior doctor and not followed up by seniors

(F 1 2)///decision not made/unaware of decisions being made
> Definition: Vague awareness that decisions are made or that the issues occur, but they get subsumed in current events (see Oddi, Cassidy and Fisher 1995:205)

(F 2)///high standards
> Definition: Examples of commitment and special relationships (see Artinian 1995)

(F 3)///silence about difficult issues
> Definition: Silence coinciding with difficult issues and some suggestion that it is used as a strategy. Particularly silence with ethical issues.

(F 4)///unpredictability
> Definition: Unpredictability of physical and psychological response to cancer treatment, and effects on decision-making

(F 5)///Hawthorne effect
> Definition: Becoming identified with ethical issues and changing situations as a result

(F 6)///resus
> Definition: Both confusion and conflict surrounding resus decisions

(F 6 1)///resus/confusion
(F 6 2)///resus/conflict
(F 7)///medical phraseology
> Definition: Examples of phraseology designed to distance emotion and unpredictability. See Paget (1982) 'Your son is cured now' and medical futility.

(F 7 1)///medical phraseology/coping
(F 7 1 1)///medical phraseology/coping/emotion
(F 7 1 2///medical phraseology/coping/unpredictability
(F 7 2)///medical phraseology/nursing phraseology
(F 8)///intervene
> Definition: Where nurses either overtly or covertly (see junior doc support node) influence medical or case management decisions

(F 8 1)///intervene/treatment
(F 9)///hierarchy
> Definition: Where decision-making is influenced either explicitly or implicitly by perceived hierarchy and status.

(F 9 1)///hierarchy/refer up

(F 9 2)///hierarchy/info down

(F 9 3)///hierarchy/confusion in the line of responsibility
>Definition: Unclear allocation of responsibility with ethical Issues

(F 9 4)///hierarchy/conflict
>Definition: Conflict generated as a result of hierarchy

(F 10) ///awareness
>Definition: Nurse, doctor or other hcp demonstrate awareness of ethical issues

(F 11) ///double recognition
>Definition: Being identified with ethical issues initially, and then with death/burnout issues

(F 12) ///ritualistic presentation of pts
>Definition: Mainly handover renditions and popular descriptions. The categorisation of patients (see Latimer 1998)

(F 13) ///negotiation of access
>Definition: Entry to the ward, but more to the informal network of the research site

(F 14) ///meth- native
>Definition: Issues concerning researching as a nurse

(F 15) ///staffing level
>Definition: The effect on patient care and decision-making of staff Shortage

(F 16) ///constraint

(F 17) ///view of nursing
>Definition: How nurses viewed themselves and their work as evidenced by field notes and verbal interchange

(F 18) ///consent
>Definition: Negotiation of nurses' consent to the research

(F 19) ///environment
>Definition: aspects of work and surrounding culture

(F 19 1)///environment/fragmentation

(F 20) ///identification

(F 21) ///ethical issues identified
>Definition: The way that issues are identified to be ethical

(F 22) ///meth-ethical
>Definition: Ethical issues associated with participant Observation

(F 23) ///meth decisions

(F 24) ///Junior doctor support

(F 25) ///patient consent

(F 26) ///truthtelling
>Definition: Clinical epsodes involving hcp's telling the truth to cancer patients

(F 27) ///bad death
Definition: Acknowledged and tacitly acknowledged incidents of poorly managed palliative care

(F 28) ///unpopular patient

(F 29) ///humour about difficult issues

(F 30) ///unpopular nurse

(F 31) ///pt/relative advocacy
>Definition: Confusion over the line of responsibility in situations where patients and relatives conflict.

(F 32) ///effect of grade

(F 33) ///rumbling issues
>Definition: Major issues which circulated in the informal networks but were never documented or openly acknowledged

(F 34) ///care/cure
>Definition: Where there is a clash of paradigms between palliative care and aggressive acute curative treatment

(F 34 1) Difficulty in making decision to begin palliative care

(F 35) ///alienation
>Definition: Incidents where people mention having an identity specific to the ward, and another specifically not there.

(F 35 1)///alienation/change over time
>Definition: The transition from being 'whole' to being separated/alienated

(F 36) ///nurses' role in treatment
>Definition: Where nurses have a direct impact on decision-making

(F 37) ///Role of ward clerk

(F 38) ///own qualities identified
>Definition: Where nurses identify their own values as crucial to decision-making

(F 39) ///Failure of support group
>Definition: Where nurses specifically mention why the institutional support group fails

(F 40) ///categorisation of pts
>Definition: Where nurses and doctors put patients into a category depending on their proximity to death

(F 41) ///nurses as family
>Definition: Nurses' relationships with each other as a coping Strategy

(F 42) ///I/they
>Definition: Where nurses cannot speak as individuals but need the support of a group

(F 43) ///Guilt
>Definition: Nurses express feelings of self-blame for the standards of care they are giving or feel forced to give

(F 44) ///key experience with a patient
>Definition: Key experience which affects values, changes belief and determines future decision-making

(F 45) ///teamwork
>Definition: Decisions/concerns affected by multiple input

(F 46) ///LW is special
>Definition: The close relationships and support amongst nurses

(F 47) ///coping
>Definition: The need to contain emotion as the definition of Competence

(F 48) ///support

Definition: Direct references to the need for support given psychological pressures

(F 49) ///need for process
Definition: The reference to process or rule-following to acknowledge what is being done, and to provide security

(F 50) ///hidden conflict
Definition: Conflicts embedded in text, not clearly articulated because of difficulties in saying anything negative, or honest criticisms

(F 51) ///'Do as you would be done by'
Definition: Operating moral principle

(F 52) ///Effect of background
Definition: Where this operates to influence the formation of ethical judgements

(F 53) ///pt-staff barrier
Definition: Where nurses refer to patients as on the other side of a divide, and vice versa

(F 54) ///micro-macro
Definition: Where nurses reflect awareness of the micro issues being influenced by bigger organisational concerns

(F 55) ///ethics and death
Definition: Where nurses link death with ethical significance

(F 56) ///ethical memory
Definition: Where the nurse remembers for long periods the ethical significance of events. Links with key experiences and also guilt.

(F 57) ///The need to leave
Definition: When nurses identify aspects of their experience on the ward which mean they have to leave

(F 58) ///power over patients
Definition: Where decisions are made that the patient has no knowledge of or role in making

(F 59) ///dr-nurse differences
Definition: Where doctors and nurses show differences in care planning priorities

(F 60) ///confidentiality
(F 61) ///overtreatment
(F 62) ///undertreatment
(F 63) ///needing to fix things
Definition: Where nurses seem unable to accept that they cannot put everything right for a dying patient - to such an extent that they block patients.
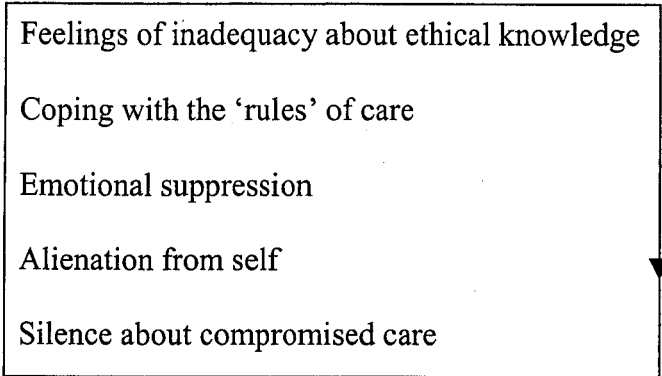
(F 64) ///patient autonomy
(F 65) ///unaware of others' opinions
Definition: Where nurses and doctors privately raise opinions that they do not realise others share
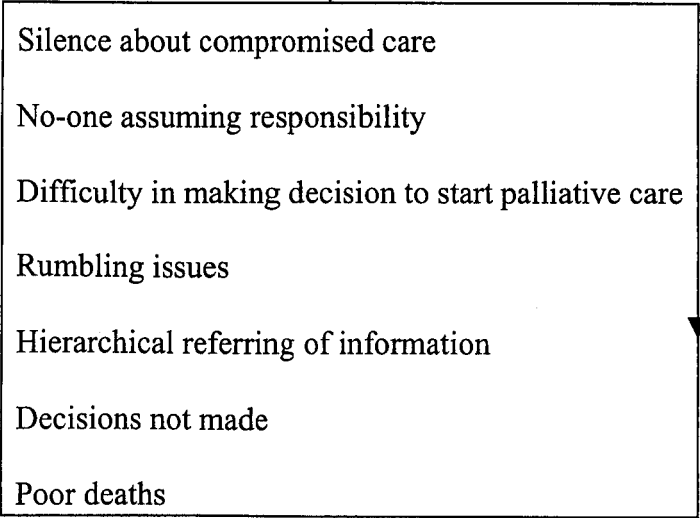
Section 2: Linking categories

The linkages between categories do not display causal relationships, but a process of related events on the ward.

Nurses' silence:

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┌────────────────────────────────────────────────┐
│  Feelings of inadequacy about ethical knowledge │
│                                                 │
│  Coping with the 'rules' of care                │
│                                                 │
│  Emotional suppression                          │
│                                                 │
│  Alienation from self                        ▼  │
│                                                 │
│  Silence about compromised care                 │
└────────────────────────────────────────────────┘
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Decision-making process:

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             ▼
┌────────────────────────────────────────────────┐
│  Silence about compromised care                 │
│                                                 │
│  No-one assuming responsibility                 │
│                                                 │
│  Difficulty in making decision to start palliative care │
│                                                 │
│  Rumbling issues                                │
│                                                 │
│  Hierarchical referring of information       ▼  │
│                                                 │
│  Decisions not made                             │
│                                                 │
│  Poor deaths                                    │
└────────────────────────────────────────────────┘
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