

How are Ethical Problems Resolved in a Paediatric Intensive Care Unit?

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Abstract.

Few studies have explored how medical ethics works in practice specifically in terms of the social processes that result in a decision regarding an ethical problem. This is particularly so in the case of children's intensive care. More than a decade of teaching healthcare ethics to both nurses and doctors prompted a study to examine how ethical problems are resolved in a children's intensive care unit.

This qualitative study addressed this question in a single large children's intensive care unit in England. The study was guided by grounded theory in examining via individual face to face unstructured and semi-structured interviews what ethical problems were encountered and how they were resolved. Interviews were conducted mainly with doctors and nurses working on an intensive care unit. Two admitting consultant doctors and three parents were also interviewed.

The analysis of data gathered in 20 interviews was developed using Strauss and Corbin's (1998) framework. A theory emerged from the analysis of the data that revealed the most prominent ethical problems in children's intensive care related to end-of-life situations. Most significant among these was the decision to withdraw life-preserving interventions from a child. The theory outlines a process by which health professionals involved in the care and treatment of a child in intensive care negotiated a consensus on the point at which it was no longer appropriate to continue life-preserving interventions. This consensus was then presented to parents. Parental assent to withdrawal was facilitated, when not immediately forthcoming, by a process of persuasion.

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Glossary of terms

Admitting consultant.

Consultant doctor under whose name a child is admitted to the hospital and who retains overall responsibility for that child's care and treatment until discharge.

Band 5 nurse

Most junior grade of professionally qualified nurse. Some nurses remain at band 5, for a variety of reasons, even though they may have many years of experience as a nurse. Usually will provide care for one child for a complete shift.

Band 6 nurse

Nurse senior to band 5 who may oversee the care of two adjacent children. May also be involved in training nurses new to intensive care.

Band 7 nurse

Senior nurses who manage the nursing staff on the unit or fulfil specialist roles such a family liaison nurse.

Intensivist

Doctor specialising in intensive care medicine. Could be a consultant intensivist or specialist registrar intensivist.

Life-preserving intervention

Active medical treatment that maintains basic essential functions i.e. respiration and circulation. Such interventions may include specific drug therapy to maintain blood pressure, kidney function, artificial ventilation and cardio-pulmonary resuscitation.

Specialist Registrar (SpR)

Junior doctor usually in a training programme preparing for a consultant post.

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Chapter One

1 Introduction

This thesis details a research study investigating how ethical problems that arise in a children's intensive care unit are resolved. This qualitative study, guided by the principles of grounded theory, was conducted utilising face to face interviews. A report of the findings, founded on an analysis of the data gathered, formed a significant portion of the thesis. As a consequence of the chosen methodology a brief review of the literature is presented in the early part of the thesis. A detailed analysis of relevant literature is an integral part of the discussion chapter.

It has been asserted that "Reasoning through dilemmas to conclusions and choices is a familiar feature of the human condition" (Beauchamp and Childress 2001). This is perhaps particularly the case in healthcare practice where even seemingly trivial decisions can have significant impact on a person's wellbeing. It is obvious that major ethical issues such as abortion, resuscitation decisions and euthanasia are not everyday issues for every healthcare practitioner. However what Melia (1989) termed everyday ethics such as which patient to attend to first, how much information to give a patient about their condition, whether or not to stay on duty after a shift has finished to cover staff shortages, are daily ethical problems that require resolution. There are some ethical problems that are centred on an individual practitioner - such as should they remain on duty to cover staff shortfalls or go home in order to discharge their responsibilities to their own family? However there are also many ethical problems that are related to the interactions between staff and between staff and patients. These problems cannot be resolved by an individual's reasoning alone and require several individuals to work together to resolve the problem.

1.1 The research aims and objectives

The aim of the study was:

- To explore how ethical problems arising in clinical practice in a hospital based paediatric intensive care unit are resolved.

The objectives to be achieved in meeting this aim were set as:

- To identify who participates in the resolution of ethical problems in paediatric intensive care.
- To explore the role that participants play.
- To investigate the process by which ethical problems are resolved in paediatric intensive care.
- To examine the implications of the findings for the education of health professionals.

I deliberately did not generate any preconceived ideas of the nature of the ethical problems that might emerge from the study. A range of ethical problems were mentioned by participants but they tended to focus on end-of-life situations with a specific focus on withdrawing life-preserving interventions. Although participants did not specifically mention the term life-preserving interventions I have used it as a blanket term to cover medical interventions such as cardio-pulmonary resuscitation, artificial ventilation of the lungs, drug therapy to support physiological functions and the like.

1.2 Rationale for the study.

Over a period of more than a decade I have been teaching ethics to both pre-registration and post-registration nurses, doctors and other health professionals; predominantly in the context of child health care. A constant feature of my teaching has, and continues to be, a consideration of tools such as the Ethical Grid (Seedhouse 1998) to aid the resolution of ethical problems that face health care practitioners. Having also taught post registration students that I had previously taught as pre-registration students, it has become increasingly apparent to me that these decision-making tools are not perceived as useful on a day to day basis and were not used. This prompted the question that if

systematised tools are not used how, do practitioners go about resolving the ethical problems they face day to day? Zussman (1992) noted there were few studies examining how medical ethics works in practice specifically in terms of the social processes that result in a decision regarding an ethical problem. This appeared to remain the case at the outset of this study. Since it appeared that no empirical inquiry existed into resolving ethical problems in children's intensive care, this was viewed as a gap in healthcare knowledge that needed to be addressed. This study, in exploring how ethical problems are resolved in practice, aims to contribute to filling this gap in the knowledge base.

There is a recognised desire to improve interprofessional working in health care (Laming 2003, Department of Health 2007a) especially in the context of the care of children. In respect of the approach to resolving ethical problems, interprofessional working can be challenging as a result of alleged differing values systems underpinning each of the health professions (McCallin 2006). It has long been held that nurses' values lead to a care or virtue based approach to ethics whereas doctors adopt a justice based approach (Baumann et al. 1998). The truth is probably less polarised than has been asserted. Developing a clearer view of the processes of interprofessional working in healthcare is important in order to support both practice development and the development of educational programmes for healthcare professionals. It is only relatively recently that the voice of the patient, and in the context of children's healthcare, the voice of the parents has been recognised as a significant element in healthcare decision making (Department of Health 2003). Thus there is an imperative that a clearer view of parent and child/young person involvement in the process of resolving ethical problems is developed.

The outcomes of this study may provide practising clinical staff with a better understanding of the processes used to resolve ethical problems in the context of a children's intensive care from a variety of perspectives. It is hoped that this will prompt child health professionals to reflect on and examine these processes in their own working practice. Additionally the outcomes aim to inform health

professionals' educational curriculum development decisions and contribute to the debates and development of inter-professional education.

An important facet of this study was the development of a sociological perspective on the process of resolving ethical problems. As Jennings (1989) asserted most bioethical analyses do not include, or only superficially include, considerations of the setting in which ethical problems occur and the attendant institutional context and cultural forces. Thus attention needed to be paid to the factors, personal and institutional, that impacted on the process of resolution. While such an analysis cannot inform anyone how ethical problems should be resolved, it can illuminate how they are resolved in the real world (Zussman 1992). The sociological insights into the differing cultural perspectives of nurses and doctors alone would be interesting, but in children's intensive care, as distinct from adult units, the central role played by parents in their child's life potentially adds a completely different dimension to the actual process of resolving ethical problems.

1.3 The focus on children's intensive care

The rationale for a focus on children's intensive care unit (ICU) was based on a number of factors. The need to focus on a relatively narrow area of healthcare provision was in part driven by the different contextual issues which might apply in different areas of child healthcare practice. What Becker and Grunwald (2000) say of neonatal intensive care units (NICU) is also true of children's intensive care units; these settings have a social structure of their own that is separate and different to general children's wards. Zussman (1992) also referred to the "culture of the ward" (p12) as a loose set of orientations to which all those working in the unit belong. Each individual member of that social structure, be they professional, patient, relative or significant other, has her/his own frame of reference for thinking about issues that arise in the context of the intensive care area. These will again differ from the social structures in other contexts in which child health care is provided.

Acknowledging the uniqueness of the cultural/social structures in children's intensive care does not mean that the findings of the study might have no relevance outside the study site. The common features of one children's intensive care unit would lead to some generalisation of findings to other children's ICUs. It is likely that there will be fewer commonalities with adult ICUs since the relationship between patient and professionals is different to that between the child, the parents of that child and the professional staff. Despite this, there are some commonalities between children's and adult ICU. The Department of Health (1996) specifically defined intensive care units as requiring one nurse per patient at all times and that a doctor must be present on the unit at all times. This definition operates for both adult and children's ICUs. The nature of ethical issues faced on children's intensive care units was not dissimilar to those faced by many health professionals wherever they may interact with patients (Melia 2004). However, due to the high nurse patient ratio and the constant presence of medical staff, the actual process of resolving ethical problems is likely to be almost unique to intensive care units. Additionally the fact that those with parental responsibility can provide proxy consent for treatment, in contrast to adult ICU, means that the process for resolving ethical problems is different in a children's ICU. No one may provide consent on behalf of patients of 18 years unless a lasting power of attorney has been granted under the Mental Capacity Act 2005. However even where a person has such responsibility the constraints on their proxy decision making are different in many ways to those of a parent choosing on behalf of their minor child.

1.4 Outline of the study

An initial literature review was conducted to ensure the topic had not already been adequately addressed. Included within the review of the literature was a consideration of the theoretical perspectives underpinning moral philosophy in healthcare practice. This was deemed important for two reasons. The first was that, in order satisfactorily to delineate ethical problems from other problems faced in healthcare practice, it was necessary to identify the component of

ethical problems grounded in moral philosophy. The second reason was to provide an outline of the theoretical positions that influence healthcare professional ethical reasoning in the context of practice. The theoretical insights outlined are in large part at the core of the teaching of ethics that occurs in both pre- and post-qualifying medical and nursing education in the UK.

A significant portion of time was spent searching the literature and reviewing research methodologies in search of a suitable approach to the study. An exploration of the ontological and epistemological assumptions guiding the study led to the choice of grounded theory as the appropriate approach to guide the study. The detailed account of the methods used and the manner in which they fitted with the grounded theory approach are presented in chapter 5. In common with all studies involving humans as participants, but especially in a study of this nature, the ethical issues arising as a consequence of the chosen methods were explored and presented in chapter 6. Within the framework of grounded theory the procedures as detailed by Strauss and Corbin (Strauss and Corbin 1998) were applied to the data analysis. The findings of the analysis are presented in chapter 7. An exploration of the relationship of the model that emerged from the analysis of the data to other existing knowledge and the implications for further inquiry and practice is then presented in chapter 8.

Chapter Two

2 Theoretical perspectives.

A detailed and extensive literature review was eschewed in the light of the decision to utilise grounded theory as the methodological guide to the research. A comprehensive literature review that forms a foundation part of other research designs is postulated as neither necessary nor desirable by its founders (Bowen 1996, Strauss and Corbin 1998) as this may stifle the researcher's efforts to allow theory to emerge from the data. Grounded theory designs do include literature reviews but this is incorporated into the discussion stage rather than as a starting point. However I did conduct an initial literature review to establish that the research question had not already been addressed.

In the UK educational programmes preparing nurses and doctors for professional practice are normally underpinned by a range of ethical theories derived from moral philosophy. Thus a significant portion of this chapter provides an outline of the major characteristics of these theories.

Literature found in the initial review largely originated in North America although there were examples from Europe, especially Scandinavian countries. There appeared to be a smaller volume of literature from the UK in this area. There was much less literature in respect of the actual practice of resolving ethical problems in healthcare. A significant proportion of the literature found in the initial review and indeed the subsequent review for the discussion tended to focus on end-of-life situations. In respect of the question for this research, no studies were found investigating the process of resolving ethical problems arising in children's intensive care facilities in the UK.

A brief literature search revealed a good deal of literature exploring ethical reasoning among healthcare professionals, chiefly in North America and Scandinavia. Studies exploring how professionals deal with ethical problems in their practice are beginning to emerge from Eastern Europe (Sorta-Bilajac et al.

2011). There were a number of studies specific to ethical issues in intensive care units (Bertolini 1994, Bowen 1996, Norrie 1997, Zussman 1992, Viney 1996, Watson 1993, Çobanolu and Alger 2004, Heland 2006, Seymour 2001). However none of these studies explored the process of resolving ethical problems in a children's intensive care unit. A number of studies also existed in relation to ethical problems faced in neonatal intensive care units (NNU or sometimes NICU) in the UK (McHaffie and Fowlie 1996, McHaffie 2001b, McHaffie et al. 2001a, Monterosso et al. 2005, Tripp and McGregor 2006).

The British studies that were found (Viney 1996, Chaplin 2002, Terry 2001, Sayers and Perera 2002, Norrie 1997) were largely focussed on adult intensive care. Some studies have explored how ethical problems were managed in both adult and children's intensive care (Melia 2001, Melia 2004). A study examining the decision making process in children's intensive care in the UK was found (Street et al. 2000). However this was focussed specifically on withholding or withdrawing treatment decisions. A French study examining end-of-life ethical decisions in children's intensive care has been reported (Carnevale et al. 2006). No studies however were uncovered that have examined the specific question for this study in the context of a UK children's intensive care unit. Since it appeared that no empirical inquiry existed into resolving ethical problems in children's intensive care this was viewed as a gap in healthcare knowledge that needed to be addressed.

At the outset I assumed that some reference or partial reference to ethical theories would be made by the study participants. This was to some extent borne out in the interviews as some participants made explicit references to one or more of these theories. Additionally participants referred to concepts such as duty and utilitarianism in a way that was not commensurate with the way in which moral philosophers constructed them. Thus a review of the major theories in the field of moral philosophy was undertaken to enable commonalities and distinctions to be drawn with the responses of the study participants.

2.1 Three theoretical perspectives from moral philosophy

The approach adopted here follows that outlined by (Beauchamp and Childress 2001) in that whilst the theories outlined herein will be examined and critiqued they will not be deemed to be ‘irreparably wounded’ (p37) notwithstanding the perceived shortcomings of each theory. The critique aims to highlight the key components of each theory and briefly highlight some alleged shortcomings and potential for application to ethical problems in clinical practice. There is not sufficient room here to undertake a comprehensive review of all the ethical theories that may underpin healthcare practice. The three considered here are probably the most influential in Western healthcare ethical thinking and are certainly the most frequently referred to in healthcare ethics texts.

Whilst the different theories of ethics take somewhat different approaches to examining the central question ‘How ought I to act?’ the actual resolution of any specific ethical problem may be the same in many instances, although not by any means all. Proponents of the theories would no doubt advocate exclusive use of a specific philosophical viewpoint in order to ensure a coherent approach to ethical questions. There are also those such as Seedhouse (1998) who advocate an eclectic approach to resolving ethical problems. However, it is essential nevertheless that an understanding of the major theories of ethics is developed in order effectively to utilise the eclectic approaches.

2.1.1 Deontology

This theory is based on the notion that right is determined by duty. The outcome of any moral act or ethical decision is not considered, it is the duty to do the right thing that counts. The best known exponent of this theory was Immanuel Kant.

“a human action is morally good, not because it is done from immediate inclination - still less because it is done from self interest - but because it is done for the sake of duty” (Paton 1991) (p19).

Thus if your reason for caring for someone is because it is your duty to do so, that is a good act. If you care for someone because you will get paid for it, this is not in itself a good act. That is not to say that being paid for the work of caring is morally wrong. Thus being a health professional carrying out caring work does not make one morally good or even the act of caring a morally good act. One may provide care as a health professional because the work is enjoyable or one perceives a feeling of satisfaction from helping someone else or one may feel there are no other career options, but bills need to be paid. This does not, in terms of Kant's idea, constitute a morally good act. Morally good acts are those that are carried out because the individual chooses to do them because there is a moral duty to carry them out. Thus in deontology it is the motivation to fulfil the duty behind the act that is important in determining whether a person has acted as they ought. There is an expectation of such a duty expressed in codes of conduct for health professionals such as those published by the Nursing and Midwifery Council and the General Medical Council (General Medical Council 2006, Nursing and Midwifery Council 2008). These codes, in common with most others in the healthcare sector, require registrants to recognise and act in conformity with the duties as determined by the profession. Both the cited codes require as a prime duty that the registrant makes the care of the person(s) their first concern. The Kantian imperative is thus evident in these codes as an expectation of those registered with the relevant regulatory body.

Kant (1994a) asserted that in order to determine whether an act is morally permissible one must apply the test of the categorical imperative.

'act only according to that maxim by which you can at the time will that it should become a universal law' (p274).

Kant's imperative must apply the universal law to all - including oneself. When constructing these maxims or laws for moral behaviour Kant also espoused what is often called the Formula of the Kingdom of Ends.

'Act as if you were by your maxims in every case a legislating member in

the universal kingdom of ends' (Sterba 2000) (p176)

Thus in constructing a maxim to test the moral obligation to act one must assume that one is constructing a universal law that is applicable to all including oneself. One must also assume that everyone else is also a legislator in the kingdom of ends. He also espoused a Practical Imperative.

'Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only.' (Kant 1994a)(p 279).

It is noteworthy that Kant asserts that there are duties to oneself as well as duties to others. According to O'Neill (1993) this is because Kant recognised that moral agents are not self sufficient and as such are in part dependent on other moral agents. Thus it could not logically hold that a rational moral agent could wish that neglecting to develop oneself become universally adopted. A moral agent then is in part dependent on others for the achievement of their own ends and so one must will that it be a universal maxim that moral agents fulfil a duty to care for themselves.

A healthcare professional may use patients to take their own practice forward by undertaking interventions that increase the professional's skills and knowledge in the pursuit of career advancement. However this is not using a patient *merely* as an end if at the same time the intention is to provide beneficial healthcare that is in accord with the patient's wishes. Of course to be a truly good act, for Kant, the professional's act would need to be done primarily out of duty to the patient rather than merely for career advancement. Having said that the development of skills and knowledge would also be a duty within his theory as such things are necessary in order to provide effective health care.

Kant's theory assumes that each individual is an autonomous moral agent able to make judgements i.e. as legislators in the Kingdom of Ends. There are numerous situations that might interfere with a professional's rationality that Kant seemed not to take account of, such as emotional involvement in the situation at hand. This leads to a perception that the theory is somewhat cold

and calculating, which can be challenging for a professional for whom caring necessarily includes a significant emotional component. Involving patients in decision making about their own healthcare or indeed others, such as parents of children and those with lasting powers of attorney under the Mental Capacity Act 2005, creates a similar problem. It would be difficult to imagine patients and their relatives/representatives divorcing themselves from the emotional content of ethical decision making.

Kant appears to have little to say about the treatment of those lacking a rational will such as babies and young children. Thus there can be ambiguities at best for those attempting to utilise Kant's doctrines in caring for young children and possibly those who have an impaired rational will, such as parents suffering emotional upset as a result of their child's critical health problem. In the context of this study where children may be participants in the process of resolving ethical problems, their uncertain status as rational beings may also militate against the application of Kant's doctrine. Additionally the notion of duty outlined by Kant should not be confused with notions of duty expressed by health professionals bound by codes of conduct, health care law and contractual obligations to their employers.

2.1.2 Utilitarianism

Utilitarianism is based on the belief that something and indeed perhaps all things have a special use or purpose i.e. they have utility. Thus utilitarian actions are those that have a good moral purpose. The theory was founded on what Bentham (1994) termed the 'Principle of Utility'.

'By the principle of utility is meant that principle which approves or disapproves of every action whatsoever, according to the tendency which it appears to have to augment or diminish the happiness of the party whose interest is in question...' (p 306).

Bentham used the term party to include communities as well as individuals. In order to decide whether an action was morally permissible one calculates the expected good over expected harm by predicting the consequences of an

action and choosing that action (or inaction) that increases (or at the very least does not diminish) the happiness of the party whose interest is in question. However it is not clear how one distinguishes the party whose interests should be in question since decisions regarding a child's care and treatment will have consequences not just for the child but the whole family.

John Stuart Mill (a protégé of Bentham) came, according to Norman (1983), to view Bentham's theory as somewhat limited and not cognisant of the human spirituality that leads to an altruistic outlook on humanity. Mill's account of utilitarianism is based on the notion of seeking the greatest happiness for the greatest number of people rather than a particular person or group of people.

'...actions are right in proportion as they tend to promote happiness, wrong as they tend to produce the reverse of happiness. By happiness is intended pleasure, and the absence of pain; by unhappiness, pain and the privation of pleasure.' Mill (2000 p226)

Both Mill and Bentham argue that the Principle of Utility is not related to an agent's own happiness but that of all concerned and that morality is founded in a duty, in our actions, to seek to promote happiness for as many as possible. Mill's philosophy differs in one significant respect to Bentham's in that he introduced the ideas of higher and lower pleasures as indicators of happiness. The lower pleasures are those of mere sensation such as a full stomach whereas the higher pleasures are those related to the intellect, feelings and moral sentiments (Mill 2000).

A serious concern with utilitarian theory is that some may need to suffer to bring about a greater happiness for the majority. It cannot be considered a good that a person is killed (certainly to that person) even if it means that many others are saved, otherwise are we not suggesting that the good, in order to become a general good, means that anyone could be sacrificed for the greater good? Thus for example one may argue that it is acceptable to sacrifice some humans in the search for a cure for cancer (or any other disease or social ill come to that). Smart (1973) addresses this issue in his response to criticisms of

utilitarianism, saying that if one was ‘...*very sure...*’ (italics in the original) that many others in the future would ‘... be saved still greater misery...’ (p 64) it may be morally permissible to carry out what on the face of it looks like a bad act. Smart (1973) draws a distinction between probabilities and certainties though and suggests that only when one can be certain of the greater happiness being served could one condone or permit an act that creates suffering for an individual or a few.

Utilitarianism is based on the premise that an action is right as it produces the greatest happiness for the greatest number (Mill 2000), or in other words has utility. This is dependent on the ability to predict the consequences of an action or series of actions, such as health care treatments. The inability accurately to predict side effects and unforeseen consequences arising from health care treatments militates against the effectiveness of Utilitarianism as an approach to resolving ethical problems. Mill’s (2000) account of lower and higher pleasures indicates that quality of consequences is as important, if not more so, than quantity, in that the higher quality pleasures outweigh the lower pleasures even perhaps if the lower pleasures were in more abundance. This notion of quality taking priority over quantity holds an appeal for health care professionals who as a general tenet strive to maximise the quality of the lives of their clients.

2.1.3 Virtue Ethics

Virtue ethics has its origins in ancient Greece and is largely attributed to Aristotle (1953). Virtue ethics is concerned with the character of a person rather than the consequences of his actions or any duties that rationality might determine as the right thing to do.

Ancient virtue ethics.

Aristotle’s view was that moral virtues do not exist in humans as some innate sense of morality but have to be learnt by practising them. ‘Moral virtues, like crafts, are acquired by practice and habituation’ (Aristotle 1953 p91). He

suggested that people may practice good or bad acts and that eventually these become habitual to that person. Thus in order to become a good person one has to practice the virtues. The goal of human life according to Aristotle is happiness.

'What is the Good for man? It must be the ultimate end or object of human life: something that is in itself completely satisfying. Happiness fits this description.' (Aristotle 1953 p73)

In Aristotle's view happiness is 'a virtuous activity of the soul'. This is based on his notion of the *proper function* of man which he perceived to be to live well or to live in accordance with virtue. As Barnes (Aristotle 1953) points out in his introduction to Ethics, Aristotle was not concerned with the outcome of a person's actions, it is rather the character of the person that is important to fulfil his function i.e. to achieve happiness or, as most accounts of Aristotle's philosophy translate the Greek, 'Eudaimonia'.

Aristotle identifies two kinds of virtue, the intellectual and the moral. I shall focus attention on the moral virtues. The virtuous person is the one who chooses virtue rather than merely being incidentally virtuous. A person can only be considered virtuous, according to Aristotle (1953) if;

1. he knows what he is doing
2. he chooses it (the act), and chooses it for its own sake.
3. he does it from a fixed and permanent disposition.

The virtues are determined by what Aristotle termed the Doctrine of the Mean. The mean being a point between two vices, although not necessarily equidistant from each. He suggests that the mean will be different for each person and they must determine what that point is. He gives the example of someone at the beginning of training as an athlete and someone else who is an acknowledged champion. If there are two weights of meat, 2 pounds and 10 pounds, the arithmetic mean will be 6 pounds. However a trainer would not give 6 pounds of meat to both trainee and champion. Each would need a sufficiency of meat but

not over much. Thus a virtue is determined by the mean relative to the individual.

'So virtue is a purposive disposition, lying in a mean that is relative to us and determined by a rational principle, and by that which a prudent man would use to determine it.' (Aristotle 1953. p101-2).

Modern virtue ethics

Renewed interest in the ethics of virtue can be traced to an article by Elizabeth Anscombe in 1958 (Oakley 2001). Much of the impetus for the resurgence in the interest in virtue ethics was borne out of dissatisfaction with consequentialist and Kantian approaches to ethics. Oakley (2001) argues that virtue ethics has now been developed to a point where it provides a convincing and plausible alternative to both consequentialist and Kantian ethics.

MacIntyre (1985) suggests that moral virtues are situated in a culture and time and that the character of the virtues that were important in Aristotle's time might not be the same as we might think today and that the virtues of the Western world might be different to that of the East. Some virtues however might reasonably be thought to transcend time and culture; for example the virtue of courage. In a situation where treatment was being proposed for some potentially fatal, condition courage might take two forms. It might be courageous to accept treatment (or allow it to be done to one's child) but it might be equally courageous to decline treatment. Both alternatives could be seen to be at the mean but different individuals or cultures may hold opposing views. Certainly some organised religions take a stance on the duty one has to accept medical treatment in certain situations (Tadd 1998). The virtue here would perhaps be having the courage to accept treatment, no matter how unpalatable, because of a spiritual duty to do so. Thus merely accepting Aristotle's theory at face value as expressed in his writings might run the risk of failing to take a proper account of the core of virtue ethics in differing cultural contexts.

MacIntyre (1985) asserts that in developing the concept of virtue one cannot ignore the moral tradition that one is born into. Humans do not grow up with a blank moral slate. He says for example that in claiming to be an American one cannot ignore the influence of the past slave trade. He says that who we are is embedded in the history of the community to which we belong. By the same token when one joins the health care community, individual practitioners are influenced by the culture in that community. This does carry the problem that virtue ethics characterised in this way could be accused of relativism. Each moral tradition might claim equal legitimacy or superiority rather than strive for a unified single concept of the good life. There is also the potential problem that if one merely accepts a moral tradition and follows one's role models, errors may be made. Slavery was acceptable in Aristotle's time but is viewed differently today. Patient consent in medical practice has gained a prominence that did not exist 20 or so years ago in Britain. In the context of this study it is important to be mindful and take account of the potential conflict of moral traditions between health professionals and the parents of the children they are caring for.

2.2 Principles of healthcare ethics

A significant problem with these ethical theories in respect of their application by professionals to clinical practice is that they tend to be too abstract and remote from everyday clinical practice. This is especially be so since they have nothing within them specific to the practice of healthcare. Beauchamp and Childress (2009) described a set of moral principles specific to healthcare practice;

"...as an analytical framework intended to express general norms of the common morality that area suitable starting point for biomedical ethics" (p12).

The four principles were developed specifically as a guide to thinking about biomedical ethics. Ethical theories are implicit within their delineation of those principles and are referred to throughout the Beauchamp and Childress book.

The four principles are the Principle of Respect for Autonomy; Principle of Nonmaleficence; Principle of Beneficence; Principle of Justice.

The principle of respect for autonomy has its foundations in Aristotle's notion of rationality (Gillon 1985) which was also foundational to Kant's philosophy. Rational beings then are those that have the capacity to;

"think, decide and act on the basis of such thought and decision freely and without...let or hindrance." (Gillon 1985).

Thus the principle of respect for autonomy requires health professionals to respect the choices that parents may make when they have legitimate authority to decide healthcare matters on their child's behalf.

The principle of nonmaleficence requires that health professionals minimise the harm they do in providing healthcare. It would make little sense to require that they do no harm since the majority of medical interventions, especially in an intensive care unit, do create physical harm to children and almost certainly emotional harm to their parents. Thus the principle allows for some harm to be done if the potential benefit outweighs that harm. However this does not mean that as long as benefit can be shown to accrue that any harmful act can be done. Killing a child on the basis that the benefit of relief of their suffering outweighs the harm of the killing is not legally acceptable even though it may be morally debatable.

The principle of beneficence refers to obligations to act for the benefit of others. Most people would accept without question that healthcare professionals work is founded on an obligation that is accepted by those entering the profession to benefit others. This principle is intimately linked to the principle of nonmaleficence in that the proper balance between the two must be settled upon in any question regarding what is the right thing to do. Beauchamp and Childress discuss at length the nature of the obligations to which they refer and attempt to draw distinctions between which beneficial acts are obligatory and which are not. Their analysis also explored what might or might not count as a

beneficial act and concludes with a consideration of the quality of life. This is important to appreciate since an analysis of these two principles will not always conclude that the most beneficial and least harmful act would be to maintain life at any cost.

The principle of justice takes two related forms. The first is justice as fairness in respect of what is owed to a person. For example all rational beings are owed respect for their rationality and must be treated as ends in themselves rather than merely as a means to an end. The second and the predominant form of justice in the Beauchamp and Childress account is that of the fair distribution of healthcare resources. Hence the balancing of nonmaleficence with beneficence does not apply merely to the individual but also in balancing the needs and rights of the individual with all others in society.

These principles might be perceived as moral rules; however their debatable nature does result in them forming guidelines for the application of ethical theory to the practice of healthcare. These four principles appear with significant regularity in healthcare professional literature and educational programmes and are evident in several healthcare professional codes of conduct. Thus it would not be unreasonable to expect to find them reflected in healthcare professionals' accounts of resolving ethical problems in clinical practice.

2.3 Conclusion

Elements of the theoretical positions outlined above are extant in the pre- and post-registration curricula of many health professionals and the codes of practice of the relevant professional regulatory bodies. Thus, to a greater or lesser extent, all health professionals attempting to address ethical problems in clinical practice are likely to have had some exposure to those theories. Some may have developed an appreciation or knowledge of these theories. It is likely that they will all, either consciously or subconsciously, be influenced by them. As I am relatively well versed in these theories, in terms of my own education and my role as a nurse lecturer, careful attention was required in the data

collection and analysis to ensure I did not overemphasise or provide more prominence to moral philosophical theory than is really there in the data. However it was important to remain sensitive to evidence of these theories influencing the process of ethical problem resolution. Similarly with respect to the principles of ethics it was important to remain vigilant for any indication of them in participants' accounts. As will be seen in the discussion of the methodology and methods it was imperative to allow the data to speak for itself and for me not to be taken down a particular path based on my understanding of the terms. The risk to the study would be that I had manipulated the data to fit with my own understanding of the application of moral philosophical theory. Some respondents used, or at least alluded to, some of the terms used in these theories in the interviews. Here again it was important not to make assumptions about either the knowledge or application of these theories to the respondent's practice.

Chapter Three

3 Identifying an ethical problem.

Since it is central to the question guiding this research an understanding of what is meant by 'ethical problem' must be resolved at the outset. There is general agreement in the literature regarding what constitutes an ethical dilemma. It is essentially a situation where two morally equal and mutually exclusive duties or choices conflict with each other (Beauchamp and Childress 2001, Braunack-Mayer 2001, Monterosso et al. 2005). The concept of an ethical *dilemma* is not always a helpful one in the context of this research. As Holm (1997) observed, it could be argued that where two mutually exclusive and equally morally bad choices are faced one might toss a coin to make the choice. That is not to suggest that the tossing of the coin absolves the decision maker from any moral responsibility in respect of the decision by blaming the coin for the choice. The decision to toss the coin would be the ethical decision in that instance. However identifying a situation as a dilemma presumes that it is clear to the parties involved what the moral choices actually are. There is evidence that this is not always the case (Hurst et al. 2007).

Most ethically challenging situations requiring resolution in healthcare begin from a point where not only is it not clear what the solution is because the actors have not yet identified the morally right course(s) of action, or even all the ethical issues that pertain. Hence the concept of a dilemma is not a helpful one. Admittedly there are some studies that indicate the more experienced practitioners feel more certain about a particular course of action in an ethically challenging situation (Wurzbach 1999, 1995). However this certainty appeared to be based upon assumptions derived from experience of similar ethical problems in a similar situation. This casuistic method has received scathing criticism when it was suggested that where casuistry is used, moral debate may as well be abandoned (Harris 1985). Beauchamp and Childress (2001) are somewhat more restrained in their criticism;

'...cases point beyond themselves and evolve into generalisations, but they may also evolve in the wrong way if they were improperly resolved from the outset.'(p 395)

For the purposes of this research then it is ethical problems that are important rather than ethical dilemmas. The aim of the study is to explore the process of attempting to resolve ethical problems in healthcare practice and part of this process must be reviewing the possible courses of action as well as choosing from the options and ultimately taking action. That is not to ignore the fact that there must be a recognition of the ethical problem in the first place and the research must allow for the possibility that certain participants in a situation may not realise that they are facing an ethical problem (Georges and Grypdonck 2002).

There is the potential to confuse an ethical problem with a clinical one; thus it is imperative to give an account of what constitutes an ethical problem whilst acknowledging that some problems will have both clinical and ethical components (Allmark 2005). The clinical components of a problem are those that require an analysis of what Allmark (2005) calls empirical questions, regarding the most appropriate resolution, based on knowledge of the effectiveness of healthcare interventions in any particular situation. Thus the clinical decision is a matter of identifying the best intervention option. An ethical problem is presented when considering the question 'ought one to take a particular course of action or not?' For example having weighed up the potential for benefit of a range of clinical interventions, it might be obvious, from a medical point of view, that a surgical procedure is the best way of dealing with a specific health problem. However the ethical problem that remains to be resolved is 'ought one to carry out this procedure at all?' There are several ethical issues that would need to be considered in respect of this. One being should one respect a person's autonomy and gain consent before embarking on the procedure. This will open a whole range of further questions such as why might respect for autonomy take precedence over what is thought to be in a patient's best interests or in the interests of society (Beauchamp and Childress

2001). A Utilitarian for example might argue that society's interest is best served by ensuring people undergo treatment to create a level of health that enables them to contribute effectively to society. This stance may suggest a presumption of a low level of iatrogenesis. However if the utility of the outcome is very positive it could be argued that this can outweigh a significant level of possible iatrogenic consequences.

Holm's (1997) analysis is useful in attempting to clarify what constitutes an ethical problem whilst taking account of the theories underpinning moral philosophy. Thus an ethical problem arises when a person faces a situation in which ethical considerations are important for the choice of action (Holm 1997). This begs the question what are ethical considerations? Holm (1997) provides three criteria;

a) it refers to a non-legal or not solely legal norm, duty, obligation or right

or

b) it refers to consequences for some specifiable person or groups of persons

or

c) it refers to what kind of person one ought to be or what virtues one ought to have.

Holm (1997) has thus constructed criteria that embrace the three major theories underpinning moral philosophy outlined above. This is an important point since there is some evidence that healthcare professionals make conscious and unconscious reference to these theories when confronted by an ethical problem in practice (Chaplin 2002, Leners and Beardslee 1997, Robertson 1996). This is not surprising since virtually without exception texts on healthcare ethics or bioethics make reference to these major theories. It is not entirely clear from Holm's account what the nature of the consequences were to which he was referring. However it was felt sufficient in the context of this research to consider

those situations that the participants perceived as having consequences that they considered significant. Thus the data collection for this study was guided by what the participants identified as ethical problems rather than any preconceived notions I might have had of the ethical problems that exist in a children's intensive care unit. Hence the ethical problems emerged from the participant accounts rather than being pre-selected by me.

Chapter Four

4 Methodological issues

As a prerequisite to identifying an appropriate methodology to guide this research a consideration of ontological and epistemological issues is necessary. The underlying philosophical foundations by which I am influenced can thus be made transparent.

4.1 Ontology

It was requisite that I explored my own world view and beliefs as this will impact on the approach taken and the choice of research strategy (Denzin and Lincoln 2000b). A fundamental issue in the context of this research must be the realisation that there cannot be a simple and single answer to the question “how are ethical problems resolved in paediatric intensive care?” Even if a multifaceted answer to the question could be posited there remains an issue regarding whether that answer represents the complete answer to the question. It would not have been possible to explore the processes that took place in the study site from all conceivable viewpoints and perspectives. Thus I was aware at the outset that the findings from this study would necessarily be tentative and partial.

A related issue relates to the notion of truth and whether such a thing exists (Power 1999a, Power 1999b, Power 2001). There may well be such a truth but only a perfect being, such as a deity, could perceive it because only such a being would be capable of “recognising all sides of the truth” (Mill 1859 p 101). This implies that truth is perspectival in nature and it depends on the position of the viewer. Imagine an interaction between a healthcare professional and a patient. It is likely that, on asking each individual to recount the encounter, one would receive a slightly different account of events from each of them. This is not because one is lying but because they viewed the event from different perspectives. For instance a healthcare professional might claim that they

offered the parents every opportunity to be involved in decisions regarding treatment or non treatment options. However the parents may perceive that the professional is the knowledgeable party in the discussion and that their own views would not be taken seriously. Both are reporting a true version of the interaction as they perceived it. Innumerable other factors, such as preconceived ideas regarding professional – patient relationships, impinge on the situation. There may thus be many aspects of the truth in this situation and merely reporting the facts as one saw them is only part of the whole truth. However that fact that the whole truth may never be known, should not deter a researcher from seeking to discover as much of it as possible. The truth in any social situation is a construction of the perspectives of all those acting in or interacting with that situation. Health care practice is by its very nature a social situation (McCann and Clark 2003a) where individuals and groups interact, act on and are influenced by the social environment they find themselves in.

Paediatric intensive care is provided in a social context with a range of professionals interacting with the child and their family and each other. Each individual will hold a personal perception of the area and the nature of the enterprise and thus the context in which paediatric intensive care is provided will hold different meanings for each individual acting in that context. For the professionals it is a place of work that may hold a range of positive associations such as providing a fulfilling purpose to their life, providing an adequate income, opportunities for career advancement and the like. For a child and their parents it is much more likely to hold negative perceptions associated with, *inter alia*, fear of pain, death and permanent disability/impairment. That is not to ignore the positive associations that may exist for parents such as confidence that the child is receiving the best of care and a great deal of individual attention as a result of their highly dependent state of health. Thus individuals interacting with each other and their environment symbolise different things to each individual. This idea of human interaction leading to the creation of meanings for individuals is explored in the theory of symbolic interaction.

Symbolic interaction

Symbolic interaction theory describes how the differing meanings held by humans interacting in an environment, guide behaviour, enable people to define events and reality and act in respect to their beliefs (Chenitz and Swanson 1986a). According to Blumer (1969) there are three basic premises underlying symbolic interactionism.

- i) humans act towards things on the basis of meanings that the things have for them
- ii) the meaning of such things is derived from, or arises out of, the social interaction that one has with one's fellows
- iii) these meanings are handled in, and modified through, an interpretive process.

Taking the above premises, one of the purposes of research is to illuminate the interactions between actors in a social context, uncover the reality as perceived by the individuals and explore how, what Garfinkel (1967) terms, accomplishments are achieved by the actors. According to symbolic interactionism the social reality of a situation cannot pre-exist (Coulon 1995) but changes from moment to moment as actors in the situation interpret and re-interpret reality in response to the interactions with others. Bilton et al (2002) cite as an example a classroom with students and teacher to suggest that if there were structural forces in place to determine the interactions lessons would look more or less the same each time they were played out. Personal experience as a teacher reveals the falsity of this notion. Even when delivering the same material to a group at the same point in a course as some other group of students, even within close temporal proximity, the situation never plays out in the same way.

A number of criticisms have been levelled at symbolic interactionism (Arnells 1996, MacDonald 2001) for seemingly ignoring macro influencing factors such as the political, cultural and historical. Taking Blumer's (1969) three premises at

face value, it is easy to see why these criticisms have been raised. Coulon's (1995) assertion that the reality of a social situation cannot pre-exist is true to an extent, but one cannot ignore the fact that actors entering a situation will hold preconceived ideas about that situation and how they may wish to respond to it. Thus the meanings developed by the actors in a social situation do not arise entirely from an instant in time and as the situation develops but also from previous experience and knowledge of the pre-existing structures.

In the context of this study, the structural macro political and cultural issues that impact on the way humans interact cannot be ignored either. The NHS is a highly structured institution that is subject to significant political influence. Indeed a political reaction to public disquiet in the early 1990s led to a review of paediatric intensive care services that resulted in the present configuration (The Chief Nursing Officer's Taskforce 1997). Additionally a culturally diverse population, especially that in which the chosen study site exists, cannot but influence the manner in which these interactions occur. Thus the research methodology framing this study must be capable of giving an account of these structural influences on the everyday world of healthcare and the attendant ethical problems.

It is questionable whether it is possible to capture the rich interactions between individuals which are at the heart of most healthcare practice with numbers. In order to capture what Flick (2006) terms the "pluralization of life worlds" (p11) one must use a research design that is open to the complexity of the subject under study. This pluralization is a central feature of human relationships where individuals develop different perspectives about the world around them. Based on personal experience of nursing children, for example, whilst I might perceive some physical intervention as bringing benefit to a child, the child, especially a pre-school child, may perceive this as punishment (Algren and Arnow 2005). This is particularly so when the child has been involved in a traumatic event for which she/he perceive she/he is to blame. In searching for insights into the question 'how are ethical problems resolved in paediatric intensive care?' a

methodology that facilitates the discovery of as full a range of perspectives as possible is required. In asking the question '*how* are things done...?' a qualitative design is needed in the absence of a definitive list of options for action. Such a list of options would be the basis for a hypothesis that could be tested. However the question *how* is not a foundation for a hypothesis but rather a basis for a search for a response.

4.2 Epistemological issues

In order to identify an appropriate methodology to guide this research it was imperative to develop a view of what constitutes knowledge, where it comes from, how best to generate new knowledge and how to judge its validity (Meleis 1991). Knowledge or knowing something is claimed as the preference over merely believing something for justifying choices (Edwards 2001). If this research was to generate information that contributes to the knowledge base that guides choices in the topic area e.g. to guide practice or educational curricula it would not be sufficient to construct a theory built on what is believed to be the process for resolving ethical problems. In order to generate knowledge it will be necessary to utilise a methodology that is capable of reconciling several different philosophical views of the source of knowledge.

Reed and Ground (1997) outline three major epistemological positions that should be reconciled i.e. rationalist, empiricist and existential. In order to address the research question in this study it will be necessary to apply rational thinking to the data. Although not possible in totality (Holloway and Wheeler 2009, Denzin and Lincoln 2000b), a degree of objectivity, or what Strauss and Corbin (1998) term gaining distance from the data will be required in order to minimise the risk of the researcher's preconceptions from influencing any emerging theory. Strauss and Corbin (1998) characterise the objectivity in grounded theory as 'giving voice' to the respondents by representing the respondents' views rather than merely the researcher's interpretations of those views. The empirical data collected from the real world of those acting in the field will need to be subjected to rational thinking to develop some order from

the seeming chaos of what Silverman (2004a) terms naturally occurring data. Additionally data collection and analysis will need to take account of the context in which the respondents are acting and the way in which they view the world. Since humans exist in a social world, responding and acting on that social world the existential foundations on which the actors develop their knowledge of that world cannot be ignored.

The hypothesis testing that is at the heart of quantitative research (Flick 2006) is not a suitable approach to exploring the research question for this study, How are ethical problems resolved in paediatric intensive care? Quantitative designs are aimed at establishing causal relationships between variables (Denzin and Lincoln 2000b) and are inappropriate for studying the complex relationships that characterise nursing interactions. The question for this research was of the type ‘*what* is going on here?’ rather than the hypothesis testing ‘*is this* what is going on here?’ Ultimately then since the initial, brief, literature review revealed virtually no empirical knowledge regarding the process of resolving ethical problems in paediatric intensive care a theory grounded in the data generated from the perspective of those involved in the social interaction was required.

4.3 Methodological decisions.

Consideration was given to two qualitative methodologies namely ethnomethodology and grounded theory as the two most concordant with the ontological and epistemological assumptions underpinning this research.

4.3.1 Ethnomethodology

Ethnomethodology analyses the beliefs and behaviours that are the constituents of socially organised milieu.

“Ethnomethodology is the empirical study of methods that individuals use to give sense to and at the same time to accomplish their daily actions: communicating, making decisions and reasoning”. (Coulon 1995) (p 15)

Thus the methodology initially appeared to be well suited to the research question. Coulon's definition, above, would suggest that resolving ethical problems in clinical practice is amenable to study using ethnomethodology. The analysis strategies associated with ethnomethodology - conversation analysis and more recently discourse analysis (Garfinkel 1967, Potter 1996, Silverman 2004b) - require data to be gathered largely by observation and ideally through audio or video recording exchanges between the actors in the situation. The data is then subjected to detailed micro-analysis of the words, syntax, intonation and gestures taking place in an interaction. This micro-analysis would provide a picture of the interactions between individuals acting in their social world. Ethnomethodology then is suited to exploring how actors interacting with others and the social environment make their decisions. The objectives for this study were focussed on the broader process by which ethical problems were resolved rather than the minutiae of individual interactions. Thus I determined that in this instance ethnomethodology was not a suitable approach in the context of the research question and the attendant objectives. An exploration of such individual interactions would be a suitable basis on which to conduct a further study.

4.3.2 Grounded Theory.

Grounded theory is an approach to research that aims to develop theory from data that is systematically gathered and analysed as part of the research process (Strauss and Corbin 1998). Data collection and data analysis occur concurrently and sample selection is guided by the emerging theory (Glaser and Strauss 1967). The theory that is developed is of one of two types, substantive and formal (McCann and Clark 2003a). Formal theories are those that attempt to describe broad concepts, whereas the substantive aim to explore specific social processes. Thus a substantive theory is specific to group and place (Strauss and Corbin 1998). This current research, focussed as it was on the specific social process of resolving ethical problems in a children's intensive care unit, was oriented to the development of a substantive theory. That is not

to say the theory that may be developed and the conclusions drawn are only applicable to the study site. The substantive grounded theory would help explain how ethical problems are resolved in children's intensive care units but would not necessarily be generally applicable to any situation where ethical problems arose and resolution was sought.

The positivist foundations of grounded theory are evident in the descriptions of the methodology (Glaser 1978, Glaser and Strauss 1967, Strauss 1987, Strauss and Corbin 1998). Glaser and Strauss attempted to provide a methodology that both embodies the hallmarks of objectivity and rationality that derive from a positivist stance, and the sensitivity to the data that recognises that theory grounded in the real world is contextual. Thus the methodology is capable of exhibiting the rigour necessary to establishing what Denscombe (2010b) terms accuracy. Accuracy is the measure of how well the design, conduct and results arising from the data analysis reflect the phenomenon under examination. The processes delineated in Strauss and Corbin's (1998) text, although criticised by Glaser (1992) and others, offers the opportunity to demonstrate accuracy through auditable procedures. These coding procedures embodied within the Strauss and Corbin framework thus offer the opportunity to apply a process that takes qualitative analysis beyond mere reportage. As I shall show in the next chapter the Strauss and Corbin (1998) framework enables the processes undertaken in developing theory to be visible and open to scrutiny.

Grounded theory brings together in a coherent methodology a range of epistemological stances. This is largely due to the fact that Glaser and Strauss learnt their trade in positivist and qualitative schools respectively. Grounded theory was thus claimed to exhibit the rigour recognisable to the positivist researcher and the contextual sensitivity recognisable by the qualitative researcher. Therefore any criticisms that adherence to a single epistemology risks missing an important perspective or source of knowledge in the data or, perhaps worse, missing some data entirely ought to be pre-empted. However

this eclectic approach should be viewed as selection of the best from a range of alternative views (Cody 1996) rather than merely a muddled mix of stances (Beattie 2002).

Following the initial publication by Glaser and Strauss (1967) there was a divergence in ideas between the two - especially in the area of data analysis. Strauss developed analytic procedures in collaboration with Corbin (Strauss and Corbin 1998) that Glaser asserted amounted to a different method (Melia 1996). This resulted in what appear to be two methodologies both claiming to be grounded theory (McCann and Clark 2003a). The literature is replete with argument and counter argument in the search for the true version of grounded theory (Walker and Myrick 2006, Bryant and Charmaz 2007a). Of course this assumes that a single *true* grounded theory exists. The waters are somewhat muddied by the fact that some researchers appear to utilise a grounded theory approach e.g. Holm (1997), Bunch (2000) rather than adhering to the methodology and methods laid down by Glaser and Strauss, Glaser, or Strauss and Corbin. Glaser might wish to claim that his version of grounded theory is the correct version (Glaser 1992). There is certainly a good deal of evidence that grounded theory has developed over time from its inception, and this is well illustrated in the field of nursing research (Chenitz and Swanson 1986a, Bryant and Charmaz 2010, Charmaz 2006, Denzin and Lincoln 2000a). Thus grounded theory is what Bryant and Charmaz (2007b) identified as a contested concept with no single description. However they go on to assert that its contested nature has not detracted from its value and contribution.

There has been over the years an expansion of the application and development of grounded theory as a methodology in nursing research (Chenitz and Swanson 1986a, Bryant and Charmaz 2010, Charmaz 2006). This suggested that it could be an appropriate methodology for this study. However to follow unquestioningly in the footsteps of others would have been a mistake. It was imperative to identify and choose a methodology that was amenable to addressing the specific research question of this study. The methodology also

needed to be capable of being flexible to in order to meet the constraints that conducting research in the NHS entails (Department of Health 2001). The diversity of application of the methodology in nursing research implied that there was flexibility within the approach. At the same time however the methodology needed to be sufficiently coherent and recognisably legitimate as a research method to satisfy gatekeepers (Bryant and Charmaz 2007a) such as the NHS human research ethics committee (REC). The significant number of publications of research using grounded theory in peer reviewed journals attest to the methodology's legitimacy. My experience as a member of an NHS REC reassured me it would be recognised and accepted by the gatekeepers to the study site. However before the final decision to adopt grounded theory as the guiding methodology for the research it was necessary to consider any potential weaknesses.

Layder (1993) criticised grounded theory on a number of counts. He asserted that the methodology develops theory which maintains the status quo as a result of the focus on the empirical or observed behaviour of humans. In developing theory that emerges from the data, there is a risk that the structural factors that may influence that data are ignored (Layder 1993). This risks leading grounded theory to identify theory about what happens which then fails to consider how it happens or why it happens in the way the theory outlines. Strauss and Corbin's (1998) explication of the conditional matrix attempts to account for the structural factors that may influence the observed interactions.

"If a researcher wants to build a theory, then it is important for him or her to understand as much as possible about the phenomenon under investigation. This means locating a phenomenon contextually or within the full range of macro and micro conditions in which it is embedded..."
(p181-2)

Thus it was necessary in my study to take account of the social, physical and psychological environment within which theory would be generated. Hence whilst a comprehensive review of literature was not appropriate at the outset of the study a full consideration of it was required following the data analysis.

Strauss and Corbin (1998) go on to recognise that what occurs in terms of actions at the micro level can be influenced by organisational, national or social factors.

It is not clear whether the social factors to which Strauss and Corbin (1998) refer include cultural issues impacting on the data. This lack of clarity is perhaps apparent from Morse's (2001b) expressed concerns regarding the lack of any descriptions of culture in grounded theory studies. This was particularly a pertinent issue for this research as the study site was a partially closed unit within the hospital and as such was likely to have developed particular ways of working as a unit over time (Strauss et al. 1978). This is something I have described to my students as culture with a little 'c' and is characterised by those basic assumptions and values that underpin and inform those both entering, and becoming part of, a professional group. From personal experience in clinical practice as a nurse and from a general reading of the professional literature, I developed the view that different specialities in medicine develop different value sets. This notion was borne out in the data from my study site as will be seen in the presentation of the findings.

In addition it was recognised that the cultural diversity of both the population served by the hospital and the health professional working in it would also have a bearing. It was thus important to be sensitive to these, and ensure that descriptions of culture both with a big 'C' and a little 'c' were included. However it was not the task of the data analysis to search for any cultural influences but rather to be open to, and recognise, any that occur so that they may be properly accounted for. Additionally it was important to be sensitive to the responses, especially perhaps from health professionals, which constituted the socially acceptable response of a person belonging to a particular profession. Probing and clarifying questions during data collection and analysis were thus employed to illicit the 'real' story rather than merely the one which respondents thought the interviewer might want or expect to hear.

In the design and execution of this study I followed the approach taken by Charmaz (2006) in viewing grounded theory as a set of principles and practices. This study was thus guided by grounded theory rather than following strictly the processes outlined by its originators. The analysis of the data was guided by the Strauss and Corbin (1998) framework. This offered a structured approach to data analysis (Holloway and Wheeler 2009). However the structured approach was used as a guide rather than a recipe to be slavishly followed to the letter. Strauss and Corbin (1998) encouraged researchers using grounded theory to use their procedures “flexibly and creatively” (p8). They suggest the procedures are aimed at enabling researchers to develop a way of thinking about data. It offers procedures to facilitate recognition and consideration of the core category, categories, properties and dimensions of the emerging theory. Definitions of the terms category, properties and dimensions taken from Corbin and Strauss (Corbin and Strauss 2008) are detailed below in table 1.

Table 1. Definition of grounded theory terms

Core Category	The concept to which all other categories are related. The central phenomenon around which all other categories are integrated.
Categories	Higher level concepts under which lower level concepts are grouped according to shared properties.
Properties	Characteristics that define and describe concepts.
Dimensions	Variations within properties that give specificity and range to concepts.

I was well aware of the need to take care not to allow the Strauss and Corbin (1998) procedures to divert my attention away from the data and merely focus on ensuring I was applying the procedures (Robrecht 1995). The procedures detailed by Strauss and Corbin (1998) were helpful in guiding my hand in the data gathering and analysis. However it was important to allow the data to direct the formation of the theory and directions in which to seek more data. In the

beginning I did worry about whether I was open coding or axial coding or applying the conditional matrix in the right way. However as the analysis and data gathering progressed, it became clear where I ought to turn for more data, what kind of participants I would need to seek out and what to explore with them. Thus whilst the Strauss and Corbin (1998) procedures were useful at the outset I found I became more relaxed about the application of them and focussed more on where the data was taking me as I shall show in the next chapter. Indeed the 3rd edition of Strauss and Corbin's text (Corbin and Strauss 2008) reinforced the notion that the distinctions between open and axial coding were artificial.

"the greatest tools researchers have to work with are their minds and intuition. The best approach to coding is to relax and let your mind and intuition work for you" (Corbin and Strauss 2008 p160)

It is perhaps worth noting that the third edition of the Basics of Qualitative Research was written post Anselm Strauss' death in 1996 and revised entirely by Juliet Corbin's hand. Whether this signalled a new direction for grounded theory or a development of Strauss' ideas might pose an interesting question but that is not one I will pursue in this work.

As the coding continued and the merging of codes led to the creation of categories it became clear that there was a single core category that formed the central phenomenon of resolving ethical problems in paediatric intensive care. Once the categories emerged from the data and started to become established I was able to focus on the identification of the properties and dimensions of those categories without the need to refer explicitly to the Strauss and Corbin framework. It was important to attend to the data and allow it to direct the analysis. Thus Glaser's (1992) criticism of the seeming mechanistic approach that forces the data holds some sway. However by not adhering slavishly to the coding procedures, and paying close attention to the data, it was possible to avoid creating theory by process alone and, as Strauss and Corbin suggest, to generate theory grounded in the data.

One issue for consideration in respect of the above is whether or not it is legitimate to adapt grounded theory in the way I shall outline in the next chapter. One response to this might be to suggest that if the methodology requires adapting to fit the circumstances pertaining to the study, perhaps grounded theory is not suited to this study. Grounded theory is often characterised as an approach rather than a single definitive entity (Birks and Mills 2011, Bryant and Charmaz 2010, Schreiber and Stern 2001, Layder 1993). That is not the same as suggesting that grounded theory is an umbrella for a research free for all. Rather it is a methodology that allows for a range of techniques to be employed that facilitate analysis and interpretation of data as part of a systematic inquiry (Strauss and Corbin 1998). As I will show in the following chapter there were constraints regarding access to the study unit, recruitment procedures and the practicalities of data collection. So whilst the data analysis utilised Strauss and Corbin's procedures as a set of techniques, other aspects of the methodology i.e. sampling, were necessarily adapted according to these constraints.

Chapter Five

5 Conduct of the study

In detailing the conduct of this study this chapter opens with a brief outline of the study site and a broad description of its day to day functioning. This is followed by descriptions of the sampling strategy, data collection processes and data analysis. Integral with these descriptions, I reflect on the processes, the issues that arose and how these were managed as the study progressed.

5.1 The study site

This study was aimed at generating a substantive theory of how ethical problems are resolved in a children's intensive care unit. In order for judgements to be made regarding the applicability of the theory to similar units I have provided a broad outline of the nature of the study site and the established ways of working. An appreciation of the structure and some of the routine processes occurring in the study site also provides a context for the presentation of the findings.

Children were admitted to the intensive care unit in two distinct ways. They could be under the care of one of the hospital's consultant doctors outside of the intensive care unit, the admitting consultant (sometimes referred to in the data as the bed-card holding consultant). The admitting consultant was a specialist in a particular aspect of children's medicine such as cardiac surgery, neurology or gastroenterology. Children could thus have been a planned admission to intensive care following surgery or for supportive treatment during an acute episode of a chronic health problem. However for some children with chronic disorders there could be acute episodes requiring unplanned intensive care admission. Children could also be admitted as an emergency either via the emergency department or from another hospital in the region for an acute illness. In all cases however the intensive care consultants were not the

admitting consultant. There was always a specialist consultant outside intensive care who had oversight responsibility for a child's complete stay in hospital.

Each consultant intensivist worked with a team of junior doctors which usually included several specialist registrars (SpR) at various stages of training. Each consultant held overall responsibility for the clinical decisions on the unit for a week in rotation. This system was adopted to prevent situations that had occurred in the past when different consultants took responsibility for different days or even portions of a 24 hour period. This had led to situations where a child might have a therapy discontinued on a morning ward round and reinstated at an afternoon round.

Qualified nurses on the study unit included the most junior on NHS band 5 through to the most senior nurse on NHS band 8. The nurses were organised with the band 5 nurses (the most junior qualified nurse) at the bedside providing one to one care for a child. These nurses were supervised by a band 6 nurse who oversaw two beds, assisting the bedside nurses as needed throughout the shift. Two more experienced band 6 or band 7 nurses would normally supervise one half of the unit each. The nurses worked either a standard 7.5 hour shift or more often a 12 hour shift on duty. However it was often the case that those providing direct care were assigned to different children each day even where a child they cared for the day before was still on the unit. As will be seen in the data this did lead to some issues for some nurses in getting to know the child and parents well during their admission.

The unit had two side rooms which were adjacent but separated from the main unit by a set of doors. These were used on occasion as an overflow facility when as a short term measure there was pressure to admit a child when all the main unit beds were occupied. Usually this would result in a child who might be well enough for transfer out of the unit in a few hours time or was stable enough to be monitored off the main unit, being placed in a side room with a member of staff in attendance. This did then lead to a problem whereby the main unit had fewer staff to provide care on the main unit. If staff were on the main unit they

could assist with another child, for a brief period, if the two they were caring for were stable. Additionally the more senior nurses who normally oversaw several staff caring for children would be the most likely candidates to be allocated to care for the child farmed out to the side room, thus potentially reducing the nursing expertise available to the children on the main unit.

Ward rounds occurred in two different phases. The admitting team, accompanied by at least one intensivist, would visit all children they were responsible for at the bedside. At this time there would be some discussion regarding the child's progress with the parents if they were present. There were also formal multidisciplinary team meetings held on most days to review all the children on the unit. These meetings were ostensibly open to any member of staff to attend and contribute to discussions. There were also separate ad hoc meetings and telephone discussions between various members of the medical and nursing teams throughout the day to discuss clinical issues relating to a child's progress.

The culture that existed in the study site was based on a notion of team working. The team was not restricted to the health care professionals working on the unit but included other professionals who had a part to play in the care and treatment of a child during an admission, or potential admission, to the intensive care. These others were principally the consultant under whose name the child had been admitted to hospital. Those children with multiple problems were often under the care of several consultant medical teams but there was always a lead admitting consultant who had overall responsibility for a child's treatment.

5.2 Sampling, data collection and analysis

The data collection and concurrent data analysis procedures at the core of grounded theory are aimed at achieving a balance between objectivity and sensitivity (Strauss 1987). The objective stance that is at the heart of the inductive method of grounded theory cannot be applied without the balancing

sensitivity. Even if one could enter the field with no preconceived ideas as Jootun, McGhee and Marland (2009) suggest, some knowledge of the field would be necessary to enable the researcher to be sensitive to the more subtle cues within the data. My background in children's nursing meant that complete objectivity was impossible to achieve. Glaser and Strauss (1967) and Strauss and Corbin (1998) emphasise the importance of an open minded approach rather than total objectivity. This open minded approach must incorporate sensitivity to significant features emerging from the data. Sensitivity to the data can be gained from professional experience in the field (McCann and Clark 2003b). Thus one can enter the field with some understanding of the context in which the data occurs and the subtleties of the data (Glaser and Strauss 1967).

It was important to consider in what ways my influence on the research, at all stages, might be evident. Although complete objectivity cannot be achieved one ought to aim to achieve it as much as possible (Denscombe 2010b) and at the same time make explicit the possible sources of subjectivity. Thus it was important to be vigilant and adopt a reflexive frame of mind in conducting and reporting this research (Lambert et al. 2010, Hall and Callery 2001, Neill 2006) . However, as will be seen in my account of the interviews, I made a conscious decision to use my knowledge of nursing and medical practice to facilitate the elicitation of information from the professionals that an individual entering the site *de novo* might not. Thus being reflexive enabled me to be deliberate about my influence on the data rather than being blind to that influence.

5.3 Sampling

In the context of a grounded theory study, in addition to identifying a research question where there is little or no existing literature, Swanson (1986) recommended that the researcher be unfamiliar with the clinical area within which the study is to be conducted. Thus it was decided not only to focus on an area of clinical practice with which I was not familiar but also a particular site to which I had no previous exposure. Whilst I had practised as a children's nurse I had never worked in an intensive care unit. Thus the particular ways of working

and social milieu in a children's intensive care unit were unfamiliar to me. Additionally I had never practised or had visited the hospital within which the study site was situated until I began negotiating entry to the site. However it was recognised that my previous experience as a children's nurse and as a nurse educator was bound to influence my perception of the data, and I shall return to this in the section on data analysis.

One positive aspect of my existing knowledge was that I was able to sample purposefully at the outset since I had a good notion of which individuals might be involved in the process of resolving ethical problems. The concept of theoretical sampling was used to guide data gathering (Glaser and Strauss 1967, Strauss 1987, Strauss and Corbin 1998). This is a process where the emerging themes determine where to turn next for the data. It is a key feature of theoretical sampling that it is the emerging categories and the search for all the properties of those categories that guides the sampling (Charmaz 2006). However the first source of data must rely on purposive sampling which is based on preconceived ideas regarding where best to begin searching for data to explore the research question. Strauss (1987) states that this purposive, or in his words selective, sampling is not the same as theoretical sampling. Nevertheless theoretical sampling cannot begin until after some initial data has been gathered on which to base sampling decisions (Charmaz 2006). Strauss (1987) indicated towards the end of his book on qualitative analysis that selective or purposive sampling must precede theoretical sampling.

5.3.1 Sampling strategy

Purposive sampling is founded on the premise that a research project begins with an idea of who the potential participants might need to be, at least in terms of their ability to inform the study if not their actual identity. Spradley (1979) describes what he calls the excellent informant. A central quality of an excellent informant is that they must have experience of the phenomenon under investigation. However whilst this is a necessary criterion it is not, as Morse (2007) indicates, sufficient. Merely having been involved in situations, when an

ethical problem required resolution, would not guarantee valid data was collected. Potential participants must also be reflective and able to articulate their experience (Morse 2007). They must of course also be willing to participate and able to spare the time to provide information.

In determining where to turn for participants, my own professional experience as a clinical nurse and nurse educator informed my assumptions underpinning the initial sampling frame. Qualified medical and nursing staff of varying grades would be likely to fit the criteria as excellent informants. As the primary professionals caring for children in intensive care they would be the persons most closely involved in situations where ethical problems would require resolving. However my sampling frame also included within its remit other health professionals who might be involved in a child's care and thus participant in the resolution of ethical problems. Such professionals included physiotherapists and social workers but I also allowed for the possibility of other professional groups to be included.

In order to ensure that participants had sufficient exposure to the phenomenon under study it was decided to only include those professionals with at least a year's experience in children's intensive care. It was important to ensure the sample also included doctors, nurses and other health and social care professionals at a variety of grades. The nature of the professionals' involvement in resolving ethical problems would, most likely, in part be determined by the role they fulfilled and their position in the study unit's hierarchy. Whilst a consultant doctor has overall responsibility for making clinical decisions the professional team as a whole usually have opportunities to participate in the discussions that precede decisions regarding a child's care and treatment. Indeed professional guidelines (General Medical Council 2006, Nursing and Midwifery Council 2008) require health professionals to work as a team. The requirement to work as a coherent team has previously been identified as a key aspect of professional health care practice by the Kennedy report (2001). In addition registered practitioners also have responsibility for

their own decision making on a day to day basis. In order to understand the process of resolving ethical problems it was thus important to enable the sampling strategy to capture data from a range of professionals' perspectives.

In my initial contacts with the study site to gain the relevant support from the clinical lead and nurse manager it was also suggested that I might wish to interview members of the clinical ethics advisory group. I was informed that this group were consulted on ethical questions relating to specific children from time to time. Therefore I included in the sampling strategy a plan to invite members of that group to interview. My sampling strategy thus attempted to employ an element of data-source triangulation (Gomm 2008) in respect of the phenomenon as a result of the different roles professionals would have in the process.

As an integral part of both pre-registration education and post-registration professional practice health professionals have long been expected to reflect on their practice in order to identify and undertake continuous professional development (General Medical Council 2006, Nursing and Midwifery Council 2008). Thus all health professionals participating in the interviews should be able to reflect on and articulate their experiences of the phenomenon. Of course that was dependant on them being able to recognise and reflect on the ethical elements of their practice. My experience as a nursing lecturer informed me that, initially in discussion, qualified doctors and nurses do not find it as easy to identify ethical issues as they do clinical issues. However they are able fairly rapidly to begin to do so when prompted to think about their practice in detail.

Children's nursing practice is founded upon a concept of family centred care (Smith et al. 2002). Embodied within this concept is a philosophy of involving parents in the healthcare of their children. The Children Act 1989 also established the rights and duties of those with parental responsibility in respect of decisions about their children. Since the judgement made in the Gillick case (Dyer 1985) it has become increasingly the case that children have become involved in healthcare decisions about them. Thus parents and potentially

children would also possibly be involved in the resolution of ethical problems concerning them. The sampling strategy that was developed and presented to the NHS research ethics committee (REC) included an approach to parents and children. Hence the creation of the participant information sheets in appendices 1, 3, 4, 5 and 6. However this part of the sampling strategy was necessarily speculative since it was unknown to what extent, if any, that parents participated in the resolution of any ethical problems in intensive care. It was also not possible to predict or select those with the desired reflective and articulation abilities.

Ultimately the sampling strategy was designed to balance the methodological imperative for theoretical sampling with the constraints placed upon NHS based research. I knew I would not be allowed to make direct approaches to potential participants and thus would not have complete freedom to allow the emerging themes direct recruitment. Therefore the strategy included provision for me to request introductory letters and information sheets to be given to specific groups of potential participants via those acting as third party recruiters.

5.3.2 Recruitment strategy

The recruitment strategy was designed and operated to elicit data to inform the study in meeting the stated objectives. The sampling process was influenced by the requirements of the NHS Research Ethics Committee (REC) approval in respect of recruitment processes. These requirements included an approach to potential participants via a third party. In the case of medical staff and parents recruitment was conducted through the good offices of the lead consultant intensivist. I was able to provide a broad outline of the kinds of people I envisaged I needed to interview. I requested that information sheets were sent to all grades of medical staff working in the intensive care unit with the proviso that they had at least a years experience in children's intensive care. This meant that to all intents and purposes it was this consultant doctor who pre-selected those to whom the information sheet (appendix 1) and invitations letters (appendix 2) were sent. Similarly the nurse manager agreed to send the

information sheet and invitation letter to nurses and other non medical health professionals such as physiotherapists, social workers and others working on the unit. It was agreed that the approach to parents would be made via the family liaison nurse for the study unit. This was an individual who maintained contact with many families following a child's discharge from the study unit or whose child had died on the unit. I held face to face discussions with all three gatekeepers to the potential sample. I clarified with the lead consultant doctor and the nurse manager the level of experience that healthcare staff should have. I also met with the family liaison nurse to agree the parameters for parental recruitment. It was agreed that the child should have left the unit at least 6 weeks prior to the invitation and that the nurse would make individual judgements regarding any approach to bereaved parents. This was particularly important as the liaison nurse was, by virtue of her ongoing relationship with bereaved parents, able to identify parents most likely to be emotionally ready to recount their experiences.

The principles of theoretical sampling were applied in guiding the selection of participants. Thus I was aware of the necessity to pick up on explicit references, or sometimes a hint, in the interviews regarding other individuals that could inform the study. I would then be able to seek out such individuals. In an ideal situation I would have, following an initial analysis of each interview, approached the next potential participant. However a direct approach was not approved by the REC and it was judged that making repeated requests to the designated senior staff to send invitation letters to specific staff would be an unacceptable burden from their perspective. Sampling was however guided by the ongoing analysis of data in that I was able to approach all three staff (lead consultant, family liaison nurse and nurse manager) on the unit sending out invitations if I needed further invitations sending as I perceived a need for further participants from specific groups. I was, for instance, able to identify, as the analysis proceeded, that I would need to interview consultants from outside the intensive care unit. I approached the lead intensivist who then facilitated the approach to these individuals. This did not mean that there should be an

equality or balance in the numbers of participants from each of the potential actors in the process of resolving ethical problems. Care however was taken to ensure that equal consideration was given to each voice contributing to the data. None was assumed to give a better or more valid account than any other.

5.3.3 Recruitment issues

Throughout the study the data collection was heavily influenced by the pattern of recruitment of potential participants. This had implications for sampling, resulting in a need to adapt to the circumstances presented. It was envisaged that utilising a purposive sampling approach roughly equal numbers of medical and nursing staff and parents would be recruited. The purpose of this strategy was to balance the data to ensure one perspective did not dominate my analysis. However it was realised that this was not possible and in any case unnecessary. First, it was impossible to dictate the order in which respondents volunteered. Second, the constraints of diary management for both me and the participant meant that I could not control in any realistic manner the order in which interviews took place. It emerged as unnecessary to control the order in which I interviewed respondents as the data analysis strategy directed the content of the interviews to a significant degree. The use of memos as part of the data analysis enabled me to pick up on issues that required checking out at subsequent interviews.

Recruitment of medical staff

Initially although invitation letters and participant information sheets were sent to the relevant senior member of staff in the unit for distribution it became apparent that several factors significantly impacted on the response rate. This had implications for the sampling frame and some pragmatic decisions had to be made to apply the concept of theoretical sampling. The lead consultant for the unit distributed the invitations to junior medical staff i.e. all those below consultant. This led to early responses from six doctors ranging from senior

house officer (the most junior grade on the unit) to senior specialist registrars who were about to become consultants.

The recruitment of consultant doctors was expedited by the senior consultant on the unit when I reported that whilst a good response had been received from junior grades no consultant grade staff had responded. Subsequent to a repeat e mail from the senior ICU consultant she and several others came forward. When it emerged, during data analysis, that consultant doctors outside the ICU played a significant part in the process of resolving ethical problems, the lead intensivist agreed to send invitations to some of them. In the event only 2 consultants agreed to participate, both of whom were responsible for the care and treatment of children with chronic life limiting disorders albeit from different specialities. A high proportion of children referred to the study site actually came from cardiac surgery specialist consultants. It was thus a limiting factor in the data to gather perspectives from a somewhat distorted sample of those who could illuminate the process of resolving ethical problems in the ITU. Initial contact was made with one surgical consultant but when it came to agreeing a specific date and time for the interview, he withdrew. The lack of volunteers from surgical specialities did leave something of a gap in the data in terms of a surgeon's perspective on the process. However a number of the intensive care doctors and nurses were able to provide clear accounts of the process of resolving ethical problems and how this may be affected by the admitting consultant speciality.

It was always recognised that the recruitment of children would be problematic and I will return to this in due course. What was not predicted at the outset were the difficulties experienced in recruiting nurses and parents to the study.

Recruitment of nursing staff

It was agreed that sending invitations to all nursing staff on the unit, circa 200, would not be appropriate in the context of a purposive sampling frame. Rather it was agreed that the manager would be provided with sufficient letters and

information sheets to distribute to five nurses from each grade band (NHS bands 5 – 8) to include junior and senior nurses. It was also agreed that this would not include staff who had been working less than a year in a children's intensive care unit, because they would have minimal insights into the question under study.

Initially no reply slips from nurses were returned. It became apparent that the invitation letters and information sheets had not been distributed to nursing staff on the unit. Consideration was given to negotiating with the nurse manager my attendance at shift handover meetings for a week in order to present a brief overview of the research and its purpose. A high proportion of nursing staff on the unit would thus have been alerted to the research that was taking place. In the meantime I developed a relationship with a research nurse on the unit who agreed to assist in facilitating distribution of letters and information sheets. As it transpired it became unnecessary to attend staff handover time as reply slips began to arrive in the post within a week of the research nurse distributing invitation letters and information sheets. However despite receiving ten reply slips expressing interest in being interviewed, only two nurses actually came forward and were interviewed at that point in time. One of these two nurses gave some insights into the possible reasons for the low participation rate. One potential difficulty they identified was the fact that during rostered shifts the nurses were fully engaged in providing nursing care. There was a period in the middle of the day for handover between shifts where an overlap occurred between the nurse coming on duty and the one going off duty. However this was usually fully taken up with handing over details of the child's progress or for professional updating on the unit. Thus nurses were not often available for interview during work hours. Furthermore many of the nurses worked 12 hour shifts to enable them to work fewer days in the week and yet maintain full time hours. This meant that there was no afternoon handover period for these staff. Both these factors resulted in the nurses only being available for interview in their own off duty hours. A request had been made by one of the nurses to the nurse manager for time off in lieu to account for the interview time but this was

declined. Many nurses were thus not keen to participate in their own time. This was compounded by the fact that the unit was uncharacteristically busy with high bed occupancy and a concurrent staff shortage due to several unfilled posts on the unit at the time data collection was initiated. Despite this one nurse did indicate that she was able to secure some time during duty hours for an interview. When I arrived to interview her she indicated that two of her colleagues had also agreed to be interviewed as long as it could be done that day. I acceded to this in order not to lose the potentially valuable data. I thus negotiated a break of 20 minutes between each of these interviews to allow time for reflection and immediate analysis of each interview. Thus I was able to adapt interview questions for the second and third interview that day based on a fresh memory of the previous interview(s).

A second issue highlighted in an interview was that my e mail to all those returning reply slips indicated that a good response to the invitation had been received. This led many of the nurses to believe that it was thus not important if they did not take things any further, since there were plenty of others volunteering. In my desire to let all those returning reply slips know that there was a chance they may not be called (in the event I reached the point of data saturation), they all assumed it they did not need to respond any further. In hindsight it would have been better to have acknowledged receipt of the reply slip and then give an indication of the time frame over which I might contact them for an appointment. I could then have let any surplus volunteers know that they were no longer needed. This would however have potentially created an issue for any other researchers as staff may then have felt that there was no point in offering to volunteer if one was not ultimately to be called.

A further problem was highlighted following the summer period when contact was again made with the research nurse on the unit who had assisted with distribution of the invitation letters and information sheets. Several of those approached by the research nurse reported some nervousness regarding responding to the request for interview. This reportedly stemmed from a notion

that the interview would 'test' their knowledge of healthcare ethics and potentially find them wanting in this area. A similar issue was noted by Harris (Harris 2005) when recruiting midwives for interviews regarding their practice. Thus it appeared that despite the provision of information sheets that explained the study and its purpose;

'You will ... be asked to discuss as freely and honestly as you feel able your experience of taking part in ethical decisions whilst caring for a child in intensive care as part of your professional practice' (NHS staff PIS p2 appendix 1)

Some potential participants remained unclear regarding what might be expected of them in the interview. This then raised a question in my mind in respect of the ethical issues arising in the conduct of the study and informed consent, and these are explored further in chapter 6. It is perhaps interesting to note here that whilst the medical staff respondents expressed some uncertainty regarding the purpose and focus of the interviews, it did not prevent them coming forward to be interviewed in the same way as the nurses. Another issue for recruitment was revealed in one of the interviews with a nurse when she mentioned that there had been a number of questionnaire based studies conducted in the unit at the time and staff were not keen to respond to yet another research request.

On reflection my assumption above that I no longer needed to attend the unit to introduce the study to staff based on the return of reply slips was perhaps erroneous. However maintaining open communications with the research nurse facilitated a renewed impetus to the recruitment of nurses. She undertook to find out why staff she had initially contacted had not ultimately volunteered for interview. The nursing staff had originally provided the reply slips to the research nurse for return to me '*en bloc*' despite the request to return the slips via a pre-stamped envelope. Thus there was no breach of confidentiality or the terms of the REC approval for the study since the nurses made their own decision to reveal their willingness to participate to the research nurse. Subsequent to the intervention by the research nurse more nurses came forward and interviews were conducted. Several of these had originally

responded and then not come forward, but some others came forward for the first time.

The Clinical Ethics Advisory Group

An approach was made to the chair of the clinical ethics advisory committee seeking potential participants from members of the group. This committee was a multidisciplinary group made up of medical, nursing and other allied health care staff plus a member of the chaplaincy and at least one lay member. However no volunteers emerged from this group. It was unclear why this was the case since the committee chair had been supportive during the initial stages of negotiating access to the study site. This did create a potential for a gap in the data. However insights into how the committee interacted in resolving ethical problems in ICU were provided by the consultant doctors who were interviewed. I had also gained some insight into the workings of the committee as I had been invited to attend a meeting as an observer but was not allowed to collect data from this observation. However this observation did assist me in making sense of the responses given by some of the participants in my study.

Other professionals

I did receive a reply slip from a physiotherapist working on the study unit expressing an interest in participating in the study. However when it came to arranging an appointment for the interview she changed her mind. I did inquire what led to the change of mind but, as was made clear in the information sheet (appendix 1), there was no requirement for her to tell me and indeed I received no response to my inquiry.

Recruitment of parents to the study

The recruitment of parents to the study was much more problematic than was initially imagined. There were a number of factors that led to difficulties. I held a meeting with the family liaison nurse to agree how many parents might be approached and to clarify that, ideally, I would like to interview parents of

children who had survived as well as those whose child had not. When no responses were received from parents, I contacted the family liaison nurse to enquire if she was aware of any issues that might be preventing parents from responding. This was some 6 weeks after the first member of medical staff had responded and been interviewed. It became apparent that the invitation letters had not been sent. It transpired that the nurse I had discussed parental recruitment with had left the unit and had not passed on any information regarding the study to the person covering her work. I subsequently met with the acting family liaison nurse to discuss recruitment, but she felt that she did not know any of the parents well enough at that point to judge whether it was appropriate to send an invitation.

Having heard that I had difficulties in securing interviews with parents, one consultant intensivist made a direct approach to a set of parents who were with their child on the unit. This was allowable under the terms of the NHS REC ethical approval since the approach to parents could be made by a consultant in addition to any made by the family liaison nurse. I took some care to ensure that these parents had read and understood the information sheet and were fully aware of what the study entailed before embarking on the interview. Their daughter had been on the unit for some months and they appeared quite relaxed about the interview and said they were keen to talk to me about their experience. These parents tended to focus on the quality of care their child received and appeared keen to avoid saying anything that might be construed as a criticism of the clinical staff. However they were able to provide some insights on some of the data provided by the professional participants.

I did also secure an interview with a father of a child who had been on the unit a year or so previous to my meeting him. He was unable to give many meaningful insights into the process of resolving any ethical problems. This was because his son had been admitted to the intensive care unit as an emergency soon after birth. He admitted that the whole event had been 'a bit of a blur' and he had not really taken much in. Compounding this was the fact that his wife was a

nurse and he intimated that he had absolute trust in the staff caring for his son, and thus accepted at face value everything he was told. He was able to give an account of his son's treatment and care whilst on the study unit but this was an almost entirely documentary account. I did not talk to the mother about her child's admission to the unit as at that time she was acutely ill herself and was not directly involved at that time.

Children as participants.

It was envisaged in the planning of the research that children who had been treated on the study unit would be interviewed. The recruitment of any children would have been via their parents as detailed in the parent information sheet (appendix 3). Separate information leaflets were created for children across three age ranges (appendix 4). A separate information sheet and an invitation letter were constructed inviting those parents whose child had not survived an intensive care admission (appendix 5).

An account of the development of the information sheets can be seen in chapter 6. Talking to children would have potentially provided some insights into any part they played in resolving ethical problems that affected them. The vast majority of children on the study unit were either unconscious or heavily sedated throughout their stay. Therefore it was thought that those children who had been scheduled for a planned admission to the intensive care unit would be suitable respondents. It was confirmed during an interview with an admitting consultant that competent children's views were sought prior to intensive care admission. Thus there was the potential to garner a child's perspective on the resolution of ethical problems related to their care and treatment. In the event the children of the parents I was able to interview were both under 5 years.

5.3.4 Diversity issues impacting on sampling

Early on in the process of identifying the potential sample for the study the issue of ethnic diversity had to be addressed. This was partially as a result of the

ethnic mix of the geographical area in which the study site was situated and partially as a function of the necessity to consider how to manage potential respondents who were unable to communicate in English. The proportion of children and/or parents admitted to the unit under study unable to converse in English was estimated by the lead clinician as less than 10%. As a non-funded PhD study the facility to employ translation services was unavailable both for the production of information sheets and conducting the actual interviews. The NHS Trust in which the study was conducted approved the study on the condition that the Trust incurred no direct costs. Thus it was decided to exclude those potential participants who could not read and understand the information sheets in English. This was partially a pragmatic solution to the funding issue; more significantly it was felt that the process for resolving ethical problems for this group of parents and children would be different. Since the majority of the staff communicate in English, even where a member of staff was bi-lingual in a relevant language or where translation services were used, the actual process of resolving the ethical problems would be significantly affected by this factor. It is also true that it is recognised that a proportion of what is translated in interviews is actually interpreted rather than translated literally (Barnes 1996). Thus the exclusion of those unable to read and converse in English was a deliberate methodological decision grounded in the research question.

The final study sample included 21 individual participants interviewed over 20 events. All but the parents of one child were interviewed as individuals. These parents were interviewed together. Table 2 shows a breakdown of the participants.

Table 2. Study participant characteristics

Role	Number
Father	2
Mother	1
Nurse Band 5	3
Nurse Band 6	5
Specialist registrar intensivist	5
Consultant intensivist	3
Admitting Consultant	2
Total	21

The father who was interviewed on his own reported that his son had been on the study unit for a total of 3 days. The child's admission was very soon after a traumatic delivery and his mother remained on the post natal ward during his intensive care stay as a result of significant blood loss.

The parents interviewed as a couple reported their daughter had been born with a congenital cardiac problem and had been in the study unit since soon after her birth for 9 months. The child remained on the unit at the time of the interview.

Two of the specialist registrars interviewed worked part time hours due to their own child care responsibilities but all the other intensive care professionals worked full time.

The two admitting consultants both treated children with chronic life limiting disorders. One consultants caseload consisted of children with degenerative neurological disorders whilst the other treated children with metabolic disorders. These two consultants then had developed relationships with the children and families they cared for over a protracted period of time. Sometimes this would

be from the child's birth through to and including that child's death before adulthood.

5.4 Data Collection

The actual data sampled for grounded theory can be gathered by, *inter alia*, interview, observation, written reports and private letters (Strauss 1987). The object of data collection is to gather information to inform theory building from a variety of perspectives in order to capture varied meanings and interpretations of events (Strauss and Corbin 1998). The common thread with all these data sources, with the exception of interview data, is that they all conform to what Silverman (2004a) referred to as naturally occurring data. Thus it is gathered in its natural state rather than created by a constraining process such as a structured questionnaire or interview schedule. Observational data, although collected in the natural state, would still be subject to researcher influence since those being observed would be aware and this would necessarily impact on the conduct of their interactions (Denscombe 2010b). Written records would provide a source of naturally occurring data but were unlikely to reveal how ethical problems were resolved, but more likely merely record the decision or end result.

The role of the researcher in grounded theory is to interpret data in the context of any other data and the ongoing analysis. Benoliel (1996) observed that in nursing research using grounded theory, interviews are the almost exclusive method of data collection. This may in part be due to difficulties in conducting extended periods of observation in clinical areas whilst adhering to strict consent and confidentiality arrangements that are a requirement of ethical approval. In any portion of a day, a significant number of people will interact with the children, parents and clinical staff. Such people will include health care staff and visitors such as other family members. Merely observing interactions could, in my experience as a member of an NHS REC, be possible with an opt-out consent process. This could be achieved by having prominent posters in an area highlighting the research activity with an option for individuals to request

observations of their interactions did not take place. However using observational techniques for my study would have also required listening in to, or recording, conversations to capture the detail of the interactions. This would have required specific individual consent from all involved in each interaction. This was deemed to be impracticable especially as some interactions might be brief and the process of seeking consent would most likely interfere with such an interaction, rendering consent virtually impossible. Additionally it was highly unlikely that the full range of interactions between actors could be captured and that ethical problems that were faced and resolved by a single individual would not be captured at all. Data was thus collected by face to face interviews between the researcher and the respondents. As Denscombe (2010a) notes, raw data that are relatively unstructured are to be preferred in grounded theory thus interviews were guided by an initial question to the respondent with further prompts guided by the preceding and concurrent analysis. The inherent risk by interviewing, which needed to be borne in mind was that participants might then choose to ignore or even forget significant factors or elements of the situations they recounted. However, probing and clarifying questions would be used to prompt recollection of such factors.

Consideration was initially also given to the use of non-participant observation in the field to gather additional data to support interview data. However, since the study was deliberately focussed on those ethical problems that the professionals perceived, this approach was not adopted. It was recognised that observations in the field would necessarily rely on my interpretation of something as an ethical problem.

A further option that was considered at the beginning of this study was that of presenting staff with a scenario or vignette to talk through how this would be resolved. Two problems were perceived with this approach. The first was that there would be a need to pre-select what the researcher considered to be the relevant and significant elements of the scenario (Hurst et al. 2005). This would run the significant risk that elements of a situation that respondents considered

relevant could be missed entirely and the more subtle elements of a situation would be missed. This was largely because no hypothetical scenario could hope to capture all of the subtle nuances experienced by actors in the real situation. Secondly, what is said in response to a vignette may not accord with what was actually done in the real situation and thus it was important to consider real cases recounted by the participants themselves (Hurst et al. 2005). Thus all data collected for the study was by face to face interview.

5.4.1 Interviews

I decided that the interviews would be conducted as far as possible as relaxed conversations. As such my part in the interviews was more than merely asking questions and listening to the responses. I was an active contributor to the discussion. As Meila (2001) noted this approach could be interpreted as the researcher leading the interview rather more than might be expected in a qualitative study. However it enabled me to make the interview more of a natural discussion between professionals rather than an interview which was assumed to encourage the participants to be more open and detailed in their responses.

The opening question for early interviews was 'tell me about the ethical problems you have faced in your role'. The conversation then proceeded from the initial response picking up on significant issues by asking "how do you do that?" type questions. Initial interviews were thus conducted with the minimum of pre-determined structure that allowed the respondent to tell their own story. This was to facilitate the reflective telling of a story from beginning to end (Morse 2001a).

Since participants were aware that I was a nurse they may have made certain assumptions regarding my prior knowledge and left things out or used short cuts to explain things. Often the phrases and terms used by participants were jargonistic. Doctors often used acronyms to refer to disease states or certain interventions. The nurses also used terms to refer to certain types of event e.g.

“declare themselves” which meant a child suffered a cardiac arrest that would not be treated due to a prior judgement that further interventions were futile. I felt a balance was needed between exploring meanings behind what participants were saying but without appearing so uninformed that they could not then talk confidently to me about some of the complexities of clinical situations. I was also able to share witty asides or in-jokes about certain aspects of the NHS and the way it worked. As an example of this when a participant was relaying some information about the difference between the approaches of doctors from different specialities, I was able to affirm that I had a similar experience in my own practice. This approach appeared to enable participants to relax into sharing some insights they may not otherwise have revealed. Neill (2006) refers to this as reciprocity between researcher and the participant which assists in facilitating the relationship. This was particularly important in respect of this study since all interviews were a one-off encounter and it was essential to establish a good relationship and put the participant at ease rapidly. This approach has been characterised as a hybrid position between the researcher as complete outsider and the researcher as an insider (Jootun et al. 2009).

The factors perceived by the participants in my study to influence the process of resolving ethical problems were explored in the interviews. Two approaches were used to explore such factors in the interviews. Follow up questions were asked seeking further detail of what participants thought might lay behind or influence what they were describing happened. However there may have been influences of which the participants were either unaware, at least consciously at the point of the interview, or took so much for granted that they did not bring them to mind. In the early interviews what Layder (1993) called structural or macro aspects of society, that might influence practice, were not mentioned by interviewees. I thus specifically asked questions, in later interviews, that arose from my own knowledge of some of these potential wider societal influences on participants thinking such as Government set health targets, legal judgements and media reports of poor practice. I also believed that exposure to, particularly, Government targets might be more acutely felt by the consultant doctors and

more senior nurses. However I explored these all these influences in interviews with the most junior as well as senior professionals in an attempt to gauge how keenly they were perceived at all levels of clinical practice.

Further questions were asked in the initial interviews as guided by the objectives of the study such as “who else was involved?”, “what role did they play?”, “how were parents and children involved?”, and the like. As the data was analysed outline interview schedules were constructed and adjusted for subsequent interviews as guided by the analysis of the data to explore emerging categories. This was especially the case where certain participants were invited because of issues raised in earlier interviews. One example of this was the obvious need to interview the admitting or bed-card holding consultants. These were consultant medical staff that held clinical responsibility for the child prior to admission to the ICU and following discharge from the unit. These consultants are ultimately responsible for the overall clinical care of the children, and it was evident from several interview transcripts that the role of these medical staff needed exploring. Thus I was able to enter the interviews with the admitting consultants armed with certain pre-determined areas for exploration. However to ensure new insights were not missed, I began even these later interviews with the open question in order to ensure I captured their perspective. In several interviews where some information was offered that I had heard in an earlier interview, I often confirmed that others had indicated a similar thing. This validation of what they were telling me often led them to expand on what they were saying with perceptible confidence. It was also helpful at times to be able to say that I had heard a slightly different perspective from an earlier account which then led participants to explain what lay behind their account.

Although I was not intending to explore the full range of ethical problems that occur in a children’s intensive care I was surprised at how focussed participants were on one specific ethical issue. The majority of participants focussed their early accounts on end-of-life (E-o-L) situations to the exclusion of all other

ethical issues that might arise. This came as a surprise to me and necessitated specific questions aimed at eliciting accounts of other kinds of ethical problems. However a deliberate decision was taken not to prompt participants with specific issues that I wanted them to talk about. Since the study was focussed on the process of resolving ethical problems I deliberately got participants to talk about problems they perceived and had experienced. This was felt to be likely to elicit more meaningful accounts that were based in reality. I did however probe for other ethical problems by asking participants if there were other ethical problems they encountered.

When considering the interviews with parents, consideration was given to the question of interviewing as a couple or separately. Swanson (1986) recommends interviewing couples where appropriate. This avoids assumptions that one person may speak on behalf of both. However as Swanson (Swanson 1986) also recognises this can create some difficulties where one partner in the couple makes a revelation of which the other is unaware. The decision was taken at the outset to allow the parents to make the decision as to whether they preferred to be interviewed as a couple or separately. Of the interviews with parents, one was conducted as a couple and one was conducted with the father on his own. The couple were interviewed in a quiet room on the intensive care unit as their child remained in the unit, and both parents happened to be present on the appointed day.

The parents opting to be interviewed separately did so largely on pragmatic grounds. The interview for this couple was conducted in their own home and whilst one was interviewed the other supervised their young children. It was also the case that the mother was a nurse and separate interviews were agreed as appropriate to enable their separate and unique perspectives to be heard independently. In the event it was most convenient for them to be interviewed on separate days. This had the advantage of facilitating the initial analysis of the first interview before proceeding with the second thus allowing some follow up questions and checking out of each parents perspectives.

All interviews were ended with a question asking whether there was anything else the participant felt I should know, or that we had not covered in sufficient detail (Schreiber 2001). This was a useful device as on several occasions the participant did go on to talk about an aspect of our discussion in some more depth. One participant raised a new issue they had just thought of and extended the interview for a further 20 minutes.

5.4.2 Location for interviews

Most writers would state that interviews must take place in private, quiet places in which the participant felt comfortable (Schreiber 2001, Swanson 1986). One key aspect of reducing perceived power imbalances between interviewer and participant and helping the participant feel comfortable is to allow them free choice over the venue (Elwood and Martin 2000). I felt that it was important to make the interview feel as informal as possible and thus the choice of venue for the interview was entirely left to the participant. This did lead to some challenges in terms of recording the interview as not everyone chose a quiet location. There were also difficulties at times in securing a location in the hospital as there were no suitable rooms that could be guaranteed not to be in use. Consideration was given to requesting the use of a room that had been specifically created for interviews by a research centre in the hospital. However the cost proved to be prohibitive and priority could not be given to my study. The majority of interviews in the hospital did take place in quiet rooms without interruption.

Health professionals were most often interviewed in a convenient location in or adjacent to the intensive care unit during normal day duty hours. This was most convenient for the medical staff as it was relatively easy for them to absent themselves from the unit for the period of time taken up by the interview. The senior medical staff were interviewed in their own office which afforded a high level of privacy. As this was also their space they may have felt more at ease and able to be candid in their responses. Several senior medics shared an office with a colleague and they were all content to conduct the interview with

that colleague present. However on all such occasions the colleague was only in attendance for a portion of the interview and none took an active part at any time.

One medic and two nurses opted to be interviewed in one of the hospital cafés. This presented a potential challenge to the confidentiality of the discussion. However on discussing this issue with a colleague who undertakes some informal counselling with staff this appeared to be less of a problem than might be imagined. Such a venue underlines the informal nature of the interview and perhaps marked it out as more of a discussion between professionals. Informal discussions often take place outside the clinical area in my experience in the NHS and indeed on most occasions when interviewing in the cafe there were several groups of staff having such discussions. As all parties were engrossed in their own conversations and it was not likely that anyone would be listening in to the interview I was conducting. This notion was confirmed by my work colleague who said there had never been an issue with confidentiality when he held discussions in such venues. Care was taken to ensure that a table was chosen that was not directly adjacent to anyone else and I maintained a view of the whole of the area by ensuring my back faced the wall. In this way I could monitor if anyone appeared to be eavesdropping on our conversation. I also positioned the participants chair to enable them to view the rest of the room so they could be assured no one was listening in.

An additional risk of the public space for interviewing was the potential for the public environment to inhibit the conversation and the willingness to address certain potentially sensitive issues such as end of life decision making. However this did not appear to occur. Participants gave no indication of an unwillingness to discuss any issues that were raised. Any occupied tables nearby had two or more people in conversation and none appeared to be listening in to the interview. In fact the café seemed to be regularly used by hospital staff for informal business meetings in which all participants appeared to be fully engaged. Certainly when in conversation with the participant, although I was

aware of the noise of conversation around, no specifics of those conversations could be discerned

One member of staff elected to be interviewed in a public café outside the hospital. This was at a quiet time and none of the adjacent tables were occupied thus the issue of confidentiality did not arise especially as the coffee making machine was noisy (although this presented a challenge on transcribing the recording). Several participants, both doctors and nurses, elected to be interviewed in their own home. This did afford privacy, and as I was a visitor, put them in the dominant position.

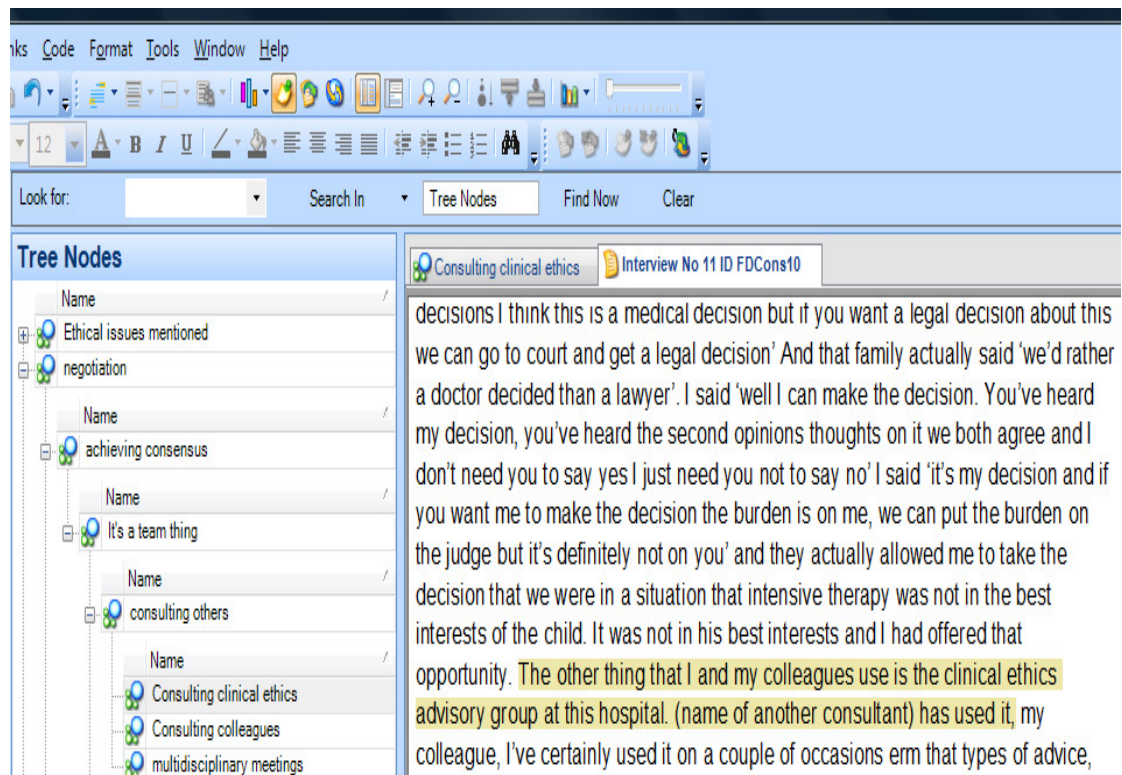
5.5 Data Analysis

Data analysis began at the first interview with immediate thoughts on the significant utterances. This was followed by transcription of the recordings. I conducted the transcription personally rather than pay a third party to undertake the work. This was very time consuming but an essential part of the overall data analysis strategy. The process of listening again to the interview and having to stop and replay sections of the recording to ensure I recorded it accurately helped develop my familiarity with the data. This enabled me to identify some themes to explore in subsequent interviews before in depth analysis of the data had begun. Once the in-depth analysis began in earnest a more directed approach was facilitated in interviews. I was able to explore in more detail the codes I was generating, and as interviews progressed, so some of the codes changed, merged or split and categories began to emerge. As the analysis progressed new interview topic guides (for example see appendix 9) were developed after the early interviews to explore the issues raised in these. The issues for further exploration were chosen for several reasons. Some were chosen on the basis that they were mentioned by one participant and had not been raised previously. Others were chosen in order to further explore and understand a different perspective. These issues were often identified from one or more memos (more of which below) that were written as analysis proceeded.

5.5.1 Coding the data

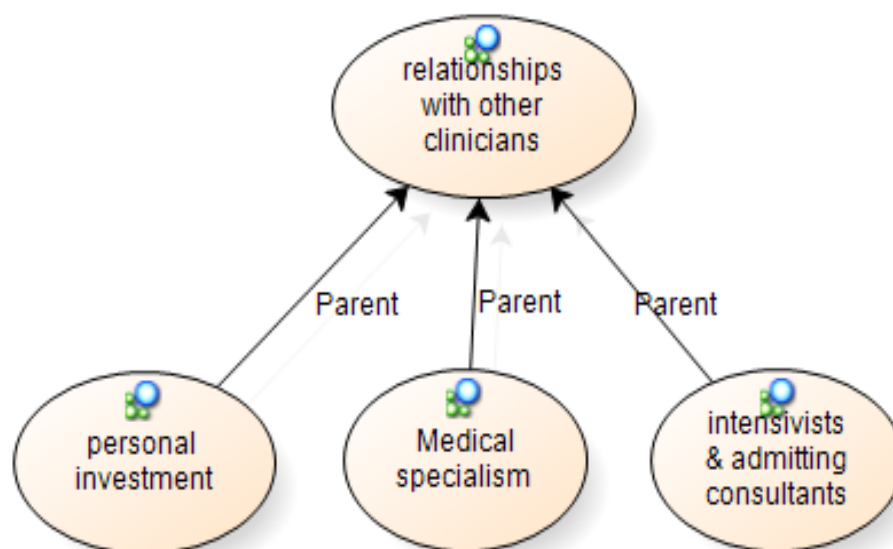
Initially data was subjected to open coding using the computer programme NVivo8 to organise the data. The process of open coding began with an almost desperate code everything in the transcript. This created a large number of free codes (termed nodes in NVivo) that I rapidly realised began to relate to each other and thus began the process of creating categories with subcategories. As can be seen in diagram 1, below, it was possible to open the interview transcripts and review them juxtaposed with the developing categories. I was able to drop sections of text into various NVivo nodes that constituted the properties and dimensions of the emerging categories (the tree nodes in NVivo 8) to see if they fitted or not. This was more than merely a mechanical manipulation of the text but a deliberate analytic procedure. Being able to view the text juxtaposed with the node tree kept the categories and codes fresh in my mind, especially after I had had a break from the coding.

Diagram 1 Tree node and related coded text



This process of constant comparison (Strauss and Corbin 1998) led to portions of interview data being organised under the node headings. This facilitated the gathering together of sections from transcripts that appeared to relate to each other under node headings that seemed to encapsulate the ideas being expressed. This moved rapidly on to comparing these node headings and noting any links between them and whether they could be related to each other under a broader heading or category. In developing the grounded theory then, as nodes were populated and links between them were being made, the categories began to be formed from the bottom up. This process is illustrated in diagrams 2 & 3 below. In diagram 2 the three codes of medical specialism, intensivists & admitting consultants and personal investment were related to each other and led to the generation of the sub-category I called relationships with other clinicians. As I shall show below this sub-category of relationships with other clinicians became part of a further higher level category when it appeared to relate to other codes and sub-categories that had been named.

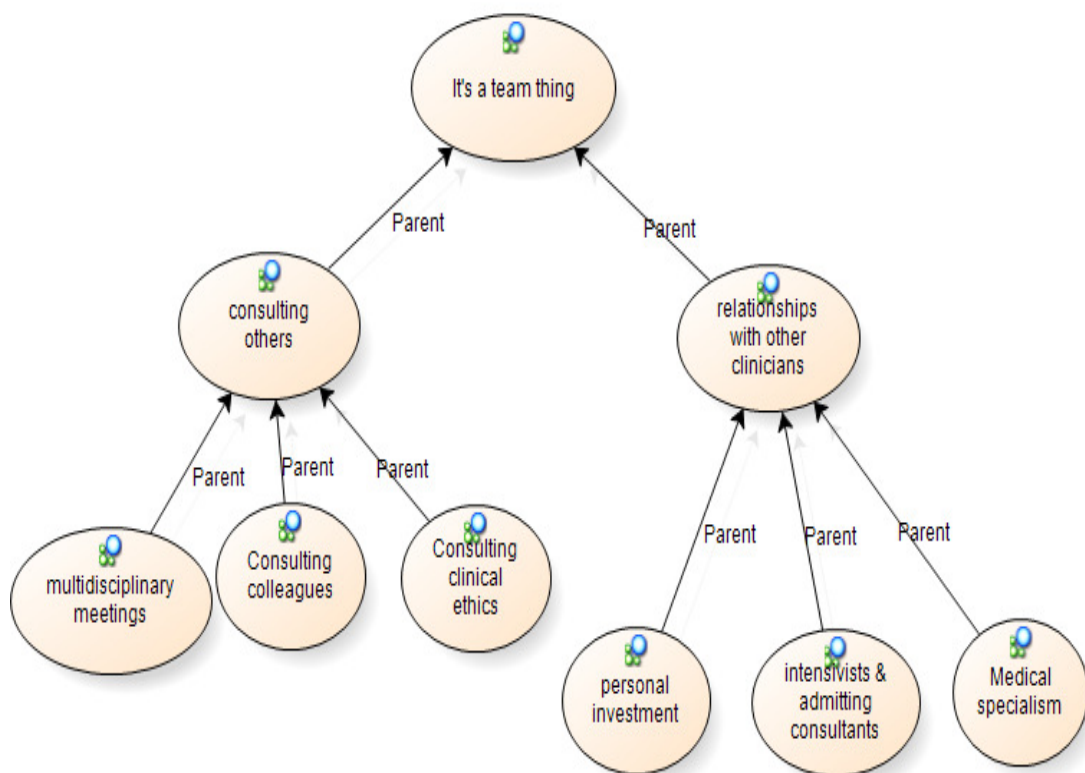
Diagram 2 Developing a sub-category.



These codes arose from several interviews with consultant doctors who mentioned that the admitting consultants often had a different relationship with

the children and parents. This was attributed by interviewees partly as a result of the type of specialism they practised and partly related to how long they had been treating the child and how well they knew them and the family. These three codes, when seen in the context of other data fitted under a more general category of relationships between doctors working in different aspects of a child's care. As coding continued, further links were made that started to develop a fuller picture as can be seen in diagram 3 below.

Diagram 3. Sub-categories leading to higher level categories



Thus the core categories emerged through a process that can be thought of as similar to tributaries of a river joining to eventually form a single large river. It is a feature of the NVivo programme that it labels higher level categories as the parents of the sub-categories and codes below. This might be thought to imply that the codes are the progeny of the categories and sub-categories. However as I hope I have shown the opposite is in fact the case. It is as the greater level

of abstraction is developed in grounded theory that the sub-categories and eventually core category emerge.

Initially a significant number of data packets/sections of interview transcript were coded to several NVivo codes concurrently. This strategy was questioned by my supervisor at the time but was continued for a few transcripts as a result of uncertainties regarding how to code various data. There is evidence in the literature that this is not uncommon in early coding (Schreiber 2001). As coding proceeded, and I began to identify clearer patterns in the data, this multiple coding became less prevalent.

In both exploring the transcripts during open coding and in developing the emerging categories I constantly reminded myself of the research question. This achieved with the simple expedient of posting a copy of the question and the study objectives on the wall in front of my desk. This ensured I maintained my focus on developing a theory of how ethical problems were resolved. In part this was because the strategy of interviewing as a conversation as outlined above led interviewees to talk about interesting asides. Within the interviews I was able to draw the interviewee back to the topic but it would have been relatively easy to be distracted in the analysis by these asides. Maintaining a reminder of the research question enabled me to avoid being diverted from the purpose of the study.

Once a transcript was coded those codes were often revisited several times in order to confirm the data was in the right code and to check the context in which the quotes appeared. A further feature of the NVivo programme was that sections of text that were placed under codes could, with a click of the mouse, take me back to the point in the transcript from which the quote was taken. This was particularly useful when similar words or phrases were mentioned in different interviews. I was able to immediately explore the context in which these utterances were made and make judgements regarding whether they were being used in a similar way by different participants.

In reviewing early transcripts as part of the process of axial coding (Strauss and Corbin 1998) data was uncovered that had not previously been coded or was moved during the process. There were also some instances of codes having been created from later interviews that were then found in the earlier data but at the time of initial coding had not been recognised. The strategy of listening to and transcribing my own interviews was particularly useful in this respect as I then had an aural and visual memory of the content of many of the interviews. This often triggered thoughts about how sections of data linked with others I had seen and heard earlier. These triggers tended to be words or phrases that were either very similar or contradictory to previous words or phrases, or struck a chord in my recollection of previous interviews. A good example of this was when several of the participants referred to what they termed negotiation. The term was mentioned in relation to how discussions might proceed with parents when it had been decided by the professional team that life preserving interventions should be withdrawn. However when exploring the interview data and the codes that had already begun to be populated I began to realise that what was emerging in respect of the health professionals interactions could be characterised as negotiation. What the interviewees termed negotiation, in respect of interactions with the parents, turned out to be aimed at persuading the parents to accept the medical opinion regarding the health status of their child. As more of the interviews were transcribed and analysed I began to realise that the way the early interviewees were using the term did not match my understanding of it as a concept. My understanding of negotiation is that both sides enter the negotiation without the outcome having been pre-determined. The notion of negotiation expressed in some interviews did not accord with this. I was prompted to examine this idea further to see if it did fit with the picture emerging from the analysis. It was necessary in this context to maintain an open mind to the data and not rush to apply permanent labels to the data. Similarly it was necessary to ensure that in analysing data with an open mind it was not with an empty head (Dey 2007). Thus rather than taking at face value what was being said about negotiating with parents I was able to contrast this with both my understanding of the concept and the content of later

interviews in which I gathered more information regarding the parents role in decision making.

An important part of the coding process was also to uncode sections of text that no longer fitted under the code heading. This was partly a result of the lack of confidence I had during early coding that led to the same quotes being cited at multiple codes. The need to uncode some items was also a result of the early opacity in my own mind about what was going on. As coding progressed I was able to clarify and refine codes, and part of this was ensuring the data focussed in on the code item. Thus the coding process with the development of the categories and their properties and relationships was much like topiary. Some data that did not fit was pruned. This process was facilitated to a significant degree by the creation of diagrams or models depicting the data. However the pruning did not always result in the loss of a code or a category's property. Many data packets and codes that were considered redundant or not part of the whole were saved in another part of the NVivo programme. This proved a useful tactic as further on in the analysis, some of these bits of data or codes were rescued and reintegrated when a clearer picture was formed.

5.5.2 Modelling/Diagramming

Models were created at various stages of the analysis from the data using NVivo that gave a pictorial representation of the NVivo nodes and their relationships to each other (Strauss 1987, Strauss and Corbin 1998, Schreiber 2001, Charmaz 2006). It is not uncommon for researchers new to grounded theory to become so immersed in the minutiae of codes that it is difficult to identify the links between them that may form the broader categories (Birks and Mills 2011). The modelling enabled me to step back from the detail of the coding to take a helicopter view of the emerging theory.

The process of creating and manipulating the models was an essential part of the analysis. It became obvious when the first level codes and emergent categories, created in NVivo, were viewed as a model that further analysis was

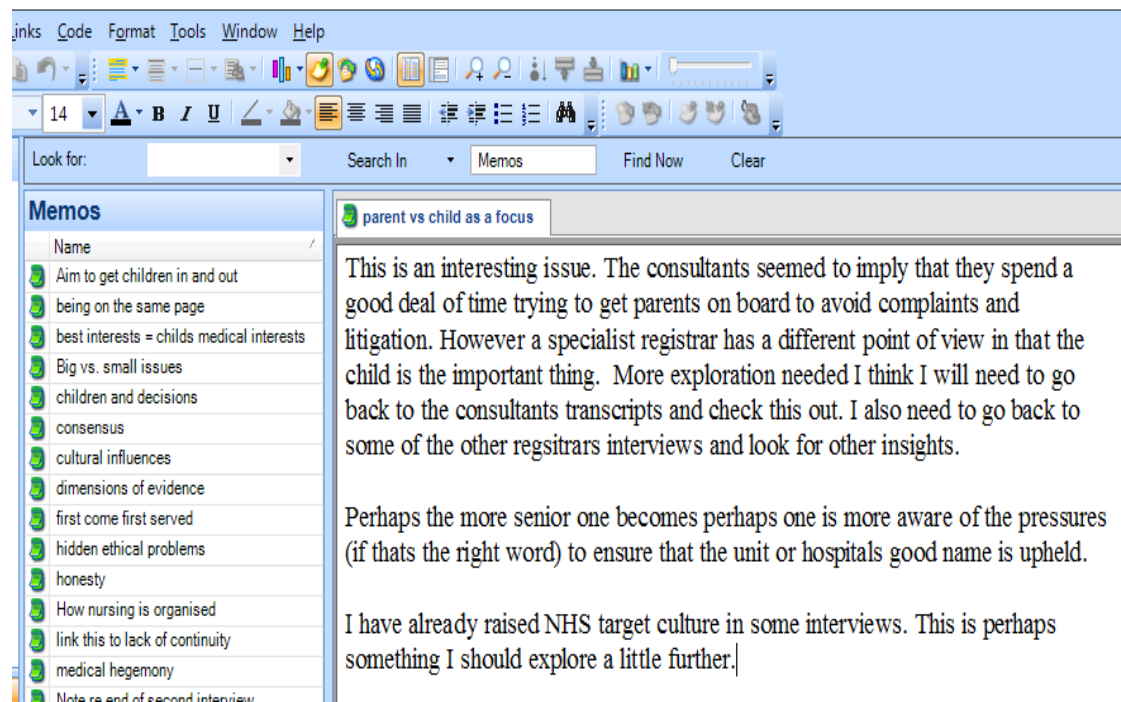
required in order to understand each of the emerging core categories and their properties and dimensions and relationships to each other. Thus as the analysis proceeded the models prompted re-entering the data via the codes, interview transcripts and memos, which in turn led to modification and clarification of the model as a pictorial representation of the categories. A key feature in NVivo that facilitated this process was the ability to click on a code shape in the model to open the relevant data held under that code.

The models however had their limitations in terms of engendering understanding of the process of resolving ethical problems in a children's intensive care unit. This was revealed when supervisors began to question the size and proximity of the bubbles used to depict categories and codes. It appeared to them as readers that there might be some assumed relationship between the size and proximity of the elements of the model and their relative significance in the overall picture. I realised that the models did nothing to aid clarity for the reader; thus although they were useful as an aid to analysis of the data they were deemed inappropriate as a tool for communicating the findings.

5.5.3 Memoing

Throughout the data analysis several methods of memoing were used. These memos recorded critical thinking as the analysis progressed. A number of memos were created inside NVivo, with links to specific portions of data or codes (diagram 4), to remind me to investigate an issue further.

Diagram 4 Example memo from NVivo8



Some memoing was done on scraps of paper when away from my computer and some was in the form of review comments in the thesis itself. As data were read and re-read, and as codes and categories were compared, memos were generated that enabled the establishment of the relationships between and within the categories. The memos were particularly helpful during coding and writing-up to assist in identifying the conditions, interaction among the actors, strategies and tactics and consequences (Strauss 1987).

Memoing also occurred during the writing-up of the analysis. Strauss and Corbin (1998) noted that the theory often becomes more refined as it is written-up in a paper or thesis. In writing this thesis, as I attempted to convey on paper the story being told by the data, memos in the form of comments in the Word document helped to remind me to review and check back on missing data or clarify interrelationships between various codes and categories that had not previously been revealed or were unclear. The process of writing for an audience prompted me to think about how to make sense of something that

sometimes existed largely in my head, and the memos were an essential part of getting my thoughts onto paper in a manner that made sense to another.

Strauss and Corbin's (1998) data analysis processes proved to be helpful in ensuring that the themes emerging from the data were truly that and not merely confirmations of my thoughts about what was going on. However as Kelle (2007) noted as a novice grounded theory user it was easy to get tied up in the apparent complexities of identifying categories, codes and properties. As they are not very clearly defined the early focus of analysis tended to be driven to identify and 'correctly' label the data. It was only after some considerable time exploring data and discussing the analysis with my supervisors that I was able to relax into the data and allow the theory to begin to emerge.

The use of NVivo 8 to manage data facilitated constant comparison of the data to check out the emerging themes. As the data was revisited and revisited again I was able to adjust the categories and attribute portions of data to those categories with more and more confidence. The use of the data management programme also facilitated what Silverman (2005) referred to as comprehensive data treatment. Thus I was able to inspect and analyse the complete data set time and time again, and using the search facility, was able to identify relevant portions of text for review very easily. This enabled me to ensure that the analysis and the presented findings were truly grounded in the data and not manufactured by my own perception of what was going on in the study site.

A potential use for the electronic storage of data and the analysis is that it could be audited by an outsider, after suitable anonymisation of the transcriptions, as there are links between the quotes held under codes and the source material. However as a novice largely self-taught user I have to admit that I did not make full use of all of the NVivo8 functionality. In addition the audit trail was not all it could have been from the early coding. NVivo8 automatically updates every 15 minutes and at closure thus earlier versions of work are overwritten. Future use of the programme would need to include regular saving of developing coding trees and models.

Verification

Part way through the analysis I decided that a verification process should be undertaken to check out the extent to which the emerging themes rang true (Denscombe 2010b). This involved presenting data to individuals who could give feedback on whether or not the categories were recognisable in the wider context of children's intensive care. This process at first appeared at odds with the characterisation of verification in grounded theory (Strauss and Corbin 1998). Verification in grounded theory takes place as part of the constant comparison of emerging categories with the data (MacDonald 2001). Thus the emerging categories and their properties were verified by revisiting data and the ongoing analysis of new data as it came in. However it was felt that both conceptions of verification were legitimate processes to apply to the study data.

The process of checking whether the emerging categories and themes rang true necessitated an application to the NHS REC who originally gave a favourable opinion to amend the study protocol. Following approval of this additional procedure it was arranged that I would present my initial findings to a group of intensive care nurses who were attending a post-registration education programme at my employing University. The group all gave consent based on information (appendix 6) they received via the module leader several weeks prior to the planned session. The data was presented in the form of the models I had generated from the codes, categories and their properties. The group recognised the themes I outlined as familiar aspects of their practice in dealing with ethical problems. It was interesting to note that in a preceding session where I was teaching the group on the topic of ethical problems in children's intensive care they spontaneously used phraseology very similar to that used by participants at the study site. This phraseology related to the perceived role of parents in respect of decisions regarding the potential withdrawal of life-preserving interventions from children.

What was important to recognise, following this presentation of the emerging categories and their properties, was that this did not constitute confirmation of

the theory. Whilst I presented the students with the main themes I had identified these were not fully formed and settled categories. What this exercise did was to imbue me with a sense of confidence that I was on the right track or at least one that was recognisable to others in the field. In presenting the models to the student group it was clear that what I had created at that point was a fractured picture of the data with some recognisable themes highlighted. I was unable at that point to articulate the theory as it became at the end of the analysis. The analysis continued beyond this point and the categories were further refined in order to delineate the theory.

Chapter Six

6 Ethical issues for the study

Prior to any research being conducted in the NHS involving staff or patients a rigorous process of ethical approval has to be negotiated. There was also a requirement to gain approval from the University in which I was studying. A prerequisite of NHS REC approval is that a sponsor is identified to accept overall responsibility for the conduct of the research. In my case the University was also required to provide indemnity against any harms arising from the research. Thus an application for ethical approval was made to the Faculty REC prior to application to an NHS REC. This chapter aims to outline the process of preparing and gaining this approval through an examination of significant issues. In addition I also explore ethical issues that arose in the conduct of the study.

There were a number of significant ethical issues that needed to be addressed in order to gain the favourable opinion of both the University and NHS REC. No data could have been collected prior to this favourable opinion. The most significant among the issues were;

- Gaining entry to the field. Ethical review and NHS Trust R&D approval.
- Informed consent procedures for all participants.
- Personal safety of the participant and interviewer.
- Procedures for maintaining confidentiality of the information discussed by professionals.
- Procedures for dealing with reports/evidence of less than acceptable/poor practice.
- Procedures for dealing with emotional issues during the interview.
- Procedures for ensuring the security of data storage and destruction at the end of any period of storage.

Additionally there were ethical issues that arose as part of the conduct of the study that required resolution and these will be explored in the final section of this chapter.

6.1 Gaining Entry to the Field

Gaining entry to the field was a three stage process. The first stage was to identify a suitable study site that would provide sufficient opportunity to gather data. The second stage was to secure an NHS REC favourable opinion that would allow the gathering of data from NHS patients and staff. The third and ultimately most problematic stage was securing the individual NHS Trusts R&D department approval.

6.1.1 Identifying a study site.

It was decided not only to focus on an area of clinical practice with which I was not familiar but also a particular site to which I had no previous exposure. This also meant that I was unlikely to encounter staff or patients/families with whom I had had previous contact. This had the advantage that my thinking was not contaminated by foreknowledge of the study site and how it operated.

The rationale for seeking a paediatric intensive care unit as the focus was multi-factorial. Firstly an assumption was made, derived partly from personal communication with clinical nurses, that it would be easier for staff to recognise ethical problems as such in an intensive care environment. This was assumed to be a function of the nature of the work in intensive care that heightens staff awareness of ethical issues. Thus potential respondents would be more likely to be able to provide data for the study.

Secondly the decision to focus on a single unit was driven largely by pragmatism, in the everyday sense (Denscombe 2010b), in respect of the ability of a part time researcher having the resources to engage with multiple sites. However this had to be balanced against the potential to develop conclusion

that would provide a picture of the process of resolving ethical problems applicable to a wider context of practice.

Thirdly the need to ensure the study could be completed in the context of a time and resource limited PhD was resolved by situating the study within a single unit. This limited the travel time required to visit multiple units, negotiate access and seek NHS Trust R&D approval for the conduct of the study.

Several NHS hospital trusts were considered before the final decision was made. The geographically nearest Trust was discounted as I had prior knowledge of both the unit and prior relationships in my academic role with a number of staff. Several units in neighbouring counties were approached with little success. None of the managers in these units responded to requests to meet to discuss the study. This was due at least in one case to a reluctance to engage until the Trust's R&D department had given approval in principle. On contacting R&D in several Trusts it became clear that as the study was essentially unfunded and would bring no financial benefit to the Trust there was an unwillingness to approve the study. I then met with the Modern Matron for the local unit to discuss the issue. He provided me with useful insights into several of the neighbouring units and suggested I approach a large unit in another health region. Two reasons were offered for this, the first was that it was a large and busy regional unit and the potential sample would be rich. The second reason was the he knew from experience that the recommended unit was supportive of research and the lead consultant was likely to support my application to the Trust's R&D. I subsequently met with both the lead consultant doctor and the nurse manager for the chosen unit to secure their support which they gave.

6.1.2 Seeking ethical approval

Following identification of a suitable study site and having secured support from the relevant managers I made an application to an NHS REC. Having supplied the application with the study protocol and all proposed participant information

sheets the application was reviewed by the committee. I was invited to attend the meeting of the committee and was asked to clarify the data security measures I intended to use and a typographical error regarding the proposed dates for data collection. I received a letter confirming a favourable opinion had been given for my study 10 days after committee met. The subsequent amendment to the protocol referred to above was dealt with by correspondence.

6.1.3 Research and Development Directorate Approval

The NHS REC procedures required that a separate, but parallel, application was made to the R&D directorate for the study site. This separate but linked process enabled the NHS Trust to determine that the relevant support existed within the Trust and that no resource burdens would accrue to the Trust. Additionally the R&D had to be assured that the appropriate honorary contract had been secured prior to final approval for the study to proceed. The honorary contract had been agreed and was in place with the required Criminal Records Bureau checks having been satisfactorily completed prior to submission to the NHS REC. It was however late November before the Trust's R&D confirmed the study could proceed. This was an unexpected delay to proceedings since it was originally planned that data collection would commence in September of that year. The delay meant that as the Christmas period was approaching it was deemed an inappropriate time to begin sending out invitation letters and information sheets to prospective participants. Thus the first invitations were distributed via the relevant manager in early January. The delays in securing final approval and the difficulties encountered in recruitment referred to above led to an application to extend the honorary contract with the Trust to ensure I could legitimately continue data collection beyond the original projected date.

6.2 The process of gaining consent

Securing consent, particularly perhaps for a study that would potentially explore issues that would raise distressing memories, was a key consideration in preparing for this study. A key part of the process of gaining consent from participants was the information provided to enable them to make an informed decision regarding whether or not to volunteer in the first place. Thus a great deal of time and effort was expended on preparation of the participant information sheets (PIS)(appendices 1, 3, 4, 5 & 6). Separate information sheets were required for NHS staff, parents and children. The children PIS was further subdivided into separate versions for 8-10 year olds, 11-15s and 16 and above. The reason for creating a single sheet for 16 years and above, which could conceivably have included individuals who were 18 years and over i.e. adults, was two-fold. The cognitive abilities and reading age for anyone 16 years and above was assumed to be the same for all. However a more important consideration was the legal age for consent to research. Without detailing the complexities of the law my experience on an NHS REC was that the European Directive regarding research into medicinal products was used as a general guide to issues relating to consent to research of those 16 years and above. Whilst this was not strictly true for interview based studies, the knowledge that RECs used that as a criterion for judging age divisions for information sheets and consent was a determining factor in my decision.

The National Research Ethics Service (2007) guidelines were used as a basis for the construction of the PIS. These guidelines largely provide guidance on the headings under which information should be included along with reference to other supporting material. This enabled me to ensure I was compliant with the minimum standards expected of PIS for research in the NHS. However the guidance regarding the preparation of PIS for children was not helpful and it has been noted that at the time there existed little empirical literature on compiling a participant information sheet for research (Ford et al. 2007).

The various versions of the PIS were reviewed by a number of individuals, who had no knowledge of this study, and thus were able to judge whether the information was clear and succinct. I asked all those who reviewed the sheets to tell me what they thought the study was about and what would be expected of a volunteer. This was particularly useful for the children's sheets as my own 10 year old read and commented on them. His view was that the children's PISs were boring as there were no pictures. He was also able to suggest alternative words and phrases, in a couple of places, that he felt would be more appropriate. Following this the children's PISs were heavily revised and copyright free pictures were applied to each section to illustrate what each paragraph was about.

As part of the construction of the PIS for children a great deal of thought was given to the issue of confidentiality. Adults have an obvious and well established right to confidentiality about their healthcare and what they might reveal as part of a research study. The situation with children under the age of 18 years is less clear. It was decided that it was important to acknowledge any children who volunteered as equal voices in the research. Thus assurances were placed in the PIS that information they provided would not be shared with their parents without their express permission. This information was also provided in the PIS for parents so that they were aware of the commitment made to their child. This enabled parents to decide for themselves whether or not to allow their child to volunteer for the study since they were to be the gatekeepers in respect of the recruitment of children.

All participants signed a declaration of consent (appendix 7) immediately prior to the interviews taking place.

6.3 Personal safety of the participant and interviewer

Safety of the participants and researcher was a key consideration for this study. The Social Research Association guidelines (Social Research Association undated) were used to guide safety procedures throughout the study. When

interviewing at a participant's own home, a number of precautions were taken with respect to my own safety. A colleague at my workplace was given my itinerary and arrangements were made that I would telephone before entering the premises. It was agreed that if I did not telephone back within one and half hours they would call my mobile phone. If there was no response the authorities would be alerted.

All participants were shown my staff identity card and the PIS carried my photograph to enable participants to identify me. Where interviews took place in private areas of the hospital, a member of staff on the study unit was informed of where we would be to ensure the participant safety. An enhanced criminal records bureau check was conducted by the NHS trust to facilitate the honorary contract which allowed access to the hospital premises and bound me to the Trust policies. This check enabled me to conduct interviews with those under 18 years. In the event any children were to be interviewed, arrangements were in place to ensure a suitable chaperone was available - whilst maintaining confidentiality (appendix 4).

6.4 Dealing with revelations of poor practice

Since the interviews were conducted as conversations and in as relaxed a manner as possible, the potential for participants to unwittingly reveal poor or unethical practice was a possibility that required attention. Even if I could have legitimately claimed that as a researcher any information given to me remained confidential, as a registrant with the Nursing and Midwifery Council, and subject to their code of conduct, I could certainly have made no such claim. Thus it was made explicit in the PIS that such revelations would be reported to the appropriate authority. It was particularly important that this was clarified to any child volunteer to the study.

6.5 Dealing with emotional issues raised during interviews

An agreement was made with the Trust that if a participant became unduly upset by discussing emotionally challenging events I was empowered to refer them to the Trust's support and counselling services if necessary. It was also agreed in the case of parents that an immediate referral to the Family Liaison Nurse could be made.

6.6 Data security

A number of processes were put in place to ensure the security of sensitive or confidential information. Reply slips with contact details of participants were locked in a secure cabinet. Similarly the paper copies of consent forms were locked in the same cabinet. In transit from interview, the digital recording device was kept on my person at all times until safe return to home or office. This was because there was no facility to password-protect or encrypt the audio files on the recording device. No names were recorded on the interview audio files but it would have been possible for someone to recognise the voice. Thus all recordings were transferred as soon as possible to password protected files on a computer that had an additional password to access the device itself. The files on the recording device were then deleted. Transcribing was completed from the files on the pc. All transcripts were stored in password protected files on the pc.

6.7 Ethical issues arising during the conduct of the study.

I was alert to the potential for ethical issues to arise as part of the conduct of the study. No significant issues arose that required reporting to any authority. There were several issues that arose that caused pause for thought. The first issue became apparent at the initial interview with a junior doctor. She revealed that the lead consultant intensivist, her boss, had positively encouraged her and the other junior doctors on the study unit to volunteer to be interviewed. This raised an immediate question, for me, in respect of the voluntariness of the

participants for the study. However I was reassured by this and the other participants that they felt free to volunteer and had made their decision to participate after having read the participant information sheet I had created. I was further reassured when it became apparent that only a small proportion of the junior doctors working on the study unit actually came forward as participants in the study. This supported a view that only those who had a desire to participate had actually volunteered.

The nurse manager, although expressing support for the study when we met initially apparently, delayed sending the invitation letters to nursing staff. In the meantime I had established communications with two research nurses working on the unit. They were able to establish on my behalf that the invitation letters had not been distributed. They therefore agreed to obtain the nurse manager's signature on the letters and distribute them as had been agreed. Additionally I supplied one of the research nurses with a brief paper (appendix 8) outlining the research for her to post on the staff bulletin board on the unit. It was agreed that if no responses were forthcoming from the invitation letters I would attend the afternoon handover meetings on the unit for a week to inform staff of the study. These two related strategies required careful handling since the recruitment process for the study had been approved by the NHS REC and the Trust's Research and Development (R&D) department and I was unable to deviate from this without prior approval. The terms of the approval did not allow for advertising to recruit to the study. Therefore the information sheet I constructed merely provided information about the study and did not constitute a recruitment device as no invitation to participate was included. Although I did include my contact details the briefing paper did not include any invitation for staff to contact me for further information since this could be interpreted as a direct invitation to participate which would be outside the existing approval. Similarly my presentation to staff was to have been in the form of information about the study to facilitate awareness of the project within the unit and the recruitment methods.

It was apparent at the commencement of a number of interviews with both doctors and nurses that the purpose of the study was not clear to them. Several doctors assumed that the study was focussed on end-of-life issues. Some nurses had been under the impression that the interview would be a kind of test of their knowledge of ethics rather than an exploration of their experience of resolving problems. A number of the health professionals interviewed confessed that they had not really read the PIS in detail. This created an ethical problem for the researcher. Could it be legitimate to take consent from a volunteer who did not fully understand the nature and purpose of the study? It is not necessary here to detail a consideration of the legitimacy and meaning of informed consent or to debate concepts of vulnerability, and whether NHS staff could be considered as such. Where it was identified, before an interview commenced that the participant was not clear about the purpose of the interview, I re-iterated the purpose of the study. I also established to my own satisfaction, through questioning the participant, that they did then appreciate the purpose and scope of the study and the implications of participating.

Chapter Seven

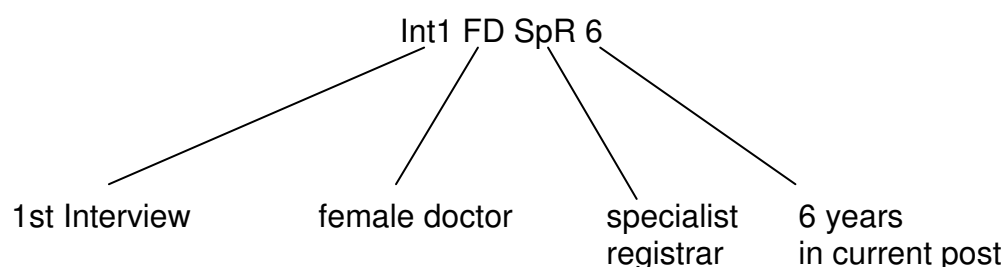
7 Findings

This chapter reports on the findings of the study that were developed from the analysis, described in chapter 5, of all the transcripts of the interviews conducted with health professionals and parents. Direct quotations from the interviews have been used throughout this chapter. These quotes generated the codes and the categories from which the theory emerged. The chapter opens with an explanation of the nature of the ethical problems encountered in the study unit as identified by the participants. This is followed by an overview and broad explanation of the structure of those codes and categories and their relationships with each other. The remainder of the chapter provides an account and explanation of the findings in respect of the core category, sub categories and the respective properties and dimensions of those categories. A theory of how ethical problems are resolved in the children's intensive care unit which is grounded in the findings is presented at the end of this chapter.

To add some context to each quote from the interviews with participants I have labelled each direct quote using the descriptor abbreviations listed in table 3 below and according to the convention illustrated in diagram 5.

Table 3. Descriptor abbreviations for direct quotes

Label item	
BP	Both Parents
Cons	Consultant
Ex-ITU	Admitting Consultant
FD	Female Doctor
FN	Female Nurse
KP	Kevin Power, the researcher
MD	Male Doctor
MP	Male Parent
SpR	Specialist Registrar
Number	the number of years in current role or in the case of parents the number of days or months their child was on the study unit

Diagram 5. Illustration of quote labelling

Thus the first item of quoted text below was taken from the first interview which was with a female specialist registrar who had worked in children's intensive care for 6 years.

7.1 The nature of ethical problems identified by study participants

End-of-life ethical problems

At the outset of interviews, when asked the opening question “what ethical problems do you face in your practice?” nearly all participants focussed on the ethical problems relating to the end-of-life issues.

“Yes well I guess the big the, big ones that you remember are always the sort of withholding and withdrawing [treatment]...” (Int1 FDSpR6).

“...the key area is about how far you should go or what you should limit therapy...” (Int12 MDCons10).

“I suppose a lot of them er the easiest ones, well not the easiest ones, but the easiest ones to think of are the ones around death and dying.” Int16 FN8).

“The most ethical issues that we come across would be being able to support the family in their wishes also knowing that maybe you’re prolonging that life of a child that it may not be ethically correct to do.” (Int17 FN4).

Indeed some participants appeared, at least at the commencement of an interview, to perceive end-of-life situations as the only source of ethical problems.

“The usual thing that we come across is er pertaining to the withdrawal of intensive care or stopping treatment that’s the most common thing you know if you asked me anything less than that er we don’t really come across...” (Int2. MDSpR6).

When referring to end-of-life situations participants talked about both the withdrawal and withholding of life-preserving intensive care interventions. Withdrawal referred to stopping or ceasing the escalation of life-preserving medical interventions. Withholding referred to situations where it was judged inappropriate to initiate life-preserving medical interventions which included decisions about declining admission to the intensive care unit.

There were two distinct ways in which life-preserving intensive care treatment might be withheld from a child. One was by declining to admit the child to the intensive care unit thus denying them those interventions. The other was to not provide certain interventions even though a child had been admitted to the unit. The withholding was a significant issue for those admitting consultants caring for children with life-limiting or degenerative disorders.

“We often have children who are quite sick and they [the intensive care consultants] and we know that if the child doesn’t have an underlying neurological condition that child would be in intensive care. However intensivists often feel that it’s not appropriate to offer these children intensive care.” (Int7 FDCons5-exITU)

“So I think some of the main ethical issues for us is always getting patients into intensive care.” (Int8 MDCons6-exITU).

Difficulties were experienced by these consultants in securing an admission to intensive care. They attributed this to a presumption on the part of intensive care clinicians that no improvement in the child’s wellbeing could be achieved or, possibly worse, that once artificial ventilation was initiated spontaneous respiration could not be re-established within a reasonable time frame, if ever.

“If we can be actually certain that a short period of PICU would make a difference then PICU’s [the intensive care consultants] more willing to take them. But I think PICU’s very concerned that we put them on to PICU and they won’t come off the ventilator.” (Int7 FDCons-exITU5).

The intensive care professionals identified the key ethical problems as those relating to withdrawal of life preserving interventions. Whereas the admitting consultants interviewed for the study talked about withholding of interventions as a key problem. Issues centred on end-of-life situations were then a major focus for all the participants in the interviews for this study.

Other ethical problems

When I specifically probed in interviews other ethical problems were mentioned by participants. These other ethical problems included questions about whether

to reveal information to parents; how far to allow a junior nurse or doctor to go in practising a clinical skill; organ donation; balancing professional and personal duties; managing resources. These problems appeared to be given much less importance than those pertaining to end-of-life situations. I had to specifically probe for these other ethical problems as they were often not volunteered when the initial interview question was posed.

Nurses talked about difficulties experienced in responding to requests for information from parents and family.

“it’s hard for me to pre-empt that if the doctor wants a word and you know they’re [the parents] saying ‘well what does he want to talk about?’ and I know damn well what they want to talk about but I don’t think it’s my place to be say what the surgeon should be saying and we’ve tried this that and the other thing.” (Int9 FN12).

“if you know bad news you can’t you know you want to you know you don’t want to ..I don’t like to say I don’t know erm so I suppose that’s why I do something like say ‘well I’ll get the doctor’ ... (Int14 FN3).

This problem seemed to relate to a desire to provide the parents with information that the nurses felt they had a right to know but felt constrained to provide.

Lack of evidence

Another ethical problem the participants referred to was related to making decisions about the most appropriate clinical interventions in the face of little or no empirical evidence. This was an issue for the specialist registrars particularly.

“I find just even daily things for instance erm even like drugs [mhmm] a lot of drugs are not licensed for children and having to work in intensive care there’s even more drugs because of the nature of the disease of the children” (Int3 FDSpR3).

“In paediatric intensive care is that a lot of stuff we do doesn’t have any necessarily research or evidence base basis so actually we’re probably making sort of reasonably ethical type decisions every day because we’re

deciding what's best for the children based on our own our own opinions.” (Int1 FDSpR6).

This second doctor seemed to be inferring that where empirical or other evidence existed to support the initiation of an intervention or treatment an ethical problem did not exist. The implication in this participants account was that there would be little or no hesitation in apply an intervention if was already established as an effective treatment under the pertaining circumstances. The issues relating to the use of evidence in deciding what is best for a child is explored later in these findings.

Junior staff learning clinical skills

Both doctors and nurses experienced problems such as when to allow a junior member of staff to undertake interventions and how far to allow a procedure to progress before stepping in.

“Just because there's a child whose on the ventilator unconscious who needs a line, because, I don't know the parents aren't around, or it's not an issue that you somehow abuse that and protectiveness from the parents by allowing 'well the junior can do this one because Mum and Dad aren't around.” (Int6 MDSpR3).

“You've got to let these new people find their feet and do you know they've got to learn their skills they need to they've not done this before. So it's quite often its letting them do stuff while supervising them but ethically I sometimes think 'could I do it better?'" (Int19 FN4).

Both doctors and nurses sometimes struggled with the question of how to balance the needs of new staff to learn and practice clinical skills with the duty to protect a child from harm. The professionals' perceived duties to children in their care emerged as a significant factor in the process of resolving ethical problems. This is addressed in more detail later in this chapter.

Organ donation

One participant talked about the difficulties she faced with respect to organ donation.

“...erm organ harvesting because again that’s another ethical issues as well, you know you’re prolonging something not in this particular child’s best interest but would again benefit somebody else as well” (Int3 FDSpR3).

The problem for this doctor was the need on occasion to maintain interventions that sustained perfusion of the vital organs, so they remained viable for transplant, without bring any benefit to the donor child. This did raise a question for me in respect of whether or not a child diagnosed as brain dead could have any interests. I did not pursue this line of enquiry since it was prompted by a single mention by only one participant.

Balancing clinical duties with family responsibilities

The same doctor was the only one who talked about the ethical problems they experienced in balancing their duties to the children in their care on the unit and their own family.

“So it’s not so much I don’t want to come to work I’m not trying to skive or whatever it is but at the same time I have a primary concern or family responsibility to my [own] children.” (Int3 FDSpR3).

I had expected to hear more from participants on the issue of balancing duties to children and families with those they owed to their own families. My clinical experience informed me that this is a common issue for NHS staff. It is not always easy to get off duty on time when a shift finishes if there is no one to take over the care being given. However as I detailed in the methods chapter the interview strategy was to explore only those ethical problems each participant identified thus this was not pursued with other participants.

Perceived resource issues

The mismatch between the availability of intensive care beds in the study site and the numbers of children needing a bed created a regular ethical problem perceived by the medical staff. The nurse participants did not refer to this issue

and that may have been related to the fact that none of those interviewed held a role in respect of the overall management of the unit.

“If you have 20 beds on the unit and you have 20 patients physically in there and you want to get the 21st patient in which then puts pressure on the nurses, the doctors the safety of the unit and therefore increases the harm to the 20 patients are primarily responsible for. You have to balance that to what will happen to that patient if you don’t take them.” (Int6 MDSpR3).

“I suppose yes that the internal sort of thought processes and the ethics of that, at a more sort of day to day level, we are constantly in conflict with everybody wanting beds.” (Int12 MDCons10).

This problem then was not one merely of capacity of the unit but was felt as an ethical problem that was founded in the perceived duty to ensure children in need of intensive care received it. To resolve the problem of bed capacity in the unit a policy was negotiated between all the intensive care and admitting consultants and hospital administrators. The policy that was developed was referred to as the 21st bed policy.

“So what we’ve got is the 21st bed policy and the 21st bed policy actually was looked at by the ethicists because of this very problem that capacity is such an issue for the intensive care unit here and around the country.” (Int11 FDCons10).

The 21st bed policy was a specific set of guidelines that determined when it was appropriate and safe to utilise a side room just outside the main intensive care unit. This covered situations where a child was too ill to be transferred out to another facility in the hospital but an intensive care bed was needed for an emergency admission.

“You have to er you have to balance up on the demands of each of the individual patients and the key would be to put a patient who is less highly dependent in that space so that you can still give the provision but you know that that patient because they are slightly out of sight.” (Int6 MDSpR3).

The demands referred to by this doctor were the clinical needs of the child rather than a strong request from the parents for a side room for privacy.

The use of the 21st bed depended on the availability of appropriately experienced intensive care nurses to care for the child. Since this bed was not on the main unit it was recognised that the potential for a lower standard of care existed. Thus only the more senior and experienced nurses were assigned to this room whenever it was used. Thus the availability of these resources was a significant factor in the negotiations regarding the potential admission of a child to the unit. However it was recognised that this practice also had to be balanced against the needs of the other children on the unit.

“So while you’re in the main unit and you’re looking after the ones [on the unit] you have to be aware that that patient you’re not looking at. Therefore you have put trust in the nurses out there [in the 21st bed room] and they [nurse managers] will generally send more senior nurses which then depletes the senior nurses’ capabilities on the unit.” (Int6 MDSpR3).

When the unit neared capacity there appeared to be an element of luck in securing an intensive care bed, in that a first come first served approach was used.

“So simplistically if there were two equally urgent cases then the one that got referred first would get accepted and also try to factor in where else the patients could go and whether there is a safe alternative.” (Int12 MDCons10).

There was also a crude hierarchy applied when allocating intensive care beds when capacity became an issue that prioritised those children who were already in the hospital.

“It’s somebody who is already in the hospital and we’ve... the hospital has a responsibility for because they’re here.” (Int11 FDCons10).

All other things being equal then, a child already resident or being treated in the study unit hospital’s emergency department would take precedence over a child referred to the unit from another hospital at the same time. This approach appeared to be related to the perception of the duties that were owed to certain children which outweighed any general duty to other children who might equally need an intensive care bed.

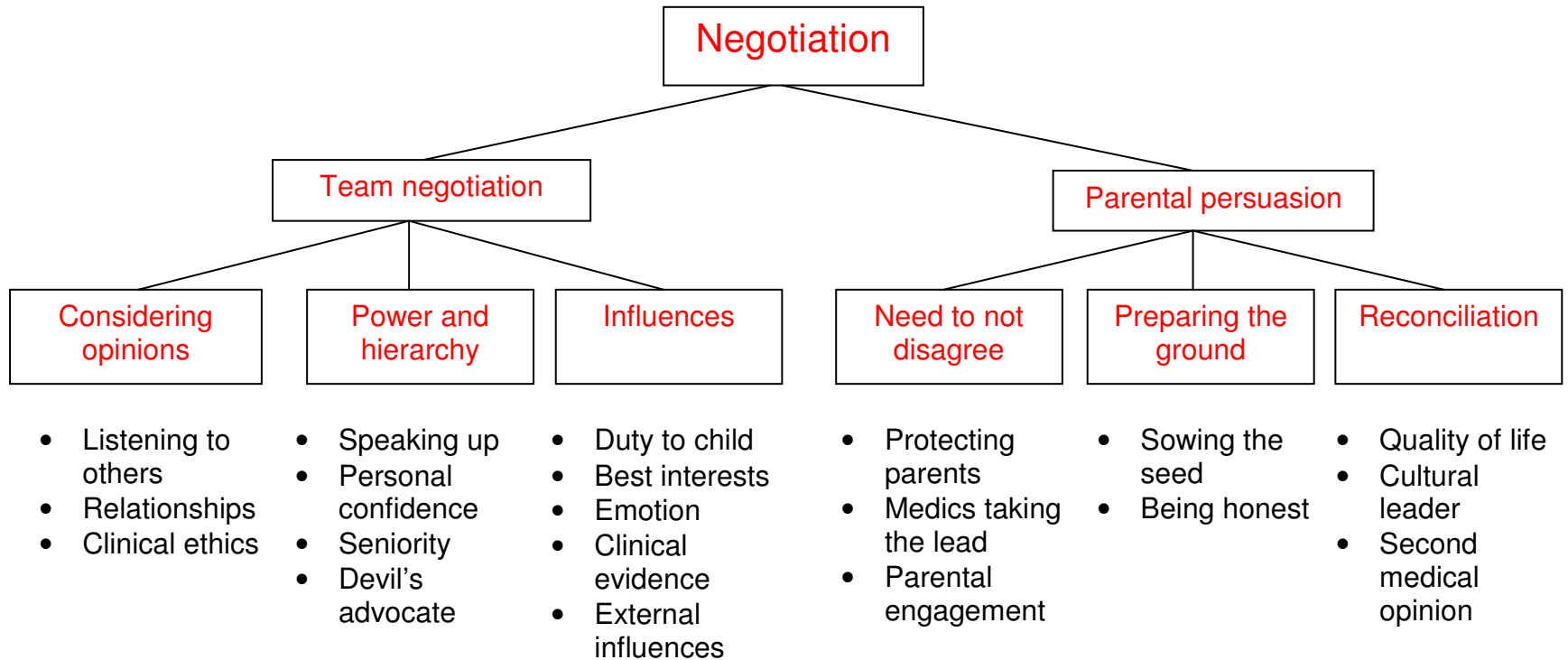
Reasoning about ethical problems

When I probed for accounts of how an individual resolved such problems participants found it difficult to articulate the reasoning process they used. Some of the participants made reference to broad ethical principles such as do no harm and the child's best interests but offered little by way of explanation of their underpinning reasoning. When attempting to gain deeper insights into the process of resolving ethical problems, participants often took refuge in the familiar territory of clinical factors that underpinned their thinking. It was difficult for them to articulate the distinct ethical issues that impact on their work. However some participants made reference to professional duties related to codes of practice and following the example of others, particularly when they had been students or were junior members of staff. Unwritten rules, of which the participant could not identify the source, were also mentioned. Participants also referred to custom and practice based on their professional education and clinical experience as a guide to resolving a problem they faced. Participants were more forthcoming about the process of resolving problems relating to end-of-life decision making.

The remainder of this chapter details the findings of the study following the structure of the core category of negotiation, the main categories within the core category and the properties and dimensions of the subcategories. The results of the analysis of the transcripts of all the interviews are presented in diagram 6 below. This depiction of the findings facilitates the presentation and explanation of the findings that emerged from the analysis rather than a description of the theory grounded in the data. The theory that was grounded in the findings of this study is unveiled at the end of this chapter. The findings as presented here were almost entirely developed from the perspective of the health professionals. This might seem obvious when viewed in the context of the profile of participants in this study (table 2). However as I shall show below there were also insights provided by the parents who did participate that contributed to the whole.

The core category labelled negotiation was generated from the two main categories of team negotiation and parental persuasion that were identified in the data. These in turn were developed from the sub-categories with their respective properties and dimensions. An overview of the core category and contributing categories and their properties and dimensions is presented in diagram 6 below.

Diagram 6. Overview of the Codes and Categories from which the Theory emerged



7.2 Negotiation: The Core Category

The core category that emerged from the data was negotiation. Negotiation first occurred as a code arising from an early interview and reappearing in many subsequent participant's accounts.

"We have one or two patients here who are just being at the negotiating stage at the moment."

KP "Ok so what does that mean when you say it's at the negotiating stage?"

"You know, medically the whole team agrees that there is nothing more we can offer" (Int2 MDSpR6)

"Western culture is very much negotiation and empowering the parent" (Int3 FDSpR3).

"you share with the family and try and go through a process of negotiation with or without other stakeholders and others in the process." (Int12 MDCons10).

As the interview data was collected and analysed and coding continued it became increasingly clear that negotiation was the concept to which all other categories were related. I also found that, when giving an account of the process of establishing a consensus in the professional team, although participants did not always use the word negotiation it emerged, as I shall show below, that negotiation was central to the establishment of that consensus. The negotiation with parents mentioned by participants contrasted in nature with the negotiations between the various professionals involved in a child's care and treatment. The negotiations with parents regarding withdrawal of life preserving interventions were not open in a way that enabled parents to affect the decisions that professionals had already arrived at. The negotiations with parents it emerged were aimed at establishing their agreement or at the very least their non-disagreement with the decision to withdraw life-preserving interventions. Thus what the participants referred to as negotiation with parents formed the subcategory I labelled parental persuasion. The two main categories

identified in the data were thus labelled *team negotiation* and *parental persuasion*. These subcategories developed out of a further subdivision of categories as depicted in diagram 6.

7.3 Team Negotiation

Team negotiation as a category arose most significantly from descriptions participants gave of the ethical problems that were encountered in end-of-life situations. However it was clear in the interviews that in any ethical problem in which two or more professionals were engaged essentially the same process occurred. The interviews revealed a key factor in this team negotiation was the consideration of the opinions of other healthcare professionals, both within the immediate team and more widely. This was influenced to an extent by the hierarchical structures that existed within the unit and the wider hospital. The content of the consultations between the various professionals was influenced by a range of factors including:

- perceived duties to the child and family
- the best interests of the child
- the emotional content of decisions
- interpretation of clinical evidence
- professionals' perception of external influences on decisions

Some end-of-life problems were those where judgements were being made about withholding interventions by denying the child admission to the unit. The majority of the ethical problems identified by participants related to making a decision about at what point life preserving interventions should be withdrawn from a child. It became clear in the interviews with health professionals that, in respect of decisions regarding withholding or withdrawing life preserving interventions from children, establishing consensus between the members of the professional team treating the child was key. It was only after the establishment of this consensus that the parents were approached to discuss

the decision that the professional team had arrived at. The pattern of negotiation was the same, albeit with varying numbers of players involved.

Sometimes there was a straightforward negotiation between two consultants regarding how to proceed with a child's treatment.

"I had a child I was convinced was dying, and I called the oncologist and said 'he's dying, is there anything else that you want to do? Can you stop him dying?' and I was clear the oncologist did not want to give up. I said 'well he's dying, you're going to have to do something different today, we have to have a change in medical therapy and then we have to assess whether that medical therapy has made a difference and if it's not we have to accept the inevitable.'" (Int11 FDCons10).

The intensive care consultant went on to say that if the oncologist could initiate some intervention in respect of the cancer that would stop the child dying then life-preserving interventions could continue. In this instance the oncologist agreed that nothing more could be achieved in respect of the cancer and thus a consensus was arrived at. It was at this point of consensus that the parents were approached with the recommendation to withdraw life preserving interventions. This then was an example of what was presented as a simple process of a discussion between consultants to establish a consensual view of how to proceed with a child's treatment. The majority of the situations discussed by health professional participants, particularly those in respect of withdrawal of interventions, involved the whole care team.

There was evidence that team negotiation had, in the past, not been in operation.

"I mean definitely it's [securing an intensive care bed for a child with a neurological condition] become less of an issue now but like 4 or 5 years ago there were certain consultants who you just didn't even want them to be on because you knew you would get no as the answer." (Int7 FDConsex-ITU5).

“I think that’s erm just one of the many things about how intensive therapy has changed in that we actually have a team rather than a group of individuals at the top of intensive care and I think a lot of decisions have a sort of corporate feel to them rather than an individual feel” (Int11 FDCons10).

Thus it seemed that the process of negotiation between the members of the whole care team had developed over a period of time. It was not clear however, if this was as a result of a deliberate strategy or something that naturally grew.

As part of the process of negotiation various forms of team meetings occurred where both formal and informal discussions with the wider team regarding a child’s care and treatment took place. There was also a strong sense from the data that professional staff were able to, and even expected to, speak up if they had something to say about a situation rather than wait to be asked for an opinion. All of these negotiations were influenced by factors that informed the process of resolving ethical problems. In large part these factors tended to relate to interpretations of clinical data. However personal and professional perceptions about a child’s best interests and perceived duties of care to the parents were also significant factors influencing the negotiation processes.

Negotiation often involved more than two consultants and frequently involved the whole professional care team. The team constituted some or all professional staff involved in the care and treatment of a child. This principally included the intensive care nurses and also involved those such as dieticians and physiotherapists.

“...it’s never ITU that are solely responsible for the child it’s the respiratory team or the neurology team or the whatever, the cardiology team so you’d have to get your team and the nursing staff and the physios and ask everyone what they think.” (Int1 FDSpR6).

“I think particularly where in intensive care and in paediatrics generally where erm it’s pretty much team work rather than..even though we do have a consultant paediatrician figurehead it is very much a team decision” (int3 FDSpR3).

“...I try and keep it as smooth as possible and that we work I try and work

as a team.” (Int7 FDCons-exITU5).

“...we’d have that discussion away [from the bedside] and sort of and say ‘this is the problem I think it’s okay to do this how are we going to solve it?’ and erm and that’s often a way that these sort of difficult issues are solved...” (Int13 MDCons10).

“It would tend to always be erm a team decision we’re very lucky we have quite a close working relationship with our consultants and our doctors” (Int17 FN4).

Consultant intensivists regularly discussed with each other how to proceed with a child’s treatment as part of the normal day to day routine.

“And the way we run the intensive care unit is every day, every week day there are three consultants at the ward round and most of those decisions are discussed at that ward round.” (Int11 FDCons10).

This process of almost continuous discussion of issues within the medical intensive care team was also reflected in the way the nurses talked to each other throughout the day to seek advice about managing situations.

“I think sometimes you might go through your team leader or you might go through the coordinator the band 7” (Int4 FN5)

“So the general process is that you you’re at the bedside and that you then talk to your team leader.” (Int16 FN8).

There were also more formalised processes as well as informal avenues for consulting with others regarding the best course of action for a child’s treatment.

7.3.1 Considering opinions

It was a consistent feature of the accounts given by participants that in situations particularly where ethical questions regarding end-of-life decisions arose all members of the professional care team had a legitimate voice. It was viewed as important to maintain good relationships between all members of the team, especially perhaps among consultants. Multidisciplinary meetings emerged as a key facet of this process that was founded on the nature of the relationships between the various members of the team. It was also clear that

as part of the team negotiation that consultation outside the immediate care team in the form of a clinical ethics committee also occurred.

Listening to others

There was evidence that even though actual decisions, and the major proportion of negotiating resolution of ethical problems, occurred at consultant level other members of the care team were listened to. Senior specialist registrars nearing a consultant's post were consulted directly for their opinion. The nurses and more junior doctors were not necessarily actively consulted in the negotiation process but did have the opportunity to put across their point of view. This was done either directly to individual consultants at ward rounds, or within one of the multidisciplinary meetings. It was acknowledged that nurses could make an important contribution to discussions.

"Often the nurses are the first people to...[identify when intensive care should be withdrawn].. they can often come to the conclusion..." (Int11 FDCons10).

"To be fair sometimes we do get a lot of things from the nurses because often the nurses will actually take the vibes, know what's going on more at the bedside." (Int3 FDSpr3).

"There's generally an open door policy in that the consultants are there [present on the unit] and more than happy to speak to the nurses. There is a good working relationship between the nurses and medics I feel that makes it easy to sort of say anything that you want to." (Int16 FN8).

It was perceived by nursing staff that their opinions were listened to and did make a difference to the outcome in some cases.

"You know you can't quite get to grips with 'what are we doing to this child it seems cruel and what is going to be the outcome at the end of this?' erm and I know in the past having raised that sort of concern and another nurse had raised it as well erm they did actually withdraw care." (Int16 FN8).

"We are asked and I'd say say most of the time those thoughts that we give them are taken on board." (Int20 FN5).

Nurses' and junior doctors' motivation to voice an opinion appeared to stem from their personal views about what was right for the child.

"If I felt that I was doing something wrong and that I was hurting the child by doing this, then absolutely I'd say 'no stop'." (Int17 FN4).

"Soyouyou have to balance what's practical and...you have to go... put the pressures on to the people around you to try and do what you feel is right for the patient." (Int6 MDSpr3).

"But it is very easy from the nursing point of view to say 'what on earth, why are we doing this to this poor kid?'" (Int20 FN5).

However there were practical issues that impeded some of the nurses' engagement in the discussions regarding issues related to the child in their care. This was because of the manner in which the allocation of duties was operated. The nurses' shift patterns did not always facilitate working with the same children every day.

"You don't get consistency so because you're with a different child every day." (Int14 FN3).

"Sometimes you lack the continuity of the care. You've met this child for 6 hours and that's the only shift you've done." (Int 17FN4).

"We're not always brilliant at having consistency with looking after patients. With the longer term ones we do make an effort. For the shorter term ones we try where possible but it's not always easy..." (Int16 FN8).

Thus the nurses working directly at the bedside sometimes had little opportunity to develop a meaningful understanding of the child's situation and the parents' perspective. They then often felt they had insufficient knowledge of the child to venture opinions. Furthermore there were difficulties for the nurses raising issues at ward rounds because often the parents would be present and the desire not to reveal dissent within the team inhibited some nurses from contributing. Additionally the way in which discussions between members of the medical team were conducted away from the immediate bedside tended to limit the degree to which they could participate.

“There’s doctor’s rounds you know. If they [child and family] were particularly in a cubicle they, we’d use if there was an acute infection risk or one thing and another, erm they’ll often have their discussion outside so you don’t even overhear that at all. Erm...and therefore you’re not involved when they come round.” (Int14 FN3).

The more senior nurses, who oversaw care of a small group of children, tended to interact over several days with the same children and families. These senior nurses would also be receiving regular reports from each of the junior nurses caring for a child. They were then able to gain a better appreciation of the full picture regarding a child’s situation. Thus they were usually better placed to speak up about any ethical problems they perceived in respect of a child’s stay on the unit.

“So that team leader’s in charge for that shift for that day. So any concerns would be sort of brought up with them as a band 6 nurse they’re then quite frequently on the same side to they [the senior nurses] get to know the patients.” (Int16 FN8).

However if a junior grade nurse brought up an issue with the team leader that team leader might take over direct care for the child and enable the junior nurse to attend the multidisciplinary meetings or the discussions occurring away from the bedside.

“So you would usually raise it with your team leader... if that team leader felt that it was important that you said your bit at the ward round you’d then go into the ward round.” (Int16 FN8).

“Yeah all the bedside nurses are going to have talks with the family and you know it wouldn’t be me as the team leader it would be the bedside nurse.” (Int18 FN6).

Regular multidisciplinary meetings between all the professional staff involved in the care and treatment of specific children on the intensive care unit were held. These were used as a forum specifically to discuss how to resolve any ethical problems in respect of an individual child. These meetings included the nurses, dieticians and physiotherapists working in the intensive care unit.

“We have our ward rounds in the morning and the sit down round which is

multidisciplinary. I mean there are nurses and there are physios and pharmacists and doctors and dieticians if they want to come and other teams that are encouraged to come along and say what they think about their patients and that sort of ticks the box.” (Int12 MDCons10).

“Multidisciplinary meetings happen with children that have been here a while which more than likely to be perhaps ones we are sort of a difficult situation erm. At the multidisciplinary meeting the nurses would be involved. You’d have a named nurse and they would be involved.” (Int16 FN8).

“I think they’re quite led again by the consultant of either the speciality or the intensivist. We had one yesterday actually and there was a lot of people there and everybody just piped up their opinion on what was happening with the parents as well.” (Int20 FN5).

Thus there was an acceptance and an expectation by consultants that staff attending the multidisciplinary meetings would speak up if they had a contribution to make rather than be specifically asked for their views. I shall return to this notion of speaking up below. One consultant intensivist did suggest that the multidisciplinary meetings were not always fully open discussion forums. The discussions tended to be kept crisp and business-like as opposed to an ethical debate.

“I really would be fibbing if I said that was a real multidisciplinary discussion that took place there. Others are available and sitting in the same room and encouraged to volunteer information if they think it’s important. So there isn’t a sort of ‘what are you speaking for?’ mentality but it’s a pretty business-like handover of information and plans for the day and a sort of operational meeting” (Int12 MDCons10).

Medical colleagues in other hospitals were also consulted on occasion. Each consultant doctor, and to a lesser extent the specialist registrars had built up a network of colleagues over time and they would also discuss difficult situations with them. These colleagues would be others working in their field that they had met at conferences or during their training as specialist registrars.

“The consultant will say well I do this or he’ll have a friend [another consultant in a different hospital] that...and and see what they do and you sort of come to a decision together about what you do.” (Int1 FDSpR6).

“At the time I had chats with a few of the different consultants and got their views.” (Int5 MDSPR4).

This was particularly the case for those admitting consultants treating children with rare conditions.

“You’ve got a very good network in the sense of being cos there’s only a few of us across the world. We do get together regularly and we then discuss and say ‘have you had a similar episode’ and somebody will start saying ‘well actually no when we look at all our data we’ve got two as well and it was exactly the same outcome’.” (Int8 MDCons-exITU6).

There were also opportunities taken at professional conferences to discuss and seek advice on how to manage ethically challenging situations both in terms of specific children and more generally about an ethical issue.

“I spoke to somebody in Rome in a conference and they said that they do this and it worked really well and here was their evidence and maybe we should try that.” (Int1 FDSpR6).

These informal consultations or seeking of views with health professionals beyond the treating team appeared only to feature in the accounts of the doctors. None of the nurses referred to such strategies.

There was evidence that consultation with a range of individuals, including hospital management, regarding a particular problem was established to agree a formal protocol or set of protocols to pre-empt ethical problems. One example of this was the establishment of a group to develop protocols for managing children who might be suitable organ donors where organ preserving interventions may be required which bring no benefit to the child This was being discussed by professionals from a range of groups.

“That’s a process that we are working through as we are embarking on... so we just have those discussions at the start. We had a meeting a couple of weeks ago where we went through a scenario you know ‘this is how it would work in real life what do you think? Does anybody have a problem with it?’.” (int13 MDCons10).

There were also formal consultation forums set up to resolve certain problems that had implications across the whole hospital. One such problem was that of prioritising intensive care bed availability. Some specialist surgical teams had developed a national and international reputation for their treatments. This had created an issue where a child geographically local to the hospital might be denied an intensive care bed because a child from a distant centre, sometimes outside England, had been transferred to the study site to receive the expert care of the local specialist.

“we do get cardiac surgeons who do get complex cases from overseas and certainly from Belfast and Glasgow on a regular basis. So we’ve got a situation where we’ve got a [local] family are denied access to emergency intensive care in order that an elective case from Glasgow can have a heart operation.” (Int12 MDCons10).

The significant issue for the intensivists was that children who could potentially wait for their operation, and thus not be in immediate need of an intensive care bed, were displacing local children in emergency need of intensive care facilities. Thus a protocol was being negotiated with all interested parties including hospital managers.

Clinical ethics

On occasions, particularly where agreement could not be reached within the treating team, formal consultation was entered into with the hospital’s clinical ethics advisory group. In common with many NHS hospitals, the study site had established a clinical ethics advisory group that convened on a regular basis. Its stated aims were to provide a forum for confidential discussion of difficult cases and to debate topical ethical issues.

“Well there’s a method in the children’s hospital where you can have an ethics committee.” (Int1 FDSpR6).

“You know if it’s a case we did feel we needed legal advice we would go and seek that or we’d get an ethical view from our ethics board.” (Int5 MDSpR4)

The clinical ethics committee appeared to be perceived by some as somewhere to refer problematic issues in the belief the committee would provide the answer or give definitive direction.

“That particular neuro er the consultant erm he went for and ethics committee opinion on that because he couldn’t come up with the opinion himself primarily because there was no particular diagnosis made we couldn’t get to a diagnosis.” (Int2 MDSP6).

An interesting aspect of this particular account is the reference to the lack of medical diagnosis as the basis for the ethical uncertainty. I will return to this issue of the impact of the interpretation of clinical data as a foundation to ethical judgement later in this chapter.

For one participant it appeared that referral of a challenging ethical issue to the clinical ethics advisory group served a double purpose.

“sometimes they [clinical ethics advisory group] will ask a question that I’ve not asked myself and clarified something in my mind that I can then assure the family and actually allows the family to realise that I am thinking quite deeply about it.” (Int11 FDCons10).

Thus not only was there the opportunity to consider a potentially different ethical viewpoint, but consultation with the clinical ethics committee also provided evidence of being seen to consider other viewpoints on a problem. This comment, regarding assuring the family that the consultant was giving the situation careful consideration, was made in the context of an earlier part of the interview in which an account was given of a family’s resistance to the recommendation to withdraw interventions.

At least one consultant viewed the ethics committee as some sort of intermediary or referee when there were differences of opinion regarding an ethical problem.

“They [the intensive care consultant] were pressurising me and I said ‘I can’t make that decision I can’t agree with you’ on the Tuesday. ‘I’m sorry I can’t agree with you. It’s an ethical issue for me I want to speak. I want the

ethical committee to convene to help me with this decision'." (Int7 FDCons5).

However consulting the clinical ethics committee was not always viewed as helpful as the same consultant explained.

"The ethics committee, although they sat there and talked, actually only talked about what words to write in the notes. So it became a legal issue." (Int7 FDCons5).

This consultant went on to explain that the committee appeared to be more focussed on ensuring the accurate recording of the decision process. She intimated that her assumption was this was to enable an effective defence in case of a complaint or litigation.

Some participants viewed the role of the clinical ethics committee as reviewing the case material and pronouncing judgement on how to proceed. Notwithstanding this there was evidence that even where advice was not entirely unequivocal, consulting the ethics committee did provide a greater feeling of security regarding a resolution that had been arrived at.

"I think in that case it was sort of said go by your clinical decision so I think it was not very useful... it is useful in that sense you know that you get a independent opinion and also you get that feeling that you know we have a second opinion of ethics so you feel more comfortable with your decision." (Int2 MDSpR6).

None of the nurses that I interviewed mentioned the clinical ethics advisory group. It may have been that the referral route to consulting the group was via a consultant doctor and only then in respect of specific cases rather than as a reference point for more general ethically challenging questions in clinical practice. The nurses would thus have no recourse to make a referral to the clinical ethics group.

Relationships

The need to negotiate with a range of professionals in the team caring for and treating the child meant that relationships between various members of that team were significant. Relationships between the intensive care consultants and admitting consultants could be difficult for a number of reasons. The reasons cited by participants included, the personality traits of individual consultants; the nature of the relationship between the child and family and admitting consultant; and the personal reputational investment made by an admitting consultant when treating a child.

Some personality traits were attributed to consultants working in certain specialities.

“It can be very difficult and er the personalities can make it very difficult so you know surgeons in general ... are just generally a bulldozer and they will come in and say ‘this is what’s goner happen’ and then walk out again and the whole discussion that you could have with most physicians to be fair just doesn’t take place.” (Int1 FDSpR 6).

It was not clear whether the difficulty referred to above related to the provision of effective care and treatment for the child or frustration regarding the lack of potential for the intensivist to influence a decision. This was an extreme view expressed in the interview and the participant did qualify this position to a degree admitting that this was a bit of a generalisation. However it was hinted at in several other interviews that the speciality of the admitting consultant did influence the perception of the intensivists as to the likelihood of meaningful negotiation regarding whether or not to continue active life-preserving interventions.

“You get to you can get the point where actual clinical relationship suffer and deteriorate over time around something that should have nothing to do with those, it’s not about how well you look after the patients it’s about whether you say ‘no you can’t have a bed today for your case’.” (Int12 MDCons10).

One of the consultant intensivists offered a potential explanation for the strain on relationship in times when intensive care beds were at a premium.

“The cardiac waiting list is one of the, it’s bigger than it has ever been since you know. I was speaking to a surgeon and he started working here in the late 80’s early 90’s and he’s never had to deal with such a big waiting list.” (Int13 MDCons10).

The relationship the admitting consultant had developed with the child and family over many years also appeared to be a factor.

“...we [names speciality]¹ have this kind of intensive relationship with the parents which the intensive cares don’t have.” (Int7 FDCons-exITU5).

This appeared to affect the manner in which the intensivists entered into and conducted their negotiations with admitting consultants.

“sometimes it’s almost like handling a parent, handling a bed card holding consultant who’s had years of investment in a child, whereas the intensivists don’t have those years of investment. So sometimes you have to handle the bed card holding consultants almost like the parents because they’ve got more invested than I have as an intensivist.” (Int11FD Cons10).

The personal distance from the child and family hinted at by this intensive care consultant was recognised and valued by at least one of the admitting consultants when dealing with questions regarding withdrawing or withholding life-preserving interventions from children with chronic disorders.

“I think that’s where ITU can help us sometimes as well. Because they’re not so interknitted with these families they haven’t gone through everything with them they actually can be more objective and they can actually help us make that decision because sometimes for you also a decision to make, you know if you’ve been looking after a child since he was 4 and it almost becomes like he’s your own child and then actually to have to say bye bye to let go is quite hard even as a doctor.” (Int7 FDCons-exITU5).

¹ The name of the medical speciality is concealed in this quote to avoid a breach of anonymity.

There was also a perception that the admitting consultant did not appear to want to admit defeat.

“I think sometimes it might be the cardiologists who won’t let go they want to stick with their patients because they want to you know they want a success.” (Int4 FN5).

The consequences, for the operating surgeon, of a child’s death following surgery was perceived to be a factor in the negotiations relating to the point of agreeing further life-preserving interventions were futile.

“I think it is mainly because once you have operated you have done an operation because then that case will go down as an operation failure and that is probably going to be a Coroner’s case as well so only if for that reason you know he will want to try and get a good end result I suppose you know which is fair enough because in this age it you know every surgeon’s rate of complications are counted.” (Int2 MDSpR6).

It was also recognised that the perceptions of the intensivists regarding certain medical conditions impacted on the relationship with admitting consultants and the manner in which the negotiations were conducted.

“They [intensive care doctors] may have a perception from medical school training [about certain rare disorders] that this is always bad news, they die. Whereas we have had research and new treatment and some of the outcomes are very different. So what we do find is that we struggle getting patients into the intensive care setting because they say ‘well they die in any case so what’s the point?’ (Int8 MDCons-exITU6).

Both of the consultants treating children with chronic life-limiting disorders who were interviewed expressed a view that they had to argue hard in order to secure an intensive care bed for some of the children they cared for. They implied that there was almost an automatic bed available for children with acute conditions or those undergoing major surgery, which potentially reduced the bed availability for children they cared for.

The potential for the breakdown of relationships between medical teams, and perhaps especially the consultants, was seen as an important issue for consideration for the intensive care staff.

“We are constantly in conflict with everybody wanting beds and that’s a real problem because you get to...you can get the point where actual clinical relationships suffer and deteriorate over time around something that should have nothing to do with those, it’s not about how well you look after the patients it’s about whether you say ‘no you can’t have a bed today for your case.’” (Int12 MDCons10).

This was seen to operate with those outside as well as those inside the intensive care unit. For the non-intensivists, at least those caring for children with chronic and life limiting disorders, the cultivation of good relationships with the intensivists was seen as essential to creating the best chance of securing a bed for the child under their care.

“I try to get the intensivist on board because I think it’s important that they understand the parental point of view” (Int7 FDCons-exITU5).

“So actually convincing them [the intensivists] was initially a big problem. (Int8 MDCons-exITU6).

Thus good relationships between the intensive care teams and the admitting medical teams, especially at the consultant level, appeared to be an important condition for an effective negotiation (i.e. resulting in a consensus) in respect of ethical problems. Since consultants were not on duty 24 hours a day there were also negotiations following a similar pattern between more junior members of the medical teams i.e. the specialist registrars (SpR), most of whom were on career paths to become specialist consultants or intensive care consultants.

7.3.2 Power and Hierarchy

The hierarchical nature of the care teams and the unequal power relationships between senior and junior medical staff in particular impacted significantly on whether an individual would speak up and offer an opinion. There was a strong sense of an underlying value of consensus across the whole team as a key facet of team functioning. This appeared to be tempered with the recognition, by individuals, of their status within the team. Some specialist registrars talked about the power that consultant doctors could exert in respect of their career prospects, at least in the short term.

“I suppose as a doctor as well we have to think ‘I’m being appraised by this boss I need to know where I stand’ because otherwise I won’t tick all the boxes and you know I wouldn’t be signed off” (Int3 FDSpR3).

“There can be a sort of a difficult conflict in juniors to question their consultant level people about the decisions that they’re making...” (Int6 MDSpR3).

One of these same registrars felt that nurses did not face the same problem and could perhaps speak more freely regarding their views about a child’s care and treatment. They felt that it was probably easier for nurses to speak up to senior medical staff as there was no direct line management relationship between the two.

“Perhaps in certain cases as well some of the nurses because they’ve got nothing to lose...they’re more erm empowered to make their views known.” (Int3 FDSpR3).

Other registrars were prepared to enter discussions with their own views about a situation but did not perceive their opinion to be influential.

“I wasn’t in any particular position where I could influence the decisions that were made although I did express my views.” (Int5 MDSpR4).

A similar view was expressed by nurses.

“I don’t think it’s my call as a nurse I think it’s down to the consultant or the doctors leading to say.” (Int17 FN4).

However the same nurse indicated that she felt that a strong hierarchy was not obvious in the way the unit worked.

“So we are quite a joint team it’s not very much hierarchical whatsoever.” (Int17 FN4).

Others seemed to be more aware of the potential for hierarchical structures to impact on who might actually contribute to a discussion about an ethical issue. Those with the perceived power to influence were the nurses in more senior positions.

“I think the consultants have more respect...I’m not saying they don’t respect us they do but I think it’s that they perhaps extend a bit more I think they [the senior nurses] have more clout sometimes particularly than someone in a very junior position.” (Int4 FN5).

“For me it is a bit more now I’m getting involved sort of now I’ve moved up [to a more senior position] a little.” (Int18 FN6).

The potential for useful insights from junior nurses not to be heard was not lost on the more senior nurses. Several of the more senior nurses said that if a junior nurse raised an issue with them they would encourage that nurse to take the issue to the specialist registrar or consultant, or take over the care of a child to enable that nurse to attend a multidisciplinary meeting.

“...unless they are very new and then we both go but we both go so that we could get some experience for them as well so yeah the bedside nurse does have a big impact and erm involvement.” (Int18 FN6).

Thus although junior nurses may have felt they were not really in a position to input into discussions about ethical problems they were encouraged and even facilitated to do so by senior colleagues.

For some, although involving the whole professional team in discussions was a fundamental value expressed by the senior medical staff, it was not always perceived to be an easy thing to do. It was apparent among the nurses that personal confidence also played a role in determining whether they spoke up in discussions about ethical issues.

“I think sometimes again because you know being in the bedspace all the time with the child erm I feel ‘ooh that’s a bit soon’ you know but again for me it’s a confidence thing. Well you know who am I to question?” (Int14 FN3).

Nurses in the more senior grades felt more at ease with raising questions about the direction of a child’s treatment and progress than they had as junior nurses. This appeared to be linked to increased personal confidence in their right to question as a result of being in a more senior grade.

“I think that now I’m senior and I can open my mouth and say, even if I have to pull one of the doctors to one side and say, ‘I’m not quite sure why you’re saying that’.” (Int9 FN12).

“At one time I’d probably wouldn’t have said anything to them as such, but now I would go to them and sort of say ‘what you’re doing’ you know, or whatever the situation might be. I wouldn’t have a problem with it now; I think I would say something to them.” (Int4 FN5).

For some though, it was merely a matter of personal confidence and possession of the kind of personality that enabled them to speak up in any forum.

“I’m quite a vocal person and I’ve never been worried about that.” (Int17 FN4).

Nurses’ confidence in speaking up both in the multidisciplinary meetings and more informally was also influenced by the nature of the relationship they felt they had with the medical team.

“You find that you do get a good relationship going with them and sometimes if you can get them on board with you and say to them ‘you know it’s time to stop now and I think it’s time to approach the family’.” (Int4 FN5).

“I would say our medical staff, or at least the more permanent ones, on whole are pretty supportive of our team and relaxed about us...I’ve certainly had no problems with anyone saying ‘you know that was...you stepped over the mark there’.” (Int14 FN3).

“There is a good working relationship between the nurses and medics I feel that makes it easy to sort of say anything that you want to.” (Int16 FN8).

There was a good deal of evidence then, that whilst a hierarchy was palpable, a sense of team working mitigated the potential for more junior staff reticence in putting forward a view to a degree.

There were several references in interviews with consultant intensivists to a previous member of consultant staff who was seen to have acted as Devil’s Advocate in many situations and used to prompt people to stop and think about

a situation that was ethically challenging. The Devil's Advocate did not act in the same way that other staff would in speaking up about an issue. This was an individual who would routinely propose an alternative view to whatever was being suggested about how to proceed, or not, with a child's treatment. That is to say he would propose a deliberately contrary view in order to enrich debate and ensure that the situation had been explored as fully as possible under the pertaining circumstances.

"We used to have one of our colleagues was the ultimate devil's advocate and he was good value actually because you do need somebody to challenge people and say 'why do you say that?' or 'is that right?'" (Int12 MDCons10).

This individual was valued at least within the consultant intensivist team.

"...if you don't have your devils' advocate I think a group of people can decide to do something stupid. And a devil's advocate is a very useful conscience check to stop you doing something stupid." (Int11 FDCons10).

This person had since left the intensive care unit and it was expressed that this was a loss to the unit. There was no evidence in the interviews that any efforts had been initiated to encourage someone else to adopt this role.

7.3.3 Influencing Factors

The third subcategory of team negotiation was generated from participants' descriptions of the factors that influenced their contributions to the team negotiations. Certain concepts such as duty to the child and best interests emerged as important properties of this sub category. There were also references to other factors that informed or underpinned participants thinking when contributing to the team negotiations. These included the emotions professionals experienced and the interpretation of evidence that informed thinking and the interpretation of clinical data about a child. External factors were also acknowledged but as shall be shown these were perceived by participants to have a minimal effect on decisions and did not impinge at all on end-of-life decision making.

Duty to the child

Reference was made by several participants to what appeared to be an internal compass regarding what was the right thing to do in a particular situation.

“I think I still go on what I feel, I still start with what I think I would do in that situation; what I believe is right for the child.” (Int1 FDSpR6).

“We would er you know definitely always want to do what seems right.” (Int12 MDCons10).

Thus individually and collectively there was a sense of wanting to do the right thing. Others expressed a personal commitment or obligation they felt to an individual child that went beyond merely wanting to do the right thing.

“So when I have an individual who needs my help albeit not necessarily in the building that I’m in, but I get called and therefore it becomes my responsibility. I want to do the best for that person [mm] and er I feel a strong obligation to do that...” (Int6 MDSpR3).

In addition to this feeling of personal obligation some participants made reference to a collective commitment that they perceived healthcare professionals have to children.

“It is difficult because then we have to have er we have a commitment to the child obviously we have to give him the best chance.” (Int2 MDSpR6).

This was expressed as a duty to act in particular ways, by a consultant intensivist, that stem from membership of a healthcare profession.

“It’s our duty as doctors caring for the child to make up our own mind what we think is best.” (Int13 MDCons10).

Nurses also expressed this notion of the duties owed to children in their care.

“I suppose what you do every day is according it’s the kind of principles that have been ingrained into you.” (Int16 FN8).

The principles this nurse spoke of are explicit in professional codes of conduct. Thus there were perceived to be duties specific to the role the professional had in healthcare and society.

“That’s what’s in the code of conduct and you know patients are your priority aren’t they?” (Int18 FN6).

However the child as the patient was not the only concern. One nurse made reference to a particular aspect of their role as someone who speaks up on behalf of the parents as well as the child.

“I think especially in the nursing role as you’re advocate for the family and the child.” (Int17 FN4).

Admitting consultants who had a long standing relationship with children and families also expressed a commitment to act on behalf of parents in negotiations with intensivists.

“I try to get the intensivist on board because I think it’s important that they understand the parental point of view...” (Int7 MDCons-exITU5).

One admitting consultant gave an impassioned account of one occasion when they pressed hard for intensivists to take into account the needs of the parents.

“There’s issues also getting the patients out of intensive care in the sense that sometimes we want to get them to one of the local hospices. As soon as they [intensivists] hear us say ‘this is a hospice patient’ we usually have the situation of ‘can we [the intensivists] just dump him on another ward until the hospice is ready?’ And what we’ve said on many occasions we’ve had we’ve said no. Because we’ve done it on a few occasions we’ve actually insisted that they do an intensive care transfer to the hospice.” (Int8 MDCons-exITU6).

This admitting consultant went on to explain that the parents’ desire was for their child to die in a hospice environment rather than in a hospital. The risk associated with transfer to a ward whilst awaiting the hospice bed was that the child would die before the bed became available. Facilitating a direct transfer from ITU to a hospice would enable the fulfilling of the parents’ wish.

There was thus an array of personal views about the right course of action underpinned by a sense of personal obligation and supported by perceived professional duties. A significant factor relating to the sense of duty the professional participants expressed was that of the child's best interests.

Best interests

A child's best interests appeared to be at the front of participants' minds when considering how to proceed with treatment particularly if considering limiting or withdrawing life-preserving interventions. Both doctors and nurses referred to the child's best interests as a locus for their thinking about the right thing to do.

"Concentrate on what's the right decision for the child." (Int8 MDCons6 ex-ITU).

"I think it's our role to act in the interests of the child and to advise parents as to what we as professionals think is best for the child." (Int13 MDCons10).

"It [the best interests of the child] would be the confidence with which I think that intervention is going to be key to that child's ongoing well being or development." (Int12 MDCons10).

"Put the patient first, patient's best interests first." (Int16 FN8).

It did not appear that everything that would maintain life for an individual child was necessarily in that child's best interests. The best interests of the child appeared to be interpreted in a number of ways. For some participants, what was in the child's best interests could include the death of that child.

"I have to admit I do get quite angry at that because keeping a child alive at all costs is not always in the best interests of the child." (Int20 FN5).

"As soon as you have a medical consensus that you're giving futile therapy or it's no longer in the best interests, because we've just talked about futility we've not really talked about best interests erm the no purpose situation or the no chance situation. So once you have a medical consensus that you're doing something that is not in the best interests of the patient you should immediately stop doing that." (Int11 FDCons10).

However, as I shall detail below in presenting the second major subcategory of parental persuasion, the actual withdrawal of life-preserving interventions was not always, if ever, immediate. The no purpose and no chance situations mentioned by this consultant were a reference to specific guidelines published by the Royal College of Paediatrics and Child Health (RCPCH 2004) regarding withdrawing and withholding life preserving interventions in children. It was a surprise to me, given the professional importance of these guidelines, that no other participants mentioned them.

When pressed on the issue, participants found it difficult to explain precisely what they meant by best interests. Participants became quite hesitant in their description of the best interests concept. Doctors made reference to the perceived degree of certainty regarding the diagnosis and prognosis for the child.

“Yeah erm...so it’s who will benefit or who needs...sort of...well it’s very much about time who needs for who er,...so if you triage you look at the list of patients and you know this patient needs this and this patient needs that erm you will you look at you need you need to understand what what’s wrong with the child and what the prognosis is.” (Int13 MDCons10).

“I suppose you have to see ... it with a...er have we got the right diagnosis you know and if we have got the right diagnosis, then what is the prognosis?” (Int2 MDSpR6).

The right diagnosis was thus linked to the prognosis or potential longer term future for growth and development for the child.

“It [the child’s best interests] would be the confidence with which I think that intervention is going to be key to that child’s ongoing well being or development.” (Int12 MDCons10).

Participants’ ideas about what constituted a child’s best interests were also linked to notions of the quality of life for that child. This was in terms of both the immediate and potential future quality of life. The immediate quality of life was perceived in terms of the degree of discomfort the child was experiencing.

“there comes a point where you wonder if you are doing anything er any

good or is it sort abuse to the child” (Int2 MDSPR6).

“...they [the family] don’t know just what we do, just how uncomfortable just how stressful it is on the child.” (Int11 FDCons10).

“Having a vascath in your neck is not comfortable and having an ET tube shoved down your throat is not nice.” (Int17 FN4).

The degree of discomfort and potential for further harm was then balanced in the professional’s mind against the prospect of eventual benefits for the child.

“When intensive care becomes burdensome and that’s another thing that’s another thing that people er there’s a perception of intensive care as a neutral intervention and it isn’t. It has risks it can cause complications er and both health professionals and parents struggle with that. There need to be clear benefits from that as well. It’s not just about keeping someone alive.” (Int13 MDCons10).

Participants recognised and were acutely aware of the physical harm that can be the consequence of many of the life-preserving interventions used in intensive care. However it was not just the immediate effects on the quality of life that were brought to bear in considering the child’s best interests.

“There have been difficult situations. I only go back to the trauma sort of bad head injury case, where the neurosurgeon kept saying to the parents ‘I think this child’s going to have some sort of recovery’. And we’re all thinking ‘she’s got a broken neck, she’s blind she’s deaf, she can’t move, she’ll be on a ventilator her whole life...’” (Int1 FDSpR6).

“I think sometimes that where the ethical problems lie is that you have a child that perhaps you know has got a poor life expectancy but the family wants to carry on [yes] and you think you know ‘it’s time to let go’. Or the other side of it is where erm I had to look after a child a while ago where you knew that they were not going to have a good life expectancy you know chest drains in left, right and centre and you just want to sort of say ‘look it’s time to stop now enough is enough really’.” (Int4 FN5).

“The decisions were based upon what kind of life that child was going to have and whether that...a life as a quadriplegic ventilator dependent child would be one that would be in most people’s eyes unbearable.” (Int5 MDSPR4).

The notion of what constituted a bearable quality of life was influenced by the lens through which the individual viewed the child's situation. Those admitting consultants treating children for chronic or degenerative conditions identified the different approaches taken to judging likely future quality of life for a child.

“Often these children are a bit floppy [i.e. they lack normal muscle tone due to the neurological problem]. So when they do go to our intensive care it takes them a lot longer to come off the ventilator and that's where the PICU staff say to us ‘it's not appropriate for these children to be ventilated because they have severe developmental delay’” (Int7 FDCons5-exITU).

The clinical knowledge and experience of treating children with severe chronic health problems enabled these admitting consultants to make a different value judgement about a child's quality of life. From the perspective of these admitting consultants being ventilator dependent was not necessarily evidence of a poor quality of life sufficient to warrant withdrawal. They also knew from experience that it could take a good deal longer for a child with a chronic degenerative condition to recover sufficiently to enable discharge from intensive care.

“With rare disorders like...so they're slow to recover, so there is the next ethical [problem] is we still do find people [intensive care consultants] wanting to pull out of patients care at too early stage really ,when it's not clear that this child is not going to survive.” (Int8 MDCons-exITU6).

The basis on which judgements were made about a child's quality of life were thus dependant to an extent on the perspectives of the health professionals derived from their professional background and experience.

Negotiations regarding what was the best way to proceed with a child's treatment then were wrapped up in an individual health professional's perceptions of their personal and professional duties to a child. Those perceived duties were linked to views regarding what might be in the child's best interests. Notions of what was in a child's interest were based on judgements regarding current or likely future quality of life. There were additional factors that had a part to play in the negotiations between professionals. Evidence relating to the effectiveness of clinical interventions played a significant part in deliberations.

Clinical evidence

Negotiating the resolution to the ethical problem was influenced by the interpretation of clinical evidence that was used to conclude that interventions should be withdrawn. The nature of evidence to inform negotiations particularly relating to decisions about whether or not to withdraw interventions came in a variety of forms. Some of it was in the form of clinical data particular to a child; some of it was as a result of empirical research studies; some came from an individual professional's experience of similar situations; some from the experience of others reported at professional conferences, or in professional journals. Participants referred to clinical data as the reference point for ethical problem resolution.

“Some of these tests, the results are not made clear. Sometimes you feel the results are, you know, unclear and we want to get some more evidence.” (Int2 MDSpR6).

Such evidence would be sought through further or repeated tests. However even where tests provided clear results, the ambiguous interpretations that could be applied to clinical data led to uncertainties regarding how to proceed.

“The classic is the blood transfusion where you know you take a line of a 100 intensivists and say ‘okay this is the clinical situation and say at what haemoglobin would you give a blood transfusion?’ you’ll get answers from 6 up to 12 g/dl.” (Int12 MDCons10).

“If you’ve had a liver transplant then your Hb [haemoglobin] is allowed to be lower but if a doctor on here, ITU, who has no liver transplant experience wouldn’t know that they’d come along and prescribe the Hb’s too low.” (Int19 FN4).

Emphasis was placed by some on the need for research evidence which could guide decision making. However there were some difficulties as such evidence was not always easy to come by.

“I guess another thing about, certainly in paediatric intensive care, is that a lot of stuff we do doesn’t have any necessarily research or evidence base basis so actually we’re probably making sort of reasonably ethical type decisions every day because we’re deciding what’s best for the children

based on our own our own opinions.” (Int1 FDSpR6).

These opinions could be based on a clinician’s experience with a similar circumstance or set of circumstances. This was sometimes because a child’s condition was rare and a body of evidence was not available, and thus past experience was the only indicator of how the child’s condition might progress.

“Because now this is a rare disease this is the first time it’s happened so the next time we’ve already discussed it as a group between us, you know we’ve got another patient maybe we should be much more negative about the potential benefit.” (Int8 MDCons-exITU6).

Sometimes the reference to personal experience was related to the process of becoming a doctor and having dealt with similar cases.

“I guess the most part of it is experience and time you know ‘I’ve done this before or er I’ve done I’ve treated so many children like this and this has worked” (Int1 FDSpR6).

Medical journals and publications were also cited as sources of evidence to aid the process of determining the best course of action. These carried a variety of research-based and experience-based evidence.

“There’s that knowledge that I have from publications that there is this range of practice, whereas there’s a lot of things where I wouldn’t have that degree of information.” (Int12 MDCons10).

“So it would be something [a drug] that you have to order because it’s not licensed for kids and if it’s rarely used in an adult, so it’s unlikely the pharmacy would have it in stock anyway. So it will be discussed and what happen is we would be looking at what the literature says.” (Int3 FDSpR3).

The references made to clinical evidence then included a range of sources and that evidence was largely founded on the experiences of health professionals rather than the findings of empirical research.

Emotion

Several of the professionals interviewed also talked about the emotions they experienced as a facet of some ethical problems they had faced or witnessed in the study site.

“Even though professionally you agree that the decision is the correct decision to take on board you know you might not be friends or related but even then it’s difficult.” (Int3 FDSpR3).

“We are emotionally involved because we know the children...” (Int16 FN8).

“It is difficult sometimes because sometimes you do get completely embroiled in that relationship with them so you almost feel the same as they feel.” (Int7 FDCOns-exITU5).

Participants perceived potential risks inherent in becoming too personally involved in a child’s situation and identified a need to maintain or develop a degree of emotional distance.

“I take it as your job you know sort of you don’t have too many problems of the emotional aspect of this” (Int2 MDSPR6).

“I think you have to step back from it because it’s such an intense place to work and it’s so erm it’s so consuming you know it’s very tiring looking after kids and emotionally draining with parents sometimes you know you just need to break from it.” (Int4 FN5).

“If you get too emotionally attached yourself I am not sure you can ...are you having that...yeah it is difficult but you need to be careful that you’re not becoming placing your own emotions before the interests of the patient.” (Int13 MDCons10).

Not everyone however was able to put aside their own feelings in all circumstances or, having made their contribution, did not wish to be party to the implementation of a decision with which they disagreed.

“Sometimes and I guess that you have to distance yourself and go with [the teams decision].” (Int1 FDSpR6).

Some individuals even felt compelled deliberately and consciously to remove themselves from the situation.

“one of the consultants I spoke to shared very similar views to me and he basically stepped back from being involved with the decision making, he didn’t feel that he wanted to be part of that decision making.” (Int5 MDSpR4).

In fact, at least among the nurses, there were occasions when individuals were positively offered a chance to withdraw from a situation with which they felt personally uncomfortable.

“I’d probably say ‘if you’re totally uncomfortable with what you’re having to do...’ and this is the management and the care plan for today; and nothing’s going to change because if the doctor doesn’t want to change it; and the family doesn’t want to change it [the plan of care]; and they’re [the nurse] so uncomfortable I’d say ‘do you need me to you know put you somewhere else? Do you need to come away from the bedspace?’” (Int17 FN4).

However whilst it was evident that individuals could withdraw from a situation they felt morally ill at ease with, there was a sense that, in accord with the personal and professional obligations expressed above, the first concern was the child. Thus professionals might have withdrawn from a situation but they would be expected not to reveal their views to the parents.

“You can be a conscientious objector but you don’t say to the family ‘I’m out of there’ because it makes us look bad.” (Int11 FDCons10).

This notion of the unit ‘looking bad’ was not restricted to how the child’s parents and family might respond. There was also evidence that there were sources of influences on professionals thinking about ethical problems from sources external to the unit and the hospital.

External influences

Several participants made reference to the manner in which negotiations could also potentially be influenced by issues external to the unit and the child’s

situation. The pressure to meet central government targets could sometimes lead to pressure from senior hospital management.

“The other thing in my view that is creating major problems are government targets cos government targets are very selective they are targeted at elective work at outpatient waiting lists there are no targets for acute work.” (Int13 MDCons10).

Such pressure seemed however to have little real impact on the decisions being made.

“Well yes you know we’ll get the nod occasionally that erm ‘just so that you know so that you factor it into your clinical prioritisation process this patients been cancelled twice’ or ‘just be aware this patient’s coming up to the 18 weeks targets’ and the [hospital] managers will make sure that if there’s something relevant like that that it’s made known.” (Int12 MDCons10).

The pressure that consultant doctors reported led to tensions, for them, between the need to meet centrally set targets and the desire to discharge their perceived duty to children.

“We’re all professionals we all want to do the best job for other people and how that can sometimes be interfered with by politics and politicians is quite difficult.” (Int13 MDCons10).

This tension was felt not only by the consultant doctors. The more junior doctors, who often had to make decisions regarding admission to a bed out of hours, also reported these pressures.

“There are so many external pressures that come on us. We’ve got the chief exec who resigned because we don’t have capacity erm issues, we’ve got press on our backs, you got the other patients, you’ve got the other pressures and you know that the boss in the morning is going to go nuts when or when you phone them up at night and you say ‘look I’m really sorry, I know I said I wasn’t going to admit anybody else but this patient has to come in’” (Int6 MDSPR3).

The perceived pressure to meet these externally set targets were exemplified by the intensive care consultants references to the duties as a health professional to the wider society in the use of finite NHS resources. However,

they were clear that whilst resources were an issue they were secondary to the duty owed to a child in their care.

“From our standpoint the decisions are never made on money...but ethically it raises a lot of other problems because is the health of one person worth more than the health of many?” (Int8 MDCons-exITU6).

“I can see the problem but on an individual basis I have to look after the individual patients even though I’m the head of department and I’m responsible for capacity, when I’m the doctor on the unit I can’t be thinking in utilitarian terms it would be wrong to make a switch.” (Int11 FDCons10).

“it’s deontology versus utilitarianism in its most stark way and for the individual patient we apply deontology not utilitarianism.” (Int11 FDCons10).

But this view was not necessarily thought by participants to be universally shared by all in the NHS. There were times when it was perceived that an individual child’s needs may become secondary to pressures on the Trust to effectively utilise NHS resources.

“On the one hand we are dealing with the best thing for the child but the way we get paid erm the way the PCTs will look at it is ‘how does the society get the most out of the NHS?’ So it’s much more utilitarian rather than er direct to that individual.” (Int13 MDCons10).

This position was a source of stress to those consultants faced with balancing the perceived needs of the child for continued treatment with the demands of the hospital budget. Negotiations relating particularly to withholding intensive care interventions, such as whether or not to admit, were linked to available resources.

“[the ethical issues] I was thinking about are the slightly less obvious ones but to do with pressures of intensive care erm provision for people. So capacity issues of having a full unit in the middle of the night and having to make the decisions about what you do when.” (Int6 MDSpR3)

The limitations on resources were particularly apparent to the admitting consultants when it meant that children they felt would benefit from an admission to intensive care could not be accommodated. For one admitting

consultant caring for children with chronic and degenerative disorders the pressure on beds created a significant issue.

“So I think some of the main ethical issues for us is always getting patients into intensive care.” (Int8 MDCons6-exITU).

For the other bed availability was an issue but less stark.

“Availability of beds does play a role but, I mean, in principle we could just transfer the patient out couldn’t we? If there wasn’t a bed. So I don’t think it’s availability of beds it plays a role in the background so it maybe that PICU’s less likely to admit so they’re more argumentative with me” (Int7 FDCons-exITU5).

For this consultant pressures on bed availability in ITU meant she had to argue the case more to admit a child than she felt was the case for consultants in other specialities.

These problems regarding the allocation of resources were primarily issues for the consultant intensive care doctors as the ultimate decision-makers regarding intensive care admissions. However nurses were also aware of these issues.

“I understand the need for resources to be limited and I can see the issue with the money.” (Int17 FN4).

NHS resources were not thought to be the only potential source of external influence on thinking through an ethical problem. One doctor also identified the potential influence of the general media on negotiations. This was acknowledged in two different ways. Firstly there was an awareness of the potential for adverse publicity.

“If something goes wrong ... it’s on your clinical responsibility. The unit as a whole will reflect badly, the trust board will reflect badly and the press will come in” (Int6 MDSPR3).

“You can’t go behaving differently just because there’s a bit of pressure on the beds today because otherwise you would end up in the newspapers.” (Int11 FDCons10).

Secondly the reporting in the media of medico-legal cases was recognised as a potential influence on decisions. However this was not something that appeared to influence the process or the outcome of negotiations regarding ethical problems. When I asked about the influence of previous legal judgements, participants indicated these were not significant factors.

“Well yes and no I don’t think so I think I still go on what I feel I still start with what I think I would do in that situation what I believe is right for the child and then and then take on board any arguments from the other side and try and make a decision because every case is different.” (Int1 FDSpR6).

“I don’t think they [high profile legal cases] have much influence actually because I think at the end of the day people will have their own views on what happens in the media and erm most of the time we would do what we think is in the best interests of the child rather than what we think the media are trying to tell us what to do or even what the courts decide” (Int5 MDSpR4).

It appeared, then, that whilst a number of pressures external to the treatment and care of children were acknowledged, the professionals deemed them not to have a great influence over the resolution of ethical problems.

Team negotiation: a summary

This team negotiation between professionals then appeared to be a process that was part of a culture of team working both within the intensive care and beyond that into the admitting consultant teams. The relationships within and between these teams was central to the process of negotiating an agreement regarding how to resolve the ethical problems presented in caring for children on the unit. A good deal of effort appeared to be made to ensure decisions about a child’s care and treatment were based on interpretations of a variety of evidence. There were also efforts to consult widely including outside the clinical teams to include others not directly involved in the child’s care. There were both formal and informal routes for such consultation such as the clinical ethics advisory group. Whilst there appeared to be a culture of positive engagement with all levels within the hierarchy of the medical and nursing teams, it was not

always easy for all individuals to have an effective voice. The interpretations of clinical data appeared to have a significant influence on individual professional and team thinking. However perceptions of what might be in the child's best interests and their quality of life also heavily influenced thinking about ethical problems. Whilst it was acknowledged that there existed external pressures such as centrally set targets and the potential for adverse publicity, these apparently had little real impact on decisions about individual children. Although the tension between the needs of society and the needs of an individual were acknowledged, the perceived duties to the individual child took precedence.

The team negotiation was explicitly aimed at achieving a consensus among the professional care team. This consensus was established before parents were approached, particularly when the negotiated consensus was that intensive care treatment was to be withheld or withdrawn.

"...first of all we have to get a consensus around the team in ITU and also the team looking after the child." (Int2 MDSpR6).

"if you are all in agreement you would put forward to the parents [right] and so because we don't often approach the parents unless we have a consensus among ourselves." (Int3 FDSpR3).

"The first consensus that you need is actually amongst the medical staff so no consultant makes this decision alone." (Int11 FDCons10).

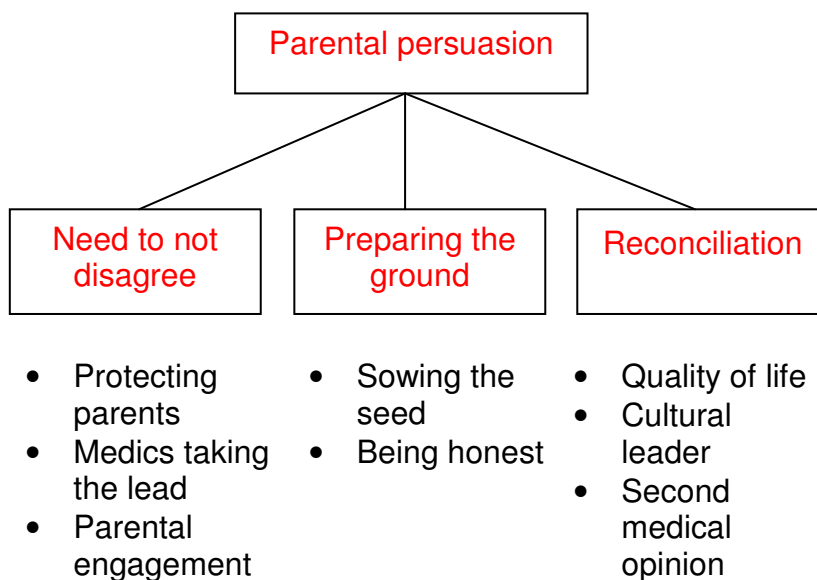
"...as a team we try and reach consensus before we approach families." (Int13 MDCons 10).

The approach to the parents to discuss, particularly, withdrawal of life preserving interventions was predicated on the fact that a decision had already been made. Thus although, as identified above, several health professionals asserted that there were negotiations with parents regarding withdrawal, it was revealed that in fact what was occurring was parents were being persuaded to accept a pre-determined medical decision.

7.4 Parental persuasion

In respect of a decision to withdraw life preserving interventions, once the medical consensus had been established a process of persuading the parents to accept that decision began. Three sub-categories were developed, from the interview data, which led to the formation of the category of parental persuasion (diagram 7). The key sub-category which emerged was 'need to not disagree' and in order to secure this state of affairs strategies labelled preparing the ground and persuading were employed by the medical teams.

Diagram 7. Parental persuasion, sub-categories, properties and dimensions.



There was some evidence in interviews with health professionals that there was negotiation that occurred between them and parents.

“You sort of get people that start telling you what you should be doing and er you have to try and negotiate with them all the time which is really difficult and they would stand there (indistinct) parents and you’re in a difficult position where they say ‘no I don’t want you to do that’ and you have to sort of take a step back and say well this is why I’m doing it and I understand why they don’t want it to be done and see if you can find a middle ground”. (Int1 FDSpR6).

This was related to a point at which parents said they did not want a particular intervention of procedure carried out on their child. This was the only occurrence in the interviews with the health professionals in which a participant indicated that a real negotiation took place. The two parents I interviewed as a couple also talked about occasions when they would be given a range of options to consider and participate in the final decision.

“Even silly things like, cos (names child)’s really funny with blood transfusions, she’s had a lot of them she doesn’t cope with blood, sometimes she’ll have like allergies to them erm what levels they want Hb to go up to and they’ll say ‘what do you think?’ (Int15 BP9).

These instances were related to a specific medical intervention rather than an end-of-life situation. In the case of decisions about withdrawing life-preserving interventions, parents were only to be involved once the professionals had reached a consensus. The approach was not to discuss the ethical issues but to persuade the parents to acceptance of the clinically indicated course of action. The ethical problem for the professionals then shifted from one of when and if to withdraw treatment, to how long to spend helping parents come to terms with the decision that had already been made by the medical team but not yet implemented. The resolution to this ethical problem emerged as the point at which parents agreed, or at least did not disagree, with the medical decision to discontinue those interventions.

At times the desire to ensure the parents had time to come to terms with the inevitable overrode what might be perceived as the best interests of the child and what might be deemed the best use of NHS resources. It was acknowledged by participants that, whilst discussions with the parents were undertaken, the child would suffer some further discomfort and potentially risk complications occurring as a result of continuing interventions that were deemed by medical staff as futile. Interventions that the clinicians believed would not benefit the child in any way were continued in order to allow time for the parents to accept the decision to withdraw life-preserving interventions. It thus appeared that a significant tension existed between what the professionals

perceived as in the child's best interests, and the desire of the parents to see their child continue living.

"Sometimes the PICU feels it's futile and they also say it's painful it is unbearable the treatment and you're just prolonging their lives [mm] but from a parent's point of view it's different I suppose and they feel everything should be offered for their child." (Int7 FDCons-exITU5).

"I don't think it's about pure ethics because if it was about pure ethics it's the child whose best interest is at heart and I should be focussed on that and that alone. But I think its child and family focussed here; I actually think the family gets in the way of what's ethically right for the child sometimes." (Int11 FDCons10).

"I think sometimes the Mums may want something totally different to what is right for the child." (Int17 FN4).

When it came to the central and most significant ethical problem perceived by the health professionals, the withdrawal of active life-preserving interventions, a process of establishing a position from which parents should at least agree not to disagree with the recommendation of the consultant was initiated.

7.4.1 Parents need to not disagree

This sub category of the category labelled parental persuasion was generated from a phrase that encapsulated the idea that the role of the parents was to accept the decision made by the professional staff. Indeed the phrase 'the parents need to not disagree' or versions of it appeared in many of the interviews.

"So I give them a strong recommendation and then say 'that it's absolutely my strong recommendation and I just need you not to disagree with my recommendation, I don't need you to say yes I just need you not to say no' (Int11 FDCons10).

"...they (the parents) are just there to not disagree." (Int2 MDSpR6).

"One of the things I have learned is that it's not just the er to get an agreement but to get the consensus for a non disagreement if that makes sense?" (Int3 FDSpR3).

“I think it’s more to do with parents agreeing with what you say rather than that they actually make the decisions.” (Int7 FDCons-exITU5).

“...so the doctor changed tack and I think said something along the lines of ‘we are going to do this unless you say no this will happen’ (int19 FN4).

Parents’ opinions were something the professionals recognised as a factor in decisions about the withdrawal of life preserving interventions from a child. However there was a strong opinion held by all participants that it was a medical decision.

“Actually this isn’t their decision they’re not making this decision. This is a decision being made by professionals and you are consulting with them but it’s not their decision to make...” (Int16 FN8).

“I think some families would like that sort of and you know we always say I mean it is a medical decision.” (Int2 MDSpR6).

Indeed specifically it was ultimately the consultant doctor’s decision.

“I think that’s important for families to realise that the burden of responsibility for the decision is a medical decision. To withdraw intensive therapy on the grounds of futility you can only make that decision if you understand the medicine.” (Int11 FDCons10).

“They [parents] have no idea what intensive care means. I mean we use a term like lightly. It’s a bit like you know when we say resuscitation we use that term lightly. I don’t think parents actually know and I think it’s quite a decision to make and I always say they need to agree with us, I make the decision. I just want their agreement.” (Int7 FDCons-exITU5).

It was evident that the notion that the decision was one the medical team should make was motivated by the professionals’ desire to protect parents from having to make the decision to withdraw life preserving interventions.

Protecting parents

This notion that the part that parents played in the process was ‘not to disagree’ was encapsulated in the view that parents shouldn’t have to shoulder the responsibility.

“For some families it’s not right to shoulder the responsibility that they somehow make the decision.” (Int11 FDCons10).

“I think sometimes we do have to take it out of their hands. Yeah so I don’t think you should ever expect a parent to decide to stop intensive care for their own child.” (Int18 FN6).

“I mean it’s a big burden to ask parents to decide. I, as parent, wouldn’t want to have to decide about the death or the life of my child.” (Int7 FDCons-exITU5).

This appeared to represent a fundamental professional value that emerged from the data of protecting parents from having to make choices that may lead to self blame or blame from others.

“sometimes the family come to the conclusion before the medics do that the kid is in a situation that’s futile and if the family come to that sometimes they actually feel very guilty if they bring it up” (Int11 FDCons10).

“It’s almost sometimes like they (the parents) need permission and they need reassurance that they won’t be erm vindicated is that the right word? But you know that they won’t be judged for allowing this to happen. (Int16 FN8).

“Quite often they will be ‘I can’t I can’t be seen to be making that decision’ I’ve had it said to me actually ‘I don’t want to have to make that decision whether or not to let my child live or die’.” (Int20 FN5).

When looking back the parents would, in the eyes of the professional, be able to say ‘I did not make the decision; I had to accept the opinion of the doctor’. Thus it was implied that parents would be relieved of the burden of the decision if it was lifted from them. The expressed desire among the clinicians was to relieve the parents of the guilt and weight of responsibility for the decision that would most likely result in the child’s death. Clinicians also appeared to perceive that the parents could not only feel guilty for thinking that further treatment was futile, but were also thought to feel the guilt of having put their child through what they recognise as an unpleasant, painful and distressing period of treatment.

“So we’ve put the child through for the liver transplant and the child has died the second day after the liver transplant. And then you’ve got all this guilt and the family said ‘but actually if we’d said no before we went into intensive care the first time we would not have had the child go through six or eight weeks of pain and discomfort; everything; intensive care; got well enough to be talking and interacting with the family to know “I’m going for a procedure which is gonner cure me” but then die’. And they find that incredibly hard to cope with that.” (Int8 MDCons6-ex ITU).

There was also evidence that clinical staff perceived that parents may potentially be subject to censure from their other family members or members of a spiritual group to which the parents belonged. The parents could then lay the blame for the child’s death at the feet of the health professionals. Thus participants tended to read this as the parents wanting the medical staff to take the lead.

Medics taking the lead

There were times when it appeared, from the professionals’ accounts that the parents were complicit in the strategy of securing their agreement not to disagree with the medical consensus.

“Most parents want to be led in this situation.” (Int7 FDCons-exITU5).

“From our experience that most of them expect us to lead, we are the experts.” (Int8 MDCons-exITU6).

“Most families don’t really want to do that [acknowledge there is nothing more that can be done for the child] they realise that they’re there but they’re waiting for the doctors to bring it up.” (Int11 FDCons10).

“Maybe we’re giving them all these options and all this information and you just sort of think ‘well they don’t want to make that decision’. Sometimes they just don’t want to hear it and you just have to take the lead then so we do it when we need to.” (Int17 FN4).

This idea that the health professionals should take the lead was also expressed by one parent.

“I mean they’re [doctors and nurses] doing the job that they know, they’re in the best position to make decisions.” (Int10 MP3days).

The trust that this parent placed in the hands of the staff was acknowledged by the other parents I interviewed but this was not something they felt they had any choice about, at least initially.

Mum "At the beginning you don't have a choice but to trust because you don't know them. You don't know what's going on you don't know what's going to happen." (Int15 BP9mths).

There was also evidence that some parents found their child's admission so bewildering that they were unable to appreciate what was going on. Hence they felt unable to influence what was happening to their child. This appeared to be the case even for a father whose spouse was a nurse, and thus had some prior insight into intensive care.

"I didn't click that when we were at the [names study site] and they had [name of child] and they were working on him and trying to get loads of tubes into him and trundle the trolley over. It didn't click with me then that it was the crash trolley that I know obviously from [names wife] talking about work that crash trolley and you know it's there for a good reason but it didn't click with me." (Int10 MP3days).

However it appeared not to be the case that the perception that medics should take the lead or the presence of parental confusion was used as an excuse to exclude parents. It was desirable that, from the perspective of the health professional participants in the study, medical consultants took, and were seen to take, the final decision to withdraw life support or active life-preserving interventions. However, it was insufficient for the parents merely to go along with the consultant's decision. It was asserted that the parent's role was not, and could not be, a completely passive one.

Parental engagement

Parents were not expected to be entirely passive in the decision. In fact efforts were made by the professionals to ensure that parents understood what was going on with their child and the nature of the decision being made.

"If it takes three or four talks that they need to have then they need to have

them and again looking at our doctors both bedside doctors and consultants sit down with parents and get them back on track.” (Int18 FN6)

This seemed to mean that the clinician’s desire was to ensure parents accepted the medical view about the child’s poor or non-existent prospects for survival. However parents needed to provide some positive indication of their assent. In fact in certain circumstances a parent might be left in no doubt about the need to at least listen to and take on board what was being communicated to them.

“I told her she had a duty as a mother to engage with me.....As the mother she had a responsibility to be involved in the decisions and I couldn’t make any of the decisions completely on my own.” (Int11 FDCons10)

It was clear in this doctor’s account of this situation that she felt she could not withdraw life preserving interventions until the mother had accepted this was inevitable. This consultant implied that although the best interests of the child were served by withdrawal this was countered by a desire not to generate adverse publicity or even court action. This linked with the findings I explored above in respect of the influence of media and legal judgements on team negotiations. However whereas these influences were perceived as peripheral influences in the team negotiations they appeared to be more of a feature in the minds of at least this consultant when persuading parents to accept the decision to withdraw interventions.

There was evidence then of a desire to shield the parents from the full responsibility of making the final decision to withdraw life support but this had to be balanced with the perceived requirement for the parents to at least be part of the process. Contrary to the majority view the picture here is complicated by the perception of some professionals that ultimately the parents make the decision.

“I guess that you have to distance yourself and go with because at the end of the day it’s the parent’s decision.” (Int1 FDSpR6).

“Because a lot of the things boil down to what Mum and Dad want.” (Int9 FN12)

“I think whilst it’s their child you can’t stop escalating treatment without them saying they don’t want to increase treatments.” (Int19 FN4).

It was acknowledged that in some instances the parents would request the withdrawal of interventions.

“A few families will sort of say ‘right you know we are at the end of the line here there’s nothing else you can do it’s time to stop’.” (Int11 FDCons10).

If the view of the medical team and the consultants in particular concurred with the parents’ perception of the situation, the process of withdrawing interventions would commence almost immediately. However the parents could not demand that life-preserving interventions were ceased.

“An adult can decide whether he wants treatment or not and parents can’t refuse treatment that’s clearly in the interests of the child. So it’s not real consent in those sort of in a way an adult will give consent for a procedure or intervention” (Int13 MDCons10).

Parents rarely if ever had the option to exercise a real choice. The choice offered to parents was often merely a choice between clinician determined options. Thus instead of saying ‘what do you want to do/happen for your child’, options were presented from which the parents could choose.

“The options were discussed with the parents and erm in this particular case and erm whether to go for just withdrawal whether to try non-invasive ventilation (i.e. without the use of a tube in the trachea) or whether to go down the tracheostomy route and ultimately ventilation that way. They chose the middle option”. (Int5 MDSpR4).

“So I would say ‘we may have to stop the machines and all the medication and things like that. But actually we can decide on a specific date or an arrangement that suits you best, so if you’ve got family members you want to bring up or anything specific like we can work around that. And that is our suggestion as the medics, what is your feeling about that?’” (Int8 MDCons-exITU8).

Mum - “They’ll not necessarily ask or say ‘can we do?’ they’re more like ‘this is what we’re trying to do, this is what we want to do. We could do it this way or that way. What do you think?’” (Int15 BP9mnts)

Initially these quotes above appear to characterise a negotiation with the parents. As I have already shown above the health professionals asserted there was negotiation with parents regarding withdrawal of life preserving interventions. However none of the options mentioned would have been offered unless the consultant teams had previously agreed that such options were available.

The perceived need to offer the parents a choice did not always sit completely comfortably with some consultants. The view expressed by one in particular captured the views of several;

“I think the pendulum’s swung too far. We used to be very paternalistic and make all the decisions not even letting the parents visit and now we let the parents make most of the decisions and actually if you think about it the parents are making the decisions to withdraw intensive therapy.” (Int11 FDCons10)

It was evident that the intensive care nurses and doctors were wrestling with the problem of ensuring the parents were able to appear to exercise their right to consent to what was being done to their child, at the same time as protecting them during an emotionally challenging time from the guilt of having made the choice to let go and allow their child to die. Thus there appeared to be a desire to balance these two competing demands. The clinicians appeared to adopt two complimentary strategies to facilitate, or perhaps cynically engineer, the parents non-disagreement or assent to the ceasing of life-preserving interventions. These strategies were captured in the sub categories labelled preparing the ground and persuading. The first of these strategies was that of preparing the ground for the parents through a process of information giving to help them to come to terms with or accept the medical decision to cease treatment. The second strategy took the form of persuasion. These two strategies were very closely linked but subtly separated in the data. It was apparent from the health professionals’ interviews that persuasion was not always deemed necessary. Following a period where prognostic information was provided some parents were perceived to have come to the conclusion that it was time to withdraw

interventions on their own. Where this did not occur further strategies of persuasion took place to assist the parents to assent to withdrawal or as shown above not disagree with the decision to withdraw.

7.4.2 Preparing the ground

Giving information to the parents seemed to be aimed at preparing the ground for broaching the subject of ceasing life-preserving interventions. In some cases this was to prepare the parents for a situation where the child might die despite the life-preserving interventions or that it might be time to consider withdrawing interventions. One admitting consultant reported that he would say to parents;

“We’ve got another week to go but we need to start thinking if we are in the same situation now a week from now we’re in deep deep trouble and we may have to think what’s the best thing for the child to do and also for you as a family and how it should be.” (Int8 MDCon6-exITU).

Consultant intensivists appeared to take a similar approach.

“Once you diagnose a child with a life limiting disorder you need to start preparing families for the fact that at some point in the future it may still be a long time away but they need to start thinking about it and preparing.” (Int13 MDCons10).

The parents I interviewed as a couple also talked about how a nurse had prepared them for the worst.

Mother *“but they did prepare...”*

Father *“but they did prepare us in the sense that [names one of the nurses] ‘look she might not make the night’ that’s happened once [looks at wife] hasn’t it?”*

Mother *“yeah ‘it would be very surprising if she made it through the night’”.* (Int15 BP9mnths).

However the doctors and nurses found it was not always easy to be as direct as this in all situations.

“Not all parents will be on board straight away, particularly coming in acutely having been absolutely well child you...accepting is a very big

step". (Int3 FDSpR3).

"The sort of the very acute ones that come in and you can't do anything for. That's always harder because you know the family's still in shock or...you know very much in shock. I mean the initial incident, and you've got to kind of scoop them up." (Int9 FN12).

This situation was captured succinctly by one of the consultant intensivists;

"They are on a bereavement path..." (Int11 FDCons10).

Several instances in the data revealed a recognition that at whatever point withdrawal of life support had to be considered, it was necessary to take into account how the parent's grieving for the loss of their child affected their ability to take in information that was being given to them. Thus there was a sense in which there was an almost linear process from initiating information about the child's situation through to signifying the end of the road had been reached.

"You're on a journey of communication with the families." (Int11 FDCons10).

Nurses and doctors worked hard to help parents to understand what was going on with their child. Where it was apparent that the parents had not appreciated or come to terms with the idea that their child is likely to die, and active interventions were deemed by the medical staff to be futile, the 'conversation' was deliberately delayed.

"So if the team members feel we are not there yet often the conversation will not take place yet" (Int3 FSpR3).

The phrase 'the conversation' was mentioned by several of the medical staff and was a reference to the moment when they had to break the news to the parents that their child was going to die. Initiating 'the conversation' was a specific reference to the point at which the parents would be introduced to the notion that their child may not survive beyond the intensive care unit.

"So we usually say 'we know that in all of the children with these kind of conditions 90% of them would either die within the first few days, 95% would die over the next week and only a small percentage would survive

beyond that, what we suggest is that we go for the 10 day period and at that point we stop all the other supporting treatments”. (Int8 MDCons-ex ITU6).

Mum - “They just said ‘well this is what’s happening it’s just up to her now. There’s nothing else we can do but there may be a time when you have to think as mum and dad and think of her not as trying to get something better, just someone who’s been through a lot and might need a rest now and you’ll know when that time is’.” (Int15BP 9mnths).

This approach appeared to conflict with what had been said by participants about the child’s best interests being the central concern. If the child’s best interests were the central concern it was not clear why general survival statistics, mentioned in the first quote above, mattered. However this did appear to fit with a number of accounts from professionals that clinical data were sometimes used to provide a rationale for resolution to ethical problems.

The time the process of preparing the parents took varied considerably depending on the acuteness of the illness and the acceptance by parents that there was deemed to be no hope of recovery for the child. In the case of a child with an acute illness the time tended to be relatively short and this commenced with an open and honest account of how seriously ill their child was. However this was not necessarily a prognostic declaration of the child’s impending death. It was usually about creating in the parents what the clinicians perceived to be a realistic view of the seriousness of the child’s condition.

Sowing the seed

Where it was apparent that the parents did not fully appreciate the extent and seriousness of their child’s illness, clinicians drip-fed information to the parents, thus sowing the seed of the idea the child may not survive, or impressing on the parents how ill their child was.

“So I suppose it was over a period of about a week that I started talking to them just generally talking to them about how he was and like trying to get them to see from an objective [point of view]. All they could see was their son who wasn’t any different he was still their son, even though he’d been back to ITU and his neurological function was deteriorating and he was

becoming more and more unwell and coming back quicker each time. So trying to get them to see objectively what we were seeing and sort of very subtly trying to talk generally about him and how he had been in the past and what had been going on over recent times..." (Int16 FN8).

This participant and several others indicated that the aim here was to prepare the parents to see things from a point of view of the interpretation of clinical data. That interpretation could thus be seen to validate the team's decision to withdraw life-preserving treatment. It was not clear whether the professionals expressing this truly believed parents could ever be objective about their child's situation. The participants appeared to feel that the clinical indicators for the child's condition were more valid than an emotional perspective in respect of decisions to withdraw interventions. The point at which further active interventions became, or were about to become, futile was apparently signalled, for them, by their detached interpretation of clinical data.

"I think it's our decision we have an overview and we can also have the distance." (Int7 FDCons-exITU5).

However, as shall be seen in the sub-category of persuading, clinical staff did tap into the parent's emotions as a lever to gaining their assent to cease life-preserving interventions.

The suggestion that it was time to consider withdrawing interventions was often introduced as part of the normal flow of information given to parents regarding their child's progress.

"So you tend to say 'We're no longer going to increase the adrenaline, we're no longer going to give extra drugs.' or whatever it may be." (Int19 FN4).

This then introduced the notion that no additional interventions were going to be initiated and signalled that the point at which withdrawal of active life-preserving treatment may be approaching.

"It would be subtle but actually that's what you'd be doing and I suppose that you know there might be some of that in some of the conversations

that you have saying 'You know he's not got much time we need to think about this you know we're prolonging his death'." (Int11 FDCons10).

The degree of uncertainty about a child's potential future well-being also appeared to lead to a conscious avoidance of any talk about a child's life beyond intensive care.

"You don't generally make reference to sort of long term future unless you're very confident that they are going to..." (Int16 FN8).

However when parents asked specific questions about their child's prospects, the degree of uncertainty was acknowledged explicitly.

"If they (parents) say you know 'Well do you think he's going to survive?' I'd say 'At this moment in time we're very very worried about him, he's very critically ill, he's on such and such drugs to keep his blood pressure going to keep his heart rate going. You know unfortunately the nature of intensive care is that I don't have a crystal ball, I can't tell you what's going to happen'." (Int17 FN4).

This process of preparing the parents for a possible future decision about treatment withdrawal was often initiated by the nurse at the bedside. The nurses' accounts indicated they did not feel it was their place to inform parents directly about a child's prognosis. However it appeared that they did feel empowered to give strong hints to the parents about the likelihood of their child's survival.

Parents would be reminded of key information several times by a variety of staff. Thus regular reminders of the medical opinion would be proffered by the staff. It was sometimes the case that the parents, longing for the child to recover and be well again, were unable to appreciate the inevitable death of their child. This was particularly so when the child appeared to be relatively stable or appear to rally from a low point.

"It's not just a one off discussion. We do prepare them you know on a daily basis you tell them 'Look your child's very ill, your child's not...their brain is not going to recover. We don't think in terms of care in your child's best option.' etcetera". (Int7 FDCons-ex ITU5).

“Sometimes that takes a few conversations so it’s a case of going back repeatedly and I tend to re-go over talks and explain the situation again and maybe a doctor tries doing it and then normally it will eventually sink in.” (Int19 FN4).

Regular reinforcement of information was also deemed useful for parents of children with chronic life limiting disorders in reminding parents of decisions they took when in a clearer frame of mind.

“We found it incredibly helpful to go back to them and say ‘listen we fully understand but remember you’re very emotional now when we discussed this two years ago. When we looked at the things you were thinking clearly. You did say you don’t want him to suffer prolonged period of time and things like that. So actually I agree with you we’re going to go to intensive care but after 48 hours we throw in the towel.” (Int8 MDCons-ex ITU6).

It appeared to be the case that at least part of the motivation to provide the parents with clear and open information was to prevent difficult situations developing in the future.

“If you are there and you’re up front and this is who I am and this is what is happening it makes life a lot easier in the long run.” (Int1 FDRReg-6).

The notion of making life easier in the long run was related by this participant to the need to ensure that good relationships were maintained between professional staff and the parents. These good relationships were part of a process of getting the parent to engage with and accept the difficult decisions that had been made by the clinical team.

“Unless you have a good understanding of the parents and had built up a good relationship with the parents I don’t it’s quite difficult for anybody to do it [broach the subject of the child dying].” (Int16 FN8).

Particular efforts appear to be made for those children with chronic disorders to ensure that the clinician who has had most contact, or at least built a good relationship with the parents, was in attendance at crucial points in a child’s stay in intensive care.

“We try and arrange that the one of us who’s got the best rapport with the family will even come in even though he’s not on-call.” (Int8 MD-exITU6).

The health professionals claimed that a feature of all of these interactions with parents was their open and honest approach.

“I would be honest with them (and say) ‘Because there is a range of beliefs on this and what you’re saying doesn’t fall out of that range of practice and therefore we’ll continue to monitor the situation, and if I think your child’s deteriorating as a consequence of not having blood I will come back and tell you again.’ ” (Int12 MDCons 10).

Even when being subtle no attempts were made to deceive the parents in any way. There was some evidence from one couple that they perceived a sense of openness and it was appreciated as a positive aspect of the care.

Father - “...that’s the best thing on being on ITU really honest ‘This is what’s happened or this is what’s going to go on if there is a choice then we’ll go through it. This is what we’re going to try first if it doesn’t happen... options or ...’ that’s great.” (Int15 BP9mths).

The openness of the communication enabled the medical and nursing team to agree the child’s treatment plan with the parents. These agreements were made between the relevant consultant and the parents. Some of these agreements were made well in advance of an admission to the intensive care unit. For example, where a child had a degenerative disorder, the parents were introduced to the notion that at some point their child would not survive an admission to intensive care, or that an admission would not be appropriate. This could take place several months or even years prior to the expected event.

“Once we get to the final stage when we think this child is now within the kind of last two years of his life we usually meet the parents and try and get a formal resuscitation plan as well. So we agree if this child stops breathing how and what we are going to do, do we give antibiotics don’t we? Are we going to feed are we not going to be feeding when the child goes?” (Int8 MDCons-ex ITU6).

“And it does give you the opportunity to talk through all of the ethical issues.” (Int8 MDCons-ex ITU6).

The ethical issues to which this consultant referred were the specific consequences of initiating certain interventions for a child with a degenerative disorder. This would include the potential risks to the child of the insertion of a feeding tube directly into the stomach through the abdominal wall (a gastrostomy).

In acute situations the process of informing the parents was initiated rapidly.

“If things are looking poor you know the family are involved very quickly.”
(Int4 FN5).

Some announcements to parents regarding the intention to withdraw life-preserving interventions were constructed, in the words of one consultant, formally as a precursor to establishing the parent’s non dissent.

“I said in a very formal sense ‘I’m announcing now that I believe that the best course of action is to switch off the ventilator because this child’s dying and the ventilator is just stopping him dying and we should allow him to pass away peacefully...’” (Int11 FDCons10).

This was not a sudden or unexpected announcement, but rather the culmination of the process of preparing the parents, and it led to the point at which they could accept the consultant’s final decision to withdraw life support.

7.4.3 Reconciliation

It was not perceived by health professionals that parents often came to the conclusion themselves or agreed to withdrawal of intervention without further persuasion. Several forms of persuasion were evident in the data which were aimed at reconciling the professional and parental perception of a child’s situation. This included references to the child’s quality of life, involving cultural or faith leaders, reference to a second medical opinion and occasionally the threat of court action.

In appealing to the parents’ emotions both nurses and doctors referred to their assessment of the immediate and long term quality of life for the child. As in the

team negotiations explored above the nurses tended to focus on the immediate quality of life whereas the doctors referred to longer term issues.

"[as though to a parent] 'Yes they are still alive but they will have no quality of life you know. They're gonna need 24 hour nursing care, you know they're not gonna be able to go to the toilet they can't feed themselves.'" (Int1 FDSpR6).

"Also we will give them a lot of information about what else could happen you know erm babies with spino-muscular atrophy actually could be ventilated for life and could survive for a long period of time but they could end up in a situation where they couldn't open their own eyes, they wouldn't be able to speak, they wouldn't be able to tell you that their nose itched." (Int11 FDCons10).

"I would say to mum 'This isn't nice for him. Being on these machines is not doing him anything better.'" (Int17 FN4).

In common with the findings in respect of team negotiation, longer term quality of life was equated with notions of the child's likely ability to interact with their parents and environment.

Cultural leader

In some instances the intensivists sought guidance from someone who could provide an opinion from the perspective of the parents' spiritual or cultural background that the parents would respect. In one situation a doctor spoke of how contact had been made with a particular individual whom the parents trusted as a source of spiritual guidance in their home town in India.

"I think it was a Sikh family and er the consultant had to speak to er one of the religious leaders who is actually in India so they are taking advice from him and he he spoke to him from here over the phone." (Int2 MDSpR6).

This was a situation where the parents believed that certain spiritual rules pertained that dictated the manner in which treatment for the child should continue. The consultation with the spiritual leader, to whom the parents referred as their source of guidance, helped clarify for the medical team what

interpretations were being made about the situation. Indeed information was clarified for the parents as well as the medical team. It appeared that the parents had misunderstood some aspects of their child's situation and passed this misunderstanding on to the spiritual leader. When the consultant and the spiritual leader, with the family's consent, discussed the issues directly, the spiritual leader modified some of their previous advice to the family.

A significant proportion of children and families admitted to the study site came from minority ethnic backgrounds. There was evidence of a deliberate strategy of developing a relationship with someone outside healthcare who might be respected by families as a valid source of advice and guidance. Such individuals would then provide general advice as well as comment on specific situations.

"The Imam can come in and almost looked at it from a different angle and we've now got some very good people within the hospital do this pastoral support and there's a lot of support material for them so that they can sort of look at different ways in which it could be interpreted." (Int16 FN8).

"They have a religious person that often plays a role too, a lot of Asian people who believe God takes and God gives and they interpret that that human beings should do as much as possible to keep the child alive and then God will decide what's going to happen. You can interpret that quite differently [yes] but that is how a lot of them interpret it." (Int7 FDCons-exITU5).

"So one of the first things we do is befriend the local leaders which we know are a particular influence in certain communities." (Int8 MDCons-exITU6).

This strategy then appeared to include two related elements. One was to aid the health care team to gain an insight into the beliefs that might be influencing the parents thinking. The other was aimed at securing parental agreement or non-disagreement with the decision reached by the medical consultants. Thus the cultural or spiritual leader's guidance was sometimes a lever to persuade the parents that the doctor's advice could be accepted.

"And on the few occasions we've actually rung him [a spiritual leader] and

we're in a difficult situation we've actually got him into intensive care, sat down and explained to him what our things are and he's been incredibly helpful." (Int8 MDCons-exITU6).

"Just thinking about religious leaders very often you know if you have got a family and you can get a religious leader on your side that then they can be a very great source of comfort to the family." (Int9 FN12).

The nurse in the second quote went on to explain that a religious leader could help the parents interpret spiritual mores in a way that helped them understand that it was not necessarily forbidden to allow the child to die. In such situations the parents were comforted to realise they would not go against their faith in allowing the medical staff to withdraw life support.

In some situations it was recognised by the professionals that in order to have the parents ready to listen and accept the recommendation of the consultant, it was necessary to ensure that members of the wider family were involved and communicated with.

"For us it's trying to pre-empt things and actually have them all [the whole family] on board is our experience is actually much better." (Int8 MDCons-ex ITU6).

Thus there were a number of occasions on which third parties would become involved in an informal role as part of the process of helping parents accept that interventions should be withdrawn. There were also more formal roles played by a third party in the form of second medical opinions.

Second medical opinion

The seeking of a second opinion from another specialist doctor could be initiated by either the parents or one of the consultants caring for the child. This would be from a doctor independent of the care for the child, usually from another hospital, who would review the information and clinical data to form an opinion. Parents reportedly attempted to use second medical opinions as a bargaining tool to secure continued intensive care interventions for their child.

“I think that parents do not understand the grey areas and the different opinions. So even though they go for second opinions actually they’re not actually looking for a second opinion they’re usually looking for a better opinion.” (Int7 FDCons-exITU5).

“Other people (parents) will be like ‘No we want second opinions’ So that’s where it then gets tricky and the Trust will have second opinions come in and again I think that is for the parents benefit because it’s not going to make any difference to the child in the long term.” (Int20 FN5).

The consultants did not resist the parental requests for a second medical opinion. However they did make it clear to parents that the second medical opinion must not merely a different medical opinion.

“All I’m insisting is that you pick somebody who knows more than me. That’s the only agreement I’ve got, so if you come up with a name of somebody I know that knows more than me I’m quite happy or a similar level of knowledge that’s fine.” (Int8 MDCons-exITU6).

The doctor-initiated second opinions appeared to be a strategy to persuade parents that it was time to withdraw life-preserving interventions.

“The other thing that makes a huge difference is a second opinion. And I remember one case, the 9 week case, was a second opinion that swung it.” (Int11 FDCons10).

The situation referred to by this consultant was one in which a mother refused to accept the view of the medical team that her child was never going to recover, and continued treatment was only extending biological functioning. The medical team had agreed that interventions should be ceased to allow the child to die. They had been attempting to persuade the child’s mother to accept this for a period of 9 weeks prior to the offer of the second medical opinion.

“in this particular kind of case [where parents are adamant they will not accept withdrawal of life-preserving treatment] we will seek a second opinion.” (Int2 MDSPR6).

The perceived need to persuade the parents to be part of, or at least party to and acquiescent with, the medical decisions regarding the child’s treatment sometimes led to the contemplation of extreme measures;

“[The] offer a second opinion and ultimately seeking a legal challenge if you felt it was key to the child’s wellbeing.” (Int12 MDCons10).

“We had to get the solicitors you know the Trust solicitors and when they were involved the Mum started coming in so sometimes you have to do these things.” (Int2 MDSPR6).

“I’ve prepared to go to court by getting second opinion and briefing the lawyers and telling the family that I was briefing lawyers but no further than that”. (Int11 FDCons10).

It seemed that there came a point at which the doctors believed they have to say ‘This is the end of the road and I will get support for my decision if you do not agree or at least not disagree’. In other situations however, the spur for reference to the courts was that the medical teams could not reach a consensus about the withdrawal or continuation of life-preserving interventions.

“And sometimes we don’t get there and we have to go and it’s important to say that if we can’t decide between all of us then we’ll have to ask someone else to make that decision and then it goes to court.” (Int13 MDCons10).

It was clear that the professionals viewed turning to the courts for resolution to end-of-life decisions as a last resort and not one taken lightly.

Parental persuasion: a summary

Parental persuasion was a process that was initiated after the team negotiation had arrived at a consensus in cases when parents would not immediately accept that consensus view to withdraw life preserving interventions. The clear aim of the professional team was to establish a situation in which a child’s parents would accept or at least not disagree with a decision to withdraw interventions. It did not seem that this was motivated by a desire for medical hegemony over decision making but was aimed at protecting parents from having to make the decision. The professionals’ perception was that the parents usually wished the medical team to take the lead in such decisions. However it was deemed necessary for the parents to remain part of the decision making process. The professional team took the time to prepare parents for the

decision to withdraw with honest appraisals of their child's situation. Where parents did not accept the recommendation to withdraw a range of strategies were used to attempt to reconcile the parents to that medical opinion. Those strategies included talking to parents about their child's quality of life whilst receiving intensive care interventions. Occasionally a third part in the form of an influential person from the parents' cultural or spiritual background would be engaged in assisting parents to accept the medical recommendations. Additionally a third party who was deemed able to provide an independent second medical opinion was also called upon. In rare cases, of either parental intransigence or equipoise within the medical team opinion, the consultants were prepared to refer matters to a court for a judgement regarding the withdrawal of life preserving interventions.

7.5 A theory of team negotiation and parental assent

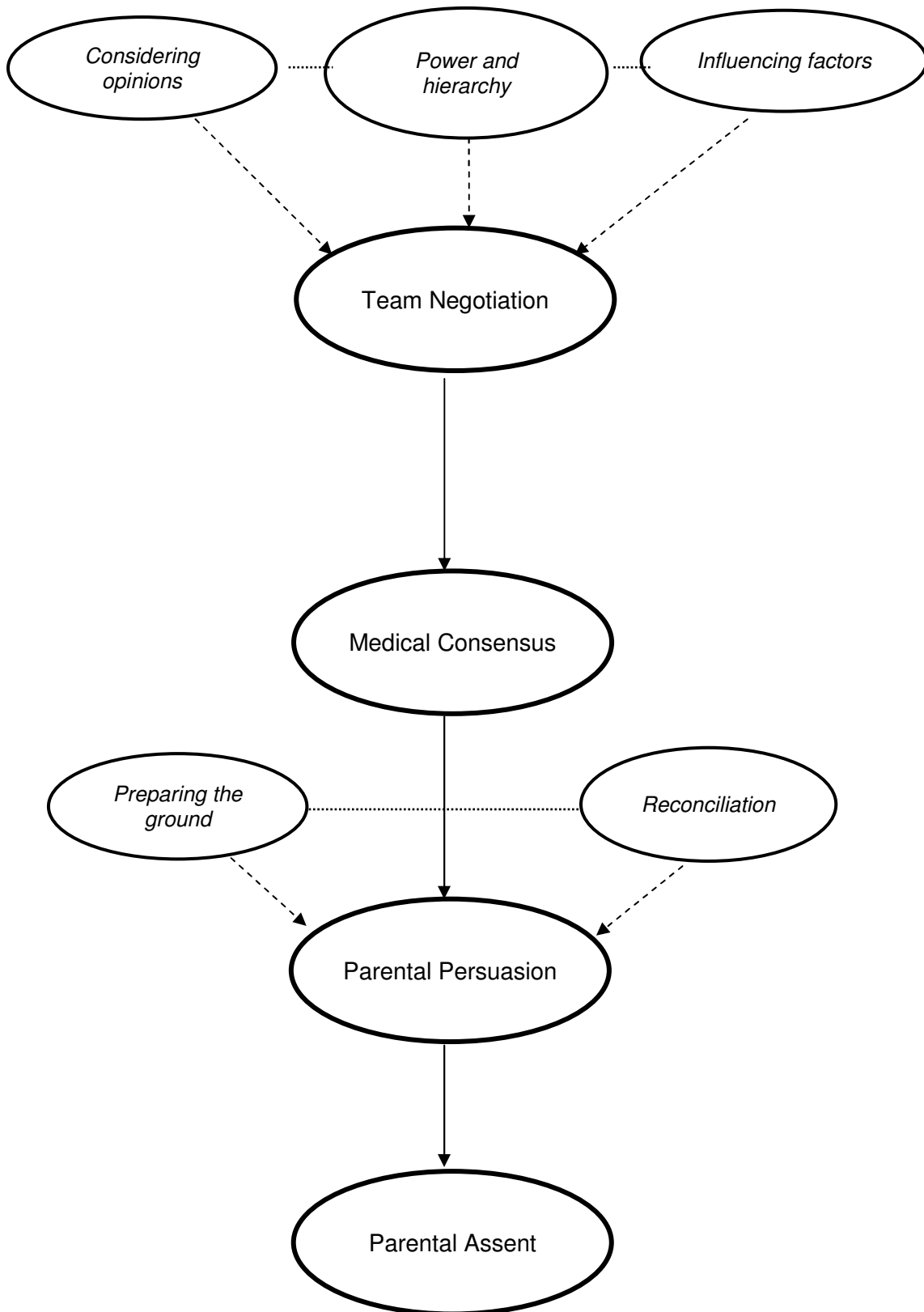
The aim of this study was to explore how ethical problems arising in clinical practice in a children's intensive care unit were resolved. A range of ethical problems emerged from the interviews with health professionals at the study unit. Some of these were ethical problems that an individual had faced and had to resolve themselves. Other ethical problems, that required a resolution involving two or more professionals, appeared to be resolved following a similar pattern to the negotiation process that emerged for the end-of-life ethical problems.

Issues specific to end-of-life situations, particularly the withdrawing and withholding of life preserving interventions, emerged as the most significant ethical problem for the health professionals. This was true for all the health professionals interviewed regardless of their position in the organisation or length of experience in children's intensive care work. The interview data with the health professionals revealed that once the medical team had reached a consensus view that interventions should be withdrawn the aim was then to

secure parental assent. Parents did not need to positively consent but merely agree not to disagree. Where parents were not ready to provide this assent persuasive strategies were employed to reconcile the medical and parental perception regarding their child's situation. The aim was thus to bring the parents to a point at which they could accept the withdrawal of life preserving interventions.

A theory of how ethical problems focussing on end-of-life situations were resolved in this children's intensive care unit emerged from an analysis of the findings of the interview data (diagram 8).

Diagram 8 A Theory of Team Negotiation and Parental Assent



The process of resolving the ethical problems relating to end-of-life situations began with negotiation between most, and sometimes all, of the health professionals involved in a child's care. This process was a function of the fact that decisions regarding the withdrawal or withholding of life-preserving intervention did not rest with an intensive care consultant alone. Negotiation involved interactions between at least two consultant doctors and their respective medical teams. The ultimate responsibility for decisions about the withdrawal of interventions rested with either the admitting consultant or consultant intensivists. The deciding factor regarding where final responsibility lay depended on whether it was the intensive care therapy or the primary therapy for the child's health problem that was interpreted as futile.

There was, among the consultant doctors, an acknowledgement that the wider health professional team also needed to be involved. Thus nurses and other health professionals involved in the care and treatment of a child were listened to and their views taken into consideration. The relative power and authority of those involved in the negotiations had a significant effect on this process. The dynamics within and between medical teams and the relative confidence of individual health professionals also impacted on the manner in which negotiation proceeded.

Negotiations were informed by clinical data that was subject to clinical interpretation in order to come to a judgement regarding whether or not to initiate or cease life-preserving interventions. Deliberations regarding what might be considered to be in a child's, and to a lesser extent the parent's, best interests were factored in to develop a consensus amongst the health professionals.

Only after a consensus view between health professionals had been achieved were the child's parents were approached with the recommendation to withdraw life-preserving interventions. The medically desired outcome was that the parents would not disagree with the decision to withdraw life-preserving interventions from their child. Consent, characterised as a decision made on the

basis of sufficient information and uninfluenced by others, was specifically not a desired outcome. This position was founded on a perception that it would be over burdensome to place the responsibility for making the decision to withdraw life support from a child on the shoulders of the parents.

In situations where the parents did not immediately assent a process of persuasion was begun. Parents were provided with prognostic information regarding their child's condition. Nurses tended to talk to parents about the unpleasant affects a child was likely to be experiencing in intensive care. Doctors tended to focus more on the longer term consequences for a child's quality of life. Both approaches were part of the same strategy to persuade parents that a child's current situation and future prospects were such that it was appropriate to withdraw life support.

Where parents remained unwilling to assent to the health professionals' recommendation, a second medical opinion was sought by medical staff. This second opinion, although independent, was sought with the intention of convincing the parents the original recommendation to withdraw was the correct one. A second medical opinion was also sometimes requested by parents. This request was always granted with a proviso that that second medical opinion was an unbiased opinion rather than one that would merely gainsay the original recommendation to withdraw.

Following these persuasive strategies the end result was almost always that the parents gave assent for the withdrawal of life-preserving interventions. In rare cases an offer of referral to a court was made to parents and in the cited case the mother in question assented to withdrawal at that juncture.

The theory that emerged as a result of the analysis of the interview data generated by this study then was of an ethical problem solving process that follows a predictable linear course. The theory, although focussed on end-of-life decision making, appeared within the limits of the data gathered to apply to

ethical problems that were not end-of-life but nevertheless required input from more than one health professional.

Chapter Eight

8 Relationship of the theory with existing knowledge

8.1 Introduction

This chapter aims to explore the relationship of the theory that was developed from the study findings with existing knowledge. As this study was guided by grounded theory an extensive prior review of literature was not necessary (Strauss and Corbin 1998). The initial literature review revealed this study was exploring a previously little researched area. However it is now important to review relevant literature from other contexts in order to explore how the theory generated from my study fits in the wider critical care milieu. Thus in the first part of this chapter I have explored the relationship between the findings of my study and similar existing works. This chapter opens with a consideration of the types of ethical problems prominent in the literature, and develops into an exploration of findings reported in the literature and the relationship with the key elements of the theory that emerged from my data. The second part of the chapter explores the properties and dimensions of the core categories in the theory of negotiation and parental persuasion.

8.2 Nature of ethical problems in critical care.

It was an unexpected finding that I needed to ask most professional participants explicitly what ethical problems other than end-of-life situations they faced. This was despite the fact that, from of a total of 1342 children admitted to the study unit in the year preceding data collection, fewer than 25 of those children died. The need to elicit by prompt other ethical problems was surprising given the detail regarding the purpose of the study provided in the participant information sheets (appendices 1, 3, 4, 5 & 6).

The participants' focus on the withholding and withdrawing of life-preserving interventions was however entirely in keeping with the dominant ethical issues

reported in both the empirical literature and the more general literature related to intensive care practice (Austin et al. 2009, Edgar et al. 2001, Jennings 1989, Melia 2001, Melia 2004, Pace and McLean 1996, Street et al. 2000, Sorta-Bilajac et al. 2011). Melia (2001), in her study of a range of critical care areas, reported a phenomenon almost identical to the one I experienced on asking the first interview question. Her respondents also focussed on the problems associated with withdrawal of life-preserving interventions. This dominance of ethical issues related to end-of-life situations has also featured in responses from students I have taught when asked about the ethical problems they faced in clinical practice. A significant majority of those students have been qualified intensive care nurses on professional development courses.

The admitting consultants I interviewed identified the most significant ethical problem they encountered was one of securing an intensive care bed for the children they were caring for. The main reason ascribed to this was that the children these two participants cared for all had life-long and largely life-limiting degenerative disorders. Hence the ethical problem was focussed on end-of-life situation but related to withholding life-preserving interventions. Thus the ethical problems experienced by professional healthcare staff, at least in critical care were identified from the perspective of the field of practice of the individual participant.

Nurses and doctors revealed some ethical problems common to both groups and some that appeared to be unique to each group. There is evidence in the literature that nurses and doctors share similar ethical concerns despite sometimes different roles in healthcare (Gaudine et al. 2011, Lindseth et al. 1994, Oberle and Hughes 2001). Such concerns revealed in my study included how much they could legitimately say in response to parents' questions, when to intervene when teaching a junior professional a clinical skill and balancing this against the desire to minimise harm to the child. Other ethical concerns, which both nurses and doctors talked about, related to a desire to minimise distress for the parents and to an extent the wider family of a child.

Some of the medical staff identified ethical issues that did not feature in the responses of the nurses. These included the prescribing of drugs that were not licensed for use in children, organ donation and macro resource allocation. Interestingly only one participant, a junior doctor, mentioned the ethical problem of the potential conflicting duties to their patients and their own family. Personal experience and anecdotes from professionals suggest such problems constantly feature in healthcare practice for professionals who have children themselves. Those individuals may often be presented with a situation where they cannot leave work on time due to the needs of the patients but have young children to collect from school or nursery. However it may well have been that most participants thought it socially unacceptable to raise such issues with a stranger (Silverman 2005).

8.3 The theory's relation to existing literature.

The process of resolving ethical problems in the children's intensive care through team negotiation aimed at achieving a consensus appeared to be in accord with that identified in other contexts (Oberle and Hughes 2001, Carnevale et al. 2007, Garros et al. 2003, McHaffie et al. 2001a, Melia 2001, Melia 2004, Seymour 2001, Zussman 1992). The roles played by professional groups in the negotiation process varied in the literature. The level of parental involvement was also variable.

Team negotiation leading to consensus

Seymour's (2001) study of death and dying in adult intensive care identified a central theme of a social process of negotiation between various professionals in the context of the organisational mores of an NHS hospital. McHaffie et al (2001a) reported on two distinct phases in the process of deciding to withdraw life-preserving interventions in neonatal intensive care. As in my study they found the first phase consisted of consultants consulting with others in the medical team to establish a consensus about the point at which it was appropriate to withdraw life-preserving interventions. A second phase ensued,

sometimes concurrently with the first phase, where health professionals would support parents through the withdrawal and dying process.

Melia (2001, 2004) and Carnevale (2007) both reported a two phase approach similar to my finding. The professional care team developed a consensus view and then aimed to persuade the family to assent to the decision. Carnevale (2007) did however identify a cultural difference in approach between European and Canadian practice in this regard. Whilst there was a significant element of medical paternalism reported in France, the Canadian experience reported by parents was more of a partnership.

The level of involvement of nurses in the negotiations regarding withdrawal reported in the literature did not always accord with that found in my study. For Example Zussman (1992) found that most nurses felt that their input into discussions regarding whether or not to continue life-preserving interventions was listened to by medical staff. However, Street et al (2000) reported that the nurses were not always involved in discussions although this did not appear to be a deliberate strategy. They admitted their finding may have been adversely affected by the terminology used in the questionnaire. Hurst et al (2005) asserted that nurses were deliberately excluded from deliberations regarding ethical problems as they were not seen as legitimate decision makers.

Garros, Rosychuck and Cox (2003) reported that a nurse was present for 75% of discussions with parents regarding withdrawal of interventions. However it was not clear in that study whether the nurses were involved in determining that the point of withdrawal of life-preserving interventions had been reached. Similarly Inghelbrecht et al (2009) in a Belgian questionnaire based study found that 50% of nurses were involved in decisions regarding withdrawal of life-preserving interventions. However 90% of them played a role in carrying out the decision. It was not clear from Inghelbrecht et al's report what level of involvement the nurses had in the process of agreeing that life-preserving interventions should be withdrawn. It was reported that a majority of the discussions regarding the withdrawal of life-preserving interventions were held

jointly between the nurse, the doctor and the parents (Inghelbrecht et al. 2009). What was not reported was whether a consensus view between the health professionals had been agreed prior to the approach to parents.

Hobson (2002) found that nurses perceived their opinions were not respected by doctors, and Chaplin (2002) reported nurses felt they had no power in the decision making process. Evidence from Europe suggests that intensive care doctors may not value nurses as part of the decision making process (Inghelbrecht et al. 2009). This contrasts with my finding that nurses reported their contribution to discussion was valued and did make a difference. However nursing contributions were limited in some instances as evidenced in participants' accounts regarding their lack of confidence in speaking up in multidisciplinary meetings. Hobson (2002) also found a lack of confidence in nurses led to a lack of full participation in ethical decision making.

Consensus

The literature relating to ethical problems in intensive care highlights the need and desire for consensus, especially regarding intervention withdrawal (Doucet et al. 2001, Hurst et al. 2005, Hurst et al. 2007, Inghelbrecht et al. 2009, Melia 2004, Seymour 2000, Seymour 2001, Zussman 1992, Melia 2001, McHaffie et al. 2001a, Sorensen and Iedema 2008). However as Gill (2005) noted, consensus does not necessarily mean all parties agree rather that any disagreements were not revealed to the parents. Respondents in my study recounted disagreements that occurred between members of the healthcare team. However both nurses and doctors made a point of asserting that these disagreements would never be revealed to parents. Thus part of the consensus was an agreement that dissenters would not relay their concern regarding the decision to parents.

Zussman (1992) reported that the nurses recognised, as appeared to be the case in my study site, that the actual decision regarding withdrawal of life-preserving interventions was for doctors to make. Thus having had the

opportunity to have their say the nurses in the study site, in common with Zussman's (1992) finding, tended to conform to the medical view. Whilst this finding might be attributed to the organisation of intensive care in the USA in the late 1980's Coombs and Ersser (2004) noted a similar situation in intensive care units in the UK.

Jennings' (1989) sociological study of neonatal units in the USA asserted that the parents' views were only sought once the medical staff had come to the conclusion that the infant was no longer "viable" (p264). Similarly Garros et al (2003) reported that consultations with the parents regarding withdrawal only took place once the health care team had collectively come to a decision that continued life-preserving interventions were no longer beneficial or appropriate. Once the clinical team at my study site had agreed that it was time to withdraw life-preserving interventions, a second phase was entered. This was focussed on seeking the non-dissent of parents to a decision that had already been arrived at.

Parental persuasion and assent.

In accord with my findings, Melia (2001, 2004) found that families were specifically informed the withdrawal decision was not theirs to make. The implication being that the family's role was to assent to the pre-determined decisions of the medical staff. Seymour (2001) also found in adult intensive care units there was an implicit aim to

"bring companions to a point where they will agree with decisions that have already been taken." (p 67) (underlined in italics in original).

It was viewed as important to secure the adult patient's companion's agreement, for whilst they do not have the same decisional rights as parents do for their children, they were seen as having a potentially significant influence on the pace and trajectory of the patient death.

Gill (2005) observed that parents in a neonatal unit were provided with a good deal of information regarding a child's progress in intensive care but had relatively little power to determine what happened to their child. From observations of a specific case, he noted that the parents' thoughts about their child's progress were determined by the treatments, rather than their thoughts determining which treatments were implemented. Thus it would appear that at least in both an adult and children's intensive care environment it is not uncommon practice to approach relatives of the patient only after the professionals have determined that life-preserving interventions should be withdrawn.

It was interesting to note that in Zussman's (1992) study, nurses avoided patient's questions about their progress and even provided deceptive responses. Meert et al (2008) asserted that;

"Withholding prognostic information from parents often leads to false hopes and feelings of anger, betrayal, and distrust." (p 2).

Nurses in my study felt it was not their role to reveal a child's prognosis; however there was no evidence in my data that the nurses or any other professional would deliberately deceive the parents. The nurse participants in the study site reported that they referred questions regarding prognosis to one of the medical staff to ensure questions were answered. It is unclear whether the difference between my finding and Zussman's was a result of different values underpinning healthcare in the USA compared to the UK or whether the passage of time has altered values regarding honesty and truthfulness in health care. Certainly the nurses' code of professional conduct is explicit regarding the professional duty to be honest with clients (Nursing and Midwifery Council 2008). The nurses in my study denied any suggestion that they would be tempted to provide deceptive responses to parent's questions. However the avoidance of answering direct questions by providing broad statements on the child's state of wellbeing was perceived as acceptable.

McHaffie et al (2001b, 2001a) found that once the healthcare team had agreed that continued interventions were no longer appropriate, they did not always recommend this to the parents. However the consensus regarding an infant's prognosis was provided to the parents. It was then sometimes left to the parents to request interventions were withdrawn. This diverges from the findings of my study when it appeared the parents were often given a strong recommendation to accept withdrawal of life-preserving interventions. It appears that although parents in neonatal intensive care want to be involved in decisions, the majority did not want to be the ones making the final decision (Brinchmann et al. 2002, McHaffie 2001b, McHaffie and Fowlie 1996). In a children's intensive care context parents may wish to make the final determination but may only be willing to do so once the doctors have informed them further interventions were not medically justified (Gill 2005).

Street et al (2000) reported that some parents initiated discussions regarding withdrawal of life support. Garros et al (2003) found 30% of parents had reportedly initiated discussions about the withdrawal of life-preserving interventions. In my study one consultant did mention that occasionally parents would actively request that life-preserving interventions are stopped, but this was a rarity. It is possible a greater proportion had thought about it but not voiced their thoughts to the staff. There was evidence in my data that the parents of children with chronic life limiting disorders sometimes raised questions regarding the withholding of an intensive care bed. This may be related to the fact that such parents tend to be well informed about their child's condition and the likely course it will take.

A comparative study of practices in France and Canada regarding parental involvement in end-of-life decisions found some degree of medical paternalism was unavoidable (Carnevale et al. 2007). In Canada parents were much more likely to be the ones deciding on intervention withdrawal. In France where doctors were more paternalistic the parents valued good relationships and

communication with professionals and were more accepting of the lead they took in decision making.

Eden and Callister (2010) in a literature review of parental involvement in end-of-life decision making found significant variation in the level of involvement of parents in decision making. It has been asserted that staff thought it would be too much of a burden for parents to make decisions about withdrawing life-preserving interventions alone (McHaffie et al. 2001a, Epstein 2010) or even at all (Gill 2005). However it appears to be a common practice to provide hints regarding the seriousness of a child's condition to parents over a period of time (Garros et al. 2003, Gill 2005, Melia 2001, Melia 2004, Seymour 2000, Seymour 2001).

Seymour's (2001) study of adult intensive care revealed that nurses tended to focus on preparing patient's companions for the impending information from the medical staff warning of the likelihood of the patient's death. Melia's (2001) study also revealed the notion of sowing the seed to prepare parents for the impending decision to withdraw life-preserving interventions. This was identified by participants in my study when nurses and one doctor referred to subtle hints that they gave to parents regarding the graveness of their child's condition. This was at odds with Gill's (Gill 2005) assertion that prognostications made behind closed doors by health professionals were not shared with the parents.

Garros, et al (2003) reported a process of first an informal meeting with parents to discuss how to proceed with their child's treatment at which the intensivists informed the parents of the options. This was followed up some time later, although it was not clear how long this was, by a formal sit down discussion to establish consensus with the parents on withdrawal of life-preserving interventions. This appeared to be similar in many ways to the approach taken in my study site in that the formal discussion stage appeared to be aimed at persuading parents to agree to the withdrawal. Garros et al (2003), in their quantitative study, stated that "A consensus about forgoing LST (*Life Saving*

Treatment) was achieved in the first formal “sit-down” meeting with families or surrogates in 51.4% (35 of 68).” (p. e373). In the remainder of cases two or more meetings were required to secure the family’s consensus. This appeared to imply that the discussions with the family were part of a process of persuasion regarding a decision that had already been determined by the clinician. These findings may need to be treated with some caution since the results were descriptive and not subject to rigorous statistical analysis.

Relieving parents of the burden of the decision

Both nurses and doctors in my study expressed a view that easing the burden on parents was an important consideration when it had been decided to withdraw life-preserving interventions. The position adopted in my study site that the decision to withdraw life-preserving treatment was not the family’s has also been reported in the literature (Epstein 2010, McHaffie and Fowlie 1996, McHaffie et al. 2001a, Melia 2001, Melia 2004, Eden and Callister 2010, Carnevale et al. 2006). In common with my findings this was reportedly justified on the grounds that it was a way of minimising feelings of guilt for the family. Epstein (Epstein 2010) described how neonatal staff felt they had an obligation to give parents time to come to terms with the decision and that had embedded within it sub-obligations to minimize suffering. The minimisation of suffering was related to both the parents and the child.

Thus from the professionals’ perspective similar motivations and processes appeared to operate in other intensive care units as in my study site. Professionals were motivated to enable the parents to have a part in the process of deciding when withdrawal but also minimise the guilt the parents may experience as a result of making that decision. Carnevale et al (2007) however asserted that where parents had taken the final decision to allow withdrawal of life-preserving interventions they found no evidence of any association with parental guilt.

It appeared that the professional's perception that the decision was too burdensome for parents was based on an assumption rather than any established evidence. When parents have been asked, in a neonatal context, they have stated they should make the decision even though it would be distressing (McHaffie and Fowlie 1996). However other evidence appears to be equivocal on this matter (Brinchmann et al. 2002, Eden and Callister 2010). The health professional participants in my study were unequivocal about their contention that such decisions were too burdensome for a parent to make. In fact they implied that they considered it unethical to place that burden on a parent. The majority of parents in McHaffie et al's (2001) study felt they had made the ultimate decision. What was not clear was whether that was truly the case or the result of skilful handling of the process by professionals in consulting with the parents regarding the point at which life-preserving interventions were withdrawn.

When life-preserving interventions were to be withdrawn at my study site there was the potential for a considerable lag between the time when the decision was made and the actual enactment. Unilateral precipitate action by the doctors at the study site to withdraw life-preserving interventions was considered unacceptable. The professionals did not rush to the point where interventions were halted to provide parents with time to accept the situation. This supporting of parents through a process that comes to an end when the child dies is also a feature reported in the literature (Austin et al. 2009, Epstein 2010, Mohammed and Peter 2009, Meert et al. 2008).

"The gradual withdrawal of life support creates an interlude where families can harmonize their understandings of the situation and address the disbelief that treatment options have run out" (Mohammed and Peter 2009) (p 299)

However in contrast to Mohammed and Peter (2009) the management of this process in the study site appeared to centre on the process of persuading of parents rather than undertaking a stepwise reduction in interventions. Once the parents had indicated they would not disagree with a recommendation to

withdraw interventions it appeared they were withdrawn fairly rapidly. However I did not explore with participants the process of actual withdrawal; thus this assertion was based on an impression given by the participants rather than any substantive data.

There is evidence that the culture of the society in which these ethical issues arise influences how much, and at what point, parents become involved in the process (Carnevale et al. 2007, O'Brien et al. 2010, Akpınar et al. 2009). The extent to which parents are likely to be involved in the process of deciding when life-preserving interventions should be withdrawn thus appears to be variable. The sociological structure of the professional team and the clinical area appear to be instrumental in the level of involvement of parents. There do appear to be significant common elements to the process of resolving ethical problems in end-of-life situations between my study and those reported in the literature in a range of different contexts.

Having reviewed relevant literature and explored the general landscape into which the theory of team negotiation and parental assent fits, I will now explore the properties and dimensions of the two main categories forming the theory.

8.4 Properties and dimensions of the theory

A process of resolving ethical problems, in particular end-of-life situations, in a children's intensive care unit has been presented in this thesis. That process was not something that was imposed on the actors in it, nor invented by them, but was a product of the sociological micro-culture of the unit. This assumption was derived from the content and form of the conversations that generated the findings of this study. The homogeneity of the accounts given by the participants was testimony to the notion that the process that was being described was embedded in the culture of the unit. No participant reported or even intimated that any formal policy underpinned the resolution process. Thus it is important to understand some of the key properties and dimensions of the two main categories in the theory that were integral to the unit's culture.

8.4.1 Team negotiation and its sub-categories, properties and dimensions

Care is needed in applying the notion of team to a group of individuals (Ovretveit 1997a, Payne 2000). In the context of my study I included, within the concept of the team, all those involved in the care of a child. The negotiations regarding whether to commence or cease life-preserving interventions involved various members of that team depending on the situation. Allocation of an intensive care bed to a child often involved just the admitting and intensive care consultants. Whereas involvement of almost every professional often occurred when the withdrawal of life-preserving interventions was being considered.

The negotiation process amongst the professionals was a function of the organisation of care in the study site, in common with the whole of the NHS, in that the intensive care consultants rarely if ever had sole responsibility for a child's treatment and care. However they did have responsibility for many aspects of a child's treatment and care whilst occupying an intensive care bed. Similarly the nurses had responsibility for certain aspects of a child's care in the intensive care. In order to be held responsible one must have power to act.

Differential power relations exist at a variety of levels within the hospital hierarchy (Ovretveit 1997a, Austin et al. 2009). A number of theories regarding what power is, and how it is applied to human interaction exist (Foucault 1982, Hawks 1991, Ovretveit 1997b, Patton 1989, Payne 2000, Turner 1995, Proctor 2002). I do not intend here to undertake a detailed review of any of these theories. I have chosen not to detail the distinctions between power over and power to that are debated in the literature but rather consider the concept as a whole. However my findings show that power was a factor that affected and influenced the negotiations that occurred between consultants and between consultants and other members of the healthcare team. Therefore a consideration of the impact of power on the process of negotiation was undertaken.

Foucault (1982) characterised power as a transactional phenomenon. That is, power cannot exist without someone who is subject to the exercise of that power taking action. Thus a doctor exercises their power when a nurse accepts a doctor's orders and does something, or parents acquiesce to a doctor's recommendation to withdraw interventions. Power matters in situations where there is an imbalance but no unilateral authority to act that creates a necessity to negotiate.

Inter-professional negotiation can be problematic in intensive care where patients are being treated by two or more consultant medical teams (Sorensen and Iedema 2008). It has been suggested that there are often different and conflicting goals of physicians such as intensivists and surgeons, resulting in competition for power and control in determining the best course of action (Cassell et al. 2003). Hospital consultant doctors have all reached the top of the profession in their own sphere of clinical activity. Thus at first view they all appear to be equals; however this is not necessarily so. Ultimately an individual is required to take responsibility for decisions and the admitting or specialist consultant had primary responsibility for the treatment and care of a child admitted to hospital. However each intensive care consultant was a specialist in their own area of clinical expertise, based on a discrete body of knowledge. They also carried responsibility for a child in their care. Thus they were able to use this knowledge to exert influence over the outcome of the negotiations regarding both the withholding and withdrawal of interventions.

There was evidence in my study that some consultants held more sway in the decisions made. For those children with chronic life limiting disorders, there was evidence that the potential for benefit to the child needed to be convincing to the intensivist before they would agree to an admission. Thus in such instances the intensivists in the study unit appeared to hold the balance of power. However cardiac consultants in particular, and to an extent all surgical consultants at the study site, were reported to have significant influence over the decision to admit a child to intensive care. This was both in terms of securing an intensive care

bed and in resisting withdrawal of life-preserving interventions. Several of the junior intensive care doctors made reference to their perception that surgical consultants were in general assertive and sometimes challenging to negotiate with. This appeared to be in accord with other evidence that surgical doctors tended to assert their authority as the final arbiter in decision making (Melia 2001, Melia 2004, Churchman and Doherty 2010). Melia (2001, 2004) noted a greater reluctance in cardiac surgery services to consider stopping life-preserving interventions.

Gill (2005) observed that specialist consultants' overruled intensivists in determining whether or not potentially life-preserving surgery should be performed. He noted that those who spent less time with the child appeared to exert more power in determining whether or not life-preserving interventions should continue, whereas those who spent most time (nurses and parents) had least influence. This appeared to hold true in my study site. Sorenson and Iedema (2008), in an ethnographic study observed that:

"...performance information is used as a weapon in a continuing battle for supremacy between high-status individuals." (p 102).

However there was no evidence to indicate this was the case in the study site. There was evidence in my study of robust discussions between admitting and intensive care consultants. However there was no suggestion that this was based on anything other than attempting to agree a consensus position on how to proceed with a child's treatment.

The consultant intensivists in my study indicated they had a more holistic view of a child's situation than the admitting consultants, at least in respect of the child's immediate situation on the study unit. Whilst an admitting consultant was a specialist in a particular aspect of medical treatment or biological system within the body, intensivists dealt with the whole of the child. Thus there were accounts from several consultant intensivists where an admitting consultant would be able to provide evidence of benefit to a particular biological system from continued interventions. However the intensivists would counter with

evidence regarding the perceived futility of continued interventions with respect to other aspects of the child's condition.

Power, nurses and doctors

Becker and Grunwald (2000) asserted that different professional value systems between nursing and medicine are manifest in perceptions of the nature of the power they possess. They suggested that doctors are attributed with the power of the technical expert, whereas nurses are attributed with referent or interpersonal power. This is significant in an intensive care unit where technical knowledge and skill are highly valued (Coombs and Ersser 2004). Medical authority derived from technical expertise can thus have a significant impact on the way nurses influence the process of resolving ethical problems (Coombs and Ersser 2004, Goethals et al. 2010).

Hurst et al (2005), in a telephone survey with doctors, found that nurses were deliberately excluded from deliberations regarding ethical problems as they were not seen as legitimate decision makers. Part of what was judged to underpin this was the desire to maintain the integrity of the decision making group, that is the doctors. Bound up in this notion of integrity, according to Hurst et al (2005), was a need to ensure that the physicians' opinion was seen by others to be the one that mattered.

A number of studies have considered the differential power relationships between doctors and nurses, and how these impact on decision making processes in clinical practice (Churchman and Doherty 2010, Coombs and Ersser 2004, Goethals et al. 2010, Melia 2004, Porter 1991). All of these studies revealed that, although there are some differences from the findings of an earlier study by Stein (1978), the 'nurse-doctor game' as he termed it is alive and well. The key rule of the game is that open disagreement between the players must be avoided. Melia (2004) and Goethals et al (2010) noted that this nurse-doctor game was played out more subtly than Stein (1978) had

characterised it, but the underlying elements remained in place in the units they studied.

Anecdotal evidence, gained from my teaching with children's intensive care nurses, supports the notion that the more senior and experienced nurses in intensive care make suggestions and subtle hints to doctors regarding the point at which they felt further life-preserving interventions would be futile. Hobson (2002) identified a similar pattern amongst nurses she interviewed. The aim of this covert prompting was, according to the students, to enable the doctors to assert that it was their idea to consider withdrawal. Whereas an overt expression by the nurses was perceived most likely to be rejected on the grounds that nurses lacked the knowledge to make such a judgement. Nurse participants in my study also indicated that they would ask questions of junior doctors that would prompt them to think about whether it was right to continue with the current interventions. It was implied that the hope was that this would filter up to the consultants and thus not be seen as a direct challenge from a nurse. Interestingly the junior doctors in my study also talked about how they felt they could not directly challenge consultants but would tread carefully when questioning decisions. This tended to be founded on the position of power consultants held over junior doctor's career progression.

Professional guidelines for doctors have for some time advocated collaborative working in both clinical and ethical decision making (British Medical Association 1999, 2007, General Medical Council 2001, 2006, Royal College of Paediatrics and Child Health 1997, 2004). Consultant intensivists in my study referred to a deliberate strategy, which had been developed over the previous 8-9 years within the unit, of moving to a more collegiate way of working with all grades of staff. This was confirmed by a senior nurse who had worked in the study unit for a number of years.

Several of the nurse participants in my study made passing reference to situations in which they would question in their own mind whether continued interventions were beneficial. The manner in which they talked about these

issues indicated a degree of moral distress. However some of them said they would be reluctant to voice such concerns to medical staff. Goethals et al (2010) ascribed this tendency largely to a function of the working environment and the dominance of doctors in decision making. This was borne out in a study of nurses' views on challenging doctors' practice where not only were perceptions of medical authority a barrier to nurses challenging doctors, but the behaviour of some doctors was a disincentive (Churchman and Doherty 2010). This finding was related particularly to surgical consultants. Several participants in my study gave testimony to the notion that surgical consultants in particular were less willing to listen to the views of others.

There exist few concrete rules that govern the actions of professionals, which results in the need to constantly negotiate how professionals work together. Strauss et al (1978) described the hospital as a place;

"...where personnel, mostly but not exclusively professionals, are enmeshed in a complex negotiative process in order both to accomplish their individual purposes and to work – in an established division of labor (sic) – toward clearly as well as vaguely phrased institutional objectives" (p 404).

When talking about ethical problems they faced and had to resolve as individuals there was a tendency for nurse and junior doctor participants to refer to unwritten rules about the correct course of action. This was especially the case when it came to questions about whether or not to reveal information to parents. Several nurse participants in my study referred to the notion that it was not their place to reveal certain types of information to parents, such as their child's diagnosis or prognosis. However they were unable to identify a specific rule or guideline that set this down. There was merely an implied reference to medical authority in such matters. Thus it appeared that sociological processes at work in the study unit, coupled with published professional guidance, established an environment in which negotiation was central to resolving end of life ethical problems.

Medical staff in the study unit were aware that often the nurses were the first to recognise that it was time to consider withdrawing life-preserving interventions. However it was acknowledged by several consultant intensivist participants that lip service was often paid to the notion of collegiate decision making in multidisciplinary meetings. This was evident from the acknowledgement by one consultant that the multidisciplinary meetings to discuss children did not do much more than “tick the box” for a full team discussion. The resulting action may not be different from one following a full debate of the ethical issues with all parties, but there is the potential that some actors may not engage with the agreed action. It was evident from my interviews that several instances had occurred in which individuals withdrew, or stepped back, from direct involvement with the agreed action. Although not made explicit in the interviews, it was implied that this was because their views were perceived to have not been taken into account.

In contrast to findings reported in Goethal et al's (2010) review, evidence in my study suggested a good level of cooperation between nurses and doctors. This may be explained by differences in the functioning of health care teams between intensive care units, closed off from the rest of the hospital, and general wards and departments. Nurse participants in my study reported that ethical concerns could readily be raised with medical staff, and that even the most junior nurses were supported by seniors in raising any concerns. However both nurses and doctors intimated that the nurses' ability to significantly influence decisions, especially in respect of end-of-life situations, was limited. Notwithstanding this it was evident that the health professionals, involved in the care and treatment of children on the unit, had developed working practices that appeared, in my findings, to lead to a shared perception of the process of resolving ethical problems. This shared perception included an implied and explicit acknowledgement of the domination of medical opinion regarding decisions regarding life-preserving interventions.

Seymour (2000) asserted that attempts to clarify legal and ethical issues regarding withholding or withdrawing treatment and a culture of risk have led to the prominence of technical issues over the ethical. Those in dominant positions of power tend to be able exert considerable influence over the issues addressed in a case discussion (Melchin and Monette 2001). Thus the values held by the dominant individual(s) in any discussion would tend to influence the resolution of a problem. It has been asserted that good moral decisions are founded on the facts of the situation (McHaffie et al. 2001a), and that before any discussion of ethical issues can occur clinical facts must be established (Wellesley and Jenkins 2009). However clinical facts are often based on value laden assumptions (Gill 2005). For example what might be assumed as factual data that establishes, in the mind of a doctor, that continued life-preserving treatment is no longer justified or even wrong could be disputed. Even with the best quality evidence in medicine, there is room for debate regarding the interpretation of clinical data.

Medical power and authority, in part, derives from the fact they have a claimed unique body of knowledge of medicine and healthcare, which allows them to exercise that power. However the special knowledge of doctors only extends as far as clinical medicine. There is no evidence to suggest that doctors are better prepared or educated in matters of healthcare ethics than nurses. This might explain the evidence that suggests that health professionals in critical care areas, such as intensive care, have a tendency to attempt to convert ethical problems in to technical problems in order to capture, or maintain control over them (Zussman 1992, Garros et al. 2003, Goethals et al. 2010, McHaffie 2001b, McHaffie et al. 2001a, Melchin and Monette 2001, Seymour 2001, Terry 2001). There was constant reference, in my interviews, to the interpretation of clinical data that guided thinking about ethical problems rather than focussing on the ethical issues.

The drive to establish practice founded on evidence based medicine is also asserted as a causative factor in this shift from the art of medicine to the

science of prognosis (Seymour 2001). Thus the deliberations regarding when it is right to withhold or withdraw life-preserving interventions would tend to naturally centre on the technical issues related to perceived utility of further treatment. This appeared to parallel the issues that were mentioned in the interview data in the current study. The nurses in my study also tended to relate, at least in the interviews, to technological issues as the grounding for some of their thinking about ethical problems. Goethals et al (2010) found in their literature review that nurses tended to afford more weight to practical issues over ethical principles when dealing with ethical problems. Seymour (2001) found in her study of adult intensive care that whilst technical data was important to doctors, both they and nurses utilised their experiential and intuitive knowledge to resolve problems. Both nurse and doctors made reference in the interviews to anecdotal evidence, opinions of other professionals and experience of others as sources for their reasoning. This may be a function of the close working relationships between the professional groups in the study unit. Alternatively perhaps it is a function of the culture of intensive care units that, after time all those working in a unit, physically closed off from the rest of the hospital, become acculturated to the prevailing values in that unit. However since no participant in my study had less than 4 years experience in intensive care it was impossible to determine if the commonality of approach I identified was a cultural artefact.

Meyer et al (2002) found that issues such as quality of life, the likelihood of improvement, and perception of their child's pain are the most significant factors for parents. So while health professionals may focus on clinical data to guide them, parents may have a different perspective. When attempting to gain deeper insights into the process of resolving ethical problems, participants often took refuge in the familiar territory of clinical factors that underpinned their thinking. It was more difficult for both doctors and nurses in my interviews to articulate the ethical issues that impacted on their work. Hobson (2002) also noted that nurses in her study were able to identify ethical issues, but found it hard to articulate them. Notwithstanding the apparent dominance of clinical data

interpretation in decision making, the child's best interests, perceived quality of life and medical futility were mentioned as significant factors in both nurses and doctors thinking in my data.

Best interests

It was perhaps not surprising that participants found it difficult to articulate their ideas about what constitutes best interests, given the recent debate regarding the nature and extent of the usefulness of the concept in children's critical care (Baines 2010, Bridgeman 2010, Lyons 2010). Issues for consideration in terms of a best interests judgement of children include, the degree of pain and suffering involved in their care, whether proposed interventions are likely to bring more benefit than harm, the likelihood of survival free of serious disability, if there is long term disability, and the extent to which support is going to be available in the family in the future (Beauchamp and Childress 2009, Brock 2001, Chiswick 2008, Nuffield Council on Bioethics 2006, Rose 1997). A number of these issues appeared in the accounts given by participants in my study. There are however a number of difficulties with applying a best interests analysis to a child.

Studies of best interests judgements, made on behalf of adults, reveal significant disparity between what health professionals recommend and what patients preferred (Carnevale 2005, Lo 2009). This may be a result of the difficulty of putting aside personal values in making determinations. Doctors tend to focus on long term survival as key, whereas patients might be more interested in the avoidance of pain or a decline in their physical mobility. Zussman's (1992) study revealed staff's recognition of the difficulties of balancing the patients' best interests with the desire to establish a cure, or at least a state which deems the patient well enough to be discharged from the unit. This desire for a cure led to situations where patients underwent or continued with interventions that were painful and distressing because of an unwillingness to accept that life-preserving interventions should cease. Thus it was not deemed to be in best interests of the patient to be allowed to die if there

was a chance, no matter how remote, that their life might be prolonged even if only for a few weeks.

Gill (2005) suggested that;

“When the patient is a child with any hope of recovery, some physicians are almost as unlikely to raise the idea of discontinuation of treatment as parents are to bring it up on their own.” (p 266).

Thus it is possible that the, very small but unquantifiable, chance that continued interventions might benefit the child outweighs, in the minds of both professionals and parents, any ethical consideration of their best interests. This could lead to situations where references to interpretations of clinical evidence delay a decision to withdraw interventions beyond what an appraisal informed more explicitly by ethical principles of the situation might suggest. It appeared to be the case in my study site that it was not until all possible avenues had been explored that the decision to withdraw interventions was presented to parents. Thus the application of any notion of best interests appeared to focus on the likely success or otherwise of interventions in leading to a situation in which the child could be discharged from the unit.

Another difficulty in assessing best interests is determining in any reliable way the degree of pain and suffering young children, children with severe neurological impairment, or the unconscious are experiencing (Chiswick 2008). Chiswick (2008) noted that reliance was often placed on physiological response indicators such as, raised pulse and respiratory rate, and restlessness as signs of distress. However suffering is an emotional experience that is not necessarily easily quantifiable through physiological measurement. Valid pain assessment tools for children do exist, but they cannot be used for those who are heavily sedated or unconscious.

It would be possible for a child in intensive care, as a planned admission, to advance an opinion about what they felt their own best interests were, if given the opportunity prior to admission. The weight given to any child's opinion

regarding any treatment options would be dependent on their capacity to make a judgement. Since capacity should be judged in the context of a specific judgement (Dimond 2005) in an unexpected eventuality the child could not be consulted if sedated or unconscious. Furthermore, whilst it is possible for adults to make advance directives this would not be possible for a child unless their parent(s) held the same view. Even then the parent(s) can be overruled by the courts (Langslow 1998, Dimond 2005).

In determining best interests it is usually expected that those who know the patient well will be consulted (Holt 2002). Primarily the parents have been thought to be the best source for information about their child's best interests (Jennings 1989, O'Brien et al. 2010, Street et al. 2000, Hallstrom 2004). However that is not the same as accepting parents are the best arbiters of what is in their child's best interests. It may be difficult for parents to separate and distinguish their child's best interests from their own (Carnevale 2005). Turner (2010) suggested that it is not an uncommon ethical problem to encounter parental preference that does not appear to be in the child's best interests. However this seems to ignore the implicit value judgement made that assumes the professional has a better or perhaps more valid view of what is in the child's best interests. There was evidence in my study that participants perceived, that because of the emotional ties to the child, it was difficult for the parents to accept when it was time to allow their child to die. Thus there is the potential for parents to focus on what they subconsciously perceive as their own best interests - that is to continue the life of the child they love.

At the study site the assessment of what was in the best interests of a child appeared to be done without specifically consulting the parents. However the parents of a child with a degenerative disease were reportedly more likely to be consulted. Nevertheless where the judgement was made that continuing life-preserving interventions would be no longer clinically indicated, it would have been difficult to justify continuing interventions merely because the family demanded it (Holt 2002). The continuance of interventions, possibly beyond

what was considered in the child's best interests, did occur during the process of persuading parents to accept the withdrawal of those interventions. Participants intimated that once the team had agreed that interventions should be withdrawn the focus of their attention shifted more to consider the parents' needs in facing the loss of their child. This was justified on the grounds that the parents would need time and support to come to terms with the decision especially if it was an acute admission.

Chiswick (2008) suggested that there are some situations, such as where a child is likely to survive but with significant disability, when the parents best interests might be seen to be as important as those of the child. Several participants in my study mentioned concern regarding a family's perception of their capacity to manage the demands of caring for a child in need of constant nursing care. However they took the view that that was a judgement for the parents themselves to make. There was no evidence in my study that a decision to withdraw life-preserving interventions had been taken on the premise that the parents' best interests were paramount.

Questions regarding what might be in a child's best interests are linked to considerations of quality of life (Beauchamp and Childress 2009). It could not be in a child's best interests to suffer the ill effects of interventions if their quality of life is, or is expected to be, unacceptable. It has been found that nurses focussed on parents' perceptions of the child's quality of life while doctors focussed on prognostic factors (Coombs and Ersser 2004, Street et al. 2000, Lo 2009). Both doctors and nurses talked about the child's quality of life as a significant element of their thinking. The nurses in my study tended to focus on matters such as the suffering the child was experiencing and the quality of the child's life at that moment in time. The doctors, on the other hand, tended to be focussed on the child's future well being and likely future quality of life, rather than the child's immediate situation. This appeared to be borne out by the evidence that nurses showed signs of thinking about withdrawal of interventions some time before doctors considered it.

It has also been suggested that doctor's assessments of what constituted an acceptable quality of life tended to be negatively biased (Lo 2009). Certainly several participants referred to children that had survived beyond all medical expectations. However it was also recognised that predicting long term outcomes, especially during critical phase of a child's illness, was notoriously difficult. Notwithstanding this, where it was judged that continued interventions would bring no benefit, or a very poor quality of life would result, several participants made reference to the futility of treatment.

Futile treatment

Medical treatment is regarded as futile when the available interventions are likely to be unsuccessful in managing, or resolving, a medical condition, offer a reasonable chance of survival, or a minimum quality of life (Cogliano 1999, Wellesley and Jenkins 2009, Royal College of Paediatrics and Child Health 2004, Akpinar et al. 2009). Brock (2001) drew a distinction between physiological, quantitative and evaluative futility. Physiological futility refers to medical interventions that are known with a high degree of certainty not to be likely to produce a physiological effect. That is interventions that are unlikely to maintain, or improve, a person's physical integrity, or prevent death. Quantitative futility refers to situations where there is a very low probability that an intervention will have the desired effect. Evaluative futility refers to interventions that may have a physiological effect but it is not certain whether the effect is beneficial, or that it would be wanted by the patient. Mohammed and Peter (2009) refer to this as qualitative futility and identify it as a controversial ethical issue in situations where it is someone other than the patient making that determination.

The term futility then may be applied to situations where medical interventions might be perceived as to no longer provide benefit or outweigh harms. However it remains a matter of judgement rather than established fact and Lo (2009) found such judgements when made by medical staff to often be mistaken or at

best problematic. This point is perhaps underlined by the conclusion to a case study reported by Robert Orr (2009);

“It is very easy in retrospect to confirm their (intensive care professionals) belief that this extent of treatment was ‘inappropriate,’ but it clearly was not futile in the literal sense since it did postpone his death for many months.” (p 146).

Thus for some it would appear that life-preserving interventions do not become futile until the point at which they fail to preserve life and the person dies in spite of the interventions. The point being that any intervention that maintained life could not be considered futile. However participants in my study referred several times to situations where children had been kept alive but that interventions were nevertheless futile. This was not surprising as it reflected the “no purpose” and the “no chance” situations outlined in the Royal College of Paediatrics and Child Health (2004) guidelines on withholding or withdrawing treatment in children. Several participants did indicate that they were familiar with those guidelines, although they did not say they used them explicitly to aid decision-making.

Interventions that are perceived as futile can have what has been termed ritualistic benefit (Mohammed and Peter 2009). There appeared to remain some utility, from my study participants’ perspective, in continuing interventions for the benefit of the family. This allowed time for parents to come to terms with the idea that no more could be done to save their child. Thus it may have been the case that continuing life-preserving interventions and the delay in withdrawal may risk not being in the child’s best interests. However giving parents time to come to terms with a decision to withdraw may be necessary (Garros et al. 2003). It was thus at the study site it appeared that the perceived duty to care for the needs of the parents override to an extent the duties to the child in terms of relief of suffering.

Consensus

Intensive care units, by the nature of the clinical work staff are engaged in, mostly demand collective rather than individual decision making (Melia 2004, Zussman 1992, Sorensen and Iedema 2008). This demand for a collective approach stems according to Zussman from the need to establish certainty in the decisions made. Even one dissenting voice could lead to an uncertainty that may call into question the decision to withhold or withdraw life-preserving interventions. That is not to say that individuals cannot express contrary views, but that disagreements should not become known outside the team. Both nurse and doctor participants stated that it was important that a consensus, about withdrawing life-preserving interventions from a child, should exist before parents were formally approached.

Symbolic interactionism explores the idea that individuals can plan how they act in social situations based on the shared meanings developed from a group's consensus (Chenitz and Swanson 1986b). For Melia (2004) consensus between nursing and medical teams was an important symbol of solidarity which enabled the team to move on from the difficult situation of withdrawing life-preserving interventions. Thus whilst differences of opinion could be aired, the negotiated consensus could ensure that such differences were not detrimental to the overall smooth functioning of the intensive care unit. The data from my study site bore out this notion. Several participants noted their disquiet at some decisions especially continuing interventions which they perceived to burden the child without any benefit. However they were able to put such disquiet aside in order to continue to function as an effective member of the team.

Goethals et al (2010) found evidence that, when faced with complex situations, nurses tended to conform to existing group practices. Practices in intensive care are usually dominated by the doctors (Coombs and Ersser 2004). One potential consequence of this could be that the interpretation of clinical data might dominate decisions rather than a full and open exploration of the ethical issues.

It was evident in my study that junior doctors also felt similarly constrained but not necessarily for the same reasons. It was evident that the more junior doctors in my study were to an extent constrained by their dependence on the senior doctors for their career progression.

There is evidence in the literature that would suggest there is a desire, among medical staff, to avoid conflict in ethically difficult situations (Hurst et al. 2005). One of the drivers of this desire, in Hurst's (2005) analysis, was the perceived need to maintain the integrity of the group. It was also evident, in my study, that both nurse and doctor participants perceived a need to ensure parents were not aware of any dissent in the team regarding the consensus about withdrawing life-preserving interventions. Dissent within the healthcare team with a decision to withdraw life-preserving interventions, if communicated to parents, would possibly lead to them losing confidence in medical recommendations.

Interestingly one interview with parents revealed that they were well aware of many differences of opinion among the medical staff. However these differences were exclusively about interpretation of clinical data, such as how low to allow their child's haemoglobin count to fall before initiating blood transfusion. It was evident that these parents were unaware of any discussions that the professionals may have had regarding whether or not to withdraw life-preserving interventions.

Summary of team negotiation

It was evident in my study that participants perceived an environment of good communication existed within the unit. However this finding does need to be tempered with the likelihood that it would be doubtful whether participants, in a one off interview with an outsider, would be openly critical of other members of their team.

There was evidence, from my study site, that some significant bargaining was necessary from time to time between intensivists and admitting consultants.

However this was always characterised as being part of collegiate working rather than a struggle for supremacy. The relative power of individuals to influence the decision making process was a significant factor. This was tempered by attempts to ensure as many of the health professionals caring for the child had an input into discussions about withdrawing life-preserving interventions. The key desired outcome of negotiation was the establishment of a consensus that could then be taken to the parents to initiate the process of gaining their assent to the withdrawal of life-preserving interventions.

The clinical team decision regarding the point at which life-preserving interventions should be withdrawn was largely driven by the interpretation of clinical data. However questions regarding what was in the child's best interests and their immediate, or future, quality of life were significant factors in the decision making process. Once the team had come to a consensus regarding the withdrawal of life-preserving interventions the interests of the parents became the priority in deciding when to act on the decision.

8.4.2 Parental persuasion and its sub-categories, properties and dimensions

Parents might be viewed as impotent in the face of dominant medical power. However child healthcare practice has evolved over many years in respect of the level of involvement parents have in the provision of care and treatment. In the 1950s and 1960s parents were not involved in their child's care in hospital (Ministry of Health 1959, Department of Health and Social Security 1976). As a result of a range of studies into early childhood and the effects of parental separation government guidelines (Department of Health 1991, Department of Health 2007b), healthcare professionals have been required to work more in partnership with parents. The Children Act 1989 also established, in public policy, parent's rights to participate in their child's healthcare decision making. In English law parents do have responsibilities for their child and this incorporates rights to make decisions on behalf of their child. However this does not confer absolute dominion (Alderson 2000, Montgomery 2003, O'Brien et al. 2010).

“Ordinarily the authority to consent to or refuse medical treatment for a child rests with her parents. But it is a right that exists only as long as what is proposed advances the welfare of the child and is demonstrably in the child’s best interests.” (Biggs 2011) (p 16).

A parent may consent to interventions on behalf of their child, but they cannot demand interventions in the face of medical opposition as long as the opposition is based on a proper interpretation of clinical evidence (McLean 2004). Where it can be convincingly shown that life-preserving interventions are not in a child’s best interests the courts have supported the medical decision to withdraw treatment (Bridgeman 2010, Lyons 2010).

It is important here to distinguish between consent and assent. Assent is where a person may agree or allow some examination, or treatment, to be carried out without necessarily being able to fully understand what is being done, or having sufficient autonomy to give true consent (Hope et al. 2003). Consent is something given freely and without coercion by a person competent to take that decision based on an understanding of what is proposed (McLean 2004). At the study site where withdrawal of life-preserving interventions was deemed appropriate by medical consensus a high proportion of parents, if not all, were not given the opportunity to consent. In fact they were specifically informed it was not their decision. The strategy of establishing non-disagreement from the parents fits with a definition of assent since an autonomous choice was not being made available. The use of the phrase non-disagreement and similes by participants appeared to be a device, which allowed parents to acquiesce with the decision to withdraw without having to positively agree with the decision. Thus in some instances one might argue that parents did not even assent, but did not protest when medical staff made a decision.

For clarity in the matter of consent it is also important to establish who those individuals referred to as parents were. The participants implied, in their responses, that there was an assumption that the adults who presented themselves as the child’s parents were the only individuals from whom they would seek agreement to withdraw treatment. Only one participant made

specific reference to those who hold parental responsibility under the terms of The Children Act 1989 and The Adoption and Children Act 2002. It was unclear whether the health professionals enquired about whether or not either of both parents held parental responsibility. It was evident, from participants' accounts, that care was taken to ensure the parents were the individuals to whom the medical recommendation to withdraw interventions was presented. In fact in several instances participants stated that they specifically requested other family members were not present when attempting to secure the assent of the parents.

Thus it was apparent in the study unit that, in terms of the decision to withdraw life-preserving treatment, parents were not being offered the opportunity to consent. The decision had already been made by the health professionals, the parents were then asked to acquiesce with that decision. The grounds for this approach as indicated above were founded on the notion of relieving the parents of the burden of making a decision that would result in the death of their child. Whilst this rationale might at first view appear to be laudable, it does seem to run counter to public policy and professional guidelines. There was no evidence in the participants accounts that parents were asked if they wished to defer the decision to the doctors. Nor was there any indication that an assessment of the parents capacity to provide a valid consent had been made.

In English law under the terms of the Mental Capacity Act 2005 it must be assumed that an adult has capacity to consent, unless there is evidence to support a view that this capacity has been reduced. However this rule specifically relates to adults making determinations about their own healthcare. The situation in respect of parents consenting on behalf of a minor is less clear. It could be argued that the emotional turmoil a parent would be likely to be experiencing might reduce their capacity to decide. However The Children Act 1989 does require decisions to be made taking account of the best interests of the child. Thus questions regarding parental capacity to make a decision might appear not to be relevant since the measure of the decision is whether or not it

is in that child's best interests. Of course what was thought to be in a child's best interests was the medically determined course, and hence the health professionals sought to persuade the parents that withdrawal of life-preserving interventions was the right thing to do.

Persuading

It has been asserted that in order to accept the decision to withdraw life-preserving interventions parents need to be persuaded that it is the best for their child (McHaffie 2001b). The act of persuasion might appear distinct from the process involved in securing a valid consent. Consent is based on the ability of an individual to make a choice from alternatives without undue influence from others (Dimond 2005, McLean 2004, Montgomery 2003). Individuals are of course influenced in their decision making from many sources, such as medical advice and their own family or friends. The important point about consent is that, having been exposed to a variety of information and views, the individual makes up their own mind having weighed information in the balance. Persuasion on the other hand is a process by which an individual is convinced by some process of human communication aimed at influencing them to choose a particular course of action (Simons 2001). Thus unlike consent, which is free from influence by the person seeking that consent, persuasion specifically involves influencing tactics. However the central element to this concept of persuasion allows the person being persuaded to exercise a choice. Under the conditions indicated in my findings parents were not able to exercise a real choice. This was exemplified by two consultant intensivists who stated if the parents could not assent to withdrawal they would refer the case to the courts. Thus the only option being offered to the parents, albeit in the main without the threat of court referral, was to not disagree with the medical opinion.

I have used the term persuasion to characterise this property of the theory in respect of parental assent. However it must be acknowledged that due to the minimisation of parental freedom to choose it does not conform to many accepted definitions of the term (O'Keefe 2002). Thus it must be appreciated

that parental persuasion was used as a category label within the theory rather than as a definition of the concept.

Evidence would suggest that people defer to those with expertise and credibility to guide their decisions (Cialdini 2001). However, despite the health professionals' acknowledged expertise in intensive care medicine, some parents would not assent to the withdrawal of interventions from their child. The participants recognised the need for the parents to come to terms with and accept that nothing more could be done for their child. The parents were offered emotional support and information aimed at aiding understanding of the child's condition and prognosis. It was apparent in the participants' accounts that prognostic information was also provided with the aim of influencing the parents to accept the medical recommendation to withdraw life-preserving interventions. Such information appeared to be offered to the parents almost as facts rather than interpretations of clinical data based on experience and research.

The information nurses tended to provide was focussed on the child's immediate situation and the potential discomfort they were most likely experiencing. This often subtle information was also apparently aimed at influencing the parents to allow the life-preserving interventions to be withdrawn from their child. The spiritual advice that was sought for some parents tended to be of a type that aimed to correct or clarify beliefs regarding a spiritual systems guidance regarding end-of-life situations.

However there came a point at which it was decided to utilise additional tactics in order to influence the parents to agree not to disagree with the medical decision. These tactics included seeking a second medical opinion and in one case declaring an intention to seek legal advice. The declaration of the intention to seek legal advice was made after a period of nine weeks from the point at which the medical team agreed life-preserving interventions should be withdrawn.

Guidance from the paediatricians' professional body (RCPCH 2004) exhorts the use of second medical opinions for clinical reassurance and legal requirements. In my study second opinions were sought, or agreed to, as part of persuading parents to accept that it was time to withdraw. Second medical opinions should be an independent unbiased expert opinion from a person unconnected with the medical team caring for the child and not in any way connected with the child's treatment (General Medical Council 2010). The consultants exerted some control over the source of those second opinions. This did not appear to be merely the exercise of power in order to ensure that second opinion concurred with the professional team in the study site. Parents were guided to seek second opinions only from those who could be relied on to provide an unbiased view of the child's condition and prognosis based on an analysis of the available clinical evidence. Additionally, and this is where the control lay, that opinion should come from a clinician whom the study site consultant was assured had the relevant expertise to give an opinion. Thus the second opinion was expected to be founded on the interpretation of clinical data about the child's condition in order to confirm that there would be no benefit for the child in continuing life-preserving interventions.

Summary of parental assent.

Those with parental responsibility under The Children Act 1989 have rights to consent to or decline treatment for a child, provided the chosen option is in that child's best interests. However in respect of a decision to withdraw life-preserving treatment it is a demanding situation for a parent to face. The professionals in the study site acted to relieve parents of that burden in cases where those parents were perceived unable or unwilling to make that decision. In such instances various strategies were employed to move to a situation where the parents assented to withdrawal of interventions.

8.5 Study findings and ethical theory and principles.

Several participants made brief reference to both deontology and utilitarianism in the context of discussion about the use of NHS resources. There were also a number of times when participants referred to concepts bound up in the Beauchamp and Childress (2009) principles. Participant's accounts included an expressed desire to minimise harm for a child by withdrawing interventions which were perceived to provide no benefit but did cause pain or discomfort. There was also evidence of the participants recognising that the needs of the child had to be balanced with the perceived duties to support the parents at a distressing time.

There was no direct evidence that a deliberate and considered exploration of ethical theories or principles underpinned the process of resolving ethical problems in the study unit. However many of the accounts provided by participants did imply that there was an underlying awareness and application of aspects of those theories and principles in their practice. Since this study was initiated by my reflections on the impact of my teaching of healthcare ethics to health professionals it is appropriate to consider here how the study findings relate to the ethical theory and the principles of ethics outlined in chapter 2.

MacIntyre's (1985) assertion that virtues are culturally located was evident in the micro-culture of the study site. Cultural identity relates not only to a society's or spiritual beliefs, but other forms of community such as professional groups (Carnevale 2005). There were two significant issues that arose in the data from the study site that related to Carnevale's notion of culture, and impacted on the resolution of ethical problems. The first was perhaps an obvious one and that was the differing ethnic or spiritual beliefs of parents and families. In this regard a strategy existed of consulting individuals perceived as respected spokespersons or authorities relevant to a child and parents background as a way of understanding differing cultural perspectives on the child's situation. Although it was implied that many aspects of intensive care might be consulted on, the main focus of these consultations was to assist in understanding cultural

perspectives on end-of-life situations. There was no evidence in my interviews that participants perceived that it would be useful to examine the cultural perspectives that guided the clinicians' reasoning.

A second issue in the data was an underlying, and implied, culture formed by a group of professionals working in close proximity within a unit closed off from the rest of the hospital by the physical barrier of the code-entry door system. This was most obviously evidenced when similar phraseology was used by a number of participants to state that parents were expected to not disagree with the medical consensus that life-preserving interventions should be withdrawn. Throughout the interview data there appeared to be a great degree of homogeneity in the accounts of ethical problem solving. That is not to say all participants were saying the same thing, but rather that the different accounts when analysed revealed no outliers. The participants' perception of the process of resolving ethical problems appeared to fit the same overall pattern. When I checked out some of my initial findings with later participants there was never an occasion when anyone refuted my understanding of the process.

Virtues relating to honesty and to kindness were manifested in participant's accounts as good intensive care practice in the study unit. These were aimed at protecting the parents from the burden of making a decision to withdraw interventions. However this appeared to be based on an assumption that parents would not want, or could not cope with, that burden rather than any empirical evidence. It would be tempting to think of this practice as a benevolent paternalism. But this begs the question as to whether any kind of paternalism, when directed at adults, could ever be benevolent. It would certainly be difficult to argue for any kind of paternalism if health professionals are to respect the parents as rational beings. That is not to say the health professionals on the study unit were acting in any other than with what they perceived to be the best interests of the child and their parents. The notion of sparing the parents the burden of making a decision to withdraw interventions appeared to be an adjunct to the expressed belief that this was a decision for doctors to make.

One consultant made a passing reference to deontology and utilitarianism in her interview. However she characterised the situation she was relating to me as “deontology versus utilitarianism”. This was in the context of a situation in which perceived duties to a child might conflict with perceived duties to the wider community. A number of participants referred to the duties they perceived existed to both the child in their care and that child’s parents. There was also reference in some accounts to more general duties to society in respect of good use of NHS resources. However these notions of duty appeared to be derived from obligations placed on them by professional codes of conduct and other professional guidelines. There was no evidence that participants were aware of the particular nature of duty as posited by Kant. Similarly there were some references in the interviews to utilitarianism. This was characterised as a need to ensure justifiable use of NHS resources. No participant talked about how utilitarian or more broadly consequentialist theory could be applied, in a healthcare context, to determine how to analyse and resolve ethical problems. Two things need to be said about this. The first is that I was not specifically looking for evidence of the conscious application of ethical theories in practice. Thus it is perhaps not surprising that they were not mentioned more often. The second thing to note is that the accounts given by participants did reflect key aspects of these theories. However without further investigation it would not be possible to identify whether this was a factor of professional education and socio-cultural mores or inherent value systems exhibited by those entering the caring professions.

The doctors in my study made several references to the nature of evidence they used to inform their judgements regarding withdrawing or withholding life-preserving interventions. It was acknowledged that a significant source of evidence was drawn from the doctors’ own or other colleagues experience in similar cases. However as McHaffie et al (2001a) identified the development of a consensus based on such a casuistic approach is not necessarily ideal. Casuistry is the application of a case system to moral or ethical reasoning (Beauchamp and Childress 2009, Gillon 1985, Harris 1985). Instead of starting

with general principles from which answers are deduced, casuistry begins with specific cases for which there is a consensus on the appropriate outcome. An essential element of a casuistic approach is to identify cases that are taxonomically similar to the case under consideration. The case in issue is then analysed in the light of those cases to discover what the proper decision in the case ought to be. The most commonly given example of casuistry today is the English legal system. The casuistic method is the basis for common law. Courts compare like cases in order to reach their rulings. A range of opinions have been expressed regarding the potential for casuistry to assist in the resolution of moral problems (Arras 2001). Gaul (1995) suggested that casuistry could provide a structure for developing insights into the complexities of moral problems but noted it fails to satisfactorily establish ethical norms. Casuistry received scathing criticism from Harris (1985) when he suggested that where casuistry is used moral debate may as well be abandoned. Beauchamp and Childress (2001) were more restrained in their criticism;

'...cases point beyond themselves and evolve into generalisations, but they may also evolve in the wrong way if they were improperly resolved from the outset.' (p395).

The absence of sufficient deliberation could potentially create a moral rut in which all apparently similar ethical problems are resolved with some predetermined action based on previous experience. Gillon (1985) nevertheless asserted that the application of casuistic analysis does have some merit. The aim of analysing difficult ethical problems is not necessarily to arrive at correct answers or resolutions or to develop solutions to all similar cases. Rather it is to prompt a deeper analysis of what may initially seem to be simple issues that can easily be resolved. This reflection could encourage a closer examination of ethical problems in clinical practice. Although it is important to attempt to resolve a dilemma, it is just as important to practice the analysis of such dilemmas in order to develop the thinking skills necessary to join in the ethical debates that occur in and around practice. This was acknowledged by

consultant intensivists in my study when bemoaning the loss of the colleague who acted as “Devil’s advocate” on occasion.

It was interesting to note that the “Devil’s advocate” in my study site was not a role that was adopted by just any member of the team. Rather the term was ascribed to a specific individual who had been one of the intensive care consultants. Several intensive care consultants I interviewed talked about this individual’s interjection in discussions, prompting thoughts regarding potentially unexplored issues. The consultant in question reportedly had the tendency to raise ‘what if?’ or ‘what about?’ questions. However it appeared that such questions were centred on prompting further discussion of the clinical evidence rather than focussing on the ethical question of what was the morally right action.

When that individual left the unit participants did not indicate that another person was being actively sought to adopt such a strategy. This was despite the fact that the participants in my study stated that it was a loss to the team not to have someone putting a contrary view to the emerging consensus. It was not clear how acceptable it would be in the study site for someone other than a consultant intensivist to undertake such a role. Having said that, all accounts provided by participants indicated multi-professional debate did occur prior to arriving at a consensus to withdraw life-preserving interventions.

It was notable that although the nurses, and to an extent the more junior doctors, identified being unsure how much and when they could question decisions being made by senior medical staff they did not identify this directly as an ethical problem. This is particularly interesting in the context of nursing practice since the professional code of conduct (Nursing and Midwifery Council 2008) specifically places a duty to act as an advocate for those in their care. It has been claimed in nursing literature that nurses are in the best position to take on a patient advocate role (Mallik 1997, Sellin 1995, Epstein 2010, Goethals et al. 2010, O'Brien et al. 2010). However this assertion is not universally supported (Allmark and Klarzynski 1992, Charles-Edwards 2001,

Seedhouse 2000). The assertion that nurses should be advocates for patients has often been based on the expressed view that nurses are the professionals who spend most time with the patient and their families, and thus have insights that no other could develop. However nurses in my study refuted this saying on many occasions the doctors developed closer relationships with the parents. The reason given for this was the way in which nursing duty rosters were drawn up that meant they often did not care for the same child on consecutive shifts. This led to the more junior nurses to suggest they did not get to know the child and family well enough to confidently contribute to discussions. Some of the nurses also felt they lacked the necessary professional experience or medical knowledge to fully participate in discussions.

It was evident throughout the participants' accounts of their practice that the principles of beneficence and nonmaleficence were at the heart of their thinking when grappling with ethical problems. There were frequent references to the desire to minimise harm and bring about good outcomes. These principles were particularly finely balanced in the study unit in terms of the sometimes competing interests of the child and their parents. It was noteworthy that once a consensus of professional opinion was to withdraw interventions, the balance of these interests shifted more to the parents. It was interesting that in focussing on persuading parents to accept no more could be done for their child it was accepted that the child would continue to carry the burden of what had become unnecessary interventions. Thus not only were the professionals attempting to balance the harms and benefits for the child but also between the child and their parents.

The findings of this study indicated then that even though the decision to withdraw was considered to be a medical one the parents' rights to make decisions on behalf of their child were not completely ignored. However this did not appear to be based on the principle that the parents' autonomy was respected. The data in my study indicated that participants appeared to operate on an assumption in the majority of cases that the parents lacked the capacity

to make an autonomous decision due to the emotional burden placed on them by their child's situation.

Holt (2002) suggested that if respecting a patient's autonomy was the most important of Beauchamp and Childress' (2009) principles, continuing interventions perceived as futile could be justified. In a children's intensive care unit the patient cannot, in the main, exercise any autonomy since they are unconscious or heavily sedated and thus could not demonstrate capacity. Parents were thus the proxy for the child's autonomy. It was not apparent however that for the participants in my study autonomy was the most important ethical principle. The participants' accounts indicated fairly clearly that because the decision was not the parents' to make their autonomy was not at the forefront of their thinking. Notwithstanding this even if we suppose for the moment that autonomy is the cardinal principle, what might be true for competent adults does not apply equally to children or parents deciding on behalf of their child. A fully autonomous person can make a decision to do something that might be deemed not in their best interests, such as smoke tobacco, but they do have the right to make that choice. However a parent's autonomy to decide on behalf of their child is constrained by the requirement to consider that child's best interests.

In terms of the principle of justice expressed as the just distribution of resources, participants' intimated that a first come first served principle was applied to bed allocation. Thus if there was a bed available and admission to intensive care was clinically justified, a child would be admitted. If shortly after this another child presented with perhaps a better chance of benefitting from admission than the previous child the second child would be referred to another centre. A child's proximity to the study unit and or hospital/local area was also a factor in securing a bed when there were more children than available beds. This was a relatively common issue since the unit was a regional centre and covered a wide catchment area. The nearer the child to the unit the greater was the expressed duty to admit them. However this only applied when all other

things were equal in terms of clinical need and likelihood of derived benefit from an ICU bed.

Unrecognised ethical problems

It was striking to me that despite the fact that several nurses and one or two junior doctors made reference to their discomfort with certain clinical decisions there appeared to be a lack of recognition that whether to challenge or not was an ethical problem. These participants implied that they perceived this to be related to their place in the pecking order of the organisational structure. For the nurses this was characterised as “it’s not my place to question” and for the junior doctors it was more to do with their prospects for advancement in the discipline if they openly questioned senior doctors. Hence it was not a question of ethics rather more of an established principle not to question in certain instances. This appeared to be founded on sociological processes that operate in the hierarchical structure that existed in the study unit and more generally in the NHS.

Another ethical problem was apparent in participants’ accounts that seemed to go unrecognised. This arose in situations where the parents either initiated or immediately agreed with the medical view that life-preserving interventions should be withdrawn. There was seemed to be a perception in participants that where medical staff and parents agreed on withdrawal it was obvious that that was the right thing to do and no further consideration of any ethical issues arose. This may be related to the lack of evidence of anyone acting directly as an advocate for the child. However I have to acknowledge this was an impression I was left with at the end of my analysis that was not explored specifically with participants.

9 Conclusion and recommendations

This qualitative study explored how ethical problems are resolved in a children's intensive care unit. Data was gathered through unstructured and semi structured interviews with health professionals and parents of children on an NHS intensive care unit. Data was analysed following the framework developed by Strauss and Corbin (1998). A theory of team negotiation and parental assent emerged from that analysis that was grounded in the data.

As a contribution to the knowledge of a particular aspect of healthcare practice the study explored an area that an initial literature review suggested had not previously been researched. The theory generated from the study revealed a process of resolving ethical problems, particularly in respect of end-of-life situations, that followed a predictable course.

Ethical problems can be what Du Bois (2008) characterised as cognitive, social or volitional. Cognitive ethical problems are those where there is uncertainty regarding the right thing to do and thought needs to be given to resolving this. Social ethical problems are those when there is disagreement between the stakeholders in a situation. Volitional ethical problems relate to acting on a decision. In healthcare practice there is no shortage of ethical problems where uncertainty about the right or most acceptable thing to do exists (Hurst et al. 2007, Pace and McLean 1996, Vogel 1991, Heland 2006, MacGowan and Maier 2008, Melia 2004, Brock 2001, O'Brien et al. 2010, Viney 1996, Gill 2005). It is also axiomatic that in most healthcare practice and certainly in children's intensive care units no person can legitimately act on their own. Securing agreement with all stakeholders in making healthcare decisions, especially in end-of-life situations, is an important feature of healthcare practice. In the context of a children's intensive care unit the stakeholders include parents as well as a wide range of healthcare professionals. However, it was evident in this study that stakeholders do not all have an equal voice in discussions that lead to the final decision. Consultant medical staff had the most

influential position whereas a child's parents had no influence in the process of negotiation that resulted in a decision to withdraw life preserving interventions. This study has confirmed assertions that nurses tend to adopt a care focussed approach which centres on the immediate quality of life, whereas doctors are more focussed on prognostic factors (Coombs and Ersser 2004, Street et al. 2000, Lo 2009).

The parents' part in the process was to accept the medical team's recommendation to withdraw life preserving interventions and not disagree or object. The findings of this study revealed that a principle of benevolent paternalism was applied by the medical teams at least in respect of end-of-life decisions. Parents were provided with a great deal of information and support to assist them in accepting the decision to withdraw. That information although factual was provided in a manner that was clearly aimed at persuading parents to accept the medical recommendation to withdraw.

Parents did have a significant influence on the volitional ethical problem at least in terms of the withdrawal of life preserving interventions. The act of the withdrawal of those interventions would not take place unless and until the parent or parents had indicated their non objection. There was evidence that some health professionals perceived an ethical principle in the requirement to ensure parental assent to the withdrawal of life support. However, it was also evident that concerns regarding parents taking legal action and to an extent the potential for adverse publicity were factors in motivating teams to secure assent. In the context of this study there was no substantial evidence that the children who are being cared for and treated were seen to be participants in decisions made about them.

9.1 Reflections on the conduct of the study

My study does not represent a pure example of Strauss and Corbin's version of grounded theory. However, Strauss and Corbin's analytic procedures were followed as closely as possible, within the limits imposed by conducting the

study within the regulatory framework of the NHS. I feel therefore, I can claim that in applying the methodology as detailed in previous chapters the study demonstrates a high degree of trustworthiness. It is important then to reflect on this study before making any conclusions regarding the soundness of the research and the theory generated by it. Guidelines for making judgements regarding the rigour of grounded theory research have been described (Chiovitti and Piran 2003) (table 4).

Table 4 Evaluating rigour in grounded theory research

Standards of rigour	Suggested methods of research practice
Credibility	1. Let participants guide the inquiry process
	2. Check the theoretical construction generated against participants' meanings of the phenomenon
	3. Use participants' actual words in the theory
	4. Articulate the researcher's personal views and insights about the phenomenon explored
Auditability	5. Specify the criteria built into the researcher's thinking
	6. Specify how and why participants in the study were selected
Fittingness	7. Delineate the scope of the research in terms of the sample, setting, and the level of the theory generated
	8. Describe how the literature relates to each category which emerged in the theory

Adapted from Chiovitti and Piran 2003.

Accounts of how these standards and suggested methods were applied to this study were detailed in relevant chapters above. However, a brief overview of the same is presented here.

Credibility

Credibility in grounded theory is the extent of the trustworthiness or accuracy of the theory generated in terms of how well it describes the phenomenon being studied (Chiovitti and Piran 2003, Denscombe 2010b). Chapter 5 of this thesis described the process of developing codes from the participants own words and extensive use of their words were used in detailing the findings of the study in chapter 7. The construction of interview guides that were developed from the analysis of the early interviews aimed to check the participants' meanings of the phenomenon.

Data source triangulation (Gomm 2008) was achieved by virtue of the range of professionals who were willing and able to provide their perspective on the study question. The degree of homogeneity of those perspectives, regarding end-of-life decisions in particular, supports the validity of the findings as reported in chapter 7. The theory presented in this thesis was grounded in the data from interviews with clinically active health professionals facing ethical problems. The initial findings and emerging categories were recognised as familiar aspects of practice by a group of intensive care nurses from a different location. Whilst this did not constitute a verification of the findings, it was contributory evidence that there were not any concepts that were unrecognisable to practitioners in a similar area of clinical practice.

The use of memoing and annotations within NVivo and in the margins of various drafts of the thesis enabled me to articulate my views about the phenomenon and examples were included in chapter 5. The strategy of memoing and diagramming as the theory developed was particularly useful in assisting me in ensuring the theory emerged from the data rather than being formed by my own assumptions about what was going on

Auditability

Auditability is the extent to which another researcher can follow in the footsteps of the original researcher (Chiovitti and Piran 2003, Denscombe 2010b, Silverman 2004b). The criteria built into my thinking were detailed in the exploration of the ontological and epistemological assumptions that both guided the choice of methodology and the approach to the analysis. The methodological decisions detailed in chapter 5 specified how and why participants for the study were selected and recruited.

Fittingness

Fittingness refers to the extent to which the findings fit with similar situations in a different context or have meaning for those in the context in which the findings were generated (Chiovitti and Piran 2003). The outline of the study site presented in chapter 5 enables a reader to understand how closely the conditions under which this study took place and how they might be reflected in other contexts. The scope of the research has been explored in detail in a number of sections of the thesis. A detailed analysis of relevant literature and how that related to the overall findings and the categories in the theory was provided in chapter 8. This analysis revealed the extent of the commonalities between the findings of this study and pre-existing research.

Using these criteria, I therefore feel justified in claiming the findings as presented in this thesis and the theory that emerged as valid in the context of the study unit. The interviews generated data detailing a particular set of healthcare professionals' perceptions regarding how ethical problems were resolved in a paediatric intensive care unit.

Acknowledging limitations

Notwithstanding the procedures followed in the development of the theory some limitations of this study need to be acknowledged. The study data was perhaps limited by the reliance on the single method of one to one interviews that did not

facilitate cross method triangulation (Gomm 2004). This meant it was not possible to compare what participants said against evidence of what actually happened in practice. Further research seeking out other data sources such as observations of practice would provide the opportunity to test the theory arising from this study. The inclusion of periods of observation and collection of documentary evidence, from sources such as children's medical notes, would perhaps have contributed additional data to the study. However, within the context of this particular study conducting periods of observations would have been almost impossible to operate. This was partly due to me being in full time employment at some distance from the study site. This meant that the availability of time to conduct such observations would have been extremely limited. A more significant difficulty would have been the complexities of gaining multiple consents from all parties that might be included in the observed interactions. It would have been impossible, conducting observations in an open unit with almost all bed spaces on view, to guarantee anyone on the unit would not be observed. Therefore it would have been necessary to gain consent from every parent and member of staff on the unit at any period of observation. Further study utilising a range of other methods would have the potential to refine the theory that emerged from my data.

The sample could have been improved by recruiting individuals in some of the professional roles that the data indicated had a role in the process of resolving ethical problems. Partly this was a problem of not being able to spend significant periods of time at the study site to enable me to support staff that were assisting in participant recruitment. This was particularly the case in the recruitment of parents and children. It may well have been that had I been visible on a regular basis in the study site, the member of staff who agreed to recruit parents would be prompted to either be more proactive or discuss concerns over recruitment with me sooner. As it was our communication was by e mail and whilst it was a routine form of daily communication in my job it was not for the staff member. Responses from this person to my emails were sparse and I was unable to secure a meeting with her to discuss any issues she

perceived with recruitment. Due to the enthusiasm and success of staff assisting with recruitment of professionals I perhaps naively thought the same would be true of this person. This led me to underestimate the level of engagement I needed to make with all those assisting me at the study site. If undertaking a study utilising third party recruiting in the future I would allow more time and effort on my part to secure full engagement with those assisting me.

I would have liked to have recruited at least one admitting surgical consultant. This was because there was an indication in the participants' accounts that surgical consultants had a different relationship in the process than was the case for those caring for chronic disorders. Those surgical doctors to whom I was referred by the lead intensive care consultant did not respond to my requests to interview them. It was also a disappointment that I was unable to recruit any members of the clinical ethics advisory group to the study for a further insight into the data provided by the participants. Despite the initial enthusiasm from the chair of the group for my study, attempts at agreeing a meeting to discuss recruitment of members were unsuccessful. This was another indication of the need, when recruiting in this way, for maintaining contact and not making assumptions of support based on initial impressions of the level of support on offer.

My own expertise in undertaking research interviews developed as the study progressed. Reviewing the transcripts of early interviews I detected a number of times when the strategy of conducting the interviews as conversation slipped into conversation that moved away from the research question. Notwithstanding this it was evident to me that some participants who were initially guarded in their responses relaxed and opened up a little more following such exchanges. Thus, although my interview technique would no doubt benefit from further refinement, relevant data was gathered to sufficiently inform the study.

The NVivo8 programme was invaluable as a data management tool for this study. It facilitated frequent revisits to the data especially enabling me to easily

find the point in an interview from which a quote had contributed to a code. This was particularly useful in checking on the context in which participants said something. I was thus able to ensure I was not misrepresenting a participant's words. With hindsight I recognised that some records of the analytic process were lost as NVivo8 updated trees and diagrams as I went along. When using of software in future I will need to ensure that I save more copies of the early coding trees from the outset.

Despite best efforts to ensure the theory emerged from the data, it was likely that my own perspectives in interpreting the data had some impact on coding and theory development. When undertaking similar studies in the future, analysis of data would ideally involve a small team of researchers. Any such team should be constituted from those without a background in healthcare practice as well as those with such experience. This would ensure that a pluralist perspective was applied to the data. The potential for researcher bias would then be minimised. Additionally unconscious assumptions made by a researcher with experience in health care practice could be identified and eliminated.

Recommendations for future research.

The most striking area for further research is that of the parents' part in deliberations particularly regarding end-of-life situations. The assumption that was apparent in this study's findings regarding the parents' desire not to be the ones who made a decision to withdraw life-preserving interventions warrants further exploration. The best of intentions appeared to lay behind the deliberate strategy of approaching parents only after a professional consensus had been reached. However, further research exploring parents' willingness or desire to be more directly involved in end-of-life decisions is required. Such research could explore parents' views about how much they feel they should be involved in the decision making process and at what stage they would prefer to be involved. No evidence of any such research in the context of children's intensive

care was found. Furthermore future study of parental views would need to include a consideration of the impact of parental culture, faith and ethnicity.

Another significant issue arising from the findings of this study worthy of further research was the exercise of power arising from the hierarchical nature of the medical professions. Such an exploration should go beyond the exercise of power of one person over another but examine the institutional aspects of power. Within this thesis I did explore, to a certain extent, the impact of differential power within and between professional teams. It was evident in the findings that nurses in particular perceived there to be unwritten rules that determined aspects of their practice. Research exploring how such unwritten rules are developed and become embedded in practices would be valuable. Such research would further illuminate factors that influence various members of the medical team in their interactions and contribution to the resolution of ethical problems in clinical practice. Additionally further studies could explore the hinted at notion that arose in the data that certain medical specialities were able to exert more leverage in negotiations at consultant level than others.

Future research should also be undertaken in respect of the contribution of clinical ethics committees or advisory groups within the NHS. There is a dearth of research in this area (Slowther et al. 2012) but, as was evident in this study, such committees were consulted on individual cases. Therefore further investigation of the role of clinical ethics committees in resolving problematic ethical questions would be illuminating.

This study was focussed on a single children's intensive care unit in England. One of the underlying epistemologies of this research was symbolic interactionism which posits that each unit operates within a unique social milieu. It follows logically that comparative studies, within the UK, in both similar and dissimilar children's intensive care units should be conducted. The study unit was situated in a large regional centre that had a significant profile in cardiac and hepatic specialities. Whether the same process of resolving ethical problems are reflected in other large centres or smaller units is an area ripe for

exploration. Similarly the scope of such research could be extended to other countries within the UK and indeed across Europe. Such research could potentially identify whether my findings were primarily an artefact of the sociological milieu of the study unit or a more general reflection of the processes in similar units.

Informing the researchers practice

My own practice as a lecturer in nursing has been informed both in conducting this study and from the analysis of the findings. In terms of supervising students undertaking or reviewing qualitative studies I have been enabled to bring to bear my personal experiences. The opportunity to bring real life experiences of undertaking research in the NHS also enabled me to augment classroom based explorations of negotiating access through ethics gateways. The delivery of teaching specifically in using grounded theory can now be enhanced with actual experience. Although there are detailed descriptions of the conduct of grounded theory research in the literature (McGhee et al. 2007, Walker and Myrick 2006, Bryant and Charmaz 2010, Schreiber and Stern 2001) there is little substitute for real life experience and conducting this study has provided me with a range of actual worked examples that will enhance my teaching.

My personal experience of using NVivo has been and will continue to be invaluable in helping students understand the place of information technology in qualitative data analysis. I now have an array of real life examples of the use of IT based data handling and techniques for making best use of such resources.

In pursuit of a commitment to disseminate research findings this thesis will be lodged on a publicly searchable database of research, administered by my university. Papers generated from the conduct and findings of the study will also be presented at relevant conferences and will be submitted for publication in peer reviewed journals.

9.2 Conclusion

The initial literature review revealed that very few studies had been conducted in the UK examining the question of how ethical problems are resolved in a children's intensive care unit. This was confirmed in the detailed literature review following the presentation of the findings of my study. Thus this study has illuminated what appeared to be an under-researched aspect of children's critical care practice. A number of studies have focussed on end-of-life decision making in a variety of critical care contexts including at least one specific to children's intensive care. The findings from my study reveal that, although a children's intensive care unit may differ to a greater or lesser extent in terms of the micro-culture, the broad approach to resolving ethical problems at least in respect of end-of-life situations is common with other critical care contexts.

This study has detailed a sociological insight into the process of resolving ethical problems in a children's intensive care unit particularly in respect of end-of-life situations. It contributes to understanding about the dynamics between healthcare professionals in intensive care and between those professionals and the parents of children admitted to the unit. The closed culture of intensive care, cut off, as it were, from the rest of the hospital by the physical barrier of the swipe card entry system undoubtedly resulted in the study unit being a unique social milieu. The resolution of ethical problems in such an environment is likely, to some extent, to reflect processes in other similar environments. This certainly appears to have been confirmed by the available literature. It is also possible to suggest that these decisional processes are likely to differ from similar environments, perhaps in subtle ways, as a result of the negotiated order within the unit that has established a way of working that operates most effectively between the individual actors in that environment. It was striking how many similarities were found to exist between the process for resolving ethical problems, at least in respect of end-of-life situations, in the study site and that reported in respect of neonatal and adult intensive care and also the general wards of hospitals (Jennings 1989, McHaffie 2001b, McHaffie and Fowle 1996,

McHaffie et al. 2001a, Melia 2001, Melia 2004). However there appeared to be some differences in the level of involvement of parents in decision making in respect of end-of-life treatment between neonatal units and the study unit.

Intensive care consultants were required to negotiate with consultant doctors from other specialities when resolving ethical problems that relate to the potential withdrawing or withholding of intensive care interventions from children. This was evidenced as a set of interactions which were significantly affected by the relative power of the consultant to influence the decision making. The findings suggested that surgical teams were able to secure an intensive care bed for children more readily than those treating children with chronic and life limiting disorders.

The social culture in the study site appeared to create a shared value system among doctors and nurses which did not eliminate disagreements and discomfiture with some decisions, but did lead to homogeneity of views. This was a positive feature in terms of being able to present a consensus of opinion to parents at least in terms of the judgement regarding the futility of continued life-preserving interventions. However there was a risk that this homogeneity would lead to a situation where the ethical issues pertaining to a situation were not considered in sufficient depth or with reference to largely technical as opposed to ethical issues. This was recognised by the consultant intensivists who accepted that the absence of a colleague acting as a 'devil's advocate' was probably a loss to the process of resolving ethically challenging situations. However there appeared to be no moves to encourage any other member of the intensive care team to fulfil such a role.

Once the professionals had reached a consensus regarding the resolution of an ethical problem, particularly in respect of decisions to withdraw interventions, parents were approached with this recommendation. In situations where parents would or could not accept that recommendation a process of persuasion took place aimed at securing the parents assent to that withdrawal. The aim of this process was to facilitate the parents' acceptance of the

medically determined view that further intervention would not benefit their child. The process also aimed to assist parents to understand that continued treatment was also causing a degree of suffering for their child in addition to not being beneficial. Parents were given time to come to terms with the medically determined recommendation in recognition of the grieving process they were experiencing. However, this period of persuasion was not open-ended. This process supported a view expressed in interviews that health professionals were required to balance the needs of a child with those of their parents.

A general culture of benevolent paternalism was thus revealed to exist in the unit based on the health professionals' stated desire to remove the weight and burden of a decision to withdraw life-preserving interventions from the parent's shoulders. This was coupled with a perception on the part of the clinicians that this was what the parents also desired.

The theory of team negotiation and parental assent presented in this thesis identifies a social process of resolving ethical problems in a children's intensive care unit. Two central components of this social process were detailed in the course of this study. First there was negotiation among health professionals to arrive at a consensus as a precursor to making a recommendation to parents. If parents did not immediately agree a process of parental persuasion took place with the aim of securing their assent to the withdrawal of those interventions. It is asserted that this study provides a basis for a fuller understanding of this social process and prompts further consideration of the nature and extent of parents' involvement in end-of-life decision making.

10 References

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11 Appendices

Appendix 1 Participant Information sheet for NHS staff

Participant Information Sheet For NHS Staff

Title

How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Invitation



My name is Kevin Power and I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. You may wish to talk to others such as colleagues about the study before deciding whether to volunteer.

Please do ask me if you feel there is anything that is not clear or if you would like more information (contact details are at the end of this information sheet).

What is the purpose of the study?

The purpose of the study is to gain an understanding of how ethical problems that occur in children's intensive care are resolved. These problems are the kind where it is not immediately obvious what the right thing to do is. Problems of this nature can range from the "should I stay on duty because of staff shortages or should I go home?" to the "should I accept that no more can be done for a child in my care?"

There is already some research looking at this in other areas of care by so far no studies of this kind have been carried out in children's intensive care.

The project is being used as part of my studies for a PhD at De Montfort University in Leicester. No one is paying me to do the research but the University is paying my course fees as I work as a lecturer for them. The whole project aims to be completed by the end of 2010.

Why have I been invited to participate?

You have been invited to take part in the study because you provide professional care in a children's intensive care and as such have been involved in the process of resolving ethical problems in that environment. I will also be inviting other health professionals, parents and children to participate in this study.

Do I have to take part?

No it is up to you to decide whether or not to take part. If you do decide to take part you should keep this information sheet and you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not be notified to your manager or employer or anyone else in the Trust.

It will not be possible to withdraw any of the data arising from the interview after the interview as the analysis of the data begins immediately after the interview is over. This is a particular feature of the approach I am using for this study.

What will happen if I take part?

If you decide to take part you will be asked to sign a consent form and be invited to be interviewed at a place that is most convenient to you. This could be in your workplace, in your own home or somewhere else you feel comfortable with such as a local café.

I would like to record the discussion with a digital audio recorder if you give your permission. This will enable me to accurately record the things we discuss. I will also be able to go back over the recording to make sure I have noted down accurately what was said.

The interview can be as short or long as you wish however most interviews would take about 40 minutes. You may be asked if you would be willing to participate in a second interview if there are questions or topics that have not been covered in the first interview. However agreeing to participate in the first interview will in no way mean you have to participate in any other interviews for this project. You may also call a halt to the interview at any point without having to give a reason.

What do I have to do?

First of all you will be asked to sign a consent form of which you will be given a copy to keep. You will then be asked to discuss as freely and honestly as you feel able your experience of taking part in ethical decisions whilst caring for a child in intensive care as part of your professional practice

What are the possible disadvantages and risks of taking part?

Discussing ethical problems that arose during the period you were providing care for a child in intensive care could be distressing. If you become distressed or state that you would rather not continue the discussion the interview will be ended immediately.

What are the possible benefits of taking part?

Participation in this study is unlikely to bring any benefits to you. It is possible that discussing an ethical problem you have encountered will help with personal reflection on the situation.

What if something goes wrong?

It is very unlikely that you will be harmed by taking part in this research project. If you are harmed by taking part in this project there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you. You may also contact the research supervisor, Ms Jennie Fleming 0116 2577873 or the Head of Research at De Montfort University Dr Graham Lawson 0116 2577129

Will my taking part in this study be kept confidential?

All information which is collected from you during the course of the research will be kept strictly confidential. Your name and address will not be used in the research except for the purposes of contacting you, when you have agreed, to arrange an interview.

You should also be aware that, as a nurse, I may be duty bound to pass on information that you provide that reveals harm has occurred.

I will wish to use your exact words when I write up the study. However if you mention any other person by name I will change it so no one knows who you are talking about.

All recordings and any transcripts will be stored in a locked filing cabinet in a locked office at De Montfort University. Files kept on a computer will be password protected. There will be no personal information on any of the transcripts or recordings. Transcripts and recordings will be identified by a code which will only be known to me. This will facilitate follow up interviews if agreed to and required. Codes linking personal details to transcripts and tapes will be kept in a separate password protected file.

All recordings and transcripts will be kept for 5 years in accordance with the requirements of De Montfort University.

The research supervisor and representatives of the research and development (R&D) department for the NHS Trust may examine the transcripts and recordings

to check that the study is being carried out correctly. Your name, however, will not be included on these transcripts or recordings.

What will happen to the results of the research study?

The results from the study will be reported in a thesis and submitted for examination for a PhD. Results will also be used as part of articles submitted for publication in professional journals and reporting at professional conferences. You will not be identifiable in any of these reports or publications.

Who is organising and funding the research?

This research is being carried out as part of a PhD project. No one is providing separate funding for the project. I am a lecturer in nursing at De Montfort University in Leicester and am not employed by the hospital where you are employed. I do have an honorary contract with the Trust but this in no way obliges me to share information gathered from you personally with the Trust.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Black Country NHS Research Ethics Committee.

Contact for Further Information

If you would like more information or would like to agree to be interviewed please contact Kevin Power on 0116 2013962 (during office hours) or by e mail kpower@dmu.ac.uk or by mail at

Kevin Power
Associate Head of School
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ

Alternatively you may return the reply slip accompanying this information sheet in the stamped addressed envelope accompanying this information sheet.

Please keep the rest of the information sheet for future reference.

Thank you for taking the time to read this information sheet.

Dear Kevin,

I am interested in participating in the EPPIC study and would be happy to be contacted in order to be invited to be interviewed.

Name:

I can be contacted;

By Phone Tel:

By E mail:

By Post:

.....

.....

.....

.....

Please note completion and return of this form does not constitute consent to be interviewed. Return of this does not oblige you to be interviewed.

A separate consent form will be available for signing prior to the interview taking place.

Appendix 2 Invitation letter to NHS staff

{hospital headed notepaper}

{insert date}

Dear Colleague,

Re: How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study).

You are being invited to take part in a research study by Mr Kevin Power who is a research student at De Montfort University in Leicester.

The research is part of a PhD investigating the process of resolving ethical problems in children's intensive care.

Taking part in this research is entirely voluntary and you are not obliged to do so. If you decide not to take part no one will know.

Please take time to read the enclosed information sheets carefully. You may wish to talk to others before deciding whether or not to volunteer.

Sincerely

{insert name}
{insert designation}
Paediatric Intensive Care

Appendix 3 Participant information sheet & invitation letter for parents



{insert hospital address}

{insert date}

Dear

You are being invited to take part in a research study by Mr Kevin Power who is a research student at De Montfort University in Leicester. I have sent you this letter to ensure that Mr Power will not know who you are unless and until you contact him.

Taking part in this research is entirely voluntary and you are not obliged to do so. If you decide not to take part no one will know. If you decide not to take part this will not affect any aspect of you or your child's current or future treatment.

Please take time to read the enclosed information carefully. You may wish to talk others such as family and friends about the study before deciding whether to volunteer.

You are also asked to consider giving permission for Mr Power to interview your child in the enclosed information sheet. Again this is voluntary and even if you consent to being interviewed you are not obliged to give permission for your child to be contacted.

Thank you for taking time to consider this request.

Sincerely

{insert name}
Family Liaison Nurse
Children's Intensive Care

Participant Information Sheet For Parents

Title

How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Invitation



My name is Kevin Power and I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. You may wish to talk others such as family and friends about the study before deciding whether to volunteer.

Please do ask me if there is anything that is not clear or if you would like more information (my contact details are at the end of this information sheet).

What is the purpose of the study?

The purpose of the study is to gain an understanding of how ethical problems that occur in children's intensive care are resolved. These problems are the kind where it is not immediately obvious what the right thing to do is. Problems of this nature include "should I stay with my child in intensive care or go home and look after my other children?" Another might be "should we accept that no more can be done for our child?" There is already some research looking at this in other areas of care but so far no studies of this kind have been carried out in children's intensive care.

This research is being carried out as part of a PhD project at De Montfort University in Leicester. No one is paying me to do the research but the University is paying my course fees as I work as a lecturer for them. The whole project aims to be completed by the end of 2010.

Why have I been invited to participate?

You have been invited to take part in the study because a child of yours has spent some time in a children's intensive care. I will also be inviting other parents, children and health professionals to participate in this study.

Do I have to take part?

No it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care your child receives now or in the future.

Once the interview is completed you will not be able to ask at a later date for the discussion to be withdrawn from the study.

What will happen to me if I take part?

If you decide to take part you will be invited to be interviewed at a place that is most convenient to you. This could be in your own home or somewhere else you feel comfortable with such as a local café.

I would like to record the discussion with a digital audio recorder if you give your permission. This will enable me to accurately record the things we discuss. I will also be able to go back over the recording to make sure I have noted down accurately what was said.

The interview can be as short or long as you wish however most interviews would take between 40 minutes to an hour. You may be asked if you would be willing to participate in a second interview if there are questions or topics that have not been covered in the first interview. However agreeing to participate in the first interview this will not mean you have to participate in any other interviews for this project.

You may choose to have a friend or partner with you while being interviewed if this helps you feel more comfortable. It is also possible to interview both parents at the same time where this is desired by a couple. It is also possible to interview you as a family with your child present if you wish it.

What do I have to do?

First of all you will be asked to sign a consent form of which you will be given a copy to keep. You will then be asked to discuss your experience of taking part in ethical decisions whilst your child was in intensive care.

If your child is old enough you may also be asked if your child can be approached for their consent to be interviewed as part of this project. If you do agree for your child to be approached they will be given an information sheet and the same free choice to decide for themselves if they wish to be interviewed or not.

If your child is under 16 and consents to be interviewed you will also be asked to sign a consent form agreeing to them being interviewed. This is not because your child cannot be trusted to make their own mind up but because I will be required to gain your consent by the authorities approving the study.

You need to be aware that unless you child gives me permission (or your child agrees to have you present) I will not be able to tell you anything that your child has said in the interview or show you any transcripts of the conversation.

Your child will be given a choice of venue for the interview. This might be in your home or in a public place such as a café. In either case if the child does not consent to you being present you will be able to be nearby but out of earshot.

Your child will also be given the opportunity to have a friend or brother/sister with them while they are being interviewed if they wish.

What are the possible disadvantages and risks of taking part?

Discussing the time when your child was in intensive care could be upsetting. If you become upset or decide that you would rather stop the discussion, the interview will be ended immediately. You will also be provided with contact details of individuals or organisations that may be able to provide counselling services.

What are the possible benefits of taking part?

Participation in this study will bring no health benefits to your child. Some people who have taken part in similar projects have said that it helps to have talked about a difficult time in their life.

The information that is generated from this study will be used to inform health professionals and may lead to changes in the way ethical problems are resolved in practice.

What if something goes wrong?

It is unlikely that you or your child will be harmed by taking part in this research. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it.

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you. You may also contact the {insert name} Hospital Patient Advice and Liaison Service Monday to Friday 9a.m until 5p.m

Telephone:
Text & Mobile:
Email:
Fax:
Pager: Contact the hospital switchboard
Office:
Letter: PALS Officer,
{insert address}

If you wish to complain about the way you were approached or treated in this study you may also contact the research supervisor, Ms Jennie Fleming 0116 2577873 or the Head of Research at De Montfort University Dr Graham Lawson 0116 2577129

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will not be used in the research except for the purposes of contacting you, when you have agreed, to arrange an interview.

If you decide to have a spouse, friend or relative present you should no longer assume complete confidentiality regarding the content of the interview.

If you mention something in the interview that indicates someone has acted wrongly I may need to inform someone else about it. I will wish to use your exact words when I write up the study. However if you mention any other person by name I will change it so no one knows who you are talking about.

All recordings and any transcripts made from the recordings plus any notes made during and after the interview will be locked in my office at De Montfort University. Files kept on a computer will be password protected. There will be no personal information on any of the transcripts or recordings.

Transcripts and recordings will be identified by a code which will only be known to the researcher. This will be to enable follow up interviews if agreed to and required. All recordings and transcripts will be kept for 5 years in accordance with the requirements of De Montfort University.

The research supervisor and representatives of the research and development (R&D) department for the NHS Trust may examine the transcripts and recordings to check that the study is being carried out correctly.

What will happen to the results of the research study?

The results from the study will be reported in a thesis and submitted for examination for a PhD. Results will also be used as part of one or more articles submitted for publication in professional journals and reporting at professional conferences. You will not be identifiable in any of these reports or publications.

Who is organising and funding the research?

The research is organised by Kevin Power as part of his study for a PhD. I am not being paid to do this research. The research is being supervised within the normal supervision arrangements for PhD students within De Montfort University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Black Country NHS Research Ethics Committee.

Contact for Further Information

If you would like more information or would like to agree to be interviewed please contact Kevin Power on 0116 2013962 (during office hours) or by e mail kpower@dmu.ac.uk or by mail at

Kevin Power
Associate Head of School
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ

Alternatively you may return the reply slip accompanying this information sheet in the stamped addressed envelope accompanying this information sheet.

Please keep the rest of the information sheet for future reference.

Thank you for taking the time to read this information sheet.

{insert hospital logo}

Dear Kevin,

I/we am/are interested in participating in the EPPIC study and would be happy to be contacted in order to be invited to be interviewed.

Name(s):

.....

I/we can be contacted;

By Phone Tel:

By E mail:

By Post:

.....

.....

.....

.....

Please note completion and return of this form does not constitute consent to be interviewed. Return of this form does not oblige you to be interviewed.

A separate consent form will be available for signing prior to the interview taking place.

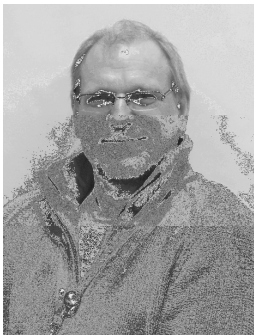
Appendix 4 Participant information sheets for children 8-10, 11-15 & 16+

Participant Information Sheet for Patients 8-10

Title

How are Ethical Problems Resolved in Paediatric Intensive Care?
(EPPIC study)

Invitation



My name is Kevin and I am a lecturer/teacher in children's nursing at De Montfort University in Leicester.

I would like to invite you to take part in a research study. I am interested in finding out how difficult decisions are made about children's treatment when they are in an intensive care.

Before you decide if you want to join in it's important to understand why the study is being done and what it will involve for you. So please read this leaflet carefully. Talk about it with your family, friends, doctor or nurse if you want to.

Take time to decide whether or not you would like to take part.

If you would like to have more information please get in touch by phone or e mail. I have put the phone number and e mail address at the end of this sheet.



Why am I doing this study?

I am doing this study to try and understand how difficult decisions are solved. These problems are the kind where no one is sure what the right thing to do is straight away.





No one is paying me to do the project. I am a lecturer in nursing at De Montfort University in Leicester. I do not work for the hospital where you were cared for.

The whole project should be completed by the end of 2009. This seems a long time but is not unusual for this type of project.

Why have I been invited to participate?

You have been invited to take part in the study because you have spent some time in a children's intensive care ward. You may be able to tell me what happened from your point of view. I will also be inviting other children as well as parents and nurses and doctors to take part in this study.



Do I have to take part?

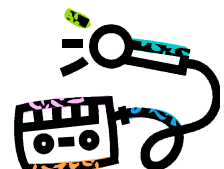


No it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. You will also be asked to sign a form saying you agree to have a discussion with me. I will also have to ask one of your parents to sign a form as well. This is not because you are not trusted to decide for yourself. I have to get an adult's signature because I have been asked to by the people who gave me permission to do the study.

You are free to stop taking part at any time during the discussion without saying why. If you decide to stop no one will be cross with you.

What will happen to me if I take part?

If you say yes you will be invited to have a discussion with me at a place that suits you. This could be in your own home or somewhere else you feel happy with such as a café. I will ask you if I can record our discussion. This will help make sure I do not miss anything out.





The discussion can be as short or long as you wish. Most discussions would take about 30 minutes or about as long as a children's TV programme.

You might be asked if it would be okay to take part in a second discussion.

Taking part in the first discussion does not mean you have to take part in any other discussions for this study if you do not want to.

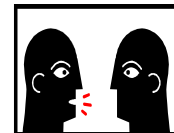
You may choose to have a friend, or brother or sister or parent with you while being interviewed if you like. It is also possible to interview you at the same time as your parents if you would like to have the discussion as a family.

What do I have to do?



First of all you will be asked to sign a form to say you are happy to discuss your time in intensive care with me. You will be given a copy of the form to keep.

You will be asked to discuss what it was like for you taking part in difficult decisions when you were in intensive care.



What are the possible disadvantages and risks of taking part?

Discussing the time when difficult decisions were made about your treatment could be upsetting. If you become upset or tell me that you would rather stop, the interview will be ended straight away.



What are the possible benefits of taking part?

Taking part will not improve your health. Some young people that have taken part in similar studies have said that it helps to talk about a difficult time in their life.

The information from this study will be used to inform doctors and nurses. The information may lead to changes in the way difficult question are solved.

What if something goes wrong?



If you are not happy about the way you have been treated in this study you may ask your parents to contact the Patient Advice and Liaison Service at the hospital. They are open Monday to Friday 9a.m until 5p.m

Telephone:

Text & Mobile:

Email:

Fax:

Pager: Contact the hospital switchboard

Office:

Letter: PALS Officer,
{insert address}

If you wish to complain about the study you may also contact Mrs Jennie Fleming 0116 2577873 or the Head of Research at De Montfort University Dr Graham Lawson 0116 2577129.

Will my taking part in this study be kept private?

All information which is collected will be kept private. Your name and address will not be used in the study.



I will not tell your parents what you have said unless you tell me I can.

If you tell me about something that somebody has done that was wrong I may need to tell someone else about it.



All recordings and copies of what was said in the discussion and written down will be kept locked up in my office.



Files kept on a computer will have a password so no one else can read them.



I will need to use your exact words when I write about the study. If you mention another person's name I will change it so no one knows who you are talking about.

What will happen to the results of the study?

I will be writing a very long story about my discussions with you and other children. Teachers at the university will give me marks for this story.



Part of the story will also be sent to a magazine so other people can read what I have found out. No one will know who you are in these stories.

If you want to know more

If you would like to know more or would like to agree to talk to me please ask your parents to contact me on 0116 2013962 (during office hours) or by e mail kpower@dmu.ac.uk or by post at this address.

Kevin Power
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ

If you prefer you may return the reply slip in the stamped addressed envelope that came with this information sheet.

Please keep this information sheet for future reference.

Thank you for taking the time to read this information sheet.

{insert hospital logo}

Dear Kevin,

I am interested in participating in the EPPIC study and would be happy to be contacted in order to be invited to be interviewed.

Name:.....

I can be contacted;

By Phone Tel:

By E mail:

By Post:

.....

.....

.....

.....

Please note completion and return of this form does not mean you have agreed to have a discussion with me.

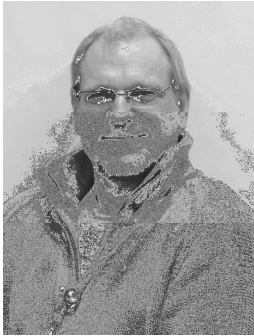
A different form agreeing to have a discussion with me will be available for signing before any discussion.

Participant Information Sheet for Patients 11-15

Title

How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Invitation



My name is Kevin and I am a lecturer/teacher in children's nursing at De Montfort University in Leicester.

I would like to invite you to take part in a research study. I am interested in finding out how difficult decisions are made about children's treatment when they are in an intensive care. These difficult decisions can be called ethical problems.

Before you decide if you want to join in it's important to understand why the study is being done and what it will involve for you. So please consider this leaflet carefully. Talk about it with your family, friends, doctor or nurse if you want to.

Take time to decide whether or not you wish to take part.

If you would like to have more information please get in touch by phone or e mail. I have put the phone number and e mail address at the end of this sheet.



Why am I doing this study?

The reason I am doing this study is to try and understand how difficult decisions that occur in children's intensive care are solved. These problems are the kind where no one is sure what the right thing to do is straight away. Problems like this can include "can I have some information about me kept private from my parents?" Another might be "should I keep having this treatment?" There may be lots of other difficult questions as well.



So far no studies of this kind have been done in children's intensive care.



This research is being done as part of a PhD project (a university degree). No one is paying me to do the project. I am a lecturer in nursing at De Montfort University in Leicester. I am not employed by the hospital where you were cared for.

The whole project should be completed by the end of 2009. This seems a long time but is not unusual for this type of project.

Why have I been invited to take part?

You have been invited to take part in the study because you have spent some time in a children's intensive care ward. You may have been involved in a difficult decision. You may be able to tell me what happened from your point of view. I will also be inviting other children as well as parents and nurses and doctors to take part in this study.



Do I have to take part?

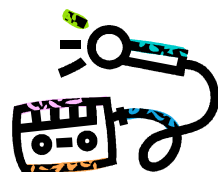


No it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. You will also be asked to sign a form saying you agree to have a discussion with me. I will also have to ask one of your parents to sign a form as well. This is not because you are not trusted to decide for yourself. I have to get an adult's signature because I have been asked to by the people who gave me permission to do the study.

You are free to stop taking part at any time during the discussion without giving a reason. If you decide to stop, this will not affect the care you receive now or in the future.

What will happen to me if I take part?

If you decide to take part you will be invited to have a discussion with me at a place that suits you. This could be in your own home or somewhere else you feel happy with such as a café. I will ask you if I can record our discussion. This will help make sure I do not miss anything out.





The discussion can be as short or long as you wish. Most discussions would take about 40 minutes. You may be asked if it would be okay to take part in a second discussion. A second discussion might be useful if I need to check out something you have said or ask some more questions about something we have talked about.

Taking part in the first discussion does not mean you have to take part in any other discussions for this study if you do not want to.

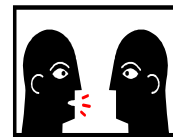
You may choose to have a friend, or brother or sister or parent with you while we talk if you like. It is also possible to talk to you at the same time as your parents if you would like to have the discussion as a family.

What do I have to do?



First of all you will be asked to sign a form to say you are happy to discuss your time in intensive care with me. You will be given a copy of the form to keep.

You will be asked to discuss what it was like for you taking part in difficult decisions when you were in intensive care.



What are the possible disadvantages and risks of taking part?

Discussing the time when difficult decisions were made about your treatment could be upsetting. If you become upset or tell me that you would rather stop, the interview will be ended straight away.



What are the possible benefits of taking part?

Taking part will not improve your health. Some young people that have taken part in similar studies have said that it helps to talk about a difficult time in their life.

The information from this study will be used to inform doctors and nurses. The information may lead to changes in the way difficult question are solved.

What if something goes wrong?



It is not likely that you will be harmed by taking part in this project. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed because someone involved in the study does something wrong that causes you harm (called negligence), then you may be able to take legal action.

If you have any concerns about the way you have been treated in this study you may contact the Patient Advice and Liaison Service at the hospital. They are open Monday to Friday 9am until 5pm

Telephone:

Text & Mobile:

Email:

Pager: Contact the hospital switchboard

Office:

Letter: PALS Officer,
{insert address}

If you wish to complain about the study you may also contact Ms Jennie Fleming 0116 2577873 or the Head of Research at De Montfort University Dr Graham Lawson 0116 2577129.

Will my taking part in this study be kept private?

All information which is collected will be kept private. Your name and address will not be used in the study. If you decide to have a friend or your parent(s) there please remember that they will know what you have said.



I will not tell your parents what you have said unless you tell me I can. I will not show your parents anything I write down from our discussion unless you tell me I can.

If you tell me about something that somebody has done that was wrong I may need to tell someone else about it.



All recordings and copies of what was said in the discussion and written down (called a transcript) will be kept locked up in my office. Any notes made during and after the interview will also be locked away. Files kept on a computer will have a password so no one else can read them.



I will need to use your exact words when I write about the study. If you mention another person's name I will change it so no one knows who you are talking about.

My research supervisor may look at the notes and recordings. A person from the hospital may also inspect them. This is to check that the study is being carried out properly. Your name or address will not be on any of the transcripts or recordings.

What will happen to the results of the study?

The results from the study will be submitted for an exam for a PhD. Results will also be sent to a magazine so other people can read what I have found out. I may also speak about the study at conferences. No one will know who you are in any of these reports or publications.



Who is organising and funding the research?

The research is being done by Kevin Power as part of his study for a PhD. No one is paying me for this research.

Contact for Further Information

If you would like more information or would like to agree to be interviewed please contact Kevin Power on 0116 2013962 (during office hours) or by e mail kpower@dmu.ac.uk or by mail at

Kevin Power
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ

If you prefer you may return the reply slip in the stamped addressed envelope that came with this information sheet.

Please keep this information sheet for future reference.

Thank you for taking the time to read this information sheet.

{insert hospital logo}

Dear Kevin,

I am interested in participating in the EPPIC study and would be happy to be contacted in order to be invited to be interviewed.

Name:.....

I can be contacted;

By Phone Tel:

By E mail:

By Post:

.....

.....

.....

.....

Please note completion and return of this form does not mean you have agreed to have a discussion with me.

A different form agreeing to have a discussion with me will be available for signing before any discussion.

Participant Information Sheet For Patients 16 and over

Title

How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Invitation



My name is Kevin Power and I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. You may wish to talk others such as family and friends about the study before deciding whether to volunteer.

Please do ask me if there is anything that is not clear or if you would like more information (my contact details are at the end of this information sheet).

What is the purpose of the study?

The reason I am doing this study is to find out how difficult decisions are made where it is not immediately obvious what the right thing to do is. Difficult decisions of this nature can include such questions as “should I agree to this treatment or not” or “should my parents be told everything about my condition and treatment?” These kinds of decisions are often termed ethical decisions.

There is already some research looking at this in other areas of care but so far no studies of this kind have been carried out in children’s intensive care.

This research is being carried out as part of a doctoral student (PhD) project that I am doing at De Montfort University. No one is providing separate funding for the project. I am a lecturer in nursing at De Montfort University in Leicester and am not employed by the hospital where you were cared for.

The whole project aims to be completed by the end of 2010.

Why have I been invited to participate?

You have been invited to take part in the study because you have spent some time in a children’s intensive care. I will also be inviting other children, parents and health professionals to participate in this study.

Do I have to take part?

No it is entirely up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to change your mind at any time and without giving a reason. If you decide to stop taking part at any time, or decide not to take part, this will not affect the standard of care you receive now or in the future.

What will happen to me if I take part?

If you decide to take part you will be invited to be interviewed at a place that is most convenient to you. This could be in your own home or somewhere else you feel comfortable with such as a local café.

I would like to record the discussion on a digital recorder if you give your permission. This will enable me to accurately record the things we discuss. I will also be able to go back over the recording to make sure I have noted down accurately what was said.

The interview can be as short or long as you wish however most interviews would take between 40 minutes to an hour. You may be asked if you would be willing to participate in a second interview if there are questions or topics that have not been covered in the first interview. Agreeing to participate in the first interview will in no way mean you have to participate in any other interviews for this project.

You may choose to have a friend, brother/sister or parent with you while being interviewed if this helps you feel more comfortable. It is also possible to interview you as a part of your family if you so wish.

What do I have to do?

First of all you will be asked to sign a consent form, if you agree to take part, which you will be given a copy to keep.

You will be asked to discuss as freely and honestly as you feel able your experience of taking part in ethical decisions whilst you were in intensive care.

What are the possible disadvantages and risks of taking part?

Discussing the time when you were in intensive care could be distressing. If you become upset or decide that you would rather stop the discussion, the interview will be ended immediately. You will also be provided with contact details of individuals or organisations that may be able to provide counselling services.

What are the possible benefits of taking part?

Participation in this study will bring no health benefits to you. Some people who have taken part in similar kinds of projects have said that they felt some benefit from having talked about a difficult time in their life. The information that is generated from this study will be used to inform health professionals.

What if something goes wrong?

It is very unlikely that you would be harmed by taking part in this project. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed because someone involved in the study does something wrong that causes you harm (called negligence), you may have grounds for a legal action but you may have to pay for it.

If you have any concerns about the way you have been treated in this study, the normal National Health Service complaints mechanisms should be available to you.

You may also contact the {insert name} Hospital Patient Advice and Liaison Service Monday to Friday 9a.m until 5p.m

Telephone:

Text & Mobile:

Email:

Fax:

Pager: Contact the hospital switchboard

Office:

Letter: PALS Officer,
{insert address}

If you wish to complain about the way you were approached or treated in this study you may also contact the research supervisor, Ms Jennie Fleming 0116 2577873 or the Head of Research at De Montfort University Dr Graham Lawson 0116 2577129

Will my taking part in this study be kept confidential?

All information which is collected from you during the course of the research will be kept strictly confidential. Your name and address will not be used in the research except for the purposes of contacting you, when you have agreed, to arrange an interview. If you decide to have a friend or relative present you should no longer assume complete confidentiality regarding the content of the interview. I will not tell your parents what you have said unless you tell me I can. I will not show your parents anything I write down from our discussion unless you tell me I can.

If you mention something in the interview that indicates someone has acted wrongly I may need to inform someone else about it.

All recordings and any transcripts made from the tapes will be kept locked up in my office at De Montfort University. The same is true for any notes made during and after the interview. Files kept on a computer will be password protected.

There will be no personal information on any of the transcripts or recordings. Transcripts and recordings will be identified by a code which will only be known to the researcher. This will be to enable follow up interviews if agreed to and required. Codes linking personal details to transcripts and tapes will be kept in a separate password protected file.

All recordings and transcripts will be kept for 5 years in accordance with the requirements of De Montfort University.

The research supervisor and representatives of the research and development (R&D) department for the NHS Trust may examine the transcripts and recordings to check that the study is being carried out correctly.

What will happen to the results of the research study?

The results from the study will be reported in a report called a thesis and submitted for examination for a PhD. Results will also be used as part of articles submitted for publication in professional magazines and reporting at professional conferences. No one will be able to tell who you are in any of these reports or publications.

Who is organising and funding the research?

The research is organised by Kevin Power as part of his study for a PhD. I am not being paid to do this research. The research is being supervised within the normal supervision arrangements for PhD students within De Montfort University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Black Country NHS Research Ethics Committee.

Contact for Further Information

If you would like more information or would like to agree to be interviewed please contact Kevin Power on 0116 2013962 (during office hours) or by e mail kpower@dmu.ac.uk or by mail at

Kevin Power
Associate Head of School
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ

Alternatively you may return the reply slip accompanying this information sheet in the stamped addressed envelope accompanying this information sheet.

Please keep the rest of the information sheet for future reference.

Thank you for taking the time to read this information sheet.

Dear Kevin,

I/we am/are interested in participating in the EPPIC study and would be happy to be contacted in order to be invited to be interviewed.

Name(s):

.....

I/we can be contacted;

By Phone Tel:

By E mail:

By Post:

.....

.....

.....

.....

Please note completion and return of this form does not constitute consent to be interviewed. Return of this form does not oblige you to be interviewed.

A separate consent form will be available for signing prior to the interview taking place.

Appendix 5 Participant information sheet & invitation letter for bereaved parents



{Insert hospital address}

Dear

You are being invited to take part in a research study by Mr Kevin Power who is a research student at De Montfort University in Leicester. I have sent you this letter to ensure that Mr Power will not know who you are unless and until you contact him.

Taking part in this research is entirely voluntary and you are not obliged to do so. If you decide not to take part no one will know. If you decide not to take part this will not affect any aspect of you or your child's current or future treatment.

Please take time to read the enclosed information carefully. You may wish to talk others such as family and friends about the study before deciding whether to volunteer.

Thank you for taking time to consider this request.

Sincerely

Family Liaison Nurse
Children's Intensive Care

Participant Information Sheet For Parents

Title

How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Invitation



My name is Kevin Power and I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. You may wish to talk others such as family and friends about the study before deciding whether to volunteer.

Please do ask me if there is anything that is not clear or if you would like more information (my contact details are at the end of this information sheet).

What is the purpose of the study?

The purpose of the study is to gain an understanding of how ethical problems that occur in children's intensive care are resolved. These problems are the kind where it is not immediately obvious what the right thing to do is. Problems of this nature include "should I stay with my child in intensive care or go home and look after my other children?" Another might be "should we accept that no more can be done for our child?" There is already some research looking at this in other areas of care but so far no studies of this kind have been carried out in children's intensive care.

This research is being carried out as part of a PhD project at De Montfort University in Leicester. No one is paying me to do the research but the University is paying my course fees as I work as a lecturer for them. The whole project aims to be completed by the end of 2010.

Why have I been invited to participate?

You have been invited to take part in the study because a child of yours has spent some time in a children's intensive care. I will also be inviting other parents, children and health professionals to participate in this study.

Do I have to take part?

No it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care or support you receive now or in the future.

Once the interview is completed you will not be able to ask at a later date for the discussion to be withdrawn from the study.

What will happen to me if I take part?

If you decide to take part you will be invited to be interviewed at a place that is most convenient to you. This could be in your own home or somewhere else you feel comfortable with such as a local café.

I would like to record the discussion with a digital audio recorder if you give your permission. This will enable me to accurately record the things we discuss. I will also be able to go back over the recording to make sure I have noted down accurately what was said.

The interview can be as short or long as you wish however most interviews would take between 40 minutes to an hour. You may be asked if you would be willing to participate in a second interview if there are questions or topics that have not been covered in the first interview. However agreeing to participate in the first interview this will not mean you have to participate in any other interviews for this project.

You may choose to have a friend or partner with you while being interviewed if this helps you feel more comfortable. It is also possible to interview both parents at the same time where this is desired by a couple.

What do I have to do?

First of all you will be asked to sign a consent form of which you will be given a copy to keep. You will then be asked to discuss your experience of taking part in ethical decisions whilst your child was in intensive care.

What are the possible disadvantages and risks of taking part?

Discussing the time when your child was in intensive care could be upsetting. If you become upset or decide that you would rather stop the discussion, the interview will be ended immediately. You will also be provided with contact

details of individuals or organisations that may be able to provide counselling **services.**

What are the possible benefits of taking part?

Participation in this study will bring no health benefits to you. Some people who have taken part in similar projects have said that it helps to have talked about a difficult time in their life.

The information that is generated from this study will be used to inform health professionals and may lead to changes in the way ethical problems are resolved in practice.

What if something goes wrong?

It is unlikely that you will be harmed by taking part in this research. If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it.

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you. You may also contact the {insert name} Hospital Patient Advice and Liaison Service Monday to Friday 9a.m until 5p.m

Telephone:

Text & Mobile:

Email:

Fax:

Pager: Contact the hospital switchboard

Office: Main Reception

Letter: PALS Officer,
{insert address}

If you wish to complain about the way you were approached or treated in this study you may also contact the research supervisor, Ms Jennie Fleming 0116 2577873 or the Head of Research at De Montfort University Dr Graham Lawson 0116 2577129

Will my taking part in this study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Your name and address will not be used in the research except for the purposes of contacting you, when you have agreed, to arrange an interview.

If you decide to have a spouse, friend or relative present you should no longer assume complete confidentiality regarding the content of the interview.

If you mention something in the interview that indicates someone has acted wrongly I may need to inform someone else about it.

I will wish to use your exact words when I write up the study. However if you mention any other person by name I will change it so no one knows who you are talking about.

All recordings and any transcripts made from the recordings plus any notes made during and after the interview will be locked in my office at De Montfort University. Files kept on a computer will be password protected. There will be no personal information on any of the transcripts or recordings.

Transcripts and recordings will be identified by a code which will only be known to the researcher. This will be to enable follow up interviews if agreed to and required. All recordings and transcripts will be kept for 5 years in accordance with the requirements of De Montfort University.

The research supervisor and representatives of the research and development (R&D) department for the NHS Trust may examine the transcripts and recordings to check that the study is being carried out correctly.

What will happen to the results of the research study?

The results from the study will be reported in a thesis and submitted for examination for a PhD. Results will also be used as part of one or more articles submitted for publication in professional journals and reporting at professional conferences. You will not be identifiable in any of these reports or publications.

Who is organising and funding the research?

The research is organised by Kevin Power as part of his study for a PhD. I am not being paid to do this research. The research is being supervised within the normal supervision arrangements for PhD students within De Montfort University.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by the Black Country NHS Research Ethics Committee.

Contact for Further Information

If you would like more information or would like to agree to be interviewed please contact Kevin Power on 0116 2013962 (during office hours) or by e mail kpower@dmu.ac.uk or by mail at

Kevin Power
Associate Head of School
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ

Alternatively you may return the reply slip accompanying this information sheet in the stamped addressed envelope accompanying this information sheet.

Please keep the rest of the information sheet for future reference.

Thank you for taking the time to read this information sheet.

Dear Kevin,

I/we am/are interested in participating in the EPPIC study and would be happy to be contacted in order to be invited to be interviewed.

Name(s):
.....

I/we can be contacted;

By Phone Tel:

By E mail:

By Post:
.....
.....
.....
.....

Please note completion and return of this form does not constitute consent to be interviewed. Return of this form does not oblige you to be interviewed.

A separate consent form will be available for signing prior to the interview taking place.

Appendix 6 Participant information sheet for students

Participant Information Sheet For Students

Title

How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Invitation



My name is Kevin Power and I would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you.

Please take time to read the following information carefully. You may wish to talk to others such as colleagues about the study before deciding whether to volunteer.

Please do ask me if you feel there is anything that is not clear or if you would like more information (contact details are at the end of this information sheet).

What is the purpose of the study?

The purpose of the study is to gain an understanding of how ethical problems that occur in children's intensive care are resolved. These problems are the kind where it is not immediately obvious what the right thing to do is.

I have already collected and partially analysed data from a Children's ITU in the UK. I now need to check my findings with practitioners from another unit in order to gauge the generalisability of those findings.

The project is being used as part of my studies for a PhD at De Montfort University in Leicester. No one is paying me to do the research but the University is paying my course fees as I work as a lecturer for them. The whole project aims to be completed by the end of 2010.

Why have I been invited to participate?

You have been invited to take part in the study because you provide professional care in a children's intensive care and as such have been involved in the process of resolving ethical problems in that environment.

Do I have to take part?

No it is up to you to decide whether or not to take part. If you do decide to take part you should keep this information sheet. If you decide to take part you are

still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your studies at De Montfort University now or in the future.

What will happen if I take part?

You are invited to attend a 30 minute session on the Charles Frears Campus which follows one of the taught sessions on the module timetable. The session will be counted within the timetabled hours for the module.

I will make a brief presentation to you of the initial findings emerging from my study and ask for your comments regarding the extent to which those findings accord with your own experience.

I will make notes on the main points raised in the discussion. No names will be recorded or used in any way in the thesis or subsequent publications.

Attendance at the session will be deemed to constitute consent to participate. You may withdraw from the discussion at any point without having to give a reason.

What do I have to do?

You will be asked to discuss as freely and honestly as you feel able whether what I have found accords with your experience of taking part in resolving ethical problems whilst caring for a child in intensive care as part of your professional practice.

What are the possible disadvantages and risks of taking part?

It is envisaged that apart from taking up some of your time there are no disadvantages to taking part. The findings of the study are relevant to the taught session in the module. The module leader has indicated that attendance is unlikely to disadvantage your progress on the module.

What are the possible benefits of taking part?

Participation in this study is unlikely to bring any direct benefits to you. However it may assist in your appreciation of ethical problems and their resolution in a children's intensive care setting.

What if something goes wrong?

It is very unlikely that you will be harmed by taking part in this research project. If you are harmed by taking part in this project there are no special

compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it.

Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms should be available to you. You may also contact the research supervisor, Ms Jennie Fleming 0116 2577873 or the Head of Research at De Montfort University on 0116 2577942.

Will my taking part in this study be kept confidential?

All information which is collected from you during the course of the research will be kept strictly confidential. Your name will not be collected or used in the research.

All notes from the discussion will be stored in a locked filing cabinet in a locked office at De Montfort University until converted into electronic files. Following transcription of the notes made in the session to electronic files they will be destroyed by shredding. Files kept on a computer will be password protected. There will be no personal information on any of the notes made at the discussion.

All files made will be kept for 5 years in accordance with the requirements of De Montfort University.

The research supervisor and representatives of the Faculty Research Ethics Committee may examine the notes to check that the study is being carried out correctly. Your name or any personal details will not be recorded anywhere.

What will happen to the results of the research study?

The results from the study will be reported in a thesis and submitted for examination for a PhD. Results will also be used as part of articles submitted for publication in professional journals and reporting at professional conferences. You will not be identifiable in any of these reports or publications.

Who is organising and funding the research?

This research is being carried out as part of a PhD project. No one is providing separate funding for the project. I am a lecturer in nursing at De Montfort University in Leicester and am not employed by the hospital where you are employed.

Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. This study has been reviewed and given favourable opinion by Black Country NHS Research Ethics Committee and the Faculty of Health and Life Sciences Human Research Ethics Committee.

Contact for Further Information

If you would like more information please contact Kevin Power on 0116 2013962 (during office hours) or by e mail kpower@dmu.ac.uk or by mail at

Kevin Power
Associate Head of School
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ

Thank you for taking the time to read this information sheet.

Please keep this information sheet for future reference.

Appendix 7 Consent forms

Participant Identification Code for this study:

CONSENT FORM FOR NHS STAFF

Title of Project: How are **E**thical **P**roblems Resolved in **P**aediatric Intensive **C**are? (EPPIC study)

Name of Researcher: Kevin POWER

Please initial the boxes below where you agree with the statement

- 1. I confirm that I have read and understand the information sheet dated 18/02/2008 (version 3) for the above study.
- 2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my employment or legal rights being affected or my employer being informed.
- 4. I understand that sections of data collected during the study, may be looked at by individuals from De Montfort University, from regulatory authorities or from the XXXXXXXXXX Hospital NHS Foundation Trust. I give permission for these individuals to have access to the data provided by me in the interview.
- 5. I understand that anonymous direct quotes from my interview may be used in published reports and/or conference presentations.
- 6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher file;

Participant Identification Code for this study:

CONSENT FORM FOR PARENTS

Title of Project: How are **E**thical **P**roblems Resolved in **P**aediatric Intensive **C**are? (EPPIC study)

Name of Researcher: Kevin POWER

Please initial the boxes below where you agree with the statement

- 1. I confirm that I have read and understand the information sheet dated 18/02/2008 (version 3) for the above study.
- 2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 4. I understand that sections of data collected during the study, may be looked at by individuals from De Montfort University, from regulatory authorities or from the XXXXXXXXXX Hospital NHS Foundation Trust. I give permission for these individuals to have access to the data provided by me in the interview.
- 5. I understand that anonymous direct quotes from my interview may be used in published reports and/or conference presentations.
- 6. I agree to take part in the above study.
- 7. I give permission for the researcher to approach my child for his/her consent to take part in the study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher file;

Participant Identification Code for this study:

CONSENT FORM FOR PARENTS

NB this version for bereaved parents only – Delete this line prior to printing and distribution

Title of Project: How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Name of Researcher: Kevin POWER

Please initial the boxes below where you agree with the statement

- 1. I confirm that I have read and understand the information sheet dated 18/02/2008 (version 3) for the above study.
- 2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 4. I understand that sections of data collected during the study, may be looked at by individuals from De Montfort University, from regulatory authorities or from the XXXXXXXXXX Hospital NHS Foundation Trust. I give permission for these individuals to have access to the data provided by me in the interview.
- 5. I understand that anonymous direct quotes from my interview may be used in published reports and/or conference presentations.
- 6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher file;

Participant Identification Code for this study:

CONSENT FORM FOR PATIENTS Under 16 years

Title of Project: How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Name of Researcher: Kevin POWER

Please put your initials in the boxes below where you agree with the statement

- 1. I have read and understand the information sheet dated 18/02/2008 (version 3) for the above study.
- 2. I have had the opportunity to think about the information, ask questions and have had these answered.
- 3. I understand that I can stop at any time without giving any reason, without my medical care or legal rights being affected.
- 4. I understand that parts of what I say in the interview during the study, may be looked at by staff from De Montfort University, from regulatory authorities or from the XXXXXXXXXX Hospital NHS Foundation Trust. I give permission for these individuals to have access to what I have said.
- 5. I understand that my words from the discussion may be used in published reports and/or conference presentations.
- 6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher file;

Participant Identification Code for this study:

CONSENT FORM FOR PATIENTS 16+

Title of Project: How are Ethical Problems Resolved in Paediatric Intensive Care? (EPPIC study)

Name of Researcher: Kevin POWER

Please initial the boxes below where you agree with the statement

- 1. I confirm that I have read and understand the information sheet dated 18/02/2008 (version 3) for the above study.
- 2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 4. I understand that sections of data collected during the study, may be looked at by individuals from De Montfort University, from regulatory authorities or from the XXXXXXXXXX Hospital NHS Foundation Trust. I give permission for these individuals to have access to the data provided by me in the interview.
- 5. I understand that anonymous direct quotes from my interview may be used in published reports and/or conference presentations.
- 6. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person taking consent Date Signature

When completed, 1 for participant; 1 for researcher file;

Appendix 8 Information regarding the study for staff notice boards

Information regarding EPPIC Study

I am a children's nursing lecturer at De Montfort University in Leicester. I am currently undertaking a PhD research study investigating the process of making ethical decisions in children's intensive care. There is no separate funding for the study apart from course costs which have been borne by my employer.

Aim:

To explore how ethical problems arising in clinical practice in a hospital based paediatric intensive care unit are resolved.

Sample:

Health professionals, parents (and where appropriate children), chair and or members of the clinical ethics committee.
Sample size is determined by the requirements of Grounded Theory (Strauss and Corbin 1998) but is not envisaged to exceed 6 parents/families and a similar number each of nurses and doctors.

Data Collection Methods:

Audio recorded interviews. Parents and child may elect to be interviewed as a family. Interviews will take place at a location determined by the interviewee. Data collection is planned to commence winter 2008.

Data Analysis:

Transcripts of interviews will be analysed according to the Grounded Theory Method (Strauss and Corbin 1998).

Dissemination:

Findings will be used as the basis for a PhD thesis which will be examined at De Montfort University. Publications are planned during the course of the study partly as a requirement of the PhD. Final findings will be published in professional journals and presented at relevant conferences.

The project has received a Favourable opinion from the Black Country NHS Research Ethics Committee. The project has now also received approval from the [redacted] Hospital Research & Development office.

Kevin Power
Principal Lecturer
School of Nursing and Midwifery
De Montfort University
266 London Road
Leicester LE2 1RQ
0116 2013962
kpower@dmu.ac.uk

Strauss, A. and Corbin, J. (1998) *Basics of Qualitative Research. Techniques and Procedures for Developing Grounded Theory* (2nd Ed). Thousand Oaks. Sage

Appendix 9 Topic guides for interviews

Topics for interviews with nurses following initial interviews with SpR and nurse interviewees.

- What factors are considered when identifying 'best interests'?
- Personal views/values at odds with what is going on with a child and or family
- Have there been times when you have felt I could do this better than a doctor but felt constrained to intervene?
- Parents involvement
- Relationships with parents and children influence some of the difficult decisions?
- consensus among the team – affect on parents choices
- Influence of the professional code
- Influence of Trust objectives and media interest in intensive care

Topics for interviews with ITU consultants after interviews with admitting consultants.

- Consensus in ITU and with wider team
- Shielding parents from the professional differences of opinion.
- NHS targets as an issue for surgical colleagues in respect of decisions regarding how to proceed with children?
- Physical resources
- Parents involvement
- Relationships with parents and children
- Good Medical Practice and RCPCH guide.