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TREATMENT-WITHDRAWAL DECISIONS IN INTENSIVE CARE UNITS: EFFECTS ON NURSES

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ABSTRACT

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The decision to withdraw treatment from patients in ICU's follows careful consideration of the facts about illness-severity and the potential for reversibility. Ethical principles are the foundation for decision-making but there are many facets to be considered in the process. The final decision to withdraw is taken when it is established that further treatment is futile.

The effects of such decisions on the nurses involved were explored in a retrospective, descriptive, two-phase study.

In phase one, 47 nurses from 12 ICU's were questioned about specific situations involving patients in their care. Questionnaires yielded qualitative and semi-quantitative data about (a) the decision-making process and participants in it; (b) the reasons nurses gave for supporting, or disagreeing-with, the decision taken; (c) revisions to the treatment-plan made as a consequence of the decision; and (d) the roles of nurses. Feelings were also ascertained about nursing activities, together with views on the best and worst aspects of the situations described. Data revealed both satisfying and troubling aspects for the nurses.

There was almost universal support from nurses for the withdrawal decisions taken but there was disquiet expressed about the limited role nurses played in the decision-making. Concerns were raised about modes of treatment withdrawal, including manipulation of drug regimens and changes to patterns of ventilatory support, because of the perceived proximity to euthanasia. Nurses expressed sadness when they were frustrated in their efforts to give sufficient time, and optimal care, to patients and families. Satisfaction was associated with open debate within the multidisciplinary team. An important factor in nurses' coping strategy was a team philosophy and structure which fostered the support of nurses in the promotion of humanitarian values.

From these data, five hypothetical case-study vignettes were devised, and questions were constructed around them to explore specific issues raised by nurses in phase one. 33 nurses from 2 ICU's participated in phase two. The data obtained confirmed concerns about quality-of-life assessment and euthanasia, and where patients have lost capacity, problems associated with consent and treatment-refusal.

Table of Contents

List of Figures and Tables

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The effects on nurses of treatment withdrawal decisions made in ICU's

The context...

> "...the remarkable advances in science and technology that have occurred in the past thirty years have brought to the bedside unforeseen dilemmas, forcing health care professionals to take an ethical look at the care they deliver. Powerful diagnostic techniques, sophisticated surgical procedures, effective drugs, and worthwhile therapeutic interventions have enabled health care practitioners to eliminate many diseases and minimise disability. Unfortunately, coupled with these dramatic results is a reality that sometimes the quality of life produced is much less than what was desired. Medical interventions have been able to maintain vital functions without always benefiting the underlying disease process."
>
> (Levine-Ariff, 1990)

> "...medicine has reached the point at which its capacity to maintain life, or at any rate some vestigial form of life, has outstripped its ability to assure the quality of that life."
>
> (Tindall, 1986)

> "In the old days, we could do everything for everybody because we could do so little for anybody. For some time now, the choice has been not whether we can do something, but whether we should do something, but our technological ability to manipulate the human body exponentially exceeds our moral capacity to decide on such manipulations."
>
> (Emson, 1983)

Introduction

Dilemmas occur in the care of patients in Intensive Care Units (ICU's). One of the most difficult is withholding treatment from a patient, which may involve discontinuing treatment already in progress or making a decision not to start one. Decision-making in the resolution of these dilemmas involves consideration of ethical principles, objective assessment of the clinical condition of the patient and possible outcome, discussions with the patient, his family and members of the health care team, and weighing-up of all the relevant factors.

The focus of this study is the process of withholding treatment from patients who are in ICU's and the effects of this on the nurses involved.

Intensive Care provision

A definition for Intensive Care offered by the Kings Fund Panel (1989) was,

> "A service for patients with potentially recoverable diseases who can benefit from more detailed observation and treatment than is generally available in the standard wards and departments".

Intensive Care should then be offered 'in the expectation of beneficial consequences when such benefits can be achieved at acceptable cost' but should be withheld 'where possible harm outweighs the remote prospects of benefit' (Kings Fund Panel,1989).

In the early days, patients in ICU were 'usually under forty, and suffering from defined diseases with a known course, such as poliomyelitis, tetanus or post-transfusion anuria,' where support was offered for the failing organ system, 'doing everything in our power to help, with no question of ethical restraint or restricted resources' (Rapin, 1987). Now the situation is different,

> "Patients are older, are being treated at much more advanced stages of illness, suffer from more serious disorders, have more than one system failing, and can be offered almost indefinite support."
> (Rapin, 1987)

Dilemmas

Dilemmas occur because of doubts and conflicts over what best conforms to the desired fundamental ethical principles of beneficence (doing good for the patient) and non-maleficence (not doing harm to the patient) among the attending team members. While all professionals involved subscribe to these principles, their underlying values and philosophies will vary, and the reality of having to deal with a dilemma involving a particular patient will highlight these differences of opinion. In addition to these difficulties, justice, in the sense of fair and equitable allocation of resources, must be considered in the decision-making, together with recognition of the autonomy of the patient, that is, acknowledgement of the rights of human beings to self-determination and respect.

Recognition of a dilemma implies that professionals perceive a difficulty in establishing what is right and what is wrong, or perhaps more commonly in clinical practice, what is least wrong, in a particular situation. Knowledge of ethical theories from which guidance may be obtained for moral actions to be taken is likely to be beneficial in the resolution of dilemmas. These ethical theories 'provide a framework of principles within which an agent can determine morally-appropriate actions' (Beauchamp and Childress, 1989), and they include utilitarianism in which the value of the results of actions is of greater importance than the components of the process, even if these components include breaking moral rules such as deception and lying, and deontology which holds that actions are right or wrong on the basis of whether duties, obligations, fidelity to promises, truthfulness and justice, have been met, irrespective of the consequences (Beauchamp and Childress, 1989). The difficulty implicit in deontological theory is that principles may conflict, and a balance has to be sought to establish which takes precedence. The principles of beneficence and non-maleficence in a particular situation may present a conflict clinically; and respect for patient autonomy in a 'life and death' situation could conflict with a fundamental belief held by the professional about the sanctity of life, as well as raising the issue of euthanasia.

The actions of professionals are also governed by codes of conduct which are based on fundamental values and beliefs about what constitutes the standard of moral activity, and which provide guidance in specific areas of practice. Guidance may also be obtained from religious doctrines, both that of the professional(s) involved and that of the patient concerned in specific situations, where beliefs will influence actions.

Euthanasia

Professionals are also regulated by legal constraints which reflect fundamental moral principles but which may be modified by case law in practice. In law, it is accepted that there is a moral difference between an act and an omission, so that active euthanasia, or a deliberate act which causes the death of someone, is against the law, but 'passively allowing someone to die through non-intervention' is within the law. (Farsides, 1992). The distinction between active and passive euthanasia becomes even less clear when one considers situations in which opiates and other drugs are used to relieve suffering in terminally-ill people, where these drugs have side-effects which are likely to hasten death.

What constitutes active and passive euthanasia is relevant to the topic of withholding treatment from critically-ill intensive care patients. Morally there may be little difference in administering a drug which will hasten death, and discontinuing a drug which is supporting the patient's circulation, when the consequences are the same.

Objective measurements in decision-making

One fundamental problem in decision-making over the provision of intensive care for many patients, is that there is likely to be uncertainty. There may be doubts about outcome, as each patient's situation is unique, with variations in age, chronic health problems, the duration and severity of the present illness, the response to treatment thus far, and the potential for reversibility of the illness.

What constitutes benefit to the patient is also in doubt, as it is not only the survival of the patient but also the anticipated quality of life of the patient, should he survive, which must be considered. The patient, too, may have an opinion in the decision-making, so to avoid the paternalism inherent in judgements made solely by doctors, the Kings Fund Panel (1989) recommended that,

> "The physician should benefit the patient according to the most objective judgements available, unless the patient expresses a competent and informed wish for an alternative course".

Knowledge about 'the most objective judgements' is therefore important to those making decisions about intensive care treatment.

> "The complexity of modern intensive care and the amount of information currently available, frequently makes it impossible for one individual to use personal, intuitive judgements to decide on the course of treatment. Often the best course of action will become apparent only through careful balancing of prognostic information with ethical, moral and legal considerations."
> (Knaus and Zimmerman, 1988)

Objective data, such as severity-scoring systems, enable not only risk assessment but also assist in evaluating the benefits obtained from different treatments, and by comparing predicted outcome with the actual outcome, the relative success rate of different departments can be ascertained. Predictive data has also been obtained from information about the number of organ systems failing, and the duration of the failure, and then examining mortality rates in these groups (Knaus et al, 1985).

The elderly in ICU

The age of the patient is relevant to discussions about intensive care, and society's attitude towards the care of the elderly will become increasingly important in the provision of treatment and the nature of what is offered.

> "...very few individuals walk as perilous a tightrope between life and death as the critically-ill elderly patient ... because of their vulnerability to sustaining devastating setbacks to multisystem integrity."
> (Stiesmeyer,1992)

With advances in diagnosis and treatment of disease, together with the increasingly elderly population, many elderly people receive care in ICU's because of acute illness, trauma or major surgery.

Decision-making about the care of elderly people who may need ICU treatment can be very difficult. Rapin (1987) emphasises the need 'to include considerations of the patient's biological age objectively' rather than go solely on chronological age.

The elderly use a 'disproportionately-high amount of health care resources' (Reigle, 1990), and issues of justice have to be addressed, where resources are limited. Callahan (1987) proposed 'shifting the goals of health care from prolonging life, to improving the quality of life for the elderly' so that the focus of medicine would be to avoid premature death. There would need to be an attitude change in society away from the 'need to forestall death at every age and at any cost' towards an acceptance that death is 'a natural end to a normal lifespan' (Callahan, 1987,p.223).

Callahan (1987,p.171) advocates three principles:-

1. After a person has lived out a natural life span, medical care should no longer be oriented to resisting death.

2. Provision of medical care to those who have lived out a natural life span will be limited to the relief of suffering.

3. The existence of medical technologies capable of extending the lives of the elderly who have lived out a natural life span creates no presumption that the technologies must be used for that purpose.

The question is whether it would be better to reserve more aggressive treatment for younger people where the likelihood of their benefiting is greater than in the elderly, whose risks of cardiovascular, cerebrovascular, respiratory and renal problems are higher (Stanley, 1992).

Decision-making in the clinical situation may not be easy, particularly in situations where the family of the patient is anxious that everything possible is tried and the patient is unable to express his or her wishes. A person's chronological age may be a poor indicator of usual health status and quality of life.

Neonates

At the other end of the lifespan, the care of premature neonates also presents dilemmas and

Ballantyne (1998, in The Times Magazine,p.80) encapsulates one, saying that 'a baby of 23 weeks (gestation) has a 5% chance of survival, and if it should survive, a one in four chance of having cerebral palsy and other learning difficulties, and a one in two chance of chronic lung problems'. Extremely difficult decisions have to be made and Ballantyne (1998) quotes a doctor who specialises in this area, who talks of the difficulty of maintaining 'a fine balance between professional detachment and sufficient emotional involvement with the parents to help them to make a fully informed choice' when treatment issues arise in the care of premature infants.

Cardiopulmonary resuscitation

A particular area of concern which involves the elderly and others, is the provision of cardiopulmonary resuscitation (CPR) in the event of cardiac arrest. In one review of the outcome of CPR in patients aged seventy or older, Brown (1990) concluded that '...CPR was rarely effective for elderly patients with cardiopulmonary arrests out-of-hospital, unwitnessed, with CPR for longer than fifteen minutes and those who have asystole or electromechanical dissociation'.

Factors advocated by Handley (1990) to be considered when decision-making over whether or not to resuscitate, were,

> "Does the patient want to be resuscitated?"
> "Is resuscitation in the patient's best interests?"
> "Can the underlying cause of the cardiac or respiratory arrest be reversed?"

Handley (1990) felt that if the reply to any of these questions was "No" then CPR should not be offered.

To a large extent in Britain, whether or not CPR is offered depends on a decision made ultimately by the patient's doctor, who has 'exercised unhurried, clinical judgement of the patient's diseases, likelihood of responding to treatment, and quality of life'. (Bayliss, 1982). Although this approach is paternalistic and involves value judgements, doctors are expected to have professional integrity and make humane decisions in the best interests of patients.

Tomlinson and Brody (1988) discuss three rationales as a basis for decision-making about withholding CPR, firstly, it is of no medical benefit; secondly, there is an expectation that there would be poor quality of life after CPR, the burdens outweighing the benefits; and thirdly, that the patient already has an unacceptably poor quality of life which would be made worse by cardiac arrest and CPR.

Other categories of irreversibly-ill patients

The main focus of this research is the decision-making process surrounding the withdrawal of treatment from a group of patients who have been receiving treatment in ICU's but whose condition is now deemed irreversible. Such patients may have undergone major surgery, and have required support of, or replacement treatment for, one or more body systems which have failed. Every effort will have been made to reverse circulatory and/or respiratory failure, and sufficient time would have been given for treatment measures to work if they were going to. Specialist opinions would have been sought where appropriate. It is now felt that there is no other treatment which would be of benefit to the patient. The next step then is either to continue the present level of support indefinitely with little or no hope of recovery, thus prolonging the dying process, or taking the decision to discontinue or reduce the level of support, and allow the person to die without further heroic measures being taken. There is, however, some difficulty with making the latter decision as there is not absolute certainty, and doctors have to make decisions (as they do in many situations) based on probabilities, outcome studies, prognostic indicators, and so on, and relate this information to the case of the individual person under consideration.

Whatever decision is made, there may be disquiet or disagreement among members of the patient's family and in the caring team. Discussions will have taken place between the patient's own doctor and others involved in the treatment, and there may be differences of opinion between these participants. The nurses who have been dealing with the patient's family may have important and relevant information to include in discussions. The patient's family may already have expressed opinions, or may do so when the patient's situation is discussed with them, and they are consulted about what they feel should be done.

The feelings of participants are influenced by a variety of factors, including the age and diagnosis of the patient; the perceived quality of life prior to illness; the usual course of events with this diagnosis; specific characteristics of the situation; and the expected duration and quality of life if the patient were to recover from this illness. Factors which are also important though, are the attitudes and feelings of the doctors, ultimately the decision-takers, and the amount and type of consultation with other team members.

If the decision is taken to continue full support, possibly because the patient's family has requested it, even though the prospects for recovery are slight, it can provoke stress in the nursing team, partly because of the continuing need to support the family when there is little hope of recovery, and partly because some nurses feel that further treatment is futile. Studies into the needs of families of critically-ill patients have consistently shown that one of the most important needs is to feel that there is hope (Molter,1979; Daley,1984; Rukholm,1990) and this is very difficult to sustain under these circumstances.

Withdrawal process

If the decision is taken to withdraw or withhold treatment, this can take various forms. It may be a decision to continue the present level of support but not increase treatment, for example, not increase or add cardiac support drugs. A decision may be made not to treat another organ-system failure, if it were to occur. It may be a decision to continue the present level of support but withhold cardiopulmonary resuscitation (CPR) in the event of a cardiac arrest. Finally a decision may be made to reduce and discontinue the support being offered and the patient is then allowed to die. Under these circumstances, if it is thought that the patient may suffer any anxiety or pain, it is likely that doses of analgesic and sedative drugs will be increased, with the intention of alleviating any distress during the process of dying. (Wilson, Smedira, et al, 1992).

Resolution of dilemmas

Dilemmas will inevitably be met in ICU's. It has to be accepted that within any team there will be differences in beliefs, values, feelings and opinions, which must be considered. The professionals involved in decision-making must have specialised knowledge of the issues involved, and be prepared to listen to other viewpoints. Intellectual skills such as reasoning and judgement, balancing of arguments, and the ability to extrapolate from possible solutions to implications, are all necessary. The views of the patient, family and anyone else they nominate to represent their views, must also be considered.

> "The ability to communicate effectively with patients and families ... is one of the most vital professional skills in appropriate decision-making. Especially in critical care situations, stress, fear, intimidation and unfamiliarity with the setting can overwhelm ... patients and families. Health professionals are responsible not merely for attempting to communicate, but for ensuring that effective communication takes place."
>
> (Ruark and Raffin,1988)

The stages in the resolution include recognition that a dilemma exists; establishing all pertinent facts; discussion with all people directly involved; referral to other sources of advice and opinion, such as an ethics committee, clinical ethicist or legal advisor; resolution of the dilemma and a strategy for action; communication of the decision to all concerned and documentation of the decision in case-notes,as necessary; and finally reflection on, and evaluation of, the problem and its outcome. When a conclusion is reached, everyone involved must be prepared to take responsibility for it, so that the burden of a difficult decision is shared among all participants (Tschudin,1992).

> "Good decision-making requires more than reliable technical knowledge. In order for everyone involved to feel satisfied that decisions are in the patient's best interests, thoughtful consideration, good communication skills and channels, and an ethically-sound approach to resolutions, are essential."
>
> (Dunaway, 1988)

There follows a series of chapters expanding areas from the introduction. As the focus of the thesis is on nurses and their involvement with treatment-withdrawal situations, the first area to be covered is about the nursing role in ethical decision-making within the multidisciplinary team and the preparation needed for this role. Secondly, methods of supporting the autonomy of the patient are considered, and specifically the role of nurses as advocates for patients and families is examined. The third area covers the ethical and legal aspects of treatment-limiting decisions in some detail as these are a fundamental part of the thesis. Wherever they work, nurses need a working knowledge of the legal issues which impinge on their practice, and ethical dilemmas arise in most settings. ICU nurses are likely to have to confront these issues quite often because of the nature of the patients for whom they care. The last area addressed is that of quality of life because it is apparent from the other topics reviewed that an appraisal of the patient's current and predicted quality of life is a major consideration when making treatment-limiting decisions.

Nurses and decision-making regarding ethical issues

Nurses are directed by the code of conduct issued by the United Kingdom Central Council for Nurses, Midwives and Health Visitors (UKCC), the organisation which regulates the registration of nurses, to 'act always in such a way as to promote and safeguard the well-being and interests of patients and clients' and to 'act in such a manner as to justify public trust and confidence' (UKCC 1992). It therefore follows that there is an expectation that nurses should participate in discussions about the care and treatment of patients, and that the role of the nurse as an advocate is,

> "an integral and essential aspect of good professional practice ... provided that it is in the interests of the patient which are being promoted rather than the patient being used as a vehicle for the promotion of personal or sectional professional interests." (UKCC,1989)

The pattern of care in ICU's is that nurses are at the bedside all the time and are in a position to be closely in touch with the views of patients (if sentient) and their families and friends, so in the event that a patient's condition is deemed irrecoverable, the nurse is likely to be able to represent these feelings in discussions, if the family cannot. As Holly and Lyons (1993) say,

> "Critical care nurses spend a greater amount of time at the bedside with each patient and family member than do physicians. By virtue of their increased presence, this group of nurses has an in-depth understanding of the benefits from advanced science and technology, as well as the patient's and family's response to these advances".

Increasingly in ICU's, nurses are caring for patients whose treatment involves some ethical dimension to the decision-making. Conflict may occur in some situations, either in terms of the ethical principles involved or because there may be conflicting views among the members of the health care team. Although nurses may be closely involved in these conflicts, the evidence indicates that nurses are 'not influential in the final decision-making' (Holly, Lyons,1993), and the same authors cite the example of decisions 'to terminate life support usually being made by the physician with little input from either the nurse or the family'.

Schattschneider (1990) comments that 'decisions regarding patient care such as the continuation or withholding of life-sustaining treatment may be made without involving the nurse who is the primary care-giver, and the resulting value conflict produces ethical problems for the nurse'.

The role of the nurse from evidence in the literature appears to be to participate in the sharing of information with other team members, but not to take part in actual decision-making where an ethical dilemma exists. Although the nurse 'may be the most appropriate person to facilitate the patient's or family's participation in ethical decision-making' (Watson,1993) or to give their views if they are unable or unwilling to participate, nurses generally do not appear to be directly involved in the discussions of the ethical issues, and the reasons need to be sought.

Possible strategies for nurses to use in addressing ethical issues

The ethical principles which would need to be used by a nurse who is engaged in discussions about withholding or withdrawing treatment are beneficence, non-maleficence, justice, fidelity and support of autonomy, and it may be that nurses can define the principles in theory but they do not take part in discussions because they lack practical skills.

Wlody (1990) feels that 'part of the difficulty in caring for hopelessly-ill patients is that ...nurses are unsure of their roles in addressing ethical issues'. Wlody (1990) suggests that the role of the intensive care nurse involves 'identifying the conflict, protecting the patient from harm, assisting with clarification of issues, providing support for the patient and family, and initiating discussions with doctors and others'. The same author goes on to suggest a strategy for dealing with issues, consisting of an *assessment* phase, an *advocacy* phase, and an *action* phase (Wlody,1990) but this model necessitates the use of ethical principles, and skills in reasoning and judgement.

Rodney (1991) used a model devised by Curtin (1982) to illustrate a process by which nurses can organise and consider ethical dilemmas. This model consists of six stages:

1. background information;
2. identification of ethical components;
3. identification of individuals involved, including their responsibility and competence;

4. options and courses of action;
5. reconciling of facts and principles; and finally
6. resolution, the development of a consensus.

Such models may be very helpful in assisting nurses to frame problems and dilemmas, and thus promote participation in discussion.

Ketefian (1989) and Parker (1990) reviewed a number of studies measuring nurses' moral reasoning ability but both commented on the lack of consistency and replication. One important weakness was the use of hypothetical dilemmas in the majority of studies, which were 'unfamiliar, irrelevant, lacking in contextual elements' and which 'may discourage the reader's identification with or emotional involvement in the situation (Parker,1990).

> "The disparity between reasoning in hypothetical situations and real situations may represent measurement error, which argues against the validity of current measures of moral reasoning."
> (Parker,1990)

The basis for a number of the 'measures of moral reasoning' used in these studies, was Kohlberg's depiction (cited by Corley, Selig, 1992) of the stages of moral reasoning and development. Kohlberg defines three successive levels of moral reasoning, each of which has two stages , through which individuals may pass, so that at the first level, there is preconventional reasoning (external rules, involving reward and punishment, determine right or wrong). At the second level, conventional reasoning in which expectations of the family are maintained and there is conformity to social pressures. At the third level, postconventional reasoning, in which the person functions autonomously in defining moral values and principles, and decisions being made on the basis of conscience. The use of Kohlberg's cognitive theory of moral development as a basis for measurement tools also possibly reduces validity when studying predominantly-female nurses because Kohlberg 'based his theoretical assumptions on data collected from male subjects only' (Cassidy,1991).

Omery (1986) used a phenomenologic research design consisting of unconstructed interviews to describe the composition of moral reasoning used by critical care nurses when faced with a moral dilemma. The results indicated that moral reasoning had three major characteristics -

principles (generalisations which provided the justification for the moral decision and direction for action), *mediating factors* (circumstances or conditions which influenced application of the principles), and *modes of reasoning* (mental orientations shaping actions).

Omery (1986) described two modes of reasoning, accommodating and sovereign, where accommodators reconciled their reasoning to conform to their group, and sovereign reasoners based their judgements on self-chosen, valued, moral principles, even if this caused potential conflict with the group.

Cassidy (1991) reviewed twelve studies published between 1970 and 1987 which were wholly or partly concerned with ethical responsibilities, and found, like Ketefian (1989), that not only were there very few studies, there was a lack of consistency in the methods and tools used, so 'despite heightened awareness about the ethical dimensions of practice and concerns about the ability of nurses to participate in ethical decision-making' it was difficult to draw valid conclusions. Cassidy (1991) comments that 'given the conceptual and measurement issues, the findings of all the studies included in the review should be viewed as tentative'.

Barriers to participation by nurses

Nurses do encounter ethical dilemmas in their practice, but may not be able to participate in discussions with others. According to Davis (1981, cited by Cassidy,1991) nurses 'have difficulty in using the language of ethics to define these dilemmas' which could create the false impression that they are not able to recognise dilemmas. Ketefian (1985) suggests that 'perceived role constraints may be a factor in understanding how nurses respond in fulfilling their ethical responsibilities'. Another deterrent to participation could be the environment in which decision-making is carried out. In a busy ICU, for a nurse to be freed physically and mentally from patient care temporarily to participate in decision-making may prove to be a very real, practical problem in an environment where sick, unstable patients are being cared-for.

Decision-making may involve complex and difficult problems and it is possible that 'it is the nurses' lack of educational preparation which is an inhibiting factor to their involvement ' (Watson,1993). Although ethics are included in pre-registration nursing programmes and in the post-registration academic and clinical programmes 'the development of practical skills in ethical analysis is not addressed' (Watson,1993).

Nurses who work in intensive care areas may have frequent contact with distressed patients and families whose circumstances may present a dilemma to the health care team. Van Hooft (1990) asks whether such nurses 'retreat into routine responses' and 'cope with the dilemmas only by ignoring the moral dimensions of their decisions ...', and goes on to advocate the empowerment of nurses to give them the insight and sensitivity in decision-making, because 'ethical action is an exercise of internal personal strength'.

This author feels that the moral education of nurses places too much emphasis on established ethical theories, such as deontology, utilitarianism and teleology, in which the implication is that there are general ethical principles to be applied to situations in order to resolve dilemmas (van Hooft,1990). In reality, when a group of professional carers are considering a moral dilemma involving a human being, using established ethical principles, there is no certainty that they will reach the same conclusion. For nurses, even if they feel strongly that a certain action is right or wrong, it may be difficult for them to voice their feelings if they feel insecure in their knowledge or debating ability. Yet in situations where treatment is being withheld or withdrawn from patients in ICU's, nurses will be responsible for providing the continuing care for the patients and their families, possibly, for example, reducing supportive drug treatment, and for giving support to the family before and after the death of the patient. Nurses therefore carry a heavy burden through this distressing time, and even if they readily acknowledge and accept that changes in treatment are explicitly medical decisions, they, because of their sensitivity and closeness to the situation, nevertheless may feel that their opinions, their insights into the family circumstances and their views on the rights and wrongs of a course of action, should be considered.

To enable nurses to participate with confidence in this type of debate, they need to develop what van Hooft (1988, cited by van Hooft,1990) defines as 'a motivational cognitive stance which needs to include the conviction born of reflection and commitment that the action is right'.

> "... many nurses may have mixed feelings when faced with a decision to discontinue active treatment. Although there may be relief that overzealous and undignified treatment has come to an end, feelings of failure may surface."
> (Bracegirdle,1994)

The less-experienced nurses who have not been involved in decision-making may 'be unsure why the all out fight to save life has suddenly ceased, or fear that important treatment may have been overlooked' (Manley,1986, cited by Bracegirdle,1994).

Values of nurses

Nurses therefore need not only the scientific knowledge which forms the basis of a great deal of the medical and nursing treatment, the application of which is very obvious in ICU's, they also need to retain their sensitivity, given the 'deep, human significance that living and dying have for people' (van Hooft,1990).

> "Death and those events surrounding death, such as resuscitation, are not objective, meaningless actions or events. Death is not just the end of the biologic life process. The death of any individual has a symbolic meaning for each health care provider. These meanings may be shared or they may not be shared. They may even be conflicting".
> (Omery,1991).

The place of religion cannot be ignored in this context, and van Hooft (1990) feels that 'nurses, whatever their own religious convictions, should develop a caring understanding of religion and of the way it provides a meaning-giving matrix for the most crucial episodes in a human life'.

Involvement of nurses may humanise the decision-making process, although humanity is not solely the prerogative of nurses. Grundstein-Amado (1992) in a study of the differences between doctors and nurses in ethical decision-making did however conclude that 'nurses placed the highest value on the caring perspective, which entails sensitivity to patients' wishes' whereas doctors 'value patients' rights and a scientific approach concerned with disease and cure'. One difficulty with the interpretation of the findings of this study, acknowledged by Grundstein-Amado, is that the group of nine doctors participating were all male, and the nine nurses all female, so it is impossible to separate professional differences from those associated with gender, particularly where the total numbers are small. One inference which Grundstein-Amado draws though, is that when questioned about the ethical issues involved in decision-making about a hypothetical patient, nurses searched for indications of the patient's feelings, intentions and interests, and did not necessarily invoke any rules of equality and justice, whereas doctors were satisfied with the amount of (clinical) information, relying on ... 'professional knowledge, impersonal and universal, and the implicit interests of society' (Grundstein-Amado,1992).

This author also infers that 'nurses tend to experience a greater tendency to moral sensitivity than do doctors' and goes on to say that moral sensitivity results from either having no power to control the action and to act as a free moral agent, or from the inclination to support and sustain patients who faced difficult moral choices. According to Jameton (1984, cited by Grundstein-Amado,1992) this may result in moral distress in which nurses feel that they have to '... compromise their integrity because of their peculiar position in the health care power structure, and because of their conflicting loyalties and responsibilities'.Non-participation in decision-making in such circumstances may result in feelings of powerlessness, lack of support and frustration (Holly, Lyons,1993; Erlen and Frost,1991), and can lead to job dissatisfaction.

Doctor-Nurse collegiality

Watson (1993) suggests that a joint approach, based on mutual participation by doctors and nurses, may enable a more balanced resolution of these difficult dilemmas.

> "Historically, physicians have been socialised to believe that other members of the health care team work for them, rather than with them."
> (Allen et al,1980)

Although both groups share responsibility for the care and welfare of patients, the traditional pattern for the relationship between members of the medical and nursing professions has been one in which 'nurses have generally held a somewhat subordinate role' (Wilson-Barnett,1986) in which the doctor diagnoses and prescribes, and the nurse follows instructions.

How much of this socialisation can be attributed to the situation historically in which medicine has been a male-dominated profession and nursing predominantly female, can be examined.

In a study of doctor/nurse interaction on hospital wards by Katzman and Roberts (1988), the ways in which traditional male/female social roles related to professional roles were explored. These researchers observed nurses frustrated in their attempts to give optimum care to patients because of their relative powerlessness in the face of opposition from doctors, and they found other evidence of the subordination of female nurses, who had to defer to male doctors over matters of any importance.

Other authors (Stein et al,1990; Haddad,1991) have commented on the demeanour adopted by nurses when communicating with doctors. Haddad (1991) comments that nurses learn to make suggestions and ask for recommendations in a way that sounds as though they are not doing so, that is, in a covert, passive manner, and Wilson-Barnett (1986) says that because the nurses' 'reasoning and intellectual skills were not fostered or valued', the passive role of nurses was reinforced in any communication between doctors and nurses.

Doctors carry the legal responsibility for their patients' treatment, so it is entirely appropriate that they should determine the course of action with regard to the drugs used and the dosages, and the surgical treatments to be offered, for example. Within the ICU context, however, nurses have to function increasingly autonomously in, for example, titrating drug dosages to the (unstable) patient's requirements, and in initiating treatment in emergency situations, pending the arrival of the doctor. In parallel with these changes in ICU nursing, there have been developments in nursing practice generally, which 'reflect increased knowledge of effective care, changing needs of patients' and which involve 'attempts by the profession to become complementary to doctors, not poor substitutes or mere ancillaries' (Wilson-Barnett,1986). Certainly, many of the tasks which nurses now carry out were formerly the prerogative of the doctor, and both professions would readily accept that where it is in the best interests of the patients to do so, nurses should expand their roles, provided that they have the appropriate preparation.

Increasingly, nurses are being educated in academic institutions, so they are being prepared for a different, collegial role in partnership with other health care professionals, so the expectations of newly-qualified nurses are changing. There is also a greater emphasis on higher education for nurses to prepare them for their senior roles in clinical, managerial and educational posts in future.

In the context of decision-making in ICU's, again, traditionally, doctors have made most decisions about patient care, however, the two professions 'differ in their roles, observe patients from different vantage points, and perceive correspondingly different problems' (Allen et al,1980). '...interdisciplinary collaboration allows input from the differing perspectives of nursing and medicine' and because each profession has special expertise, it can 'lead to enlightened patient management' (Baggs et al,1992). The indications are that nurses are often not involved in such decision-making and nurses have reported dissatisfaction with the process of ethical decision-making related to patient care.(Allen et al,1980; Erlen and Frost,1991; Holly,Lyons,1993).

The main purpose of having nurses and doctors working in collegial relationships where treatment-withdrawal decisions are being made, is that it is likely to be in the best interests of patients for them to do so. One example cited by Luce (1990) is that where discussions about withholding CPR from a non-sentient patient are being held, doctors should consult nurses who 'frequently have explored these issues with patients at the bedside while the patients were lucid', thus supporting the patient's autonomy. The same author feels that 'as important members of the ICU team, they should be consulted about this issue and may wish to be present when it is discussed with patients and surrogates ... and their presence is particularly appropriate because they are often the only health professionals in attendance at the patient's death' (Luce,1990). Nurse involvement in ethical decision-making has been demonstrated to offer support for patient autonomy and support for patient or family involvement in the decision-making process (Davis and Jameton,1987; Zorb and Stevens, 1990).

Another reason for interdisciplinary collaboration, is that without it, the quality of patient-care may suffer (Wilson-Barnett,1986) whereas 'with more collaborative interdisciplinary care, recent studies have demonstrated improved patient outcomes and care-provider satisfaction' (Baggs et al,1992). Stein et al (1990) comment that 'more open communication between doctors and nurses uses nurses' observational and intellectual skills better, enhances their job satisfaction, and improves their ability to contribute to patient care.

Where nurses may add an important dimension is in the assessment of the patient's previous and predicted quality of life, because this may be a major factor in the decision-making where treatment-withdrawal is being considered. Because of their closeness to the patient and family, and 'because of their roles and expertise, nurses have access to information regarding patients' responses to health problems and the meaning patients give to the phrase, quality of life' (Haddad,1991).

Another important reason for doctors to discuss these situations with their nursing colleagues is that the nurses may feel that what they are being asked to do is morally wrong, and as moral agents in their own right, they should be consulted about activities which they may find morally offensive (Gillon,1986a).

In the preface to an article describing a demonstration project in which an acute-care unit was dedicated to the 'study and development of collegial relationships', Pike (1991) states that moral outrage is disturbingly common among nurses working in acute-care settings. This author feels that,

> "Moral outrage ensues when the nurse's attempts to operationalise a choice are thwarted by constraints, and that the outrage intensifies when these constraints not only block actions but also force a choice of action that violates the nurse's moral tenets."
>
> (Pike,1991)

Pike (1991) speculates that these constraints 'may be internal, such as a lack of professional confidence, timidity, fear, insecurity or inferiority' or they may be external, rooted in history, ... and part of the socialisation of health care professionals and the organisation'.

Areas of conflict

Particular problem areas for nurses include resentment of medical paternalism in governing, for example, what information about a diagnosis and treatment should be shared with the patient, so that even if a patient were to ask a specific question of a nurse with whom he or she has a close, confiding relationship, the nurse cannot disclose 'forbidden' facts. Within ICU's, there may be disquiet about the perceived over-treatment of a patient, despite, perhaps, what the patient's family may feel and the nurses' opinions. This apparently inappropriate treatment can lead to the nurse working with a patient and family where hope is impossible to sustain, and in which the nurse may feel increasing resentment about the lack of peace and dignity for the patient.

> "There are some obvious factors which contribute to the nurses' perceptions that they are only bystanders in the life-death, decision-making process. They do not ultimately make the decision to prolong or end life, the physician does. Yet nurses spend countless hours with patients and their families, witnessing first-hand the lingering pain and sorrow that is endured when the decision is made to prolong life."
> (Allen et al,1980)

Because of the constraints of the traditional relationship, nurses may well feel that they cannot openly disagree with a medical decision, and in situations where there is a moral dimension to a decision, this may be a major barrier to discussion amongst the staff involved.

> "Attributes of collaborative practice, such as shared decision-making, responsibility, and accountability, effectively dismantle some of the most prominent internal and external constraints."
> (Pike,1991)

To think that all doctors would come to the same conclusion when considering a problem would be as great a mistake as to assume that all members of a group of nurses would agree about a decision. When ethical issues arise, there is likely to be disagreement both among and between groups, and data from Allen et al (1980) indicated that no decision was totally acceptable to all involved. For this reason, although there should be debate, someone must have the authority to make the final decision and this falls to the doctor who carries responsibility for the patient. If, however, the decision-making has been shared among all interested parties, the responsibility for the ethical aspects of the decision (as opposed to the clinical, medical facts), is a shared one.

Support of patient autonomy

An important reason for nurses to take part in decision-making is that because of the relationship which they have with patients and families in ICU's, they are likely to have insights in a treatment-withdrawal situation which other team members do not have, and are then in a position to contribute to the support of patient autonomy when patients are incapable of expressing their own views.

Both British and North American Codes of Professional Conduct for nurses refer to the advocacy role of nurses in supporting patient autonomy. An obligation is placed on nurses to,

> "...promote and safeguard the interests and well-being of individual patients and clients"

and to,

> "ensure that no action or omission on your part, or within your sphere of responsibility, is detrimental to the interests, condition or safety of patients and clients."
> (UKCC,1992)

Many patients in Intensive Care Units (ICU's) are unable to speak due to illness resulting in unconsciousness, modes of treatment, or sedation, so it may be impossible to hold discussions with them about their care.

> "Choices among treatment options should promote the well-being of the patient according to the patient's own understanding of well-being. When patients lack the capacity to make choices for themselves, someone else must represent that patient's particular values and preferences."
> (Rushton, Glover, 1990)

Advocacy

The nurses who care for these patients may feel that they should function as advocates for patients in such discussions, presenting the views of both patient and family when these people are unable to participate themselves. Often, nurses, in their day-to-day work with families, gather important, relevant information which needs to be included. This is particularly pertinent where treatment-withholding decisions are being considered, because it is likely that nurses will have spent long periods at the patient's bedside, participating in conversations with family members about the patient's care and treatment, developing rapport with them, and becoming familiar with their views, feelings and anxieties.

Brown (1990) describes the nursing advocacy role as having four components,

> "...*the guardian of patient rights; preserver of patient values* (assuming that the nurse is in a position to discover through contact with the patient what his or her personal values and needs are); *conservator of patient's best interests* (supporting patient autonomy or where this is not possible, promoting beneficence); and *champion of social advocacy* (implying the promotion of equality and justice in provision of health care)."

However, Allmark and Klarzynski (1992) argue strongly that the roles of nurse and advocate are incompatible, saying that it is not possible for the nurse to function as an advocate for the patient as well as be a member of a multidisciplinary team. These authors base their argument on the definition of an advocate as a 'mandated person pleading the cause of the person, as the person (not the advocate) sees it', which could mean that the nurse could be asked to plead on the patient's behalf for a course of action which, seen from the experienced nurse's professional viewpoint, would not be in the patient's best interests.

Randall and Downie (1996,p.55) also disagree with the role of advocate being ascribed to nurses because 'such a policy would potentially deny the nurse her own professional autonomy, and would create practical as well as ideological divisions between professionals'.

Norrie (1997), too, questions the advocacy role of nurses, firstly, because of their possible lack of ability to use ethical models in debate, secondly, because nurses have no legal recognition of their role as patient advocates, and thirdly, because their academic preparation for such roles is inadequate.

The argument rests to some extent on semantics, because ICU nurses would probably feel that they were functioning as advocates in situations where, for example, they were interpreting lip-reading for other members of the team, or were speaking for the family where the patient's family was absent, or too distressed to participate, when discussions were going on. Presenting the views of patients and their families does not preclude the nurse from expressing a professional and personal viewpoint. This may be very important where the values of the nurse and patient do not coincide.

> "...being an advocate for a patient who wants to be allowed to die may be a real problem for a nurse ...where their respective values differ."
> (Ney,1989)

Autonomy, the right to self-determination, is a fundamental ethical principle involved in guiding the conduct of professional care-givers. Kant (1785) defined the deontological viewpoint that

> "...persons act morally well only when they act out of a sense of duty, without regard to their inclinations, and that their duty involved treating all persons with the respect that arose from seeing them as autonomous rational agents..."
> (van Hooft,1990)

This author feels that this implies that it should be possible to develop basic moral principles from the sense of duty which would oblige us to act in defined ways to situations, however, in clinical practice, this is not the case, because no two situations are the same (van Hooft,1990). The other difficulty, of course, is that what professional care-givers see as their duty may differ, their values and viewpoints varying with time and circumstances.

> "Respect for autonomy recognises an individual's right or ability to decide for himself according to beliefs, values and life-plan ... these decisions may be opposite to the course that is advised or deemed wise in a given situation."
> (Latimer,1991)

'It places a moral duty on care-givers ...not to force unwanted treatment on unwilling patients' because the patient has the right to accept or reject medical treatment (Wold,1992) and this obligation was upheld recently in a court case involving a woman on whom a caesarean operation was carried out against her wishes (Duce,1998).

The autonomous person 'acts in accordance with a freely, self-chosen and informed plan...'(Beauchamp and Childress,1989).

> "Because of the unequal distribution of knowledge between professionals and their patients, respect for autonomy necessitates ensuring that there is disclosure of information, understanding of that information, and adequate discussion and decision-making."
> (Beauchamp and Childress,1989)

Having respect for a competent patient's autonomy therefore involves discussion of treatment options, effects, expectations of possible risks and anticipated outcome. Voluntary consent is then sought, the patient making a decision free from coercion. Even with competent patients, it may be difficult for a decision to be reached freely, because of the patient's vulnerability; the influence and persuasiveness of the doctors; and possibly fear and intimidation. Medical paternalism in decision-making could well be justified on the grounds that the doctor is always going to be more knowledgeable than the patient about treatment options, however the patient is the only person who can make valid judgements of, for example, his/her quality of life. Doctors may feel that acting humanely, in the patient's best interests, is an appropriate defence, when possibly withholding test results or other potentially-damaging information, but this involves assumptions made by the doctor of what the patient wants, which may be incorrect (Gillon, 1985a). Gillon (1986b) gives another plausible justification to override a patient's decision, 'where the patient does not have sufficient autonomy of thought for their self-damaging decision to require the respect due to autonomous agents'.

The courts in the USA have been involved in a situation where a mentally-competent patient, suffering from an incurable illness which had resulted in the patient being dependent on carers and the provision of artificial feeding, has requested that support be withdrawn, so that death may ensue. The dilemma is that while patients have a right to refuse treatment, the rights of the care-givers such as 'preserving life, preventing suicide, safeguarding the integrity of the medical profession and protecting third parties' (Mackay,1988) are also involved. Because of the nature of this type of case, the courts are being asked to make judgements not only to protect the patients who are suffering, but also to ensure that neither families nor doctors will face criminal or civil actions following the patient's death.

Do Not Resuscitate orders

Whether or not cardiopulmonary resuscitation (CPR) is offered to a patient is one treatment decision over which the patient and family may be consulted. During the terminal stages of a patient's life, it is necessary to decide at which point attempts at CPR would constitute useless treatment, 'offering no hope of medical benefit' (Hackler and Hiller,1990).

As Saunders (1992) states,

> "Inflicting or perpetuating pain, grief or suffering, or interrupting a timely death where there is minimal potential benefit, constitutes cruelty,"

and when discussing the contrast between the mayhem of CPR and the desire for death with dignity, comments,

> "If the expected outcome is death, a procedure less dignified and peaceful could hardly be devised."
> (Saunders,1992)

Guidelines issued by the British Medical Association and Royal College of Nurses jointly, state that the 'responsibility for the resuscitation policy lies with the consultant concerned' and the decision 'made after appropriate consultation and consideration of all aspects of the patient's condition', then indicate,

> "The perspectives of other members of the team, the patient, and with due regard to patient confidentiality, the patient's relatives or close friends, may all be valuable in forming the consultant's decision."

These guidelines indicate that '... a sensitive exploration of the patient's wishes should be undertaken...' where patients are at risk of cardiac or respiratory failure, or who have a terminal illness. 'If a Do Not Resuscitate (DNR) decision is based on quality of life considerations, the views of the patient, where these can be ascertained, are particularly important.' The advice given is that it is appropriate to consider a DNR policy 'where CPR is not in accord with the recorded, sustained wishes of the patient who is mentally competent' (BMA and RCN statement,March,1993).

In the USA, hospital policies 'typically require that CPR be initiated ... unless a DNR order has been written, and that the patient or family permission be obtained before the order is written.'This approach can lead to situations where futile treatments are carried out, 'adding to the patient's suffering, without corresponding benefit' (Hackler and Hiller,1990). These (medical) authors advocate the adoption of DNR policies 'over family objections' when the patient lacks decision-making capacity; the burdens outweigh benefits; the surrogate does not give an appropriate reason in terms of patient values, prejudices or best interests; and the physician has made efforts to mediate the disagreement'. They go on to state that 'when resuscitation would clearly provide no medical benefit to the patient, policy should not require that it be discussed with either the patient or the family' (Hackler and Hiller,1990).

A group of 251 North American nurses in one study appear to hold the view that support of patient autonomy is paramount and that when consideration of a DNR order is happening, the patient should decide, if he or she is competent to do so. In this study, using hypothetical case histories, it was apparent that when asked who would be the best decision-making agent, nurses thought that these patients should decide for themselves whenever possible, on whether they should be resuscitated, although in these nurses' own departments, 'physicians would make the decisions, regardless of the agent selected as best able to support patient autonomy' (Bristow Ott and Nieswiadamy,1991).

Some doctors do feel that to discuss the CPR decision with a patient who is already very ill, imposes an added, unacceptable level of distress and 'psychological pain' (Schade and Muslin, 1989). These authors cite as examples seven case histories of patients, some of whom were involved in DNR decisions and were distressed by them, and others for whom a decision was made by doctors and family members with the patient unaware of the decision, and therefore unconcerned about it. These doctors believe that 'faced with a patient whose illness is of such a nature, discussions of resuscitation simply add to the agony of the dying process' (Schade and Muslin,1989).

It is difficult to see how these differing views can be reconciled. Where a patient is suffering from a terminal illness, it is understandable that care-givers would not want to add further distress by discussing a DNR order. Neither the patient nor the family can be expected to be always able to think clearly and rationally about this type of decision under these circumstances. It is therefore inevitable that, as paternalistic as it may seem, doctors will continue to make some of these very important decisions for their patients, 'to do what is in their best interests, possibly with a measure of deception...' (Gillon,1985a). This approach has provoked a recent British case in which the health ombudsman commented on a situation where an 88-year-old woman with pneumonia was 'designated not for resuscitation' on admission to hospital, and her son, on discovering this order, complained that it was not discussed with him. The health ombudsman advised establishing a written policy on resuscitation (The Guardian,14.6.91, cited in Saunders,1992).

Advance Directives

The problem of patient autonomy in life and death decisions could be addressed by wider use of advance directives (living-wills) or through use of an enduring power of attorney, under which a person nominates another to act on his behalf in medical decision-making as well as in other matters, if the former becomes incompetent. These measures could be helpful in decision-making because they can remove the doubt over what the patient's wishes would have been. In general, advance directives give instructions regarding the extent to which the person wishes to be treated once incompetent and facing potentially life-threatening illness. The directives could instruct doctors to limit treatment (ie. offer no CPR or other supportive treatment) or could ask that everything possible be done. Again, there may be difficulties as the directives could suggest a course of action which offers more harm than benefit, in the doctor's opinion, and could even ask for (illegal) euthanasia. The intention of an advance directive is, in the words of a draft living-will from the 'Age Concern Institute of Gerontology and the Centre for Medical Law and Ethics' (1988),

> "...to minimise distress or indignity which I may suffer or create during an incurable illness and to spare my medical advisors and/or relatives the burden of making decisions on my behalf."

Even with legislation, advance directives may present conflicts in clinical situations in ICU's, particularly where the patient's family and/or the doctor disagree with the patient's decision.

> "Ethical problems arise with the honouring of living wills when a physician ... places the duty of beneficence or non-maleficence above the autonomy of the person in question."
> (Wold,1992)

Discussion about the wider aspects of the use of advance directives is continued later in the section on ethical and legal issues.

Conclusion

Returning to the initial discussion about the role of nurses in supporting patient autonomy, from the literature it seems that there is a need for nurses in the decision-making process. Nurses need to be able to discuss ethical considerations in the care of patients and be given the opportunity to do so by other, possibly more powerful, professional care-givers.

> "The degree of power one has over another is dependent on the extent of the imbalance in the relationship."
> (Erlen and Frost,1991)

If nurses perceive themselves as being less powerful than doctors, for example, in decision-making, the nurses' own autonomy is compromised and their capacity to support patient autonomy effectively is limited. In Erlen and Frost's study (1991), involving 25 nurses, in which the investigators sought evidence of how nurses responded to ethical situations, 84% of participants 'included descriptions of powerlessness' leading to feelings of 'anger, frustration and exhaustion' because of their inability to change the situation'. Reasons cited by the informants for their perceived powerlessness were a lack of knowledge about possible alternatives; a lack of recognition of their clinical knowledge and expertise; and physicians resisting the nurses' attempts to advocate for the patient and intervene in ethical decision-making (Erlen and Frost,1991).

If there is disquiet among nurses about ethical decision-making and the support of patient autonomy, it is important that the education and preparation of nurses addresses these issues, but van Hooft (1990) feels that it is not simply a matter of teaching about ethical theories.

> "... the task of moral education for nurses would not be just to impart knowledge of moral norms or to train the intellect to think in certain ways about moral problems, but also to develop the sensitivity and caring which would motivate nurses to act well."
>
> (van Hooft,1990)

Intensive care nurses are likely to be ideally placed to facilitate discussions between family members (and the patient where possible), seeking their views and opinions on treatment plans. Support for the nursing role is given in the DNR decision model described by Bristow Ott and Nieswiadamy (1991) in which the professional care-giver who has the optimum therapeutic relationship with the patient, is designated the decision-maker.

For nurses to fulfil this role, they therefore need to be not only knowledgeable, but also 'empowered to act in difficult or stressful situations in which objective guidelines are not, and possibly cannot be, available' (van Hooft,1990). In order to function more effectively they must be able to make use of appropriate ethical models because without this, they may be forced to rely on 'naive, intuitive responses' (Norrie,1997). ICU nurses are affected by decisions made about their dependant, incompetent patients, and should therefore be part of the decision-making process (Murphy,1984). Education and preparation for ethical debate is essential, particularly if the nurse feels that advocacy is a nursing role, however nurses have to be aware of their limitations under these circumstances and consider whether they are the right people to act as advocates for their patients. It may be that the patients' interests would best be served and protected by the nurse seeking the involvement of an independent advocate, such as an ethicist, and where necessary, having recourse to legal opinion, for everyone's protection.

Ethical and Legal Aspects

This chapter concerns treatment-withdrawal from patients in ICU's, differentiating between the process of cessation of treatment and the practice of euthanasia. Primarily it will focus on patients who have been given maximum treatment, probably including respiratory support, inotropic drug support of circulatory failure, possibly renal replacement treatment because of kidney failure, in the context sometimes of a chronic health problem, and who are now thought to be irreversibly-ill but who are not in permanent vegetative state (PVS) or brainstem dead.

PVS

The vegetative state consists of 'a clinical condition of unawareness of self and environment in which the patient breathes spontaneously, has a stable circulation (implying preserved hypothalamic and brain stem function) and shows cycles of eye closure and eye opening which may simulate sleep and waking' and it is deemed 'permanent' and irreversible, when the vegetative state has continued for more than twelve months (in head-injured patients) or six months (for other causes of brain injury) (Royal College of Physicians,1996). This working party devised clinical criteria to enable the diagnosis to be considered, described other clinical features of the condition and also gave guidance in distinguishing PVS from other causes of real or apparent coma. Once the diagnosis has been made, it may be appropriate to consider treatment withdrawal and the legal precedent for this was set in the Bland case (Airedale NHS Trust v Bland,1993).

Brainstem Death

Brainstem death is a diagnosis made in the context of a major neurological insult which has led to loss of perfusion of vital areas of the brain for a sufficient length of time that restoration of function is impossible and no recovery can occur. It is essential that before the diagnosis is made, preconditions have been met, primarily that the patient has a condition which can lead to brainstem death, that is a 'positive diagnosis of the cause of apnoeic coma indicating irremediable structural brain damage' (Pallis, Harley, 1996) and that any drugs or conditions which could create a clinical picture which may resemble brainstem death, have been considered and eliminated, by, for example, measuring blood drug levels where the effects of that drug could give a misleading clinical picture. Any situation therefore which may cause, or compound, the death-like impression must be ruled-out, so this would include primary hypothermia or electrolyte disturbances known to lead to a reduction in the level of consciousness.

Once these preconditions have been met, the diagnosis of brainstem death may be made by a process of carrying out a series of clinical tests on reflexes which are mediated at a brainstem level, the last of which involves observing if the patient can breathe at all unaided under conditions where the major stimulus to breathing, the blood carbon dioxide level, is at, or above, a level at which breathing would be stimulated, if the person were capable of doing so. For brainstem death to be diagnosed, all the tests must produce no evidence of reflex activity, and when the tests are repeated after an appropriate time interval to confirm the findings of the first set of tests, they must all prove negative again (Conference of Medical Royal Colleges and their Faculties,1976).

The process of diagnosing brainstem death has to be carried out by two doctors of appropriate seniority 'one of whom must be a consultant and the other a senior registrar or consultant' (Pallis,Harley,1996), neither of whom must be members of the transplant team, so as to avoid any possibility that there might be perceived to be a conflict of interests.

Brainstem death is a diagnosis made with certainty under these conditions. The diagnosis is made by doctors following guidelines set out by the Medical Royal Colleges (1976) and a death certificate can be issued following confirmation of the second set of tests, unless certification has to be withheld until after a coroner's inquest. Decisions about the patient who has died have to be made by 'the person lawfully in possession of the body' (Human Tissue Act,1961,SI, cited in Kennedy, Grubb, 1994,p.1147) generally accepted to be the 'person who has physical possession of the body, the hospital administrative officer' (Mason, McCall-Smith,1994, p.301). This person, under the Act, has to 'make such reasonable enquiry as may be practicable' to ascertain that the deceased patient had not expressed an objection 'to his body being so dealt with' and neither had the 'surviving spouse or any surviving relative' (Kennedy, Grubb,1994,p.1147). If the patient is to be an organ donor for transplantation, he/she will still be receiving ventilatory support and have a heart beat and circulation.

Under these circumstances the doctors would have sought the views of the family about what they felt the patient would have wanted and also the family's own views on transplantation in order to ensure that they had no objection to the use of the patient's organs for this purpose, although in law the doctors 'have legal justification to proceed' (Mason, McCall-Smith,1994,p.301) but humanity and respect dictates that no additional burden of suffering is imposed on the family.

Aims of Intensive Care Provision

The context of this discussion is then that treatments have been given to 'create opportunity for natural healing to occur or specific therapeutic agents to achieve their desired effects' (Branthwaite,1996) and for the majority of patients, the treatment is successful in saving life and beginning the process of restoration of health.

One major difficulty is predicting at the time of referral, what the outcome may be and decisions have to be made at an early stage about whether the patient will benefit from the intensive, invasive, expensive treatment. Once in the ICU, the progress of the illness is monitored and response to treatments closely observed.

Problems inherent in this process are that resources, in terms of available ICU beds, are finite, ICU care is very expensive with the greatest expenditure likely to be allocated to non-survivors (Atkinson et al,1994) and if the treatment does not help, it is futile and therefore is 'mere prolongation of dying' (Branthwaite,1996).

Patients referred to ICU have a 'clear and urgent need for immediate interventions' (Weg,1994) and if action is not taken, death will occur. When the patient presents for treatment, if all the relevant history and data about the current condition are not known, the 'consensus is that intervention is required under these circumstances, for it is better to err on the side of maintaining life' (Weg,1994). Even with the availability of scoring systems which enable objective assessment of a patient's current illness-severity in addition to relevant chronic health problems, and which can be used in conjunction with other parameters, to make a prediction about likely outcome, it is still most likely that the latter approach will be adopted, if there is uncertainty, by an experienced clinician evaluating the patient's condition realistically (Branthwaite,1996). In other words, where doubt exists, it is most likely that life-support will be begun, then an attempt made subsequently to ascertain exactly what the situation is, and the plan of treatment revised accordingly.

Moral Principles

In dealing with incompetent patients, 'we should begin with the moral presumption in favour of the prolongation of life' and carers should then 'work diligently to determine the patient's actual interests' (Beauchamp, Childress, 1989,p.162).

The moral principles which determine the approach taken by clinicians are,
respect for the patient's autonomy in decisions about treatment,

1. beneficence, doing good for the patient;
2. non-maleficence, not causing harm to the patient;
3. disclosure, veracity in dealings with the patient;
4. distributive or social justice, allocation of resources fairly and equitably;
(Beauchamp, Childress,1989, Luce,1990)

to which Gillon (1994) added 'attention to scope' implying a need not only to recognise the prima facie moral obligations, but to consider the boundaries of each principle, the extent of their application, and 'to whom and what we owe them'.

Respect for the person

Respect for the person and the intrinsic value of life is fundamental to these principles.

What defines a person can be considered. The 17th century physician and philosopher Locke (cited in Harris 1994,p.15) thought a person was a 'thinking, intelligent being that has reason and reflection' ... having 'consciousness which is inseparable from thinking and essential to it, it being impossible for anyone to perceive without perceiving that he does perceive', which would distinguish people from animals but would not satisfy the need for a definition when dealing with, for example, temporarily or permanently unconscious people.

To be a person implies consciousness, self-awareness, capacity for cognitive function and rationality and an ability 'to value ones own life' (Harris,1994.p.17) but this again does not satisfy the need for definition in ICU practice where moral dilemmas arise in situations where carers recognise the intrinsic value of a person, a patient who has lost capacity, and this could be made more difficult where a patient has attempted suicide, clearly signalling a loss of value of continued existence.

Evans (1996, in Greaves, Upton, pp.23-35) considers a series of definitions of personhood, none of which encompasses satisfactorily the characteristics of being a person as opposed to being biologically human, and yet in clinical practice, there is general acceptance that individual patients have worth and deserve respect for the preservation of their dignity.

Autonomy

Respect of autonomy involves a need for clinicians to seek consent from patients for treatment, to allow patients to make balanced and informed decisions about their care, to give time for discussion and deliberations, and to facilitate two-way communication. For ICU patients there are major difficulties with these aspects as the patient may be unconscious as a result of sedation. Even if conscious, the patient may not be able to communicate readily because of the obstructions and barriers created by the need to use equipment, tubes and lines to support breathing, for example. In unstable, deteriorating patients, there may be little time or opportunity to discuss matters and so decisions about treatment may have to be made for the incompetent patient by the doctor acting in the best interests of the patient, possibly involving surrogate decision-makers (family or friends) whose task is 'to represent the patient's interests and previously-expressed wishes so physicians can maintain a fiduciary relationship with them' (Luce,1990). Ideally, these surrogates would have been designated Other participants in the early discussions and decisions about treatment are likely to be members of the referring multidisciplinary team.

Advance Directives

An advance directive, drawn up by the patient, may be of help in supporting the patient's autonomy in decision-making about a course of treatment. Definitions suggested in the BMA Code of Practice (1995) are that 'people who understand the implications of their choices can state in advance how they wish to be treated if they suffer loss of mental capacity' (an advance statement) whereas an advance directive is a ’clear instruction refusing some or all medical procedures’.

The Walton Committee Report (1994) gave support to the development of advance directives which would enable patients to express in advance their preferences and priorities in respect of medical treatment should they subsequently become incompetent (p.54). The Committee’s opinion was that an advance directive can ’express refusal of treatment or a procedure which would require consent if competent’ but that the directive should not ’contain requests for unlawful intervention or omission, nor can it require treatment which the health care team judge is not clinically appropriate’ (Walton Committee Report,1994, para.263).

In the United States, the term ’living will’ is also used, where this is a ’form of the right to refuse medical treatment, even when foregoing medical treatment ultimately leads to death’ (Bellocq,1988). California was the first State to enact living will legislation in 1976 (Wold,1992; Bellocq,1988) and since that time, many States have followed suit. For these to be valid, conditions have to be met regarding the status and illness of the person making the declaration, and the statements must be countersigned by an independent witness ’who cannot be the person’s primary physician or nurse, potential heir, or person responsible for the medical bill’ (Wold,1992). Interestingly, a pregnant woman cannot, in Florida, make a valid advance directive, ’because of the state’s interest over innocent third parties, that is, the unborn baby’ (Bellocq,1988).

In 1990, a Patient Self-Determination Act was enacted by Congress which requires health care facilities ’to provide written information on the patient’s right to refuse medical treatment ... and this is to include the right of a patient to have advance directives, such as the living will’ (Wold,1992). Encouragement is therefore given to patients to think about their future care.

One group of patients for whom advance directives may be particularly relevant are those with acquired immunodeficiency syndrome (AIDS) because the natural course of the disease is known to a large extent, and can be planned for. The Terence Higgins Trust, together with the Centre for Medical Law and Ethics, have issued a draft living will document designed for people with HIV and AIDS (Terence Higgins Trust, cited in Lloyd,1992).

Patients with HIV/AIDS need to know the risks and benefits of treatments so that they can make informed decisions about their care. They may decide to refuse transfusions and antibiotics, and when faced with life-threatening situations, may not wish to have life-sustaining treatment, such as mechanical ventilation or CPR. In the later stages of AIDS, the patient may suffer dementia, so an advance directive drawn up at an early stage of the illness will be helpful in developing a strategy for treatment, because they can indicate their wishes about the limits of treatment at a time when they are mentally competent to do so.

Recent court decisions in Britain regarding treatment-withholding have rested on whether it is legal to discontinue nutritional support, that is, the definition of whether artificial feeding is a medical treatment which can be legally withheld, because, as such, it is a futile treatment from which the patient can obtain no benefit (Gibb,1992). A similar case in the USA has been considered in the courts, but the focus of attention was the decision-making process, because the court 'concluded that a competent patient has a constitutionally-protected (but not absolute) right to refuse treatment (Marsden,1990). As the patient concerned was in persistent vegetative state (PVS), it was the court's responsibility to determine from surrogate decision makers what the patient's decision would have been, but there was initially 'no clear and convincing evidence of the patient's wishes', so the state's obligation to protect he lives of its citizens took precedence, and permission to discontinue feeding was refused. Subsequently, friends of this patient were found who could attest to the fact that in earlier discussions about such a situation, the patient had indicated that she would not have wished to have support continued (Marsden,1990).

Problems arising out of legislation in the USA covering advance directives could include situations where the patient is refusing 'heroic' treatment but the family wants it to be offered, and it is not felt that the patient is likely to die imminently. Similarly, a competent, critically-ill patient may be requesting that no 'heroic' measures are taken but doctors may dispute this and 'the concept of commitment to patient self-determination comes up against the clinical perception of what is best for the patient' (McLean,1996, in Pace, McLean, p.75). Another problem area in the legislation is the need to be terminally-ill to 'qualify' to be able to refuse treatment, because some competent patients who are reliant on artificial, supportive treatment, and feel that their quality of life is poor, could not be deemed terminally-ill and likely to die imminently. For some terminally-ill patients, an advance directive would be unnecessary in making a decision to discontinue treatment, because it is already accepted that doctors are not obliged to offer treatment which is futile. Further difficulty may arise if the patient or family proxy decision-makers are demanding treatment which is felt to be of no benefit by the doctors (Ney,1989; Bellocq,1988; Wold, 1992).

Because people do not have the right to demand medical treatment as doctors have the obligation and authority to ultimately determine a patient's treatment, an advance directive has to be a form of refusal, that is, patients can only say what they would not want under certain circumstances.

> "Competent, informed adults have an established legal right to refuse medical procedures in advance. An unambiguous and informed advance refusal is as valid as a contemporaneous decision. Health professionals are bound to comply when the refusal specifically addresses the situation which has arisen."
> (BMA Code of Practice,1995,para.2.2,p.5)

Competence or capacity to be autonomous indicates that the person is capable of fully understanding information, can be given choices of alternative forms of treatment and can make a balanced judgement about what should be done.

Criteria for determination of competency in treatment refusal suggested by Buchanon and Brock (1989, cited in Wear, Brahams,1991) include,

1. The ability to understand and communicate, including the capacity of a person to become informed and to express a choice for treatment.
2. The ability to reason and deliberate, involving the individual in considering information and drawing inferences about making certain choices, where short-term memory is essential.
3. A set of values, or conception of what is good, which has been stable over time and with which the individual's choice is consistent.

One problem lies in the requirement for the person in writing an advance directive to be able to predict the circumstances which may arise and consider the boundaries of treatment at that point. Some guidance is given to doctors in making a judgement of whether an advance directive is applicable.

> "If the situation is not identical to that described in the advance statement or refusal,

> treatment providers may still be guided by the general spirit of the statement if this is evident."
>
> (BMA Code of Practice,1995,para.14.5,p.37)

The position of health care staff has been clearly established where an adult refuses treatment, and where an advance directive is 'known of and applicable to the circumstances, health professionals may be legally liable if they disregard its terms' (BMA Code of Practice,1995).

The Walton Committee Report (1994,p.54) expected that 'a doctor who acted in accordance with an advance directive where clinical circumstances were such that the patient had considered, would not be guilty of negligence or any criminal offence'.

There is a difficulty regarding the provision of what could be called basic care, that is care given by staff to promote comfort, provide nutrition and hydration, because the patient may wish to decline this also. This may conflict with the views held by the staff involved and the BMA's guidance (1995,p.5) was that 'although a clear refusal is potentially legally binding, a refusal seriously likely to affect other people adversely, such as exposing them to the risk of harm, may be invalidated', adding later (p.15) that advance directives 'refusing basic care and maintainance of an incompetent person's comfort should not, as a matter of public policy, be binding on care providers' although the law 'is not free from doubt'. As nurses and their assistants are the main providers of such basic care, this does have important implications for them, and outside institutions, there will be carers connected to the patient who have 'emotional interests' as well.

In the matter of conscientious objection, the BMA Code of Practice (1995,p.35) recognises that health professionals are 'entitled to have their personal moral beliefs respected and not be pressurised to act contrary to those beliefs' but concerns itself mainly with the medical care, directing that where a health professional is managing a case and 'cannot for reasons of conscience accede to a patient's request for limitation of treatment, management must be passed to a colleague'.

In terms of the nurses' role in decision-making where the patient's views are not clear, the BMA's opinion (1995,p.32) is that nurses are likely to gain 'an understanding of the patient's feelings and opinions' and,

> "Whilst these views should be taken into account, they should not necessarily be determinative if in conflict with other evidence."

There is some evidence now that increasingly cases are being referred to the courts for resolution and in a recent review, Slapper (The Times,18.03.97,p.41) suggests that the 'boundaries of permissable involuntary treatment are being extended 'where there are conflicts of interest between supporting the patient's autonomy in determining the extent of treatment and society's interest in 'upholding the concept that all human life is sacred and that it should be preserved if at all possible'. The balance, according to Slapper (1997), should be determined as follows,

"If the patient's capacity to decide is unimpaired, autonomy weighs heavier, but the further capacity is reduced, the lighter autonomy weighs".

Limiting Treatment

Conforming to the moral principles of beneficence and non-maleficence on the surface seems simple until the real issues involved in clinical decision-making are explored. It is easy to take a decision to add another drug to the regimen, to support another body system which has failed when it is clear that the patient can potentially, and seems likely to, make a good recovery, but when this is not so, adding further support may be contributing to a more-prolonged dying process with a loss of peace and dignity. The alternative strategy of withholding additional treatment may present moral and practical difficulties, particularly if family members challenge this decision, even though it is generally felt by team members that the treatment would be considered futile and burdensome to the patient who cannot express an opinion.

This matter was addressed by the Select Committee on Medical Ethics, the Walton Committee (1993-4) in para.252 in which was stated,

> "There is a point at which the duty to try to save the patient's life is exhausted and at which continued treatment may be inappropriate, but this is a point which cannot readily be defined, since it must be identified in the light of each patient's individual condition and circumstances. Obviously it is inappropriate to give treatment which is futile in the sense that it fails to achieve the hoped-for physical result. Indeed to

> continue a treatment in such circumstances would be irresponsible. A decision not to do so will rarely be controversial."

This same committee considered the problem of making these decisions for incompetent patients and commented,

> "Controversy arises when treatment-withdrawal decisions based on the balance of burdens must be made in respect of incompetent patients. The spectre of one individual judging the quality of life of another gives rise to potent fears. But such decisions must be made if incompetent patients are not to be subjected to the aggressive over-treatment to which competent patients would rightly object,"
> (Walton Committee,1993-4,para.254)

and in a discussion about the basis on which decisions about treatment are made, Weg (1994) states,

> "Withholding or withdrawing life-sustaining interventions near the end of life has had solid medical, legal and ethical support for many years. There is a foregoing of harmful treatment. We recognise our inability to reverse the disease process and let it progress to its natural ultimate fate."

The basis on which a withholding decision is made under these circumstances is that it is permissable to limit treatment 'that provides no benefit or is not wanted by patients or their surrogates' (Luce,1990) or that the patients 'have no prospect of returning to a reasonable quality of life' (Pace et al,1991), a point exemplified in the 'C' case
(Re C, 1990) which concerned a four to five month old child who sustained physical injury at birth and who at the time of hearing was moribund. The hospital clinicians 'were given authority to treat her so as to allow her life to come to an end peacefully and with dignity'. This treatment could include agents which would 'relieve pain, suffering and distress' but it would not include 'antibiotics, intravenous infusions or nasogastric feeding' (Mason, McCall-Smith, 1994,p.152).

Difficulties in Decision-Making

The difficulties experienced by clinicians in decision-making in emergency situations and the need to reason and make balanced judgements, were illustrated in a case history cited by Pace et al (1991) who described an occasion when an elderly man was admitted to hospital as an emergency following a road traffic accident, and active, supportive treatment was begun, but shortly afterwards, the patient's son refused consent for urgent surgery, saying that his father thought that his quality of life was already poor and he did not want to go on living, an opinion which was corroborated by the patient's own General Practitioner (GP). With a knowledge of the current clinical situation and an insight into the recent history, plus the patient's previously-stated views, the medical team decided to withhold further treatment and allow the patient to die. An added dimension to this scenario was introduced by the GP who felt that this accident was a suicide attempt.

There are a number of points raised by this example.

Firstly, the urgent, imperative nature of the initial decision on admission to hospital to begin treatment, when there is insufficient time to deliberate over longer-term concerns. There is little choice but to institute life-saving measures at this stage in such situations, unless it is obvious that recovery is not possible from the injuries sustained. The moral principles motivating the decision are therefore beneficence and justice, the latter in the sense that everyone presenting to a casualty department would be equally deserving of treatment, and the only area of debate would be if prioritising were necessary because more than one patient presented simultaneously with similar problems, and only one could be treated immediately.

Consent

Secondly the issue of consent is raised. The patient in the situation cited was not competent so could not give an opinion about treatment, nor could he give consent or withhold it. Responsibility for decisions about treatment therefore has to devolve to the doctors under these circumstances and so an 'assumption must be that there is a preference for survival and that consent can be assumed under the doctrine of necessity'(Branthwaite,1996). This assumption is supported by Mason, McCall-Smith (1994) who feel that it is legitimate to 'apply the necessity principle' and prescribe and administer 'non-voluntary treatment'. They comment,

> "...in both criminal and civil law that there are certain circumstances in which acting out of necessity legitimates an otherwise wrongful act."
> (Mason, McCall-Smith,1994,p.220)

This is based on the principle that 'acting unlawfully (without consent) is justified if the resulting good effect materially outweighs the consequences of adhering strictly to the law' (Mason, McCall-Smith, 1994,p.220), thus demonstrating not only the utilitarian nature of this approach (Beauchamp,Childress,1989) but also the dilemma encountered commonly in clinical practice, that of conflicting moral principles in terms of what carries the greatest importance among support of the patient's autonomy, beneficence and non-maleficence, requiring 'interpretation and balancing' to resolve (Stanley,1989).

The Role of Family Members

The other aspect of consent which is relevant in the situation described is that Pace et al (1991) say that 'the patient's son refused consent for the patient to have an exploratory laparotomy for possible ruptured spleen' that is, surgery for a potentially life-threatening injury, however 'in the case of an adult patient, the next of kin has no legal right to consent or refuse consent to treatment' (Mason, McCall-Smith,1994, citing Re T (Adult refusal of treatment, 1992)).Re T involved a pregnant girl who had to be admitted to hospital for emergency treatment after an accident, but her mother, who was a Jehovahs Witness influenced the daughter to refuse treatment which would have included a blood transfusion. The court overruled the daughter's refusal of consent because of undue influence. Relatives may be asked about whether or not treatment should be given but as Fennell (1994) says, 'there is a myth that relatives are empowered to give consent on behalf of incapacitated adults, but although it is regarded as good practice to consult relatives, their consent or refusal does not alter the legal position'.

> "In the absence of capacity of the patient to make a decision (or any advance directive) the doctor must act in the best interests of the patient."
> (Greaves, Upton,1996,p.54, citing Re F (1989))

The best interests of the patient are determined by applying the Bolam test (Bolam v.Friern Hospital Management Committee, (1957)) which asks what would any reasonable professional following the accepted approved standard of care determine would be in the interests of the patient (Greaves, Upton,1996,p.59).

In a review of Law Commission consultation papers (numbers 119 (1991) and 129 (1993)) Fennell (1994, p.42) sets out the factors which should guide decision-makers,

1. the ascertainable past and present wishes and feelings (considered in the light of his or her understanding at the time) of the incapacitated person;

2. whether there is an alternative to the proposed treatment and in particular, whether there is an alternative which is more conservative or less intrusive or restrictive; and

3. the factors which the incapacitated person might be expected to consider if able to do so, including the likely effect of the treatment on the person's life expectancy , health, happiness, freedom and dignity.

To return to the case cited by Pace et al (1991), the primary purpose of consulting the son should therefore be to ascertain the views of the son, and his agreement-to, or denial-of, the form of treatment suggested, but, more importantly, if the patient's autonomy is the over-riding moral principle, to find out what the son feels that his father would want under the circumstances, perhaps what his father has actually said, when apparently rational, about life-prolonging treatment, and then, if possible, corroborating that evidence with views from another reliable source where any other interests are not potentially compromising the opinions, such as the GP, as in this case. What is important is that the doctors acknowledge that their duty and responsibility is to the patient, not the family, and that treatment decisions must be made on what, it is judged, the patient would have wished (Pace et al,1991), but still allowance must be made for considering whether the patient might have changed his or her mind since making the original declaration of requests. Views may be different when the person is actually facing the illness and disability envisaged, and then feels that even with the limitations imposed, 'life is precious'(Pritchard,1995,p.164).

Stanley et al (1989) in guidelines drawn up in the United States to address these ethical problems, suggests approaching people 'who are available and competent, have been involved with, and are concerned about, the patient, are knowledgeable about the patient's values and preferences, and are willing to apply the patient's values to making the decision'. Decisions can then be made on the basis of 'substituted judgement' or on the grounds of 'best interests' in collaboration with family members when they agree with the plan of care. If there is discord, then it may be necessary to resort to 'more formal conflict resolution processes, such as ethics committees or the courts (Stanley,1989).

Pritchard (1995, p.164) considers the proposal that the use of an additional advocate for the patient under the circumstances, may be appropriate, but questions the objectivity of such a person or committee, raising 'slippery-slope' anxieties.

Treatment Withdrawal

The justification for withholding and withdrawing treatment rests on a 'recognition of an inability to reverse the disease process...(Weg,1994) but because the death of the patient will result from 'acts and omissions' (Gillon,1986c) of health care staff, differentiating between killing and letting die is essential.

In the conclusion of a discussion about quality of life issues in the care of babies, Kuhse and Singer(1989) talk about 'how the infant or older patient dies' once a decision has been made. They refute the distinction between killing and letting-die, saying that there is no moral difference between taking active steps to end life and 'merely standing by and allowing nature to take its course', adding that if 'motivation and outcome are the same' in both, 'killing a patient and letting a patient die are morally equivalent'.

According to Beauchamp and Childress (1989), the principle of maleficence implies that we should not inflict harm, and we should prevent and remove harm and promote good, so if death is a major harm, it is prohibited, but the act of withholding and withdrawing treatment concerns 'justification for actions that have a causal connection with another's death'. Whether or not the treatments concerned are considered ordinary or extraordinary is also relevant to the discussion, where generally 'ordinary' means involve basic aspects of supportive care, such as hydration and nutrition and 'extraordinary' means could involve the use of advanced life support, such as inotropic drugs and artificial (mechanical) ventilation

(Pace et al,1991). This differentiation was spoken of by Pope Pius XII (1957, cited by Gillon, 1986d) who indicated that doctors are 'held to use only ordinary means - according to circumstances of persons, places, times and cultures - ...means that do not involve any grave burden for oneself or another' and Gillon's (1986d) interpretation of this doctrine is 'that the good of saving life is morally obligatory only if its pursuit is not excessively burdensome or disproportionate in relation to the expected benefits'.

Mason and McCall-Smith (1994,p.334) talk of the contrast between 'productive and non-productive means - whether the treatment is doing the condition any good' and they go on to say that the focus 'firmly concentrates decision-making within the context of the individual patient and his unique condition' and that 'factors such as the physical and psychological pain involved in the treatment, its claim on scarce resources and the general prospects for the patient and his family, may all be taken into account in deciding whether or not a treatment is productive'.

Double Effect

The principle of double effect is relevant here when considering the practical aspects of treatment-withdrawal. The objective, of course, once a decision to withdraw has been taken, is to ensure that the patient is allowed to die peacefully, without pain, or anxiety if sentient, which means, in practice, that analgesic and anxiolytic drugs are used to achieve this. Since under these circumstances there is no concern about blood levels rising and accumulating in the patient and therefore depressing the level of consciousness or ability to breathe, higher doses may be given, and in fact may be necessary to obtain the control of pain because of tolerance, particularly with repeated or long-term use. An inevitable consequence of this commission is that these depressant effects may shorten the dying process, but similarly, omission of say, antibiotics, would increase the likelihood of infection supervening and shortening life, and cessation of cardiovascular support drugs would allow the patient to die of circulatory failure.

Beauchamp and Childress (1989) feel that within the principle of double effect there is 'a morally relevant difference between the intended effects of a person's action and the non-intended but foreseen effects of the action' implying that although the act is wrong in itself 'it may be permissable to allow the bad effect if this is a consequence of an action performed for the sake of a good (overriding) effect'.

According to these authors, four conditions must be satisfied for an act to be justified:-

1. The action itself (independent of its consequences) must not be intrinsically wrong;
2. the agent must intend only the good effect, not the bad effect. The bad effect can be foreseen, tolerated and permitted but not intended, allowed but not sought;
3. the bad effect must not be the means to the end of bringing about the good effect; the good effect results from the action, not by way of the bad effect;
4. the good result must outweigh the evil permitted, a favourable balance between the good and bad effects of the action;
(Beauchamp, Childress,1989,p.128)

although the relative importance of each may vary with individual situations.

The incident involving Dr.Cox

The intention of the action taken by Dr.Cox (R v.Cox (1992) cited by Mason, McCall-Smith,1994) clearly did not fall within this double effect principle, and his conviction for the attempted murder of Mrs.Boyes resulted from the fact that he used a drug, potassium chloride, which has no analgesic effect while the person is living, although the death caused by its administration would, of course, end suffering. Mrs.Boyes was terminally-ill, was already designated 'not for resuscitation' and had pleaded with Dr.Cox to have her suffering ended. The action he took was controversial as 'some people were concerned that Dr.Cox had been prosecuted at all, since he had acted in accordance with the wishes of the patient and her family, and with a merciful motive' but the judge in summing-up, said,

> "If he injected her with potassium chloride with the primary purpose of killing her, of hastening her death, he is guilty of the offence charged."
> (R v Cox, 1992, cited in Mason, McCall-Smith, 1994)

Mrs.Boyes' sons 'were grateful that in the end Dr.Cox took positive action to curtail her appalling suffering' (Davies,1996, in Keown,p.93) but euthanasia as practised here, was unlawful.

Subsequent to this case, the Walton Committee (1993-4,p.49) reported that the objective of the doctor must be to 'give relief of pain or distress with no intention to kill'. If the intention is to provide relief 'and the treatment given is appropriate to that end, then the possible double effect should be no obstacle to such treatment being given'.

Treatment Withdrawal in cases of PVS

Another case which went to law for resolution did so because the hospital involved wished to cease enteral feeding, a means of providing hydration and sustenance to a patient who cannot eat or drink, and allow a patient in PVS to die. Whether enteral feeding constituted 'ordinary or extraordinary means' of support was important, and more specifically, whether it could be defined as a medical treatment. If it were deemed medical treatment, then as such, it could be withheld if considered futile and not in the patient's best interests. However, withdrawing something as basic and simple as hydration, even though it involved prior invasion of the patient to insert the feeding tube, was a major step as it would inevitably lead to death over a matter of days to weeks. The fact that the death could be foreseen, although it would result from an omission rather than an act, meant that morally there was little difference between this deliberate act which would result in the death, and the process of euthanasia. In addition, the coroner involved warned that the withholding of further treatment might be a criminal act, which prompted the Hospital Trust concerned to seek clarification of the position (Scowen,1993).

The hospital sought to 'lawfully discontinue all life-sustaining treatment and medical support measures', and also 'that any subsequent treatment should be for the sole purpose of enabling him to end his life in dignity and free from pain and suffering, that if death should then occur, its cause should be attributed to the natural and other causes of his present state, and that none of those concerned should as a result, be subject to any civil or criminal liability' (Airedale NHS Trust v Bland,1993).

The point was made in hearing the appeal that 'the law must reassure the people that the courts do have full respect for life, but that they do not pursue the principle to the point at which it has become almost empty of any real content and when it involves the sacrifice of ... human dignity and freedom of choice'(Hoffman (1993) 1 All ER 821 at 855).

This judgement then resulted in an acceptance in law that an omission of the medical treatment of enteral feeding, even though it was linked with the death of the patient, did not cause it, instead it was the original disease or injury which had led to the need for treatment, that ultimately led to the death (Mason, McCall-Smith,1994,p.343).

Between 1992 and the end of 1996, ten successful applications were made to the courts to discontinue feeding in cases involving patients in PVS and there have been more since then. Concern has been expressed about one case being considered at present (March,1997) where the diagnosis of PVS has been doubted (Macdonald,1997).

When this case involving Miss D. was heard, it was learnt that the woman had been left paralysed and brain-damaged after an accident eight years previously and had become comatose following a fit eighteen months before. Miss D. 'did not meet the strict guidelines for PVS ... her eyes appear to track moving objects, (she) flinches if a gesture is made and reacts to the feeling of ice on her body', but the judge, having heard the evidence from experts felt that 'there was no possibility of any meaningful life whatsoever'.
He said,

> "... it is in this patient's best interests to withdraw the artificial feeding and hydration which is keeping her body alive"

but also said that 'he did not feel he was altering the boundaries of who could be allowed to die because Miss D. was in reality in PVS' (Bale,1997).

The response of the chair of the anti-euthanasia group 'Alert', Dr.Norris, was to say that the 'barbaric practice of cutting off life support systems to brain-damaged patients should be made illegal' (Bale,1997) and on the 'Today' radio programme 22.03.97, Dr.Norris said that certainly for the nurses involved (ie.in considering their feelings) people are going to feel gradually that it would be better to give a lethal injection in preference to the slow process involved in treatment-withdrawal from people in PVS, thus expressing the 'slippery-slope' concerns. Because an accurate and reliable diagnosis is crucial in such situations, it is also the doctors who must reassure the people about safeguards in the process of examination and evaluation.

Euthanasia

Clarification of the law in these areas is very important because of the anxieties associated with any tendency towards legalisation of medically-assisted euthanasia, which is 'prohibited on medical, ethical, religious and legal grounds' (Weg,1994).

Euthanasia is generally defined now in terms of the person's capacity to request it, but essentially it indicates that there has been a 'deliberate action by a physician to terminate the life of a patient... an example of which would be a lethal injection' (Singer, Siegler,1990). The enormous difficulty associated with accepting that patients not only have the right to decline treatment, provided that certain conditions are met, but also have the right to seek euthanasia, is that the 'values of society... and the rights of other people' (Singer, Siegler,1990) have to be considered. Conflict is inevitable when attempting to balance these rights, values, the moral principles and prohibitions.

In her essay in support of euthanasia, Davies (1996) defined it as voluntary when 'deliberate action is taken to shorten an incurably-ill patient's life at that patient's steadfast request' (Davies,1996, in Keown,p.84). The definitions offered by the Walton Committee Report (1993-4) were that,

> "Voluntary euthanasia occurs when the patient's death is brought about at his or her request; non-voluntary euthanasia may be used to describe the killing of a patient who does not have the capacity to understand what euthanasia means and cannot therefore form a request or withhold consent; and involuntary euthanasia has been used to describe the killing of a patient who is competent to request or consent to the act but does not do so." (vol.I, para.23)

The terms active and passive euthanasia have also been used, where the former implies 'killing by use of techniques... for hastening death' and the latter 'killing by omitting to supply sustenance and/or treatment, which, but for the decision and intent to terminate life, would have been supplied' (Finnis,1996, in Keown,p.23).

Singer and Siegler (1990) give four arguments against the adoption and acceptance of voluntary euthanasia, all based on the likelihood that there would be abuse of such a system.

firstly, that there could be covert involuntary euthanasia; secondly, that involuntary euthanasia could be encouraged where chronically-ill or dying patients were pressurised to seek euthanasia to spare their families financial or emotional strain; thirdly there would be a risk of another party acting as a surrogate in seeking euthanasia for an incompetent patient; and fourthly, vulnerable groups who feel worthless and were discriminated against in society, might be coerced into seeking euthanasia. It is certainly possible that a sick, dependant person, out of altruism, may feel obliged to seek euthanasia to relieve the burden on others. Gillett (1988) talks of a patient's request for euthanasia being a 'test to see if he or she is still worth something despite being distressing, ugly, helpless and doomed'.

Proponents of voluntary euthanasia argue that to allow it is simply an extension of supporting the patient's right to accept or refuse medical treatment and 'return to the patient a measure of control over the process of dying, thus shortening the duration of emotional and psychological hardships and also eliminating fears about how and when death will occur (Singer, Siegler,1990).

The evidence from the palliative care setting refutes the idea that patients facing life-threatening illnesses seek to end their lives deliberately and prematurely. On the contrary, where patients can be cared-for well, have support from staff and families, have pain and other distressing symptoms controlled, they very rarely seek euthanasia. Twycross (1996 in Keown,p.142) cites the case of a patient who, when sick and debilitated having deteriorated rapidly following diagnosis, 'wished that euthanasia could have been administered' but later, following referral to the Macmillan service, had his pain and other problems controlled and so reduced his anxieties and feelings of isolation, that he could again enjoy his remaining life, eat normally again and his fears of an agonising end were allayed.

Twycross (1996, in Keown,p.155) adds that in his experience, 'patients who request euthanasia almost invariably change their minds' reasoning that 'it relates to good palliative care, they obtain relief from distressing symptoms, the depression is treated and they no longer feel abandoned and alone'. The fact that people may change their minds is crucial to the discussion of euthanasia because if it is available, patients may be deprived of a period of time during which they could perhaps have a reasonable quality of life, deal with their affairs and arrangements for the family's future, and come to some reconciliation and acceptance of what is happening.

An important message which Twycross (1996 in Keown,p.144) feels must be conveyed to the dying person is that he/she is important, of value and will not be abandoned, and the same author states,

> "No patient should be forced to request euthanasia because of unrelieved pain or other distressing symptoms such as vomiting or shortness of breath (because) methods exist to control such symptoms either completely or to a great extent."(p.147)

The contrast between this situation and that in the Netherlands is important. Twycross (1996) citing evidence from Dorrepaal et al (1989), feels that education in cancer care and pain control is not as good as that in Britain, for example, 'only a quarter of cancer patients receive optimal treatment for pain...'.

Euthanasia in the Netherlands

In discussions about euthanasia, the evidence from the Netherlands is often cited because following a prosecution and conviction of a physician for participation in active euthanasia in 1973, the court stated that euthanasia would have been acceptable providing certain conditions were met. These included,

1. the patient must be incurably ill;
2. the patient must be experiencing unbearable suffering;
3. the patient requested the termination of his or her life;
4. the patient's physician performed the euthanasia;
   (de Wachter,1989)

and the Royal Dutch Medical Association (RDMA) in the same year, issued a statement to the effect that 'legally euthanasia should remain a crime, but that if a physician, having considered all the aspects of the case, shortens the life of a patient who is incurably ill and in the process of dying, the court will have to judge whether there was a conflict of duties which could justify the act of the physician' (Gevers,1987, cited by de Wachter,1989)

These courts subsequently have set out a number of criteria by which it may be determined whether there is a defence against the charge of euthanasia,

1. the request for euthanasia must come only from the patient and must be entirely free and voluntary;
2. the patient's request must be well-considered, durable and persistent;
3. the patient must be experiencing intolerable suffering with no prospect of improvement;
4. other alternatives to alleviate the patient's suffering must have been considered and found wanting;
5. euthanasia must be performed by a doctor;
6. the doctor must consult an independent colleague before performing euthanasia. (Evidence from the Netherlands, in the Walton Committee Report,1993-4, p.65)

The position has evolved since into a situation where although euthanasia remains a criminal act, 'prosecutions are rare provided that physicians follow strict guidelines' (van der Maas et al,1991). Some of the anxieties concerned with this position relate to evidence from a series of studies carried out during 1990-91 by van der Maas et al. The three studies involved

1. interviews with a sample of 405 physicians;
2. a sample of 7000 deaths;
3. a prospective study of all deaths occurring in the six months following the interviewing of the physicians in (1) above;

and they covered not only euthanasia, the intentional termination of life by someone other than the person concerned at his/her request but also other related situations where a medical decision might hasten the death of a patient (van der Maas et al,1991) such as the withdrawal or withholding of treatment where this might have prolonged life, the alleviating of pain and other symptoms with opioids or other drugs using dosages which may shorten life and euthanasia, involving the supply and administration of drugs with the explicit intention of shortening life (van der Maas et al, 1991).

These studies indicated that 1.8% of deaths (2300) in the Netherlands are the result of euthanasia involving a physician in some way with about 0.3% (400) of the deaths being categorised as assisted suicide, the patient administering lethal drugs prescribed and supplied intentionally by the physician (van der Maas et al,1991).

54% of the 405 physicians interviewed 'confirmed that they had practised euthanasia at the explicit and persistent request of the patient or had assisted in suicide' at some time, 24% of them within the two-year study period. A further 34% said that although they had not practised euthanasia, they would be prepared to do so, and of the remaining 12% who would not carry out euthanasia, more than half said that they would refer the patient to a colleague who would be able to assist them (van der Maas et al,1991).

One comment made by van der Maas and associates (1991) was that requests for euthanasia are not rare, but many patients 'want an assurance that their doctor will assist them to die should suffering become unbearable' although in these studies, 'about two thirds of requests never end up as a serious and persistent request at a later stage' and of the remainder, 'two thirds do not result in euthanasia because the physician can offer alternatives'.

That alternatives to euthanasia can be found is very important to the discussion of whether or not euthanasia should be legalised in Britain. There are obvious misgivings about taking this step because of anxieties over defining conditions and setting boundaries in situations where each patient's problems are unique to that individual and even the definition of the point at which an illness can be deemed terminal, is difficult.

Major concerns exist if euthanasia were allowed over the welfare and best interests of patients, particularly where suffering, pain, distress, anxiety and relief of unpleasant symptoms can to a large extent be obtained now with the range of drugs and other treatments available, although Dr.Cox (R v Cox,1992) acted as he did because his patient 'was in severe pain and had asked to be killed' (Fisher,1996, in Keown,p.318).

Singer and Siegler (1990) assert that 'the hospice movement has demonstrated that managing pain appropriately and allowing patients control over the use of life-sustaining treatments, reduce the need for euthanasia'.

Concern exists over the paternalism of doctors in decisions about involuntary or non-voluntary euthanasia, and there is evidence from the study by van der Maas and associates (1991) that 0.8% of all deaths (about 1000) were associated with 'life termination by administering lethal drugs without an explicit and persistent request from the patient' although the justification for this in more than half of these patients rests on the fact that the decision had been discussed with the patient at some point, or the patient had previously 'expressed a wish for euthanasia should suffering become unbearable'.

In evidence to the Walton Committee (1993-4), the Dutch Physicians League said that 'many prospective patients, especially elderly people, feared that they would be subjected to euthanasia against their wishes, or would not receive adequate medical treatment', thus expressing important concerns, although this was refuted by others, for example the RDMA, who said that 'far from being afraid, most patients were reassured by the knowledge that euthanasia was available as a last resort'(p.66).

Reichel and Dyck (1989), however, express the concerns of many in saying that 'in a society that is dominated by cost-containment, we must fear for the debilitated elderly, the mentally-ill and mentally retarded, and the victims of AIDS, Alzheimer's disease, and other devastating disorders'. In their argument against euthanasia, Singer and Siegler (1990) also feel that 'in the current era of cost containment, social injustice and ethical relativism', euthanasia presents too great a risk.

Another major concern is that acceptance of voluntary euthanasia may lead to tolerance of non-voluntary euthanasia because as Keown (1996,p.276) argues, the former involves a judgement by a doctor that a person's life is not worth living, where that judgement has been prompted by a request from the person, but the same judgement could be made by a doctor where the person is incompetent or incapable of requesting euthanasia, with the justification for acceding to the demand relying on an evaluation of the person's situation.

In attempt to address this problem, subsequent to the original guidelines, Leenan (1985 cited by Keown,1996,p.285) chaired a State Commission on Euthanasia at which it was reaffirmed that there was a necessity for the person involved to make an explicit request for euthanasia and that the request could not be made by a third party on behalf of the person, in the event that the person was incompetent, so people who are incapable of making a request are not eligible for euthanasia.

The question which then needs to be asked is whether there were cases of non-voluntary euthanasia in van der Maas and associates' study (1991) and Keown (1996,p.269) concludes that 'there was an intention to accelerate death in far more than the 2700 cases classified as euthanasia and assisted suicide' because there were 'a further 1000 cases of intentional killing without request'. In addition to these, Keown (1996,p.269) estimates that 22,650 deaths were associated with an act or omission intended to shorten life' but the problem with this figure is that it depends on the definition of what constitutes euthanasia. For example, where a patient's palliative drugs were increased with the intention of shortening life 'following an explicit request in two thirds of cases' this did not conform to the survey definition of euthanasia, but in reality there was little difference morally, and Keown (1996,p.273) asserts that if all the cases where 'the doctor's primary intention was to kill' were included, the number of people who died as a result of euthanasia by this definition, was 10,558, about 8% of all deaths.

The dilemma, then, is defining accurately the boundaries of what constitutes acceptable palliative care measures in all clinical settings, and what is meant by the term, euthanasia, and these problems underpin the disquiet and the 'slippery-slope' arguments.

Reporting of Euthanasia in the Netherlands

Another area of concern is over reporting of euthanasia incidents in the Netherlands. One of the requirements of the Dutch guidelines is that where a doctor has carried out euthanasia, the death cannot be certified as natural and it should be reported to the local prosecutor for investigation and consideration. In the survey by van der Maas (1991), 72% of the cases of euthanasia were certified as being due to natural causes, with doctors citing such reasons for non-reporting as 'the fuss of a legal investigation, a desire to protect relatives from a judicial inquiry and fear of prosecution' (Keown,1996,p.281). This point was made in the BMA's report of the guidance on euthanasia (1988) in which it is stated that 'a number of cases are still reported as natural deaths because the doctors concerned do not want the intrusion and disturbance created by a police inquiry, however well-handled, to upset a grieving family', and the paragraph continues,

> "...it is mandatory that such an inquiry take place and some practitioners have made arrangements with the local police to handle the situation with sensitivity and a minimum of trouble,"

but, of course, any attempt by doctors to conduct matters quietly, if not covertly, leaves them open to doubts and criticism about the safety of decisions.

Pritchard (1995,p.165) too, citing evidence from studies carried out in the Netherlands, reports that 'nursing home physicians observed all the requirements in only 41% of cases, most often erring on the side of certifying death from natural causes'.

Capron (1986, cited by Mason,McCall-Smith,1994), expressing misgivings where the essential trust between doctors and their patients is potentially compromised, says,

> "I never want to have to wonder whether the physician coming into my hospital room is wearing the white coat of a healer, concerned only to relieve my pain and restore me to health, or the black hood of an executioner,"

and Singer and Siegler (1990) advise that 'physicians should distance themselves from euthanasia to maintain public confidence and trust in medicine as a healing profession'. The prohibition of euthanasia has avoided the 'potential conflict of interest between healing and killing' (Singer and Siegler,1990) and has enabled patients to trust doctors with their welfare and their lives. Recent events in the Northern Territories, Australia, where euthanasia was legalised but subsequently revoked, again highlight the concern of both the public and the medical profession in this area.

Health Care Staff

While the interests of patients are of paramount importance, the rights and interests of the health care staff who must participate in the process of euthanasia must be considered.
In the BMA report on euthanasia (1988), there is discussion of the problem of supporting the autonomy of the patient, 'involving patients in decisions about their care and the alternatives open to them' and in resisting 'a treatment which does not accord with the best standards of medical practice'(p.39) and this paragraph continues,

> "Autonomy does have its limits. In particular it cannot compel a doctor to end a patient's life,"

however, in paragraph 142, it also states that 'the patient should not be submitted to prolonged and distressing medical treatment which is both inconsiderate and undignified', thus recognising the dilemma for the doctor in clinical practice.

In the discussion of their study findings, van der Maas et al (1991) comment that 'many physicians who had practised euthanasia mentioned that they would be most reluctant to do so again' and go on to say that 'only in the face of unbearable suffering and with no alternatives would they be prepared to take such action'.

The State Commission on Euthanasia (1982) in the Netherlands, which had the task of advising the government of the need for changes in law, recommended 'the insertion into any new legislation of a conscience clause, stating that no medical worker should be obliged to participate in active termination of life' (Gevers,1987, cited by de Wachter,1989) however, during the collection of material for the Walton Report (1994), a Ministry of Welfare deputy head reported that 'there had been some suggestions that applicants for nursing posts would not be employed if they expressed conscientious objection to abortion and euthanasia, but there was no evidence that this was a significant or widespread problem'. Other relevant comments made to this committee included that 'Dutch practice did not require doctors to perform euthanasia but permitted them to do so in certain circumstances ... and any doctor could refuse to be involved and no pressure or coercion were exerted'. (Walton Committee,1993-4,p.68).

Nurses

Broadening the discussion into the area of passive euthanasia, treatment-withdrawal or selective non-treatment, and looking at the role of nurses, the difficulties are recognised and acknowledged by some writers.

Nurses, for example, may express a conscientious objection to participating in treatment by abortion (Mason, McCall-Smith,1994,p.163) and these authors 'drew particular attention to the role of nurses and to the importance of safeguarding their position' because 'it is the nurses, not the doctors, who will bear the brunt of selective non-treatment' when discussing this issue in the care of neonates.

In commenting about Re C (a minor, wardship:medical treatment,(1990)) in which 'the clinical option to relieve suffering rather than prolong life in the face of accepted terminal illness was reconsidered' Mason and McCall-Smith (1994,p.330) say that it would be followed as a general principle and add,

> "The interesting inclusion of the whole caring team in the decision-making process might be thought to be confined to paediatric practice, but there is no reason why such a routine should not be extended to hospitals for adults; to do so would not only ensure open decision-making, but would also serve to emphasise that the effects of any treatment decisions fall not upon the doctor but on the nursing staff who will care for the dying person."

The point was also made in para.255 of the Walton Committee Report (1993-4) when they were considering treatment-withdrawal from incompetent patients, saying,

> "Treatment-limiting decisions in respect of an incompetent patient should be taken jointly by all those involved in his or her care, including the entire health-care team and the family or other people closest to the patient."

Similarly, in the explanatory notes accompanying the section on resolving disputes about advance directives, in the BMA Code of Practice (1995,p.35), is written,

> "All staff involved...should have an opportunity of presenting their views. From a patient's viewpoint, nurses are often the most accessible professional. ...nurses may have had closer contact than others with the patient, and those close to the patient. Nurses are often adept in translating technical medical language and discussing practical aspects of outcomes of treatment and care. They may gain particular insight into whether patients were consistent and coherent in their views."

Viney (1996) in a study of the roles of senior nurses and doctor in ethical-decision making in these situations, however, comments that 'the doctors felt that as the final decision was theirs, then they should act as the patient's advocate' and that 'nurses feel unable or powerless to act as advocate'. Viney (1996) says,

> "Nurses saw their role as limited, but accepted this, as they were unwilling to share

> the responsibility of decision-making with the doctor,"

and goes on to add that 'there was consensus among doctors and nurses that the main role of the nurse was to relay information, mainly between the relatives and the medical staff'.

The death of any individual, any person, 'has a symbolic meaning for each health care provider' (Omery,1991) and death could be equated in an ICU with failure. For the nurse at the bedside with the family of the patient, to change the focus and aim and withdraw supportive treatment may feel close to abandoning that patient after having made every effort to support life, for hours or days. This feeling may be emphasised if the patient has to be discharged out of ICU to a ward area to die following treatment-withdrawal. Within ICU during treatment withdrawal, ensuring that patients are enabled to die in comfort and with dignity 'will require every bit of the time, technology, resources and ourselves that we can supply'(Omery,1991).

In a discussion following the Bland judgement (Airedale NHS Trust v Bland,1993), Wright (1993) asks whether under these circumstances 'letting the patient die is the ultimate caring act or the ultimate betrayal of nursing values' and goes on to argue that the care being given to this patient was essentially nursing care, including feeding the patient, albeit artificially, and withdrawal of treatment may not have accorded with the wishes and values of the nurses involved, a point recognised by Lord Mustill (cited by Wright,1993) who said that the nurses following this judgement, 'may be called upon to act in a way which must be contrary to all their instincts, training and conditions ... as they will encounter the ethical problems, not in a court or lecture room, but face to face'.

Nurses involved in caring for patients during the process of treatment withdrawal, especially when the patient appears in some distress, do reflect on the interests of competent and incompetent patients. There may well be difficulties 'if nurses see their primary obligation as acting in the patient's best interests' because as Kuhse and Singer (1989) say,

> "Good reasons would have to be given why allowing to die should be preferable to helping to die, when the former is clearly often not in the patient's best interests,"

so these decisions are of moral importance to nurses.

The effects of the possible moral distress were described in Viney (1996), one of whose senior nurse respondents commented that 'these situations keep on happening ... and you start to distance yourself and therefore perhaps you are not giving your best to the family, to represent the patient and support the junior staff'.

It is therefore imperative that the issues, as they affect nurses, are addressed. Moral dilemmas and their resolution inevitably impinge on the care given by nurses. It is important to nurses that they can participate if they wish in the decision-making and feel that their views, and those of the patient and family, are represented and considered. To be satisfied with this process, nurses need to be able to competently discuss and reason on ethical matters. Only in this way will the moral outrage, characterised by 'energy-draining frustration, anger, disgust and a sense of powerlessness' (Pike,1991) be minimised.

Quality of Life

> "Quality of life may include freedom from pain, capacity for self-care, mobility, social interaction, independence and plans for the future ... but not everyone would demand all these criteria for a life worth living ... a life which appears to be of negligible quality to one set of people may appear differently to another."
> (Tindall,1986)

Quality of life is a familiar phrase which is heard frequently now in a variety of contexts. It is a theme which is relevant to the treatment-withholding debate in generally three areas.

Firstly, when a patient presents to a doctor for possible treatment, an assessment of the patient's past and present quality of life is pertinent in the decision-making process, and evaluation of it will affect the decisions taken about whether or not any treatment should be given, and where treatment is indicated, what forms of treatment it would be appropriate to offer.

Secondly, where a patient is already undergoing treatment, their current quality of life whilst treatment is in progress, is relevant to the decision-making when the duration of such treatments is considered, and the potential outcome of care is assessed.

Thirdly, anticipated quality of life following treatment is relevant to discussions at all stages of the patient's stay, from the initial decision concerning forms of treatment available and possible, through problems, complications and failures to respond during treatment, to an evaluation of the situation once appropriate treatment modalities have been employed.

The stated objective of providing intensive care is 'for patients to return to their previous state of health and to survive for a reasonable length of time after discharge with an acceptable quality of life' (Munn et al,1995).

The very great difficulty is that a person's own evaluation of his/her quality of life and its acceptability, will vary in time, in relation, for example, to the phase of the illness or to the extent of symptom control, but also expectations change, and will affect feelings and views about quality of life. In the ICU context, an added difficulty is that at the time when this issue is most relevant, usually the patient cannot give any views on the matter, so any judgements about past, present and projected quality of life have to be made by others, that is, the patient's family and friends, and members of the health care team, both the ICU staff and all the other team members in the hospital and community who are in a position to contribute.

Quality of life is multidimensional, and it is apparent that where treatment decisions are being made, the focus cannot be solely on the health-related factors but has to encompass some of the wider aspects.

The definition offered by the WHOQOL group implies that consideration of the broader aspects is appropriate,

> "Quality of life is defined as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and their relationships to salient features of their environment."
>
> (WHOQOL group,1993b, cited in Bowling,1995,p.3)

A very-broad view of the attributes of quality derived by Dalkey (1972, cited by Bowling,1995,p.6) included:-

novelty	(newness, surprise, variety)
health	(physical well-being, feeling good)
dominance	(superiority, power,control)
self-respect	(self-confidence, self-understanding)
challenge	(stimulation, competition, ambition)
freedom	(individuality, spontaneity, unconstrained)
comfort	(economic well-being, relaxation)
affection	(love, caring, relating, understanding)
security	(peace of mind, stability, lack of conflict)
achievement	(sense of accomplishment, meaningful activity)
status	(prestige, social recognition, positive feedback)
involvement	(participation, concern)

Health-related quality of life includes physical, psychological and social aspects and when treatment decisions are being made, it should probably be made explicit what the goals of treatment are in each of these areas, for example, whether a form of treatment would offer functional improvement and provide a satisfying outcome, say, in activities of daily living. In a study of public health services in East London, Bowling (1995) used an instrument which included a priority-marking exercise of six items in relation to perceived effect on health-related quality of life. 'Being free from pain or discomfort' ranked as most important; being able to walk freely', next; followed by 'being able to care for self'; 'being free from stress, nerves, anxiety, depression'; 'being able to do my main activity such as work, study, housework'; and 'being able to pursue social and leisure activities' was the least important.

A crucial question which has to be addressed in an ICU context is related to the desperate nature of the disorders affecting patients. Where decisions are being made about whether certain forms of treatment are indicated, a major consideration is not only the likelihood of the treatment improving the chances of survival, but importantly, the quality of that survival.

In a case reported recently (Duce,1997), the importance of this to families was illustrated. The case involved a baby who had a heart transplant which was successful but who, in the course of surgery, had sustained irreparable brain damage and some ten years later, still 'was incapable of doing anything for himself and will need lifelong nursing care ... can laugh and cry but cannot communicate in any other way'. The baby's parents, when outlining the discussions surrounding the decision about whether to carry out the surgery, said,

> "We were told M. had an excellent chance of pulling through and he would have two or three extra years, but for us, they had to be quality years, otherwise it would not be worth it. We were after quality of life for M.. We didn't want him to have extra time that wasn't quality time"

and the baby's father, giving an insight into the values held by the family, said,

> "The heart is not just a pump, it is part of the person, part of the mind, body and soul. Just to reduce it to something mechanical is missing the whole point about life."

These comments add weight to the need to evaluate the predicted quality of life when making treatment decisions.

Purcell (1997) in discussing the issues surrounding treatment withdrawal from a small child who had developed multisystem failure following surgery for a complex cardiac defect, includes the need for quality of life assessment when deciding on the child's best interests. In the case of a child, 'who is not competent to express a view, nursing and medical staff must act in the child's best interests' (Purcell,1997) but it is vital that the parents are involved as they will carry a heavy burden were the multiply-handicapped child to survive, and the quality of both the child's life and that of all the family members are jeopardised. In this situation though, carrying the burden of feeling responsible for the child's death may also have longer-term consequences for the parents, which must be considered in the approach taken by professional carers.

Instruments

To address the problem of whether certain forms of treatment improve quality of life, a great many instruments have been developed to help quantify disability or to evaluate the effectiveness of a drug treatment, or surgery. Many of these instruments are related to specific disease entities.

Where a patient has cancer, quality of life is an issue whether the treatment being considered is potentially curative or is palliation, and as Bowling (1995) says, 'when there is a reasonable prospect of cure, patients and doctors are likely to accept the associated risk of toxicity, with less concern for effects on quality of life' although the adverse effects of treatment and/or disfiguring surgery, cannot be ignored.

Consideration and measurement of quality of life becomes important when choosing between treatment options in a palliative care setting, because issues related to quality/quantity of life have a major impact on decision-making. Often though, in reporting the outcome of cancer treatment, studies are quoted in terms of survival or reoccurrence, and the impact on quality of life is not included (Mosteller et al,1980, cited in Bowling,1995,p.21).

Selby (1993,cited by Bowling,1995,p.21) recommended that quality of life assessments in patients who have cancer should include *physical well-being* (symptoms and toxicities, such as pain, fatigue, nausea, physical activity and work, recreation and self-care activities); *psychological well-being* (body image, self-esteem, emotional distress, anger, depression); *social well-being* (effects on social activities, isolation, social support from family and friends, and sexual relationships).

It is likely that to be of any real help in assessment of patients with cancer, quality of life instruments would have to be disease-specific and focus on, for example, patients who have cancer of the larynx or breast cancer, as well as covering more-generic aspects of the disease.

In other areas, disease-specific quality of life instruments have been developed, including those for patients who have rheumatological conditions, psychological and psychiatric conditions, respiratory disorders, neurological conditions (such as stroke and epilepsy), cardiovascular disease and renal disorders.

Application in ICU

Many patients who present to ICU for care and treatment, particularly the more-elderly people, will suffer from chronic disorders as well as the acute condition which has necessitated the admission. The nature of these underlying disorders and the effects of them on the person's life previously, must be considered in the context of the decision-making over the treatment of the acute condition. This is in addition to evaluating the predictable consequences of the acute problem(s). For example, a person who has underlying chronic respiratory disease who then develops acute cardiac failure perhaps secondary to a heart attack, will be severely compromised both acutely and in the longer term, if he or she survives, because the problems compound one another. Similarly, a person with chronic respiratory or cardiac disease who has an accident and sustains limb and head injuries, will have major difficulties in a rehabilitation programme, and the predictable outcome in terms of achieving a satisfactory quality of life, must be poor.

Indicators of the effects of chronic respiratory disease on quality of life are of particular relevance when seen in an ICU context, because, for the majority of patients referred, acute respiratory problems constitute a major reason for the ICU admission, and the nature of the underlying problems will play a significant part in deciding on the appropriateness of treatments available.

The physical effects of chronic respiratory disease include breathing difficulties, limitation of activity, anxiety, increasing dependence on others and reduced ability to work, leading to perhaps loss of self-esteem and depression, all of which are progressive. Bowling (1995,p.150) reviews a number of tools which may be helpful in evaluating the effects of respiratory disease on quality of life, covering aspects such as dyspnoea, functional limitations, activity tolerance, depression, role-changes, morale and life-satisfaction. These measurements would be used to complement the specific objective measurements of respiratory capacity and blood gas levels.

The accuracy of measurements of quality of life indicators must be greater when people can answer for themselves, although other factors may impinge on their abilities, such as the timing of the interview/questionnaire completion; their location at the time of assessment (a person's mood and mobility may be better when at home rather than in hospital); and the degree of symptom control (pain, breathlessness). Holmes (1989) disputes this however, feeling that acceptance of subjective data from the patient as 'accurately describing some real feature or quality with temporal persistence' is a mistake because of the 'constantly-changing nature of views about experiences'. Gibb (1985) too questions individual subjectivity in quality of life assessment because although this will accurately reflect the person's feelings, views and values, it very much depends on the scale against which the person is measuring. For example, the person may be quite unrealistic in his/her goals and expectations, and although the assessment of quality of life is being seen from the patient's perspective, accurately reflecting his/her opinion, objectively, when compared with others in similar circumstances, the quality of life may be rated differently.

In ICU, most assessments of quality of life, both current and predicted, have to be made by people other than the patient, which inevitably casts doubt on their accuracy and reliability, because 'objective assessment of the quality of life may project the professional's own values and priorities which can be poor predictors of patients' happiness, morale and life-satisfaction (Hunt,McEwen, 1980, cited by Brooks,1996). Bowling (1995,p.17) too comments that 'the case against observer ratings of another person's quality of life which is then taken as a proxy indicator has been made by several empirical studies comparing doctors and patients' ratings, and by the increasing literature on discrepancies in treatment preferences, and this author feels that 'this literature serves to indicate that the patient's feelings, values and opinions cannot be assumed'.

The evidence of the accuracy of health care workers' evaluations of patients' quality of life indicates that there is a lack of agreement between these assessments and those made by the patient. Slevin (1988, cited by Brooks,1996) in a study involving patients who had cancer, found that 'doctors were not adequately measuring the patient's quality of life, with an approximate 30% unexplained variability between doctors' and patients' scores'.
Bowling (1995) feels however that the subjectivity involved in patients' own rating of their quality of life 'as it reflects the patient's point of view, should be viewed as a strength' but that 'there may be a practical need for supplementary, indirect measures of quality of life when the patient is too frail or ill to respond'.

The role of nurses in the assessment of quality of life should also be considered. Slevin (1988, cited by Brooks,1996) found a variability of 54% between patients' and nurses' scores of quality of life, however Holmes (1989) feels that the nurse should be a key figure in quality of life assessment. Of major importance are the instruments being used and the context in which the assessment is taking place and Holmes (1989) comments that 'at the very least, nurses need to question both the values and philosophies underpinning these efforts' and goes on to say that 'at best, nurses should be clarifying their own ethical and epistemological positions as a preliminary to constructing measures which reflect the health care philosophy of nurses'.

Perhaps nurses should be involved because as Kuhse and Singer (1989) say,

> "Value-laden quality of life judgements are made in the guise of supposedly value-neutral medical judgements,"

and they talk about a life-sustaining treatment being withheld, not because it is futile, of no benefit, but because the quality and quantity of life that the treatment could give is judged insufficient. These authors term this an ethical judgement about the undesirability of prolonging the patient's life because of what the life is like.

Quality of life after intensive care

When treatment decisions are being made, one factor involved is the anticipated quality of life should the patient survive the ICU stay. It is pertinent to examine the evidence available about the quality of life of patients following their ICU stay, and a number of authors have reported studies in this area (Ridley, Wallace,1990; Vazquez Mata et al,1992; Zaren, Hedstrand,1987; Mundt,1989; Munn et al,1995).

Comparisons are difficult between these studies because although essentially the same information was sought, covering health status, functional status in physical, psychological and social areas, and employment status, the instruments used, differed. Zaren and Hedstrand (1987) make the point that not only is there 'no generally accepted method' for assessing quality of life, but that the ICU patient population varies widely in terms of pre-ICU condition, illness-severity, age and length of stay. The timing of the follow-up studies also varied, again making comparisons difficult.

Included in the follow-up studies were questions related to:-

Perceptions of health status before and after the ICU stay.
Ability to live independently.
Effects of current state of health on work, social life, relationships, hobbies.
Employment status.
Ability to drive.
(Munn et al,1995)

Residence.
Health status.
Work status.
Length of ICU/ hospital stay.
Ability to live independently.
(Zaren, Hedstrand,1987)

Ability to walk.
Ability to care for self.
Ability to do housework.
Ability to sleep.
Ability to think clearly.

Depression.
Stress.
Involvement in leisure activity.
Contact with family, friends.
Employment status.
(Mundt et al,1989)

Oral communication.
Sphincter control.
Precision of movements (dexterity).
Tolerance of effort.
Level of independence.
Level of activity appropriate to age.
Pharmacologic dependence.
(Vazquez Mata et al,1992)

Activity levels.
Mobility.
Level of independence.
Limitations in activities.
State of health.
Ability to think and remember.
Happiness.
Activities outside work.
Income.
Help needed.
Meaning and purpose of life.
Distress at state of health.
(Ridley, Wallace,1990)

The authors of this last study acknowledged that some previously-validated methods and instruments were used in compiling their questionnaires in relation to disability-scoring, functional abilities, activities of daily living and quality of life. Their questionnaire concentrated on Rosser's disability categories, which, they say, are 'well-known ... and based on a British population' and form the basis of the calculation of 'quality-adjusted life years' (QALY's). Rosser's classification of illness-states was derived from a group of doctors who were asked to describe criteria used in deciding on the severity of a patient's current illness, and this produced essentially the two categories, observed disability, divided into eight levels, and subjective distress, divided into four levels, each of which consisted of descriptive criteria indicating the severity of illness (Rosser,Watts,1972, cited by Kind et al,1990,p.58).

The results of the study by Ridley, Wallace (1990) indicated that 'many patients had a poor quality of life before admission to ICU but there was an important decline in quality of life after critical illness in those who had previously enjoyed a good quality of life' and this decline was most significant in young patients and trauma victims, which the authors attributed to 'the long-term effects of serious orthopaedic injuries'.

Findings that 71% of patients with a good activity level pre-admission had deteriorated at follow-up were reported by Munn et al (1995) whose purpose was to assess the health and activity of ICU survivors, rather than quality of life which, they felt, is 'a subjective assessment and takes account of the patient's perception and satisfactions with his/her health and abilities'. Data was gathered in a short questionnaire sent three months after discharge of the patient from intensive care in which patients were asked about their health relative to others of the same age, their health prior to the ICU stay and whether their health was affecting employment, home life, ability to drive and other activities. These categories are indicative of quality of life and the findings demonstrated that at three months post ICU, the patient's health did adversely affect each of these activities in between a third and one half of patients, but as the authors say, 'three months after discharge may be too soon to investigate health and activity' (Munn et al,1995). Interestingly in this study, 'significantly more of those aged 76 or older, assessed themselves as 'better than average', and fewer as 'worse than average' than younger patients' and the authors comment that perhaps 'elderly people may perceive their own quality of life as better than that suggested by an objective assessment', indicating that this group might be satisfied with a more-restricted life-style.

This finding was echoed in a study by Rockwood et al (1993) into the outcome for elderly and younger ICU patients who found that despite their higher functional dependence, 'more older (70%) than younger (59%) of survivors satisfied with their current health status' at one year post-discharge, and among those patients impaired in activities of daily living, 7% of elderly patients compared with 15% of younger patients were unhappy with their health and felt that their ICU stay had not been worthwhile.

Of course, these studies involved those elderly people who were offered intensive care. It is likely that other elderly patients would have been denied admission on grounds which would have included past,present and anticipated quality of life, as well as illness-severity, chronic health status and futility of treatment, producing what Rockwood et al (1993) referred-to as a 'selection bias favouring intensive care admission for aged patients with a better prognosis'.

In a study of the outcome of (34) patients aged 85 or older following an intensive care stay, using a telephone interview of surviving patients or a family member, it was found that (21) (62%) of the patients were discharged from hospital, (13) went home and (8) to a nursing home or rehabilitation or psychiatric hospital. Of these, (10) were alive at the time of the interview, (7) deceased and (4) lost to follow-up, and of the (10), (3) rated their quality of life as good and (5) as fair, and the authors conclude that 'better prognostic indicators' are needed and that 'routine discussions with patients concerning the expected quality of life' are indicated so that an informed decision about the provision of intensive care can be made by the patient (Chelluri et al,1992).

Quality of life after cardiopulmonary resuscitation

One important and relevant prognostic indicator is whether during the course of treatment the patient requires cardiopulmonary resuscitation (CPR) because of cardiac arrest.

Studies of outcome following resuscitation indicate that the mortality is much higher in those ICU patients who have a cardiac arrest, (about 50%), than those who do not (17%) (Miranda,1994). An important factor in those who survive CPR is the medical condition which caused the life-threatening cardiac event, as well as the age of the patient and the location of the patient at the time of cardiac arrest, with a reduction in success rate of out-of-hospital resuscitation attempts.

Miranda (1994) concludes that,

> "Patients who have recovered from cardiac arrest in an ICU environment after CPR

> find their capacity for resuming work diminished ... and experience a postponed negative effect on their mental functioning, especially those functions related to awareness of the environment,"

and these problems were related to mental depression and worsening of memory.

Tomlinson and Brody (1988) cite quality of life as an important issue in making a decision about whether or not to resuscitate a patient who suffers a cardiac arrest and suggest that the outcome evidence indicates that CPR should be withheld if 'the quality of life that would result after the cardiac arrest and CPR effort is unacceptable' given the patient's condition at the time the decision is being considered and the threat to quality of life.

What cannot be assumed from any of these studies is that the elderly should be denied admission to intensive care solely on the basis of age, although mortality is likely to be higher, and from the studies cited, the important conclusion is that 'health satisfaction should not be inferred from functional capacity in the elderly' (Rockwood et al,1993).

Quality-adjusted life years (QALY's)

Quality of life is a variable used in the evaluation of benefits likely to be obtained from forms of treatment and these measurements have been used by health economists to justify the allocation of resources when it is felt that decisions and choices have to be made between 'competing' clinicians and their patients.

The principle underlying the QALY's is that it is not only the length of survival likely to be obtained from a treatment which is of value, but it is also the quality of that life, and where priorities have to be established in allocation of resources, advocates of them, feel that QALY's are an appropriate measurement to use. One problem, however, is the premise in QALY's that life in itself has no monetary value (Rawles and Rawles,1990) and as has been described above, even where a patient's quality of life has become poorer after intensive care for example, there is still value in that life, and satisfaction to be obtained from it. Making resource-allocation decisions purely on the basis of QALY's must be inequitable because patients needing a relatively-expensive form of treatment for a chronic problem, for example, dialysis in renal failure, would always lose out in favour of patients needing a one-off procedure such as a hip-replacement operation. There is inevitably an ethical problem in these types of decisions, not just a value-for-money issue (Rawles, Rawles,1990).

Williams (1988) who was instrumental in devising QALY's measurements, argues that survival is not the be-all and end-all of human existence and therefore should not be given over-riding priority in treatment decisions. He goes on to say, in relation to ICU treatment, that if priority were to be given always to life-saving manoeuvres, the patients' lives would be 'racked with pain and offer no hope of anything remotely approaching a normal existence' and asks that 'surely no-one really holds the view that quality of life is secondary'.

A major reason given by Williams (1988) for practitioners to measure quality of life is that it would 'encourage them to devote more time and effort to finding out what it is their patients value about good health, and what aspects of ill-health cause them most distress' and this cannot be disputed.

In conclusion then, quality of life is an important area which must be included in decision-making about patients in intensive care.

It seems from the studies reviewed that a major deficiency in the measurement of quality of life is the lack of consistency among researchers in the tools used, leading to difficulties in making comparisons, yet clinicians, both doctors and nurses, regularly cite quality of life as being relevant to treatment decisions, although the criteria on which they are basing these judgements are not always made explicit and the various participants may not agree on what those criteria should be. What is obvious, is that patients and their families may not share the values of the health care team members.

Williams (1988) talks of 'a capricious and non-retrievable element in casual observation which is likely to lead to capricious and inexplicable decisions' and feels that,

> "This is an insecure basis for a professional practice which gains a great deal of its respect from the widely-held belief that it is both caring and scientifically based."

Summary

The preceding chapters have covered a range of disparate topic areas concerned with treatment-withdrawal, all of which impact on professionals working in ICU's. Although the focus of the research is the effects on the nurses of caring for patients where treatment-withdrawal decisions are being considered, the much-wider issues must also be addressed, as they will impinge on the work of nurses.

The purpose of providing intensive care has been outlined and a review presented of the dilemmas which now confront ICU staff who have to make choices over which patients can and should receive care. The special problems associated with decision-making about patients at the two extremes of age, the elderly and the neonates, have been identified.

The very-real problem of measures which can be employed to support the autonomy of incompetent patients who are experiencing life-threatening illness, but whose outcome is uncertain, has been discussed. Particular reference has been made to the nursing perspective in these situations. This has included evidence from the literature about what nurses want for their patients, together with some possible approaches which might make nurses more effective in achieving greater success in overcoming the barriers identified, as well as more satisfied with their roles. Problems with multidisciplinary collegial relationships were also reviewed, with special reference to evidence about the power of nurses relative to others.

A detailed review of the legal and ethical issues has been presented, as these areas are fundamental to the thesis. Relevant case-law has been cited, together with a discussion about the topical issue of euthanasia.

The last section reviewed the issue of quality of life as this is a very important component when evaluating the whole picture. Doubts were cast on the situation when someone other than the patient is making judgements about quality of life, as the values and expectations will differ. The topic of whether nurses can give an added dimension to these discussions was addressed. The areas reviewed form the basis of the study. A series of questions follows which are drawn both from the literature and from reflection on issues from the perspective of a practitioner-researcher.

Research methodology

Research questions

The objectives are to understand the process of decision-making and to describe the subsequent events, with a focus on the involvement of nurses.

1. How is the treatment-withholding or treatment-withdrawal decision made?

2. What objective data about the patient's illness and outcome are explicitly used in the decision-making process?

3. Who participates in making such decisions?

4. Who has the greatest power and influence in the process?

5. Where patients are incapable of participating in decision-making, is any evidence sought about what their opinion would have been, were such a situation to arise? Have they prepared an advance directive or appointed a proxy?

6. Where patients and families do not participate in decision-making, how is the decision conveyed to them?

7. Does the timing of such decisions seem appropriate to the nurses involved?

8. Are there occasions when nurses feel that active treatment is being inappropriately prolonged and that treatment withdrawal should be considered?

9. In the nurses' opinions, what has prompted consideration of treatment withdrawal?

10. If nurses are not included in the decision making process, is this acceptable to them?

11. Do nurses feel adequately prepared for the roles required of them throughout the process?

12. Are channels available for nurses to participate in decision-making?

13. Are nurses prepared to share and accept responsibility for the decisions and actions taken?

14. Do nurses experience disquiet about some decisions which are taken, and if so, what is the nature of these concerns?

15. Once a withdrawal decision has been made, what is the likely course of events subsequently? What instructions are likely to be given to the nurses taking care of the patients? What do the nurses feel about these instructions?

16. What specific responses and reactions from patients' families cause anxiety and distress in nurses?

17. How do nurses cope when they are involved with these situations?

Methodology

The chapter will begin with an overview of methodological theories, then will continue with a review of research methods with relevant examples cited, and will conclude with a discussion of the methods employed in this study, the first phase of which was carried out in 1995. Descriptions are given of studies published subsequent to this project and evaluative comments made. The studies quoted could not, of course, have informed this study, but are very useful in making comparisons about the methods adopted when exploring the topic of ethical dilemmas and their impact on nurses, and are particularly helpful in considering what alternative approaches there may have been.

Purpose of research

The intention of a researcher may be to develop theory, to broaden knowledge in order to enable anticipation of behaviour or consequences and to allow some predictive ability, perhaps to improve the performance of an activity or prevent injury. Much of the work carried out by medical and paramedical researchers is intended to discover where remedies might be applied therapeutically, where that remedy could be a drug whose efficacy has been demonstrated, or perhaps it would be an approach to behavioural change.

Traditional research strategies can be divided into

Experiment:	the effect of manipulating one variable on another;
Survey:	collection of information in a standardised form;
Case-study:	development of detailed intensive knowledge about a single case or of a small number of cases.

(Robson,1993,p.40)

Nursing is carried out in a wide range of settings, so nursing research reflects this, seeking explanations for phenomena, testing the effectiveness of forms of treatment, indicating which techniques should be employed to be most beneficial in the restoration or maintainance of health. Some research is purely descriptive of attitudes or behaviour of nurses in a particular field of work and may explore congruence between, for example, what they say based on the underpinning values, and what they do in practice.

The boundaries of nursing are blurred in that the activities of nurses vary with the context in which they practice. Some activities are prescribed and regulated by people from other professions, mainly doctors, whereas others are self-directed. In Intensive Care Units (ICU's), many activities are devolved to nurses which would elsewhere be considered tasks carried out by doctors, in the same way that specialised nurses working in other fields take on expanded-role procedures where it is in the patients' interests to do so.

In ICU's, there are a number of issues which nurses may question. Fowler (1990) cites examples of these in an article in which she reflects on her work as an ethicist in ICU nursing, listing problematic areas such as 'inappropriate admissions to critical care units, overtreatment at the end of life, failure to define the patient as dying ... until he or she is dead' and a failure to write "Do not resuscitate" (DNR) orders, '... thus (by U.S.law) forcing nurses to resuscitate where it is inappropriate'.

Practitioner-researchers

Practitioner-researchers who are carrying out a systematic enquiry which is relevant to the area in which the researcher is working, have both benefits and disadvantages. Robson (1993) feels that there are 'insider opportunities providing knowledge and experience about situations and the people involved, and that the practitioner has insights which help in the design, carrying-out and analysis of useful and appropriate studies'.

If the goal of research is to obtain the viewpoints of participants, seeking understanding of their perspectives, then a practitioner-researcher is in an ideal position to develop research questions grounded in experience, where that experience has been informed by literature and reflection in, and on, practice.

The possible disadvantages for practitioners include a lack of time, expertise and confidence and the research may not be valued by the investigator's colleagues as much as that carried out by an outsider (Robson,1993,p.447).

There are special problems associated with participant observation in terms of selectivity, observer bias, maintainance of objectivity, and the practical difficulty of functioning as a researcher in a setting where it is difficult to separate this role from that of the professional in the team.

Simpson (1997) employed some participant observation in a department with which she was not familiar, in her study of nurses caring for hopelessly-ill patients, but described the process as '...close observation, but not participation, in the care and activities of the group'. The objectives were to obtain an insight into events of the Unit with its rapidly-changing workload and the demands on the nurses, to enable identification of issues and a greater understanding of the data collected during subsequent interviews, particularly seeking evidence of congruence between what was said and the actual behaviour.

Treatment-withdrawal decisions

The focus of this project is the impact on nurses of treatment-withdrawal decisions made in ICU's. It impinges on the nurses involved because they may take part in discussions with the prime decision takers, the doctors. They are almost certain to participate in discussions with the patient and family. The consequences of the decision will impact on the nurses who are likely to be the people to carry out the instructions resulting from it, such as reducing support-drug dosages, or failing to commence cardiac resuscitation when in other circumstances it would be appropriate.

The principal aim of this research is therefore to analyse the process during which treatment-withholding decisions are considered and taken; where nurses fit into this process; what roles they carry out; and what their feelings are about such decisions and the consequences of them. What the researcher wants to discover is whether these situations are causing anxiety, stress or disquiet among nurses, to seek explanations for these feelings, and if so, what actions could be taken to alleviate them. The researcher is also seeking evidence of where, and under what circumstances, nurses are satisfied with the process and their role in it. From this, it may be possible to make recommendations about improvements in decision-making, if they are needed, and to formulate guidelines which would help in the resolution of ethical dilemmas which arise because of the need to apply value judgements to the facts of individual cases, where uncertainty exists. The fact that there is uncertainty in these situations and that professional participants in the decision-making process experience anxiety and stress may be very important, in that it is then much more likely that debate will take place, involving a detailed exploration of the facts, issues and concerns. It may be that some nurses under some circumstances feel that decisions are taken which are seen as inhumane in some sense, because of ignorance of, or indifference to, the disquiet and stress experienced by some of those involved.

The importance of these types of decisions to all involved is obvious. These are literally life and death decisions being made about vulnerable people in an alien and remote clinical environment by strangers whose trustworthiness has not been established, and who may be perceived by the patient and family as being authoritative and powerful. This is an environment in which the lay person has difficulty establishing who the allies might be, if they are needed, and from where support might be obtained. For a variety of reasons, people may not feel able to negotiate or discuss what should be done, and they may look to others to advocate for them, or want to leave the decision-making entirely in another person's hands.

For a practitioner to conduct an enquiry in this type of area, there are particular problems to be considered. The enquiry 'needs to be rigorous, systematically grounded in justifiable and coherent principles ...' (Winter, 1989, cited by Robson,1993). There is a need to go beyond 'we know that already, do it every day' and it must add new knowledge and understanding. (Robson,1993,p.448).

Validity

Internal validity is an important issue, and it 'depends on how we define the concept it is designed to measure' (de Vaus,1993,p.56). To assess it, criterion validity, content validity and construct validity are all examined.

Criterion-referenced validity involves comparisons between the new research instrument and 'existing, well-accepted measures' (de Vaus,1993,p.56). Content validity 'examines the extent to which the method of measurement includes the major elements relevant to the construct being measured ' (Burns, Grove,1997,p.777). Construct validity involves examining whether the research instrument 'actually measures the theoretical construct it purports to measure' (Burns, Grove,1997,p.232).

External validity relates to the extent to which findings can be generalised, so that if sampling is faulty, external validity is threatened, and Robson (1993,p.126) also adds that this is a problem where 'we seek to generalise from what people say in a survey, to what they actually do' in practice.

Researching in sensitive areas

There are ethical problems posed by this researcher's proposed project. The most important ethical issue is that of raising awareness of decision-making in a very sensitive area involving vulnerable people. These are always likely to be distressing situations where the outcome for the families involved will be loss and bereavement. These are situations in which all involved are going to be affected in some way. The professionals concerned have to take decisions where uncertainty exists, and then subsequently live with those decisions and become reconciled to the outcome. They all involve the '...careful balancing of prognostic information with ethical, moral and legal considerations' (Knaus and Zimmerman,1988).

According to Rees (1991, in Allan, Skinner,p.141), this type of research raises questions such as:

> Are there research topics... or methods of enquiry which should be off bounds to researchers?
>
> Should researchers be able to avail themselves of a public interest defence in which the social scientific or public policy importance of enquiries or findings overrides other considerations?
>
> Should the aim be the avoidance of any foreseeable harm to research subjects, especially placing them in physical, legal or moral danger?
>
> Should researchers have in the forefront of their minds the interests of those who may come after them, since their own activities, and the reputation they engender, may

close off settings for further research, at least until wounds heal?

These questions are relevant to the area under study, and validity of findings from data have to be questioned if constraints preclude reliable and accurate information-gathering.

Researching in sensitive areas does raise particular problems. Lee (1993) discusses the topic and acknowledges that such areas have a 'constraining influence on research' but equally, there may be positive benefit from such research in increasing knowledge, and for some participants, taking part in research may be cathartic.

Lee (1993) makes a number of practical suggestions for obtaining accurate, truthful and complete responses from research subjects when carrying out surveys in sensitive areas. One widely-used method which has the intention of allowing the subject to answer truthfully without discrediting him- or herself, is to 'load' the questions, so that statements in the question presume that an activity has taken place, or that it is usual or common for it to occur, using phrases such as, "Everybody does this sometimes ..., how often do you ...?" or the casual wording, "Do you happen to ...?" Another approach suggested is to 'use an authoritative source to justify it, thus endorsing positive aspects of the activity' (Lee, 1993).

The approach suggested by Jones (1991, in Allan, Skinner,p.206) is to preface the question 'in such a way as to enable the individual to feel that their experiences are shared by others and thereby encourage them to talk more openly'.

When asking questions on sensitive or threatening topics, Lee (1993) suggests ways of embedding them in questionnaires, 'leading up to a sensitive topic gradually through a series of less-threatening questions'. The same author also suggests embedding the sensitive research questions in a series of questions on more sensitive topics, the responses to which are discarded.

Informed consent

Ethical problems may not always be anticipated and it is feasible that during any project difficulties may arise. Ethical committees exist to protect participants, whether these are staff, patients or families, where research projects are being carried out.

> "...ethical responsibility is essential at all stages of the research process, from design of a study (including how subjects are recruited and how they are treated) to the consequences of their participation after having revealed certain information which would increase their own vulnerability or the vulnerability of others".
> (Kimmel,1988,p.15)

Informed consent, the 'procedure by which individuals choose whether or not to participate... after being given information that would affect their decision' (Kimmel,1988,p.28) may not be sought explicitly where participants in research are being asked to volunteer to take part and consent is therefore implied.

Viney (1996) discusses the issue of truly informed consent in relation to qualitative research, citing the difficulties associated with asking participants to narrate stories and reflect on experiences because it is impossible to predict what may be disclosed and the consequences of this for the individual. This problem has to be considered by researchers. There has to be a strategy for protecting and supporting informants where required, and withdrawal from the study must be possible at any stage of data collection and analysis.

There may be difficulties in giving sufficient information to gain consent to participate without influencing the outcome or mislead participants about the true purpose of the research, so as to 'avoid distortions and limit the applicability of the findings,' and there is 'a dilemma for the researcher who wants to be open and straightforward with the subjects, but realises that to do so might jeopardise the validity of the findings' (Kimmel,1988,p.28).

The same author talks about the subtle coercion which may be operating because the experimenter has, or holds, power and the potential participant trusts the experimenter to look after the welfare of volunteers in matters of confidentiality and privacy (Kimmel,1988,p.58). The amount of information given to potential participants may also influence the level of participation. Issues which are of current interest may encourage participation and promote debate. Potential participants may welcome an opportunity to describe and discuss their feelings about a topic in which they have an interest. The better informed people are, the greater the participation rate.The characteristics of non-participants may be very informative, however it would be impossible to learn anything about, or reach these non-participants, in a project in which absolute anonymity is being guaranteed about the identity of participants.

Information about non-respondents could only be obtained if there were access-to, and knowledge about respondents which would then enable comparisons between the two groups. In relation to the current study, non-participation may be associated with an absence of treatment-withdrawal decisions during the period allocated to the collection of data.

Qualitative-quantitative considerations

The choice of methodologies and research methods is therefore important. In general, a quantitative researcher 'isolates and defines variables, then links these together to form hypotheses which are then tested on the data'. In contrast, the qualitative researcher ' begins with defining general concepts which, as the research progresses, change their definition, so that the variables form the outcome, and hypotheses gradually emerge and are tested and reformulated as the research findings evolve' (Brannen,1992,p4-6).

To say that quantitative methods give better accuracy and precision can also be disputed, because the research data is only as exact as the study design allows. An important consideration at the design stage of a project is the expected degree of generalisability and replicability of the findings, because these determine the method to be used and the sample population.

With quantitative research methods, statistical analysis of the findings is involved and care has to be taken in selecting the sample so that the group size is sufficient for variables to be tested out reliably, and the sample must be chosen without introducing bias. If these precautions are taken, conclusions may then be drawn from the results about whether relationships or associations exist between variables, the strength of these relationships, and the probability that the findings are due to random error or chance, or are positive links which are generalisable (Brannen,1992,p.8).

Discussions about the relative merits of qualitative and quantitative research methodologies are more useful if it is recognised that there is a place for both. What is much more important is that the appropriate approach is selected, given the nature of the research questions. There is little to be achieved by maintaining a stance that one is superior to the other, regardless of the question.

Grounded theory

With qualitative research, the sample is selected on the basis of theoretical criteria, and the sample size may well be determined by the findings as the study develops. When using the 'grounded theory' research approach the sample size is determined by the point at which the researcher feels that there is saturation of data, that is, no new ideas are forthcoming, there is a 'repetition of discovered information and confirmation of previously-collected data' (Viney,1996).

Grounded theory was the approach employed by Simpson (1997) in a study of the experiences of nurses who were caring for hopelessly-ill ICU patients. Simpson (1997) justified the use of the methodology by saying that 'the nature of the research question did not lend itself to quantitative analysis'. The grounded theory approach utilised to study nursing 'enables the construction of theory which represents the reality of those practising in an area, thereby making it easily comprehensible to them' (Simpson,1997).

Generalisability is an issue though, when grounded theory methodology is employed because in-depth, exploratory interviews, transcription of data, and the process of on-going data analysis, may limit the sample size and nature in small studies. Simpson (1997) acknowledges this, saying that the findings may possibly only be applicable to the one site studied, although the purposive sampling used once themes are beginning to emerge, does enhance validity of findings. The purpose of grounded theory is to 'explain, predict and generate theory' (Sorrell, Redmond,1995).

Phenomenology

Grounded theory differs from phenomenology, another qualitative methodology which is used 'to interpret and understand the lived experience rather than explain it' and Viney (1996) very successfully used narratives obtained from unstructured interviews with five senior doctors and five senior nurses, in an attempt to 'uncover meanings in everyday practice' associated with treatment-withdrawal from ICU patients, focusing particularly on any differences between the two professional groups. From these data, Viney (1996) was able to conclude that there was a need for improved doctor-nurse collaborative decision-making to enable satisfaction with these situations, and she developed an algorithm to guide channels of communication.

Andrew (1998) also used a phenomenological approach to explore the experiences of seven intensive care nurses who were caring for the families of dying patients. The evolving central theme from the nurses' narratives was how they seek to make the time and experience as positive as possible, or as Andrew (1998) terms it, 'optimizing the human experience'. Andrew (1998) concluded that nurses adopted the strategies 'being there, supporting, sharing, involving, interpreting and advocating' to achieve their aims, working within the domains 'nurse as person, practitioner and colleague'.

Sorrell and Redmond (1995) describe the purpose of phenomenological interviews as 'to understand shared meanings by drawing from the respondent a vivid picture of the lived experience, complete with the richness of detail and context that shape the experience' in which the researcher actively listens, using 'an engaged, profound approach to listening', to enable interpretation of the experience. These authors distinguish the phenomenological interview from an ethnographic one, in which the purpose of the latter is 'to discover categories of meaning' in a cultural or group context, so that what is being explored in each interview is the individual's perspective on activities, so as to determine why group members behave as they do, and 'to identify shared values among members of a cultural group' (Sorrell, Redmond,1995).

Where ethical dilemmas are being considered, although the approach to the analysis of narratives may use hermeneutic phenomenology (Annells,1996), it seems likely that ethnography is also relevant, as the values, and therefore behaviour, actions and interactions of team members, are a fundamental part of the data. Certainly in the study by Soderberg and Norberg (1993) of the experiences of sixty ICU nurses and doctors using narratives of 'ethically-problematic care episodes experienced by them', the authors expected to find differences in 'perceptions, feelings, reasoning and actions' amongst team members, and to find that relationships between participants were determinative in levels of satisfaction with decisions and events.

In a follow-up study, Astrom et al (1995) used a phenomenological approach to explore nurses' feelings of adequacy in managing difficult ethical situations, again using narratives as sources of data.

Bassett (1995), too, used phenomenology, justifying its use by saying that there was an attempt made to understand another person's subjective experiences and feelings by a study of their 'field of expression, made up of speech, expression, gestures and intonation'. This was a small, limited study of the experiences and beliefs of ICU nurses in relation to the moral and ethical dilemmas encountered. Data were derived from a five-person group discussion, in which the researcher was a participant and facilitator. The discussion was recorded, transcribed and analysed, and themes derived, labelled by the researcher as 'senselessness, stress and impotence' (Bassett,1995).

Another study using a phenomenological approach 'to research the nature of skill acquisition in nursing practice and to delineate the kinds of practical knowledge exhibited in expert practice' was carried out by Benner et al (1992). In this study, informants were interviewed in groups of four to six nurses clustered by levels of expected practice (advanced beginner, intermediate and expert) and they gave narrative accounts of specific patient care situations. Group settings were used rather than individual, to create a natural, conversational setting, with group members expected to ask questions of one another and add their own examples of similar or contrasting experiences. In addition to the group interviews, about 50% were seen individually and observed in practice. Use of triangulation of method and interviewers enhanced the quality of this successful study which built on earlier, widely-known work by Benner (1984).

A qualitative study using a different approach was carried out by Grundstein-Amado (1992) to explore the differences between nurses and doctors in ethical decision making. Two-phase, semi-structured interviews were used, and in the first, the questions were unstructured and open-ended, allowing an analysis of the health-care professional's past personal experience with ethical decision making processes, and 'participants' value systems, reference to ethical principles and theories, and patterns of decision-making... were analysed'. The second phase 'probed participants' responses to a hypothetical case in which structured, sequential questions were asked following a proposed model' and the two sets provided complementary data.

Survey methods

Descriptive research 'begins with the identification of a problem or problematic situation' and the analysis of the descriptive data may 'reveal relevant factors or relationships hitherto undetected which could form the basis for further research' (Carter, in Cormack, 1996,p.179). It follows that descriptive research involves seeking data related to the research questions without any attempt being made to formulate an hypothesis or manipulate variables.

Methods such as interviews, questionnaires and observation are used in descriptive studies, and while they may be prescriptive in terms of the restricted nature of the context and the questions asked, they may also be exploratory, and give respondents the opportunity to volunteer unsolicited information.

There are three main types of interviews. Structured interviews which involve the use of predetermined questions are the most prescriptive. With semi-structured interviews, although areas of questioning will be identified, respondents have a greater opportunity to discuss matters, and interviewers are able to probe and clarify answers. In unstructured interviews, respondents are invited to give their own thoughts, views and reflections on themes suggested by the interviewer, thus yielding richer material.

Cormack (1996,p.233) lists the advantages of interviews carried out by the researcher over self-completed questionnaires, as follows:

1. People ignore questionnaires or leave sections blank. A fuller response is likely with an interview.

2. Areas of uncertainty or ambiguity can be clarified.

3. Interviews can allow expansion of responses when a questionnaire may not encourage detailed or lengthy answers.

4. The interviewer has control over the respondent's replies, so that consultation is not possible and other influences are minimised.

5. Additional data on performance, attitude and degree of understanding can be collected in supplementary, contemporaneous notes.

Interviewing in depth may give more valid information because as Lee (1993,p.104) says,

> "...interviews provide a means of getting beyond surface appearances and permit greater sensitivity to the meaning context ..."

particularly because if contemporaneous notes are made, the associated emotional responses and non-verbal signals can be linked to answers and provide complementary, informative material.

There are weaknesses associated with interview methods in relation to the effect of the interviewer on the research subject, because the former may unconsciously influence responses by communicating approval or otherwise, leading respondents to feel that there is a right answer, and this would be exacerbated if the researcher is perceived as being the more powerful in the relationship. The converse may also occur. Lee (1993,p.110) talks about the 'relative powerlessness of the interviewer ... which is reinforced by the etiquette of the interview', so that informants may recount at great length, and even if offensive remarks are made, the interviewer may simply have to listen.

Where research methods are employed which necessitate freedom for the research subject to set the agenda, it may be difficult for the researcher not to inadvertently manipulate the direction taken, and introduce bias.

> "Attempting to keep an open mind, to foster new lines of enquiry, is a central tenet of qualitative work"

with the aim of using the informant's own understanding of events (Allan,1991, in Allan, Skinner, p.181).

There may be difficulties too with maintaining consistency of approach over time, through a series of interviews, leading to 'a lack of standardisation and raising concerns about reliability' (Robson,1993,p.229).

There are problems with the maintainance of anonymity for informants in face-to-face interviews, and even when guarantees have been given, they may be wary about disclosing confidential information, parts of which may be published in excerpts from narratives. Jones (1991,in Allan,Skinner,p.209) discusses the difficulties associated with interviewing employees in a workplace situation, where access has been granted by the department manager, because of the conflict of interests which may arise when informants may feel they must participate and 'gatekeepers' have expectations about disclosure of information obtained. There may also be conflict between the researcher and informant on the ways in which the material might be used.

Lee (1993,p.102) talks about some of the problems associated with conducting interviews, where 'personal, threatening or confidential information' is sought, and comments that 'in written reports, (respondents) are easily identified by themselves and others close to them, because the data are unique and personal' and that 'identification carries with it the risk of sanctions or stigma from various sources'. The researcher, under these circumstances, has a responsibility to protect respondents and their privacy. Such interviews are likely to be time-consuming, because trust and confidence have to be established, and, of necessity, the number of respondents may therefore have to be small.

Survey methods employing questionnaires have been used extensively in social research, and can allow sampling of a wider population, particularly where that group would otherwise be difficult to reach. Although, as Cormack (1996,p.118) says, '...the way that questions are constructed ... tends to reinforce the questioner's assumptions', it is possible to explore attitudes and beliefs in well-designed questionnaires.

Functions of survey analysis include both descriptions of 'the characteristics of a set of cases' and also, where possible, the 'attribution of causal links between variables (de Vaus, 1993,p.5).

de Vaus (1993, p.7) lists the commonly-cited criticisms of surveys as:

1. They cannot adequately establish causal connections between variables.

2. They are incapable of getting at the meaningful aspects of social actions, because people make choices, have memories, wills, goals and values which motivate behaviour.

3. They just look at particular aspects of peoples' beliefs and actions without looking at the context in which they occur.

4. They are equated with a sterile, ritualistic and rigid model of science centred around hypothesis-testing and significance tests which involve no imagination or creative thinking.

5. They merely collect a mass of facts and statistics and provide nothing of theoretical value.

6. They are too restricted because they rely on highly-structured questionnaires which are necessarily limited.

7. They are too statistical and reduce interesting questions to totally incomprehensible numbers.

de Vaus (1993,p.7) however, goes on to counter each criticism, giving examples of methods of constructing surveys to avoid the pitfalls.

Questionnaire development

> "...trustworthiness of data depends to a considerable extent on the technical proficiency of those running the survey. If the questions are incomprehensible or ambiguous, the exercise is a waste of time. This is a problem of internal validity where we are not obtaining valid information about the respondents and what they are thinking, feeling or whatever".
> (Robson,1993,p.125).

Involvement of respondents is a relevant issue and 'securing involvement is also a technical matter, because a poorly-designed and printed questionnaire' is likely to discourage participation and may lead to difficulties with recruiting people to take part (Robson, 1993,p.126). When faced with a non-response problem, the question which has to be addressed by the researcher is, 'Do those people who have responded differ from those who have not responded in ways which are relevant to the aims of the research?' and the answer to this question is crucial to the validity of the research findings (Cormack,1996,p.211).

In a comparison between other survey methods (personal interview, telephone) and a mail survey, de Vaus (1993,p.107) reports that 'in specific, more homogenous groups (members of organisations, teachers, nurses) mail surveys seem to be about as good as other techniques - especially when the topic under investigation is of particular relevance to the group'.

Questionnaire design has to be considered carefully. de Vaus (1993,p.109) talks about issues such as the length of the questionnaire, the complexity of the questions, the sequence of questions, and the use of closed- and open-questions, as all being relevant to the response rate and quality of answers.

In this project, a balance has to be struck between covering the topic adequately and in sufficient depth, and imposing too great a burden on busy people, thus reducing returns. Where subjects are topical and engaging, and the language used is accessible and readily comprehensible, more returns are likely.

Robson (1993,p.243) outlines some of the problems, such as 'the data being necessarily superficial' and there being 'no check on the honesty or seriousness of responses ... which have to be squeezed into predetermined boxes which may, or may not, be appropriate'.

> "... to have any hope of meaningfulness, the questionnaire must be painstakingly constructed, with very clear and unambiguous instructions and careful wording of questions".
> (Robson,1993,p.243).

de Vaus (1993,p.83) gives detailed guidance about the wording of questions, mentioning such issues as:

1. using simple language but avoiding condescension;

2. avoiding confusing and ambiguous long questions, and double-barrelled ones;

3. avoiding leading questions as these may cause the respondent to feel that they are going to give the wrong answer or one which will meet disapproval;

4. using words which mean the same to everyone, and a clear frame of reference;

5. considering whether direct or indirect questions, or personal or impersonal wording, are more appropriate;

6. avoiding questions which may lead to either an acquiescent or social-desirability response set.

Other considerations involve the use of closed questions which can be readily analysed, or open questions yielding data which have to be coded and categorised for analysis, with some loss of meaning and information. The use of attitude-measurement scales, or semantic-differential scales may also be relevant.

Provided that attention is paid to the construction of questionnaires, it is possible to obtain useful and informative material from respondents, and these data may be enhanced by the use of more than one instrument or methodological approach.

Factors encouraging better response rates include such aspects as the appearance, layout, and design; mailing questionnaires in personalised envelopes with stamped, addressed return envelopes; covering and follow-up letters; and the possible use of incentives (Robson,1993,p.250; de Vaus,1993,p.116).

Hypothetical vignettes

The use of survey methods to explore values and attitudes involves very careful question construction and coding of responses in order to derive valid and reliable data. Reliance has to be placed on 'crude and highly-questionable attitude measurement scales ' (Finch,1987). This author discusses the use of vignettes as a research method which may enable exploration of beliefs and values in the context of realistic, but hypothetical, case situations.

> "Vignettes allow for features of the context to be specified so that the respondent is being invited to make normative statements about a set of social circumstances, rather than to express his or her beliefs or values in a vacuum. It acknowledges that...morality may well be situational specific".
> (Finch,1987).

The use of vignettes may allow sensitive topics to be discussed in a non-threatening way because 'situations presented to respondents are hypothetical, so there is a distancing effect' (Finch,1987). Questions can be asked in the form "What should these people do next?" rather than "What would you do next?" and vignettes 'can employ projective techniques which allow an interviewee to define the meaning of a situation for him- or herself'(Finch,1987). It should be possible to incorporate specific features in the vignettes which would enable testing of particular aspects of research questions. For example, Ott and Nieswiadamy (1991) developed four hypothetical case study vignettes where a DNR decision was involved. The first tested the proposition that if the patient were competent, the patient should make the decision. The second tested the proposition that if the patient were not competent, but there was a family member who knew the patient well and could represent the patient's wishes, the family member should decide. The third and fourth vignettes tested the propositions that if the patient were not competent, but a close therapeutic relationship existed between either the doctor and patient, or the nurse and patient, then the doctor or nurse should decide.

Vignettes may vary considerably in format, from a single sentence to a detailed description of a set of circumstances, with perhaps a story developing over a series of vignettes, allowing probing of different aspects. Questions may be simple yes/no/not known format; may involve responses on visual analogue scales indicating a degree of feeling and in what direction; or may be completely open-ended, although comparisons between respondents' replies may be more difficult to make with this last approach.

Hypothetical vignettes were used in a study by Davis and Slater (1989) in which the purpose of the study was to describe the attitudes and beliefs of Australian and American nurses about various situations in which the patient was likely to die. The vignettes were developed by a clinical nurse with a background in ethics, then they were evaluated by a panel of clinical experts and specialists in ethics. In study interviews, one vignette at a time was presented to the nurse and the questions asked, "What do you think is usually done in this situation?" and then, "What do you think should be done?" with both questions being probed for detail, clarity and ethical justification. The authors commented on the limitations of the vignettes for this study, citing the fact that 'where there is a reluctance to, or sanction against discussing topics, they are removed from experienced reality and its complexities', although they 'gave form to the interview when there might be reluctance to discuss topics'. One disadvantage of using these vignettes for this group of respondents, was that some of them covered patient situations which were outside their clinical knowledge. To be valid, vignettes need to be relevant to the group under study. The vignettes were successful in enabling comparisons between the two groups of Australian and American nurses which revealed differences in culture and practice (Davis, Slater,1989).

Grundstein-Amado (1992) used vignettes in the second phase of a study which probed participants' responses to a hypothetical case study vignette in which systematic, structured, sequential questions were asked, using a research model as a framework for questioning. Grundstein-Amado (1992), in reflecting on the methodology, commented that '... it is unlikely that there were no errors or biases' because the data involved interpretation by the researcher, although 'transcriptions were passed to another evaluator for verification of the researcher's interpretation'.

Ketefian (1989) reviewed a series of studies involving the constructs 'moral reasoning' and 'ethical practice' and, using the findings, attempted to distinguish between the two, where moral reasoning was defined as the 'cognitive and developmental process of reasoning about moral choice' and ethical practice as the 'domain of nurses' moral behaviour, actions, ...and decision-making about ethical dilemmas'.

Although there were common themes, disparate instruments were used, and Ketefian (1989) was critical about the investigators who had 'neither learned from preceding research, nor built on the work of predecessors in any direct way', but commented that this may be the result of the instruments being developed 'in the context of dissertations and therefore not reported to a wider audience'. Ketefian (1989) also felt that the measures of ethical practice lacked validity and reliability because of poor conceptualisation.

The instruments reviewed included real-life scenarios or hypothetical case-study vignettes depicting ethical dilemmas for the nurses involved. Within each instrument, a variety of dilemmas were generally covered, based on codes of conduct, as opposed to focusing on reasoning and practice in one clinical setting. For example, one ethical decision-making questionnaire (Husted,1983, cited by Ketefian,1989) involved four real-life case-studies, and tested areas such as 'the patient's right to know and the nurse's right to tell; unethical conduct; CPR and the nurse; and insubordination', seeking nurses' attitudes to patients' rights to safety and self-determination.

One instrument, the Judgements About Nursing Decisions (JAND), again based on the code of conduct for nurses, and developed by Ketefian, used six stories of ethical conflict followed by six or seven nursing actions and respondents were asked 'should the action be implemented?' and 'Is it likely to be implemented?'. Ketefian (1989) concluded that reliability of the first of these two questions was poor.

Another study involved an interview between researcher and participant being interrupted by a simulated situation of a person seeking help for illegal drug use, where the real, but covert, subject under investigation was the behaviour of the participant towards the person in need (Turner,1984, cited by Ketefian,1989).

These examples illustrate the very varied nature of the investigations with the common focus. It was apparent from data cited about reliability and validity that instruments using case-study vignettes could be used successfully, within the specific studies and contexts, but that as 'simulated measures of moral behaviour', they do not necessarily predict how 'persons would actually behave in given situations'.

Parker (1990) also reviewed some of the methodological concerns surrounding the measurement of nurses' moral judgements and comments that,

> "Hypothetical dilemmas, unfamiliar, irrelevant, and lacking in contextual elements, may discourage the reader's identification or emotional involvement in the situation. The disparity between reasoning in hypothetical situations and real situations may represent measurement error which argues against the validity of current measures of moral reasoning",

adding that where vignettes are unfamiliar to the nurses they 'may not engage the respondents either cognitively or affectively'.

This author goes on to say that 'open-ended questions are also used to identify how subjects individually construct the moral problem' and that this process can be extended further into the use of the subject's own experience in real-life situations which would 'offer a more direct reflection of the individual's true experience in resolving moral conflicts' (Parker,1990).

Diaries

Diaries, when used as a means of obtaining research material, may be a useful method of gaining an insight into participants' thoughts and observations, when direct observation and interviewing by the researcher are not possible.

An interesting and relevant method suggested by Robson (1993,p.254) is to use a 'critical incident' approach as a variant of the diary, so that participants are directed to focus on specific aspects of a situation or task.

Norman et al (1992) describe this approach as a 'systematic, inductive, open-ended procedure for eliciting verbal or written information from respondents' in which the objective is to 'analyse actions and observations associated with particular tasks, then use these to develop a set of critical behaviours which were more likely to achieve success' in completing the task. This approach is likely to be useful in the current study as it will allow analysis of, and insight into, the crucial factors in determining nurses' feelings about their roles and actions in treatment-withdrawal situations.

Multi-method research

Brannen (1992,p.22) feels that '...there are grounds for arguing that both qualitative and quantitative approaches need to be applied in combination', and that 'while the qualitative approach may overcome some of the problems of giving voice and language to groups, through which they may better express their experiences, the quantitative approach would serve to indicate the extent and patterns of their inequality at particular historical junctures'.

Measurement, in research terms, is 'the operation of assigning either qualitative or quantitative values, (either names or numbers) to social phenomena' (Brewer, Hunter, 1989,p.17). Measurement in this context has two phases, firstly development of an appropriate tool or instrument, and secondly, validation of it.

> "Triangulation measurement tries to pinpoint the values of a phenomenon more accurately by sighting in on it from different methodological viewpoints. To be useful, a measuring instrument must give consistent results and measure the

> phenomenon that it purports to measure."
> (Brewer, Hunter,1989,p.17)

Robson (1993,p.291) gives examples of the possible benefits of multimethod research, citing the use of qualitative, narrative material to support the interpretation of statistical analyses, and the use of quantitative material to follow-up the findings of a qualitative study.

Interviews, questionnaires and a variety of scales and tests 'lend themselves well to be used in combination with other methods, for example, a case study might employ some kind of formal interview or questionnaire to complement participant observation' (Robson,1993,p.227).

Triangulation enables reflection on how the subtleties in the different techniques of measurement have uncovered variations in results and responses and should enhance understanding and expand knowledge, but the methods selected have to be assessed in terms of their weaknesses as well as their strengths, so that valid inferences can be drawn from results.

If a multimethod approach is selected, the sequence of the use of each method should be determined at an early stage in the design of the project. There could be a combined approach throughout, or a quantitative survey could be followed by qualitative follow-up employing observation or interviews. A qualitative survey, perhaps involving interviews or focus-group discussions, raising issues, topics and questions to be addressed, could be followed by a larger quantitative study.

Multimethod research findings need to be integrated and this integration should be built in at an early stage in defining the research questions and designing the project. Links could possibly be made between the results of single-method studies on a related topic which could then be used as a basis for new development.

In a discussion about triangulation, Burns and Grove (1997,p.241) define it as the 'combined use of two or more theories, methods, data sources, investigators or analysis methods in the study of the same phenomenon' with the purpose of increasing the overall validity of studies.

Triangulation can be divided into five types:

Data triangulation involves the collection of data from multiple sources for the same study, with the intention of using data from one source to validate data from another source (Kimchi et al,1991, cited by Burns, Grove,1997,p.241).

Investigator triangulation involves two or more investigators with different expertise and research approaches examining the same phenomenon (Mitchell,1986, cited by Burns, Grove,1997,p.241).

Theoretical triangulation involves the use of a variety of theoretical perspectives in examining the phenomena, including, for example, feminism, phenomenology, cultural studies, then the empirical data is examined using the theoretical frameworks (Denzin,1989, cited by Burns, Grove,1997,p.242) so '...hypotheses are developed based on the different theoretical perspectives and tested on the same data set' (Burns, Grove,1997,p.796).

Methodological triangulation involves 'the use of two or more research methods or procedures, such as different designs, instruments and data collection procedures in a study' (Burns, Grove,1997,p.787) and may be divided into *within-method triangulation* and *across-method triangulation* (Denzin,1989, cited by Burns, Grove,1997,p.242). Within- method triangulation involves the use of more than one quantitative instrument or qualitative method to measure the same phenomenon whereas across-method triangulation (or between-method) involves 'combining research strategies from two or more research traditions in the same study' so that both qualitative and quantitative methods may be contained in the same study, and Burns and Grove (1997,p.243) give the example of using different data collection methods, such as questionnaires, physiological instruments scales, interviews and observation techniques to obtain material. Methodological triangulation may also be classified as *simultaneous* (more than one method being used at the same time) or *sequential* (one approach following another in which the results of the first are essential to the planning of the second) (Morse,1991).

Analysis triangulation involves using two or more techniques to analyse the same data to enhance validation (Burns, Grove,1997,p.243).

The combination of qualitative and quantitative methodologies within one study is possibly contentious as the theoretical perspective of each is quite different, and Morse (1991) feels that they cannot be weighted equally but instead that projects 'must be theoretically driven by qualitative methods and incorporate a complementary quantitative component' or the reverse. The same author suggests that 'the greatest threat to validity of methodological triangulation is not philosophical incompatibility but the use of inappropriate or inadequate samples' because, for example, quantitative methods dictate that large, randomly-selected samples are used, whereas qualitative methods generally employ fewer participants, using purposive sampling (Morse,1991).

Robson (1993,p.291) supports the use of multiple methods in a complementary way to enhance interpretability, giving the example of a primarily quantitative study yielding statistical data being combined with qualitative narrative accounts, or of the findings of a qualitative study being clarified by the use of statistical information.

Morse (1991) warns though that is essential for each methodological component to be analysed 'with adherence to the assumptions and principles appropriate', in order to enhance validity. She also suggests that the use of descriptive statistics in an essentially qualitative study, does not constitute a quantitative study and methodological triangulation. Similarly, where the principle of the methodological approach involves a combination of techniques, this does not constitute triangulation, and Morse (1991) cites ethnography as an example of this, as, to be ethnography, it has to involve 'interviews, observation, examination of records and perhaps questionnaires'.

Analysis of qualitative data

The aim of data analysis is to preserve the meaning of the raw data in context but at the same time, to provide an interpretation of the material. The main task is therefore to categorise the varied data, so that links can be made between them which explain events (Allan,1991, in Allan, Skinner,p.186).

The specific objectives will vary with the methodology, so, for example, analysis of data within a phenomenological framework will have the aims 'to interpret and understand the lived experience' (Viney,1996).

With a grounded-theory approach, interview data is coded immediately after the meeting has taken place, then condensed into themes which are gradually ordered into categories from which a core category is obtained. This process of analysis enables progressive development of themes which emerge from earlier interviews, and which then shape the questioning and the choice of participants in later interviews (Simpson,1997). With grounded theory, 'data analysis occurs concurrently with data collection rather than sequentially', so that simultaneously, the researcher is gathering, managing and interpreting the meaning of data (Burns, Grove,1997,p.565).

Content analysis is 'designed to classify the words in context into a few categories chosen because of their theoretical importance' and it needs to provide a 'systematic means of measuring the frequency, order or intensity of the occurrence of words, phrases or sentences' (Burns, Grove,1997,p.564).

Burnard (1991) suggests a systematic approach to the analysis of qualitative data obtained during interviews which is also applicable to data collected by other methods. The initial stage of qualitative data analysis requires the researcher to establish familiarity with the data by reading and re-reading material, making notes on general themes as they emerge. The objective is to gain awareness of the respondent's frame of reference, so that the perspective taken in analysis is that of the research subject.

From here, Burnard (1991) describes a process of open-coding and categorisation, followed by refinement and reduction of the lists of categories to reduce repetition. At this stage, Burnard (1991) suggests that validity of data analysis can be enhanced by 'asking two colleagues to generate category systems independently' which are then used with the researcher's to create a final category list. The transcribed data can then be sorted, and divided into sections using the derived category headings, thus enabling logical organisation of the material for recording and reporting purposes, always maintaining the links with the context of the narratives, which then preserves the original meaning of the material.

Burns and Grove (1997,p.264) feel that the 'construction of idea categories and the selection of words considered representative of these idea categories is a crucial phase of content analysis' but they add that the researcher may also be seeking some latent meaning within the text, perhaps associated with 'ideas, reality and language'.

Allan (1991, in Allan, Skinner,p.181) adds a reminder that 'it is important to be systematic to ensure that examples of phenomena are not overlooked' because it is easy to recognise those which fit readily into developing theories, but there may be evidence found during a thorough exploration which is contradictory'.

Criticism has been levelled at qualitative studies because of difficulties with verification and replicability where the researcher's own assumptions, perceptions and disposition affect not only data collection, but analysis as well, which is the reason for emphasising the need for methodical investigation and scrutiny (Allan,1991,in Allan,Skinner,p,182). Of course, this reflexivity which the researcher brings to the analytical process may well enhance the quality of the findings (Viney,1996).

Qualitative data analysis may be complemented by some quantitative material, such as descriptive statistical data, perhaps including indications of frequency of events, or the proportion of respondents expressing a particular view.

Analysis of qualitative data derived from a survey will be a different process from that resulting from unstructured interviews, as the former is likely to be more prescriptive and possibly restrictive, but as the sample size will tend to be larger, greater diversity in responses could be expected.

Whatever qualitative approach is employed, the same care has to be taken with applying the analytical process in order to organise, and derive meaning and understanding from, the data.

In summary, then, analysis of qualitative data involves a systematic process of organising and categorising material, where the interpretations reported accurately reflect the respondents' perceptions and meanings in their defined contexts.

Quantitative data

Analysis of quantitative data, involving, for instance, the compilation of descriptive statistics and tests of comparison between groups of respondents, is normally carried out now using a computerised statistical programme. At the design stage, the level of data required to test research questions has to be carefully considered, together with the statistical test(s) then appropriate for use with these data to enable analysis. Factors such as sampling and group-size(s) are also relevant here. Some research designs, for example, are likely to involve larger group sizes, random sampling, and the collection of interval/ratio data in order to give greater accuracy, reliability, generalisability and predictability in the analysis of results.

Research Approach

Background

The researcher had been employed as a senior nurse, clinician and teacher in the critical care field for a number of years prior to carrying out this project. Dealing with ethical dilemmas was therefore a relatively-common event, particularly within the most-acute intensive care settings. With increasing seniority came greater responsibility for the researcher in participating directly in decision-making, and also in supporting team colleagues in their care of patients and families through sad and difficult situations. These situations prompted reflection on events, wide-ranging discussions with multidisciplinary team members, and mediation on behalf of families, all underpinned by knowledge of ethical theories obtained during courses and from literature, reviews of which continued throughout the process of data collection and analysis. Research questions were derived from consideration of the issues surrounding treatment-limiting decisions. They were informed by ideas from many sources, and were the result of questioning and debate arising from experience, the process of reflection discussed by Hagland (1998) in which learning results from the analytical process supported by findings from literature.

The researcher had specific concerns about the sensitivities of those involved in treatment-limiting decisions which ultimately determined the research approaches adopted.

For the researcher, the absolute priority was the need to maintain anonymity of nurses and their places of work in order to protect them and the patients and families who might be the subjects of the situations described. The researcher was very anxious to avoid raising doubts or concerns in the minds of the bereaved families, if it were possible to identify departments. It was also imperative to protect nurse respondents who might be disclosing concerns about decisions taken by others, differences of opinion, conflicts with medical and nursing team colleagues, or aspects of patient care in their departments, of which they were critical.

Other very-sensitive areas included the possible actions of nurses during treatment-withdrawal which may have raised concerns about causation in connection with patients' deaths.

Exploration of issues like these necessitates the use of a primarily qualitative methodology, so that respondents are able to introduce their own thoughts, perceptions, feelings and evaluations of their activities in the context of treatment-withdrawal decisions. Reporting of this material involves using examples of narrative from respondents, and the researcher has the task of protecting the subject by deleting or disguising identifying details while still maintaining the sense and meaning intended by the respondent.

The need for anonymity was felt by the researcher at the time of project design to preclude the use of interviews, so a survey method was planned using an instrument devised by the researcher which was to be completed by the participants themselves. Lee (1993,p.97) talks about the difficulty of asking informants about 'aspects ... which are in some way intimate or personally discrediting', but adds that it becomes easier 'where privacy and anonymity are guaranteed and when disclosure takes place in a non-censorious atmosphere'. It was essential then to ensure respondents about anonymity, and also to use appropriate language in the construction of questions which both engaged the respondent and conveyed the customary nature of activities surrounding treatment-withdrawal decisions. The researcher's intention was to seek richer qualitative material by asking some open-ended questions, to enable respondents to express their own thoughts, ideas and reflections.

Other researchers have referred to the problem of maintaining anonymity when carrying out studies in highly-sensitive areas. For example, McHaffie and Fowlie (1997) in a study of withdrawing and withholding treatment from neonates, conveyed the contextual dilemma and the likely sensitivities of practitioners, in saying,

> "Faced with the reality of human experience in those circumstances where every choice is a tragic choice, even carefully reasoned arguments can sometimes sound hollow",

and they go on to say that differences in viewpoints among individual professionals involved 'are matters of fundamental scruple ... because for someone who believes in the absolute sanctity of life, there can be no truck with even passive measures which hasten death'. Although these authors say that 'every effort was made throughout to protect the identity of both study Units and individual respondents', they do give identifying details about the six departments participating (McHaffie and Fowlie,1997).

There is a difficulty to overcome, in that although there is recognition of the need for anonymity, supplying sufficient detail to justify the choice of sample may compromise the principle.

In another study, Simpson (1997) used participant observation of the activities in an ICU to complement data obtained in unstructured interviews. As her focus was on nurses who were caring for hopelessly-ill patients, there were very real issues of confidentiality and the maintainance of anonymity under these circumstances. Simpson (1997) says that she 'had no formal connections' with the ICU involved, but where practitioner-researchers are the working colleagues of research subjects, additional concerns about anonymity are raised, as well as threats to internal validity.

Sampling

Sampling is an issue whatever the research approach, and in this study, choices had to be made about which ICU's should be invited to participate.

When this project was begun, there was little empirical work in the specific area of the impact on nurses of real decision-making and its consequences, and the intention was to carry out an exploratory study to raise awareness in this increasingly-important aspect of the work of intensive care nurses.

Robson (1993,p.141) discusses the use of convenience sampling, that is 'choosing the nearest and most convenient persons to act as respondents', and suggests that 'all kinds of largely unspecifiable biases and influences' are likely to be introduced, but adds that the method may be sensible in 'getting a feeling for the issues involved or piloting a proper sample survey'.

The sample sought for this first part of the study was nurses who had been recently involved in the care of a patient in ICU who had been the subject of a treatment-withdrawal decision within the previous two months. Recency was important because of the need to recall details.

In any one ICU, it is not possible to predict accurately the number of such decisions in a two-month period, because the incidence varies, so it was not possible to estimate the size of the potential sample. Mortality rates vary in ICU's with patient acuity and range from the 10-

13% reported in departments where the patient population includes both ICU and high-dependency patients, to the 20-25% reported in departments, often tertiary-referral centres, taking patients where illness-severity is greatest. Of these, estimates of the frequency of treatment-withdrawal decisions associated with the deaths of patients range from the 40-60% quoted by Phelan (1995) to the 90% more recently in North America by Luce (1997).

A convenience sample of twelve adult and neonatal ICU's was chosen by the researcher for this exploratory study. Units were invited to participate where there were professional contacts with whom the researcher had previously studied or worked in the critical care field, because these people were willing to support the project, facilitate access and encourage participation. Highly-specialised departments were not included becuase it would have been necessary to have at least two Units of the same speciality, in order to avoid easy identification of the source from the patient's diagnosis.

Preliminary access was obtained through telephone contact with department managers. Where they agreed to allow staff to participate, more-detailed written information was sent, asking the manager to discuss the project with staff, then write back to confirm or refuse access. The researcher offered to talk about the proposed project with staff, if wanted, and one Unit took up this offer.

None of the Units approached required submission of the proposed project to an ethical committee prior to carrying out the survey.

The number of Units participating was determined by rough estimates of the number of treatment-withdrawal decisions in relation to department size, and the desire of the researcher to obtain data about approximately sixty situations from a number of different Units. On this basis, the researcher planned to distribute questionnaires according to the number of available ICU beds/ cots in each department.

As the researcher had worked as a senior nurse and teacher in a variety of critical care settings, handwriting-recognition was a realistic possibility, enabling identification of individuals. A system was devised in which respondents would return handwritten responses in addressed envelopes supplied to the University department, where the material was transcribed before being passed to the researcher. Questionnaires were not coded in any way, and postmarks were not revealed to the researcher, so sources of data were concealed.

Strategy

Timetable: Phase one

February, 1995	Access permission sought and gained for 10 ICU's and 2 SCBU's
April, 1995	Pilot study
September, 1995	Questionnaires disseminated, to be returned by October
October, 1995	Letters expressing appreciation sent to participating Units
	Analysis of phase one
	Concurrent literature review
	Formulation of questions arising
January, 1996	Feedback to participating Units (summary of findings)

Timetable: Phase two

May, 1996	Development of second phase questionnaire
July, 1996	Access permission sought from two centres
August, 1996	Access granted to both centres, with one requiring ethical committee approval, which was granted
August, 1996	Pilot study followed by amendments to instrument
August, 1996	Questionnaires disseminated, to be returned by October
October, 1996	Letters expressing appreciation sent to participating Units
	Analysis of phase two
	Concurrent literature review
January, 1997	Feedback to participating Units (summary of findings)

Questionnaire one (appendix 1)

Respondents were asked to focus on a recent specific incident in which they had been involved where a treatment-withdrawal decision had been considered.

One objective in this questionnaire was to obtain descriptions of the context in which the decision was being made. This included information about the patient's age-group, initial diagnosis and complications.

Next, nurses were asked to report on the participants in discussions and give some assessment of their relative influence in decision-making, because evidence from the literature would indicate that nurses may feel powerless even when they hold strong views about the rights or wrongs of a particular situation, or when they feel that they must support the views of the patient or family.

Nurses were asked to consider the facts as they perceived them about the reasons for a treatment-withdrawal decision to be considered, and for other influencing factors. They were asked to assess the adequacy of their knowledge about ethical decision making because it is self-evident that the better-prepared and confident nurses are, the more likely it is that they will feel able to fulfil their obligations regarding advocating-for, and defending, their patients' interests.

A question was asked about whether they saw their own views as more or less important than those of the patient and family. Nurses were therefore being asked to consider the possibility that patients and/or families' views could be at odds with professional opinions about treatment outcomes, possibly because of differing values.

Events subsequent to the decision being taken were next explored, including actions taken by nurses and others to reduce the treatment being given to the patient, because the issue of feelings of causation in relation to the patient's death is relevant here. Communication patterns amongst those involved were also sought.

The next sections of the questionnaire covered nurses' feelings about whether or not the right decision had been taken, together with some exploration of nurses' reflections on the nature of the team within which they worked, and whether there had been support available from this source. Data about possible conflicts among team members were also requested.

Nurses were then asked to reflect on the best and worst aspects of the situation described, and this offered them the opportunity to give some detailed views of key aspects as they saw them.

The final section sought views of nurses about another treatment-withdrawal situation where some aspect still upset or troubled them. The intention was to elicit information about particular situations which continued to affect nurses, and perhaps influenced their attitudes and feelings towards such events.

Process

A pilot study was carried out in one ICU, involving 10% of the projected sample size, to test both the questionnaire and the system set up for maintaining anonymity of respondents. No modifications were necessary to either instrument or process, so the study proper began in September, 1995. An acknowledged weakness of this system is that it was impossible to have certainty that nurses from all twelve participating Units had actually taken part, but as only between five and ten questionnaires were distributed to each Unit, 102 questionnaires in total, the responses obtained represented a range of opinion from 47 individual intensive care nurses from up to twelve different settings.

Analysis of these data were carried out.

Quantitative data were analysed and descriptive statistics produced using SIMSTAT statistics programme. Qualitative data were analysed by compiling all responses to each question into one document, then using a manual process of categorisation similar to that described by Burnard (1991), with the objective of identifying issues, then gradually grouping these items into themes, all the time ensuring that the link with the contextual detail was maintained, so that the sense and meaning intended by the respondent were not lost. The intensity of feeling was apparent in respondents' answers, usually from the choice of words and degree of emphasis, and it was possible to reflect this in reporting data. It was also possible to report how frequently items such as words or phrases occurred, and these data gave indicative information of how prevalent such feelings or concerns were amongst the group of respondents. The themes derived from these data gave some answers to particularly research questions 3 (participants), 7 (timing), 8 (inappropriate prolongation), 10 (acceptability of non-participation, 11 (nursing roles), 13 (responsibility for decision and actions), 14 (disquiet and concerns), 16 (family concerns) and 17 (methods of coping), and enabled theory development regarding these areas. Validation of the derived themes was initially carried out with the research supervisor.

Because of the issues arising, a further survey was planned, this time using hypothetical, case-study vignettes, constructed around the main areas which warranted additional probing. The material from phase one, including the derived themes, was discussed with the professional colleagues described below during the development of the phase two vignettes and questionnaire.

The literature review was also extended at this time, both for updating purposes and to explore areas prompted by topics and questions raised earlier by respondents. It was necessary to do this because of the duration of the project and the increasing topicality of ethical matters in intensive care practice in the mid-1990's.

Questionnaire two (appendix 2)

General aspects

This questionnaire consisted of five realistic case-study vignettes and a series of associated questions for respondents to complete themselves.

In three vignettes, the situations depicted replicated the ethical dilemma described by specific respondents in the first phase, as detailed below, with clinical contextual elements supplied by the researcher. Use of these scenarios enabled comparison between the views and feelings of these individuals and the second, larger group. The remaining vignettes portrayed situations which were indicative of the dilemmas raised by a number of respondents, and were constructed by the researcher from clues supplied by respondents, informed by knowledge of likely clinical events. Where possible, a variety of elements were incorporated into the vignettes, but selectivity was essential to ensure that this second questionnaire was an acceptable length to potential respondents.

General areas explored in the vignettes covered:

1. Doubts about patient autonomy where patients are unable to participate in decision-making.

2. The role of family members in decision-making and the extent of their influence. In the first phase, there were seventeen situations in which family requests to cease treatment were a factor. Nurses did not necessarily agree that families should carry the burden of the final decision.

3. Quality of life was an important factor for 75% of nurses when considering influences on decision-making, and the researcher wanted to identify clues which nurses were using about the patient's previous, present and predicted quality of life, to form their own opinions about what should be done. This was felt to be particularly important where the outcome was uncertain.

4. Whether nurses felt that their knowledge about ethical decision-making was sufficient to equip them to carry out their professional role.

5. Whether nurses do have qualms about their actions in connection with treatment-reductions.

6. Moral issues surrounding the use of analgesia and the reduction of inotropic (cardiovascular support) drugs and the proximity of these actions to the death of the patient, raising anxieties about euthanasia.

7. The importance of the ethical principle of veracity, truth-telling, throughout the handling of situations, so that nurses can maintain the trust and rapport which they felt was fundamental to the professional role.

The 'best and worst aspects' section in the questions following each vignette was incorporated to form a link between the first and second phase and enable comparisons to be made between the two groups of respondents about their feelings.

Specific aspects

Vignette one

The situation portrayed in this vignette is typical of many of those described in phase one, in which the patient has abdominal sepsis, has multisystem failure despite maximum treatment, and is aged over 70. Although there is not absolute certainty, statistical evidence concerning such situations is that the probable mortality is 100% with three or more body systems failing for over five days. Nurses were questioned about the importance of truth-telling and their actions in connection with inotrope reduction, thus exploring the moral difficulties projected here which had been raised by nurses earlier.

Using the grounds cited by nurses in the first phase, this group of respondents was asked to justify their decisions under these circumstances. The next question mirrored the situations described by nurses in the first phase where patients had died immediately following treatment-reduction, and this enabled testing of nurses' feelings about proximity to euthanasia.

Vignette two

This situation replicated that described by one respondent, although the contextual detail was supplied by the researcher. The nurse involved had been very distressed over the sudden death of the patient directly as a result of his/her action, and the researcher wanted to explore how others would feel under these circumstances.

Vignette three

Vignette three again mirrored a situation described by a nurse in phase one, with the researcher supplying the likely contextual detail. This nurse had disputed the withdrawal decision taken, and the intention was to test how widespread this disquiet was, when patients lacked capacity to give their own views.

Many of the probable clinical clues were given by the researcher, for example, the number of hospital admissions in the previous year, which indicated worsening of the chronic problems. The situation portrayed was likely to be familiar to nurses who would therefore have supplied their own details and insights about indignities associated with recurrent gastro-intestinal bleeding. The nurse in the first phase had been unhappy about the amount of influence exerted by a relative, so the researcher's intention was to ask the second group or respondents for their ideas of who should participate-in, and have influence on the decision taken.

The final question associated with this vignette concerned an intrusive test requested by doctors which would be of no benefit to the patient involved, and this type of moral problem was identified by a number of nurses in the first phase who had qualms, not only about the inappropriateness of the experimentation and intrusion as they saw it, but also about the lack of opportunity to obtain the patient's consent.

Vignette four

The researcher's intention was to explore the issue of quality-of-life assessment, retrospectively and prospectively, and its influence on decision-making. The vignette also portrayed a situation in which the nurse knew the patient well and would have been in a position to make an informed judgement about the patient's views on treatment, and could, therefore, represent those views in discussion. Differing views among the team members were also introduced, which would have complicated decision-making, as differences and conflict between doctors featured in nurses' descriptions of aspects which troubled them in the first phase.

Aspects of this situation would again have been familiar to most ICU nurses, who could then have easily imagined the patient's distress associated with attempts at weaning from the ventilator, especially where it was apparent that success was unlikely.

Questions related to this vignette explored nurses' feelings about each of the options likely under these circumstances, especially the extent to which nurses supported the patient's wishes. One question specifically explored nurses' views about who could best advocate for the patient.

The use of diamorphine under these circumstances was also questioned, as this type of moral dilemma where opiates were used to relieve distress during treatment-withdrawal, rather than to treat pain, did occur in situations in phase one. Supporting this approach did indicate acceptance of the double-effect principle.

Vignette five

This vignette incorporated a variety of issues which arose in the first phase.

The hypothetical patient was relatively-young and had become very ill unexpectedly after elective surgery, a situation which nurses had described earlier as being particularly difficult to comprehend and support families through.

In the situation described, the patient, as a result of surgical complications, would have been severely disabled if she had survived, and nurses were asked to consider whether they felt that the patient would have wanted to live with such a change in her way of life. Respondents were also asked to indicate what they would probably do if faced with this dilemma. The indication from the earlier phase was that whatever their personal views, nurses felt most satisfied with such decisions when the views of all relevant parties were sought, and consensus decisions reached. In this phase, nurses were therefore asked who they felt should be consulted.

Process

The vignettes and questionnaire were devised by the researcher, with the objectives outlined above. Vignettes were modelled on examples from literature cited earlier, particularly those exploring the nurse's role in ethical decision-making (Ott,Nieswiadamy,1991; Davis,Slater,1989; Grundstein-Amado,1992; Ketefian,1989). The researcher's insights were invaluable at this stage in the provision of realistic, but hypothetical, clinical contextual detail. Similarly, the language used in both vignettes and questions would have been familiar to nurses in ICU's, so readily accessible, and because of this, more engaging.

Two professional colleagues scrutinised this second questionnaire. They were experienced and well-qualified in intensive care nursing and had worked as senior nurses and teachers in the field for many years. Both colleagues held Masters degrees, one in Nursing, and the other in Law and Ethics. The former had research interests in policy-development in ICU's and nursing roles in this, and the latter had a particular interest in the role of clinical ethicists in intensive care. Both examined the instrument critically and offered supportive and helpful suggestions about possible modifications which were responded-to.

Before submission to the Research Ethics Committee, approval of the questionnaire had to be gained from the Director of the Research Department within the School of Health Care where the researcher is employed (not the department where registered for the higher degree). Ethics Committee approval was then sought and gained, with their advice followed about modifications, primarily to the accompanying letter rather than the instrument itself.

A pilot study of this second questionnaire was then carried out in one ICU, using 10% of the projected sample size, and nurses in this department made very helpful suggestions about modifications to questions, the accessibility of the vignettes and questions, the language used, the length of the questionnaire and the options available. Minor modifications were made to the questionnaire, shaped by the feedback from informants taking part in the pilot study.

The researcher was able to gain access to an ICU which had a clinical ethicist, so for the second phase, this Unit, plus another of comparable size, were involved, with the objective of making some comparisons between the two. Ethical and legal issues were important to nurses in the first phase, so it was very useful to be able to take advantage of this offer.

60 questionnaires were distributed to the two Units, with all nurses being invited to participate, and 33 (55%) were returned.

Analysis of qualitative data was carried out using the same process as in phase one. Quantitative data were analysed, descriptive statistics produced, and two-centre tests of comparison using the Mann-Whitney-U test were carried out using the SIMSTAT statistical programme.

Reflection on methodology selected

The sensitivity of the material which might be collected was thought by the researcher to be of over-riding importance in the selection of an appropriate method to be used to obtain data, and although other researchers cited (Viney,1996; Simpson,1997) had used face-to-face interviews in similar circumstances, this researcher felt that absolute anonymity of hospitals, departments, patients and nurses had to be preserved.

Using a phenomenological approach would have enabled exploration in much greater depth of the feelings of nurses about their involvement in these situations. An ethnographical approach, using participant or non-participant observation would have been helpful, particularly in exploring the roles of, and interactions between, participants in decision-making, however, on ethical grounds, this researcher could not support the strategy because of anxieties about the intrusiveness of a researcher under these circumstances. It would be useful in a future study to explore this issue further, ideally in a multidisciplinary session which was taking place away from the clinical area, using a real or hypothetical case study, with the purpose of identifying methods of effective facilitation.

Another factor which strongly influenced the decision about method, was the need to include data from different ICU's, because it was apparent from personal experience and evidence from the literature, that the management of such situations varied considerably.

The decision was therefore taken to collect data using a questionnaire developed by the researcher, in order to carry out an exploratory, descriptive study.

The acknowledged limitations of using the methodological approaches taken are, firstly, that the use of a respondent-completed survey precluded the detailed exploration and probing of participants' own thoughts, ideas, concerns and attitudes. The use of questionnaires is inevitably prescriptive, in terms of the topic areas covered.

Secondly, the 'remote' approach adopted meant that the actual number of participating centres could not be ascertained.

Thirdly, although pilot studies were carried out with both questionnaires, there were still ambiguities which made the interpretation of some answers more difficult. In questionnaire two, vignette one, question 1.2A, for example, there was uncertainty over whether respondents meant that they were unhappy about reducing support drugs because of concerns about dishonesty with the family, or because of disquiet over drug-reductions associated with treatment-withdrawal.

Fourthly, although the intention was to compare findings from the two centres in the second survey, it was impossible to establish whether the lack of differences was real, so despite the exposure of nurses from centre two to a clinical ethicist, which meant that 'ethics' had a high profile in the department, and nurses were exposed to ethical debate, the nurses from both centres had similar knowledge and attitudes. The alternative explanation could be that the instrument used was not sensitive enough to enable detection of differences.

Fifthly, the moderate number of returns with the use of survey methods is acknowledged. In this study, of the 102 questionnaires distributed to 12 centres for the first survey, 47 (46%) were returned, and of the 60 questionnaires distributed to 2 centres for the second survey, 33 (55%) were returned.

Sample

With the first survey, eligibility criteria for respondents where they needed to have cared for a patient where a treatment-withdrawal decision was considered within the previous two months, would have restricted the numbers of potential participants.

The other very-relevant fact is that ICU's are used as research sites frequently now that nurses are increasingly going into higher education, and the resulting pressure on departments to participate in projects is becoming a real problem (anecdotal reports from potential research sites approached). Considerate approaches to Unit staff are imperative, and researchers have a responsibility to demonstrate the extent to which they value the participation in project work by giving prompt feedback about findings, and by acknowledging the assistance given with completion of the project.

Lastly, because no specific sampling frame was used, the extent to which findings can be generalised is limited, so results have to be evaluated accordingly. The findings do represent the views of a group of 47, currently-practising, ICU nurses, whose attitudes and actions would have been shaped by those prevailing at the time.

Evaluation: first phase

The shortcomings of the questionnaire are now outlined.

Categorising patients into age-groups caused no problems, but the researcher did have to keep some information supplied by respondents about diagnoses confidential, because disclosure would have increased the likelihood of identification of the source of data.

The factual questions about the clinical condition prompting discussions, and the participants in those discussions covered predictable areas (space was allowed for other options) and there was evidence from the literature about the likely grounds to be included in discussions about futility.

With the factors listed in question three, it would have been helpful to ask respondents to consider how much influence the identified ones had on the decision, that is, to offer a scale similar to that in question six. Question six was not answered consistently as respondents did not assign a tick to each person listed, so, on analysis, cross-referencing with question one had to be carried out. The relative influence of those people who had participated though was indicated, and it was therefore possible to rank them.

In question seven, the options supplied are all predictable from literature and from experience. The question was intended to cover the tasks undertaken by nurses following instructions given by doctors. Further evidence was obtained in the sections asking nurses to identify the best and worst aspects of situations.

Question eight sought evidence from respondents about the person or people informing family members about the decision and the changes to be made to the treatment plan. This list should have included other options and spaces as others may well have been involved. One respondent said that no-one had explained, and that possibility was not included.

The communication channels between doctor and nurse were explored in the next questions, as evidence from the literature would indicated that nurses may have to care for the patient through treatment withdrawal but are not included in discussions, or have the opportunity to ask-for, or receive, explanations.

The listed options in question twelve were drawn from literature highlighting sources of distress, particularly moral, and frustration, and respondents were given the opportunity to add comments, which some did. The list could have been more comprehensive. Certainly a more-extensive list could have been compiled from the findings in this study, and this should be recognised in any replication.

The remaining questions were answered well and complemented the data obtained earlier.

Having acknowledged these limitations, the researcher feels that the material obtained was detailed, fascinating and very helpful. In the first phase, the data allowed an insight into not only the 47 situations described, but also the 32 situations which respondents felt had continued to upset or trouble them in some way.

In their responses, nurses shared concerns and misgivings about situations in which they were involved. Replies were thoughtful and constructive, and reflected the very-real distress associated with the care of some patients when ideals of a 'good death' could not be achieved, and desirable objectives, in terms of the maintainance of peace and dignity for patient and family, were not attainable.

One could speculate on the fact that there was very little disagreement among nurses over the decision taken, just two respondents saying that they disagreed with the decision in the main situation described, and three disagreeing with the decision when reflecting on the 'troubling' cases. This is not surprising. The vast majority of respondents were experienced nurses, and they would be able to weigh up the facts of situations, and make considered judgements about the expected outcome for patients in the same way as the ICU doctors. The main purpose of this project was to explore the feelings of nurses about treatment-withdrawal decisions in specific instances, and the information obtained does allow considerable understanding of the process involved and the effects on nurses. Nurses not only commented on their disquiet and their objections, they also identified sources of satisfaction and highlighted recommendations for good practice.

Nurses then, to a very large extent, supported the withdrawal decisions taken but they did express many reservations about aspects of each situation which are important to discuss and remedy where possible.

Despite its limitations, then, the findings of this phase demonstrated successfully the roles nurses have in these situations and the effects on them of such decisions.

From these data, issues were raised which indicated a need for further study.

Evaluation: second phase

In the second phase, it was apparent that nurses were engaged by these vignettes, and the findings from this second phase confirmed the fears and concerns expressed by nurses in the first phase, as well as corroborating some views held about modes and practicalities of treatment-reduction and withdrawal.

Although the second-phase instrument was generally successful, there were again shortcomings.

At the design stage, the number of issues and patient contexts had to be restricted because of constraints such as the need to keep the questionnaire to an appropriate length. It was, however, possible to incorporate a number of different elements in the vignettes, and they did represent likely scenarios.

In the questions where respondents were invited to give an answer to all option statements (questions 1.2B, 3.7), asking them the reasons for their decisions, they did not always do this, so data were missing concerning these questions. The format of these questions should be altered in any replication as although the content was appropriate, arising as it did from data in the first phase, respondents do need to know that an answer to each component is expected.

The other area for amendment is in the space available for respondents to give their views on the best and worst aspects. The length of answers did vary from one word to about a 100-word paragraph, and two or three lines extra for each of these sections would have enabled respondents to give fuller answers without leading them to think that a much-longer response was expected, which would have been off-putting.

Returns from the second phase were lower than planned, but nevertheless achieved the purpose of exploring specific issues raised in the first survey. The vignettes developed by the researcher did highlight some key concerns with ethical matters, and they were also very useful in illustrating legal aspects of these situations. They contributed to the identification of important issues for nurses and others. For these reasons, they may be helpful to others as a basis for discussion and for future research replication.

Strengths of project, phases one and two

As some measure of the success of this project in highlighting topical issues, reports of aspects of both phases have been published recently (Schneider,1997; Schneider and Young,1998).

Exploring the reasons for this success, albeit with limitations, the researcher feels that the insights available to a practitioner-researcher played a large part.

The language used in the questionnaires was readily accessible to respondents, and the questions asked would have conveyed to the respondents that the researcher understood the context in which ICU nurses are functioning during treatment-withdrawal situations. The technical detail used conveyed knowledge and acceptance of nursing activities and the difficulties involved.

In the vignettes, the situations described were realistic and readily understood by any respondent, who would then have been able to identify with the nurse caring for the patient. Some evidence to support this assertion came from feedback from participants in the pilot study.

It was apparent from the data that nurses empathised with the people in the dilemmas depicted, so these vignettes avoided the pitfalls where patient situations are not familiar to respondents.

The researcher's understanding of the problems associated with increased nursing audit and research activities, leading to many demands on staff for participation, meant that the instruments had to be constructed to enable easy completion and return. Sufficient detail to establish the credibility of the researcher was also given in the accompanying letter, to allay anxieties about disclosure of information and the maintainance of anonymity, and this was clearly accepted, judging by the sensitive and very-enlightening material supplied by respondents.

While the limitations are accepted, the purpose of this research was achieved, with insights gained into many aspects of nursing roles in these situations, particularly in areas such as concern over euthanasia, perceptions of helplessness and powerlessness, sources of satisfaction for nurses, the importance of the supportive team culture and the need for training in ethical debate. Although observation of the decision-making process in different departments and interviews with participants would have offered greater insight into the organisational culture, interpersonal relationships and communication, the respondents in this study gave many indications of aspects which helped or hindered matters with these situations.

In terms of construct validity, the first survey instrument did allow an exploration of the research questions, highlighting important areas. The second instrument was specifically designed to probe and test findings and theories arising from the first, and used examples of aspects of real situations to frame vignettes and questions. Scrutiny by both clinical experts and members of a research ethics committee also enhanced content and construct validity.

Methodological triangulation was used, in that two surveys were used to explore the same phenomenon, and some quantitative data were sought to support and complement the qualitative material. Essentially this was therefore a qualitative study, informed by some indicative and descriptive statistical data, so there are elements of both within-method and across-method triangulation, but if the definition by Morse (1991) is accepted, this study conforms to the requirements of within-method triangulation.

Conclusion

The areas identified for exploration were addressed as follows:

1. **The process of decision-making**

   Real situations were reported by phase one respondents in answer to a series of questions using pre-determined, comprehensive options derived from reflection on experience, informed by findings from literature. Question 12, phase one, enabled respondents to comment about differences of opinion within the nursing team, their feelings about coping and the value of team support, and specific concerns associated with nursing activities during treatment-withdrawal.

   Aspects of the process were explored further in phase two, as detailed above.

2. **Nursing roles in these situations**

   Roles in decision-making, informing and giving explanations to families, and activities during treatment-withdrawal were explored in phase one, using both closed- and open-ended questions. Each patient context in these real situations was obviously unique, and the research approach adopted did allow examination of not only the tasks involved, but also nurses' reflections of the good and bad aspects of their roles. With the second phase, there were opportunities for comparisons to be made between respondents in relation to the nursing roles in the hypothetical situations described.

3. **Stress and disquiet**

   In the section at the end of the first questionnaire, comments made by respondents about the worst aspects of situations were enlightening concerning specific problems which caused misgivings, and the instrument used allowed identification of concerns, some of which were probed in the second phase. Disclosure of many of the worst and troubling aspects of situations were a vindication of the success of the approach taken.

4. **Addressing concerns**

   The instruments enabled the respondents to suggest approaches to remedying some of the problems. The need for increased education in law and ethics, for example, was highlighted, as nurses felt that this would equip them better for the advocacy role they wanted to adopt, to ensure that the actions taken were in the best interests of patients. Some of the questions in phase one explored collegial relationships, and the instrument did enable disclosure of the importance of the culture in the department and the value of team support.

5. **Sources of satisfaction**

In both phases, nurses were able to identify some positive aspects and sources of satisfaction associated with caring for patients and families under these circumstances. The instruments did allow some conclusions to be drawn about the experience and preparation of nurses, standards of care, methods of reducing or counteracting stress, strengthening the role of the nurse in multidisciplinary decision-making, and the coping mechanisms which need to be supported to enable staff to continue to manage these situations well.

In conclusion, the researcher does have some misgivings about the approaches adopted from a methodological point of view because of the limitations identified. Further study is warranted in this area of nursing practice as it is increasingly of concern to practitioners. The issues have been highlighted very well in this study, and the extent of the problems needs to be quantified. Possible developments from this study, which would also then benefit from further research, include the implementation of ethical decision-making tools in parallel with expanded education programmes about ethical matters for nurses, with further studies to assess the impact on the activities and feelings of nurses. Analysis of the interpersonal dynamics and department culture in Units which are models of good practice would be of great value to all involved in such situations.

Analysis and report of findings

Report of findings from questionnaire one

Demographic Data

Gender

The respondents (n = 47) consisted of 38 female and 9 male nurses.

Years of nursing experience

Mean	13.641
Median	13.000
Mode	10.000
Minimum	2.000
Maximum	28.000

The majority of respondents had been nursing for between 8 and 18 years. Although no attempt was made to sample selectively, the group does represent a wide range of experience.

Years of ICU/SCBU experience

Mean	7.365
Median	7.000
Mode	8.000
Minimum	.500
Maximum	21.000

The majority had been working in these specialities for between 5 and 9 years.
If this group is indicative of the duration of service in ICU's, one conclusion that can be drawn is that despite the often-cited stresses, nurses find satisfaction in working in ICU's and SCBU's and are therefore willing to stay.

Numbers of patients by age group and diagnosis

Diagnosis	baby	child	teenage	young person	middle-aged	elderly
Abdominal sepsis secondary to perforation or cancer					3	17
Pancreatitis					2	
Abdominal aortic aneurysm					2	
Brain injury				1	2	
Endocarditis					1	
Chronic respiratory disease						2
Pulmonary embolus						1
Cancer of lung or elsewhere					2	1
Trauma				2	1	
Prematurity	9					
Totals	**9** **19%**	**0**	**0**	**3** **6.4%**	**13** **27.7%**	**22** **46.8%**

The exact age of the patient was not thought to be relevant to the findings, so was not sought. Respondents were asked to band patients. One inference from these data is that patients in general ICU's, about whom treatment-withdrawal decisions are being made, are likely to be in the middle-aged or elderly groups.

Participants in the discussions about treatment-withholding or treatment withdrawal?

In none of the situations described did the patient participate in discussions about treatment withdrawal, although it is apparent in situation 31 that the patient, having accepted the irreversible nature of his injuries, had indicated that he did not want the process of dying to be protracted.

That none of the patients was included in discussions is a reflection of the severity of illness in these situations. Patients were unconscious either as a result of their illness or as a consequence of the drugs being used to control pain and achieve control of ventilation, so were unable to talk, and in 9 of the situations, the patients were babies.

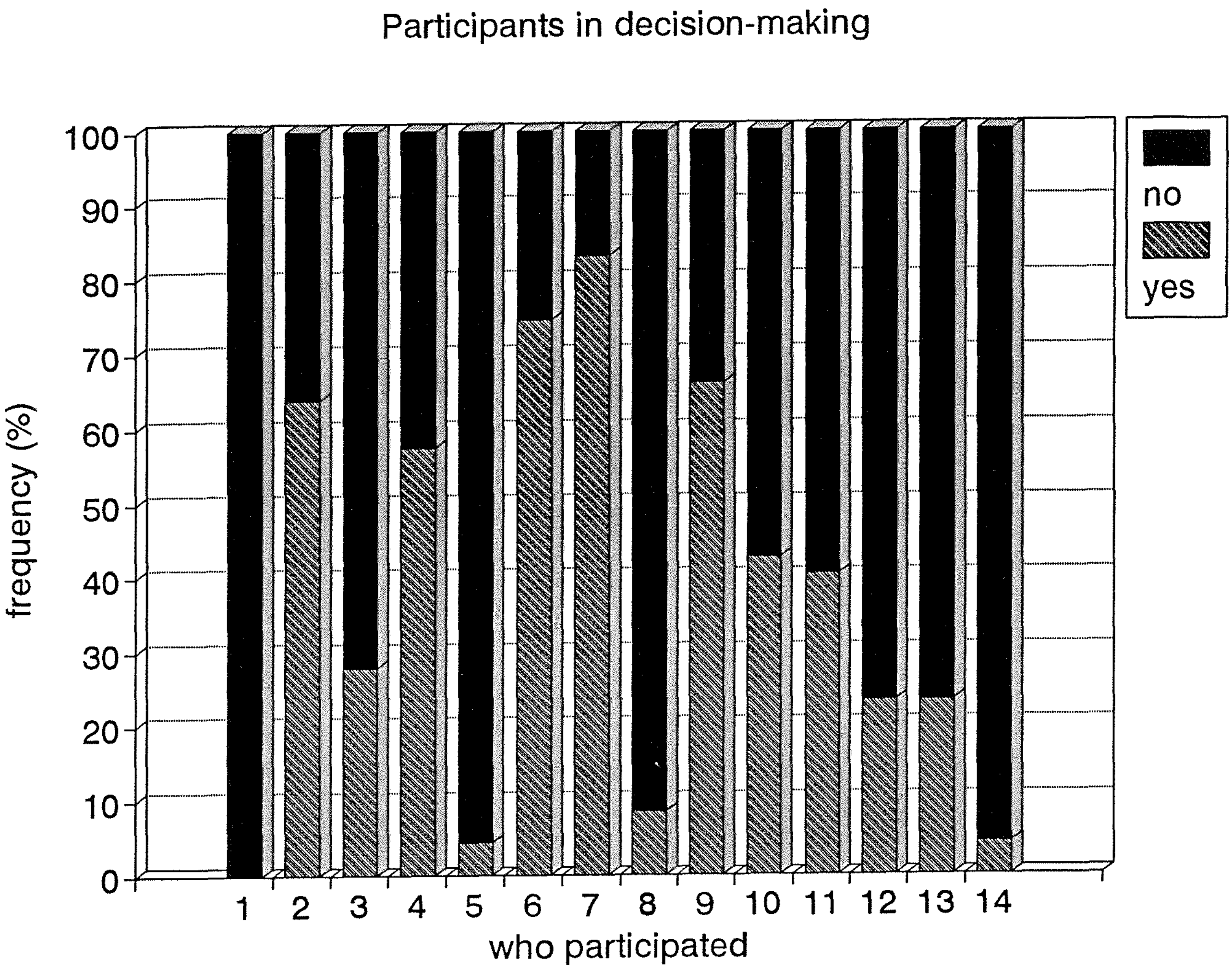
This inevitably means that the maintainance of patient autonomy is compromised, however in the majority of cases, family members were involved in discussions about treatment-withdrawal, either partners (63.8%), parents (27.7%) or sons/daughters (57.4%).

In all the situations involving ICU patients (38), the ICU Consultant participated in discussions and in the majority (74.5%), (which would include the SCBU babies being cared-for by Consultant paediatricians), the patient's own Consultant participated. In very few situations (8.5%) other doctors from the own Consultant's team participated and the majority of other doctors who participated (66%) were from the ICU team.

In the majority of cases, either the patient's nurse or the Sister, or both, participated in discussions but in 4 situations, no nurse took part. These situations all involved elderly patients. In 2 of these 4, the nurse describing the situations was experienced in ICU (13 and 9 years), in the third, the nurse had 1.5 years experience and in the fourth, the nurse was very junior, having had less than one year of experience.

In 11 cases, other participants were identified. 6 of these involved babies, and in these situations, other participants were grandparents (2), Chaplain (1) and 'all staff' (4).

In the remainder, they involved elderly (4) and middle-aged (1) patients, and the physiotherapist (2), Chaplain (1) and 'all staff' participated.



1. Patient
2. Patient's partner
3. Patient's parent(s)
4. Patient's son(s),daughter(s)
5. Patient's friend(s)
6. Patient's own Consultant (eg.surgeon,physician,paediatrician)
7. ICU Consultant
8. Another doctor (own doctor's team)
9. Another doctor (ICU team)
10. You, the nurse *
11. You, the ICU Sister/Charge Nurse *
12. ICU Sister/Charge Nurse (not you) *
13. Other
14. Other

* exclusive categories

The amount of influence each participant had in the decision-making process

This question explored the relative amount of influence which participants had in the decision-making discussions, from the nurse's viewpoint. Although none of the patients participated in discussions about treatment withdrawal, one patient did have some influence over the decision by communicating that a protracted dying process would be intolerable.

Family members did have influence in decision-making. The patient's partner had at least some influence in 32 (91.4%) situations, and carried quite a lot or the most influence in 19 (54.3%) situations. Where patients had parents, or sons or daughters, they also carried influence in many situations. Parents had at least some influence on 13 occasions (59.1%), mostly those concerned with babies, although they had the most influence in just three situations, all of which concerned babies. The other situations in which parents were involved and had some or quite a lot of influence were those concerned with two of the three young people and two situations concerned with middle-aged people.

Sons and daughters, where applicable, also played quite a large part in the decision-making, having at least some influence in 30 (85.8%) situations, and of this group, being reported as having quite a lot of influence on 15 occasions (42.9%) and the most influence on 3 (8.6%) occasions.

Friends played only a small role in the decision-making process but did have some influence in 5 (22.7%) situations, three involving middle-aged people, one a young person and one a baby.

Doctors, predictably, had the most influence in the decision-making process. The patient's own Consultant was reported to have at least some influence on 36 (76.6%) occasions and carried the most influence on 7 (17.9%) occasions. What is perhaps surprising is that there were three occasions when this doctor did not take part or had no influence, but the most likely explanation for this was that a doctor in that team represented the Consultant's views, or perhaps there was consultation by telephone which was not apparent to the nurse reporting. The ICU Consultant was by far the most influential in the decision-making process, being reported to have quite a lot, or the most influence on 37 (94.9%) occasions. ICU Consultants carry the responsibility for the care and treatment of patients in Units, so it is logical that they should be in a position when appropriate to judge when to initiate discussions about treatment-withdrawal. As the experts in the field, they are likely to be seen by the nurses involved as carrying the most weight, and carrying the most influence in these decisions.

Nurses also played a role in the decision-making but felt that they had less influence in the process. Predominantly, respondents reported that nurses had some influence. In the nineteen situations where the Sister/Charge Nurse was reporting that he/she had taken part, they felt that they had quite a lot of influence on eight occasions and the most influence in one situation.

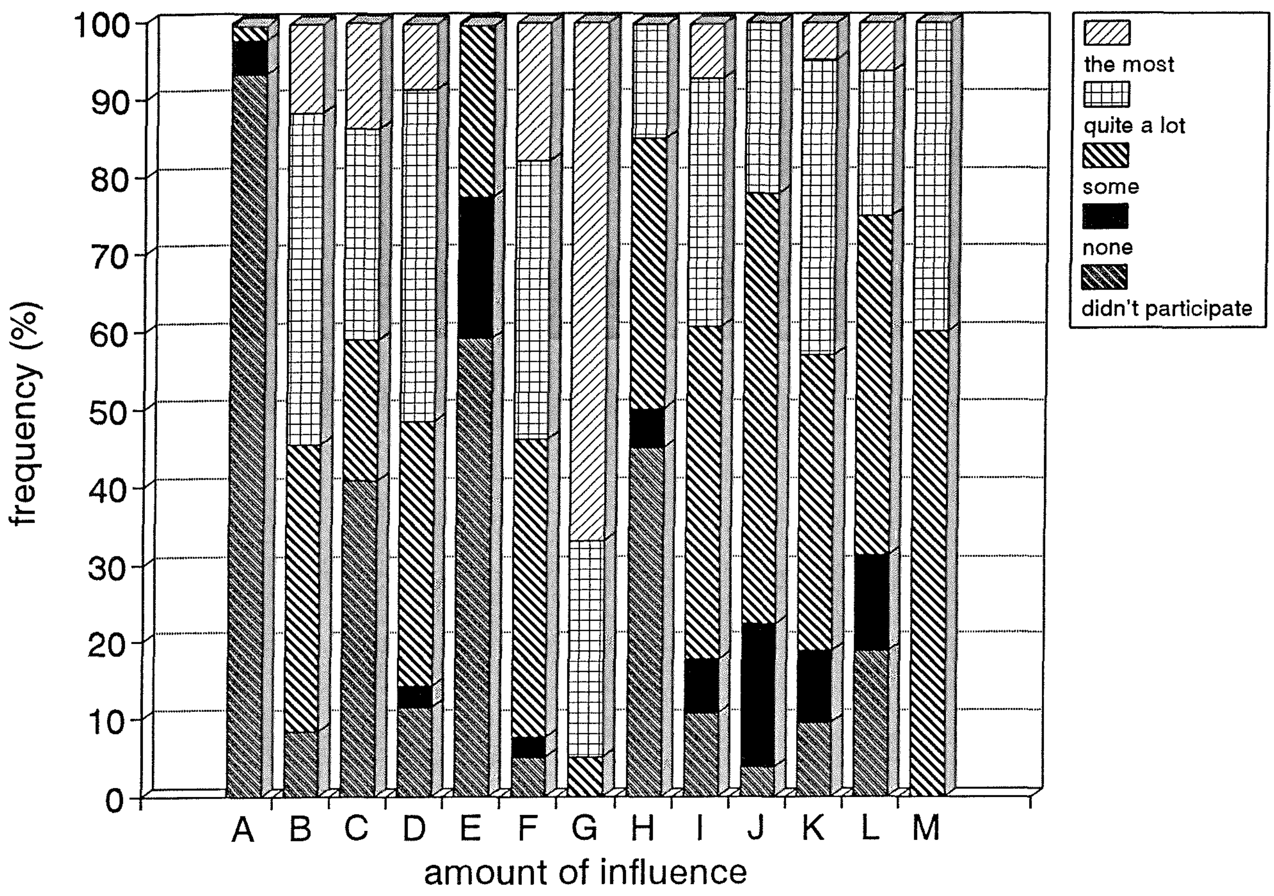
Nurses' influence in relation to the age of the patient

Age group of patient (actual numbers)	Baby (9)	Young person (3)	Middle-aged (13)	Elderly (22)
No influence		2 (15.3%)	5 (71.4%)	2 (7.4%)
Some influence	4 (36.4%)	6 (46.2%)	2 (28.6%)	18 (66.6%)
Quite a lot of influence	6 (54.5%)	4 (30.8%)		7 (26%)
The most influence	1 (9.1%)	1 (7.7%)		
Total number of reports of nurse participation	11 (100%)	13 (100%)	7 (100%)	27 (100%)

From the above table, which accumulates information compiled from questions 6J, 6K and 6L, and relates it to the age groups of patients, it can be seen that nurses taking care of the nine babies (the SCBU group) always felt that they had at least some influence in the decision-making discussions and more than half felt that they had quite a lot, or the most influence. If this is compared with the group of nurses reporting about the 22 elderly patients, two felt that they had no influence at all, 18 (66.7%) had some, and just 7 (26%) felt that they had quite a lot of influence.

Although the group sizes are very different, there is a definite trend for SCBU nurses to feel that they have more influence in discussions than those nurses caring for the elderly patients in this study.

Other participants who carried at least some influence were for example, the grandparents, Chaplain, or physiotherapist, but this represented only a small group of ten in total.



Participants and their influence

Key (reported group size in brackets)

A. Patient (n=44)
B. Patient's partner (n=35)
C. Patient's parent(s) (n=22)
D. Patient's son(s),daughter(s) (n=35)
E. Patient's friend(s) (n=22)
F. Patient's own Consultant (eg.surgeon,physician,paediatrician) (n=39)
G. ICU Consultant (n=39)
H. Another doctor (own doctor's team) (n=20)
I. Another doctor (ICU team) (n=28)
J. You, the nurse (n=27)
K. You, the ICU Sister/Charge Nurse (n=21)
L. ICU Sister/Charge Nurse (not you) (n=16)
M. Other (n=10)

Factors which prompted discussions about treatment-withholding or treatment-withdrawal.

In 4 (8.5%) situations, brain-stem death was diagnosed and these involved 2 young patients and 2 middle-aged patients.

In the majority of situations, a failure of a vital organ system (72.3%) and/or a failure to respond and improve on maximum inotropic drug support (55.3%) were the triggering factors, prompting discussion about treatment-withdrawal. This reflects situations in which very sick patients have been given treatment in attempt to reverse their illness and prevent further progression and deterioration, but despite this, have not responded.

In 7 (14.9%) cases, metastatic disease was diagnosed; in 10 (21.3%), an irreversible illness or injury was diagnosed, and in 5 (10.5%) a new illness in the presence of chronic health problems was present, and these reflect the multifactorial nature of these patients' illnesses.

In 1 (2.1%) situation, the patient requested cessation, and in 17 (36.2%), the family requested discontinuation of treatment.

In 6 (12.8%) situations, another factor prompted discussions and these included:

-a diagnosis of likely severe brain damage in a baby with meningitis

-severe, multisystem disease in a baby

-a recognition that a middle-aged patient would need major, disfiguring surgery in attempt to reverse the already severe problems

-an elderly person who had cancer and for whom further surgery for the same disease would have been inappropriate

-a middle-aged person who had a newly-diagnosed malignancy and who had a significant underlying psychiatric illness

-a baby who was in respiratory failure but to whom, due to congenital anatomical problems, it was impossible to give breathing support.

Requests from family to discontinue treatment

There were 17 situations in which one trigger was a family request to cease treatment, and these involved four babies, six middle-aged people and seven elderly people. It was always one of two or more triggering factors. In none of the situations did the nurse report specifically that he or she supported the withdrawal decision because this was what the family wanted, but in some, this fact reinforced the views of the nurse.

In 5 of these situations, the nurse felt that the family's views should be paramount, although in one situation, this was qualified by the nurse saying that their views should be paramount 'if they can make informed decisions, which in ICU they frequently cannot'. In one of these situations, the nurse commented that 'the partner was strongly in favour of withdrawal' but only had some influence in the decision.

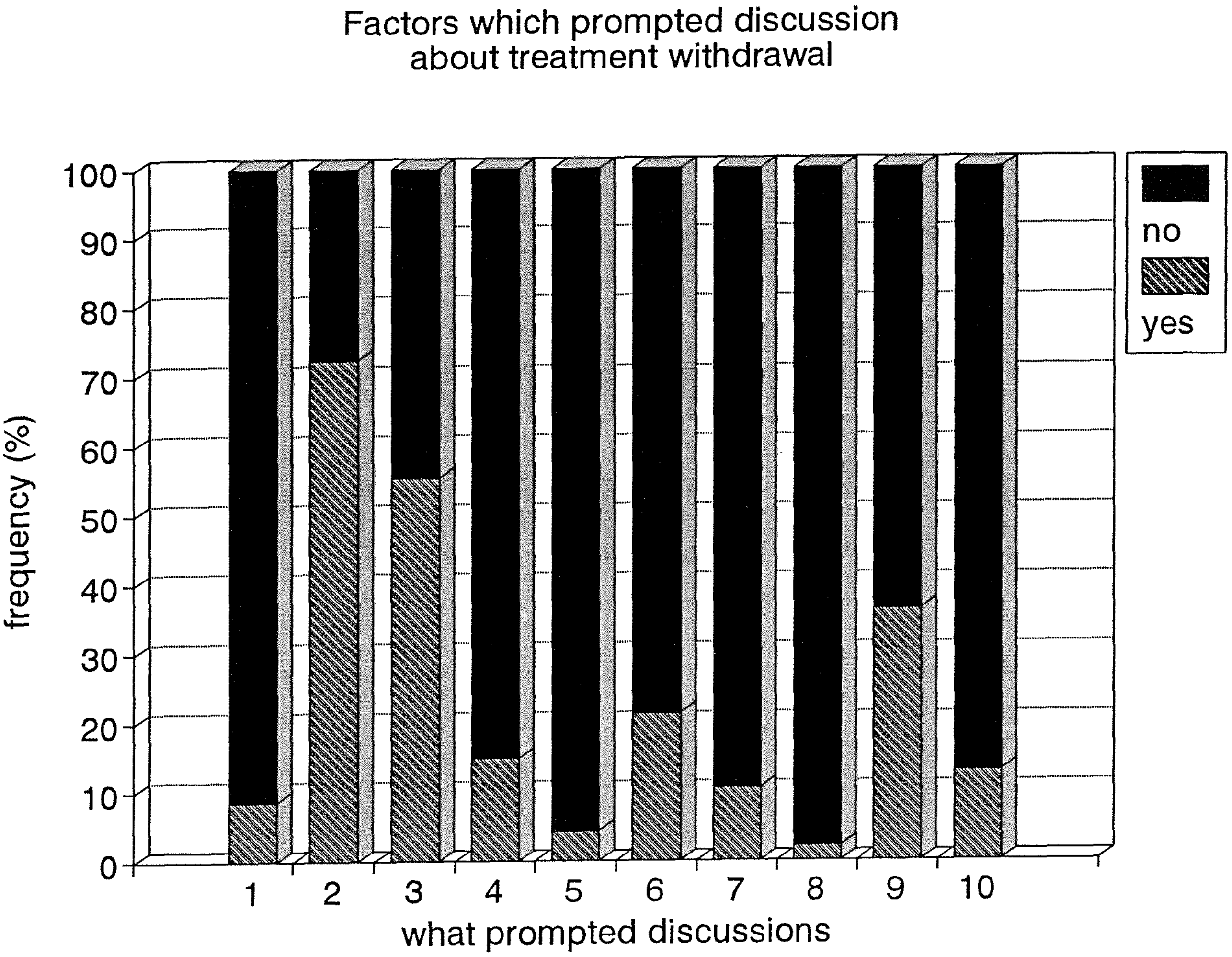
In 7 of these 17 situations, the nurse disagreed that the family's views should be paramount. In one involving a baby, the nurse felt that although the family requested cessation of treatment, professional views were very important and that 'we shouldn't let families bear the burden of guilt about the decision'. In another of these situations, involving a middle-aged person, there was a major issue over the anticipated poor quality of life if the patient survived and the family said that 'the patient would not want to live with such a change in life'. Both the nurse and the family had quite a lot of influence in the decision. Where a middle-aged person's family requested cessation and had quite a lot of influence, the nurse still felt that the family members needed a lot of support through the treatment reductions and withdrawal process. In a situation involving a baby, the parents had the most influence, but all team members participated in the decision and agreed with it, and the nurse commented that 'we tend to guide parents towards a decision, but ultimately the decision is theirs'.

In 5 situations, the nurse was unsure about whose views should be paramount. In one of these, involving a baby, the nurse said that 'for religious reasons, some nurses in the team thought that withdrawal was wrong' and in another contentious situation involving a middle-aged person, the nurse said that there was conflict among the nurses over the withdrawal decision and that he felt strongly about something but was not listened-to. In another of these situations, the nurse said that she was satisfied that the family felt that 'the patient had received excellent care', were grateful for this and supported the process.

No particular features of these situations seem evident from this review. Where families had requested cessation, the numbers of patients in each age group were quite even. Similarly, the fact that the family had requested cessation did not seem to have increased the likelihood that the nurse should feel that their views should be paramount.

Relationship between whether family views should be paramount (question 5) and age group of patient in the sub-group in which the family had requested cessation of treatment

Feeling about whether family views should be paramount	Baby	Middle-aged	Elderly
Disagree	3	3	1
Agree	0	1	4
Unsure	1	2	2



Factors which prompted discussion about treatment withdrawal

1. Diagnosis of brain-stem death
2. Failure of an organ system eg. kidneys, liver, heart
3. Failure to respond to maximum inotropic/cardiac support
4. Pathology report of metastatic disease
5. Pathology report indicating irreversible disease
6. Diagnosis of irrecoverable injury or illness from x-ray test or similar
7. Diagnosis of new illness in presence of a number of chronic medical problems
8. Patient requested cessation of treatment
9. Patient's family, or appointed next of kin, requested cessation of treatment
10. Other

Other factors which had some influence in the treatment-withdrawal decision

This question asked nurses what other factors, apart from the clinical conditions, they felt had influenced the treatment-withdrawal decision and it sought nurses' perceptions of what had impinged on the decision-making process.

Prominent among the responses was the 'anticipated poor quality of life if patient survives' with 35 (74.5%) of nurses saying that this was a factor. Another major influence was the age of the patient (21 or 44.5%), with two-thirds of these situations involving elderly patients and the remainder divided evenly between babies and middle-aged patients.

Factors such as cost of treatment (2 or 4.3%), predicted outcome from scoring system (1 or 2.1%) and advance directive (1 or 2.1%) were all mentioned. Religion was only mentioned once in the category 'religious beliefs of a health care team member' and this was not expanded-on. This last situation involved an elderly patient and although the (experienced) nurse did support the decision to withdraw, she did not agree with the 'inappropriately-high' amounts of analgesia which were going to be administered. Bed shortage was cited by 3 (6.4%) respondents and these situations all involved elderly patients who had multisystem failure, with other factors such as age, poor predicted outcome and quality of life, and irreversibility of illness also given, with one respondent adding that continued treatment would 'extend suffering' and would be 'an inappropriate use of precious resources'. Even in the context of such ill patients, it is still notable that respondents cited 'bed shortage' as a factor.

Social factors were mentioned by three respondents, to whom this meant that families were already enduring stresses, which, if prolonged, with no reasonable likelihood of a good outcome, were unacceptable. These situations included a baby with pulmonary hypertension and poor growth, a middle-aged person with multiorgan failure, and a middle-aged person, with a husband and family, who had a psychiatric illness. In two of the three, families requested cessation of treatment.

Other factors identified by 13 (27.7%) nurses were,

'Brain-stem death'

'Patient's condition not compatible with life' (one an elderly person with abdominal sepsis and the other, a baby)

'Relatives' wishes' (elderly person with cancer)

'Surgery may have been successful but patient unlikely to survive surgery' (a middle-aged person with complications following aneurysm surgery)

'Long-term prognosis poor' (elderly person with cancer and abdominal sepsis)

'No response to drugs and treatment' (2 elderly people with abdominal sepsis)

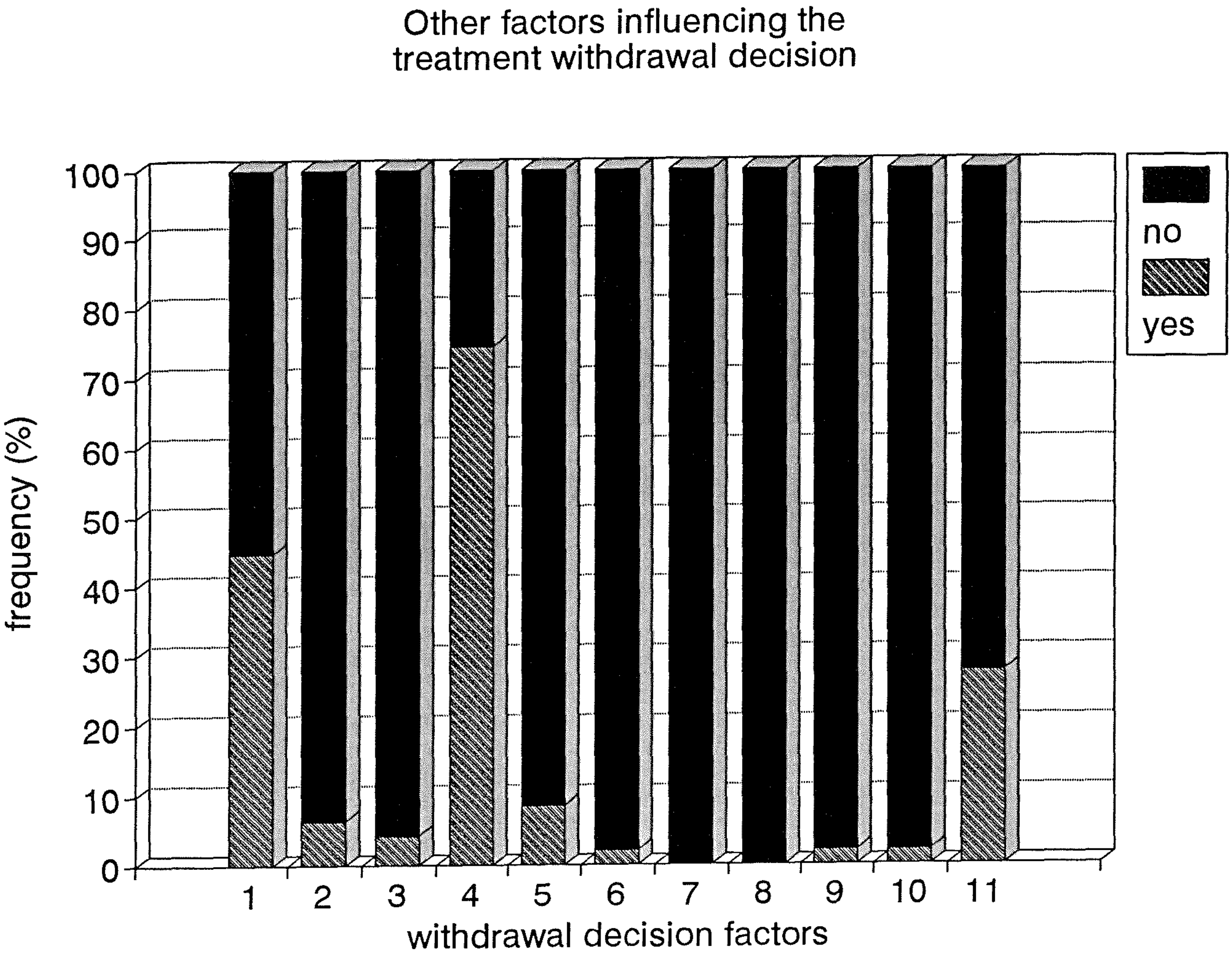
'Family wished for patient not to suffer' (elderly person with abdominal sepsis)

'Certain outcome death' (middle-aged person with severe injuries)

'Multisystem failure' (elderly person with sepsis)

'Unlikely to survive' (young person with severe injuries)

'Continuing deterioration despite maximum support' (middle-aged person with heart disease and complications)



1. The age of the patient
2. Bed shortage
3. Cost of treatment
4. Anticipated poor quality of life if patient survives
5. Social factors
6. Predicted outcome obtained from scoring system
7. Patient's religious beliefs
8. Religious beliefs of patient's family
9. Religious beliefs of a health care team member
10. Advance directive (living will) from patient
11. Other

Whether knowledge about ethical decision-making was sufficient

In response to this question, 32 (68.2%) said that they did feel that they had sufficient knowledge about ethics to enable them to take part in discussions, 2 (4.3%) said that they did not, and 13 (27.7%) were unsure.

Further analysis was carried out looking at gender in relation to the responses to this question and exploring the influence of years of ICU/SCBU experience on the responses and these are illustrated.

The gender distribution was very uneven, so little can be obtained from this data, however there was an obvious link between the length of ICU/SCBU experience and the confidence in knowledge about ethics, with a positive correlation between the duration of experience and the respondents answering in the affirmative.

The difference between the nurse and Sister reporting about knowledge of ethics

Of the Sisters (n=19)	18 (94.7%)	said that they felt that they had sufficient knowledge about ethical decision-making to take part in discussions,
and	1 (5.3%)	was unsure

Of the nurses who did participate in discussions (n = 20)

	10 (50%)	were satisfied with this knowledge
	2 (10%)	were not
and	8 (40%)	were unsure

indicating that with greater experience and seniority, respondents were more secure in their knowledge about ethics. This does imply, though, that the staff nurses, who may well have been closest to the patient and family, and who may be carrying the continuing responsibility for the care of the patient during the withdrawal process, are less likely to have felt confident enough in the discussions to represent their own views or to advocate for the patient and family.

"The professionals' own ethical and philosophical views are irrelevant in these situations. It is the views of the patient and/or the family which are of paramount importance".

Feelings about this statement were sought. The question addressed the problem of the influence of the attitudes of the health care team towards the dilemmas surrounding treatment-withdrawal decisions. There was some uncertainty about this, 8 (17%) being unsure. 13 (27.7%) agreed that the professionals involved should set their own views aside and put the views and values of the patient and family first. 26 (55.3%) disagreed with the statement.

For 21 (44.7%) then there would potentially be conflict between the values of the patient/family and the team members. Both professional and societal values may be challenged. Two extremes are possible, one situation could involve a patient where the professional view was that the patient's condition was hopeless and that treatment should be withheld and the other could involve a patient, where, for example, the family felt that the patient should be allowed to die and this was at odds with the professional view.

For the 26 (55.3%) who disagreed, team conflict is a possibility because the respondents in this group are likely to feel that their own views should be considered and agreement among all team members cannot be assumed.

Further analysis was carried out looking at the influences of gender and of experience on the responses to this question and these are illustrated. No obvious pattern emerges from the relationship between the years of ICU/SCBU experience and the response to the statement about professional or family interests.

The difference between the nurse and the Sister reporting about whether the patient's and or families' views should be paramount

Of the Sisters (n=19) 3 (15.8%) agreed
12 (63.2%) disagreed
and 4 (21.1%) were unsure

and of the nurses (n=20) 7 (35%) agreed
9 (45%) disagreed
and 4 (20%) were unsure

In these groups, about the same proportion were unsure, but more nurses agreed with the statement than Sisters, and proportionately more Sisters disagreed, which would imply that the longer the experience and the higher the seniority, the more likely it is that professional views will be of greater importance. Certainly, some respondents qualified this by indicating that although patient/family views were important, they did not have the knowledge or insight of the professionals, so would need advice and guidance in this type of decision-making. Another suggestion was that it was better for families to feel that it was not their decision to withdraw, and so, on reflection, would not have regrets about decisions taken.

The patient's treatment after the decision was made

This question covered the period after the treatment-withdrawal decision was made. These options cover the customary approaches to the withdrawal of treatment and their application emphasises the change from active support of failing organ systems to the priority of keeping the patient comfortable and pain-free. In parallel with this, is the need to not unduly prolong the process of dying but at the same time, not rush the process, with the feeling that families need time to adjust-to, and accept, the change in emphasis of treatment.

The modes of withdrawal would have been included in the discussions and treatment changes prescribed by doctors. The actions resulting would then largely be carried out by nurses.

What is surprising in some respects, is that despite the change in approach, some treatments are continued following a treatment-withdrawal decision. The patients described in this group are very likely to be receiving antibiotics and other drugs, and be needing supplementary oxygen, but for 36 (76.6%) patients, antibiotics were not stopped; for 36 (76.6%), other drugs were not stopped; and for 24 (51.1%) oxygen administration was continued. This may reflect only that it is not felt necessary to withdraw or reduce these treatments, because the other actions will be sufficient to meet the objectives, or perhaps some ambivalence about the decision. It is also possible that a treatment-withholding decision has been taken, implying that some level of support is continuing, but one or more forms of additional treatment are to be withheld in the event of a further system failure.

Not to be resuscitated

With option 1, treatment was continued as before but the patient was not to be resuscitated in event of cardiac arrest, 7 respondents indicated this but there was actually only 1 nurse who interpreted this correctly, the remainder of respondents having said that other treatments were also discontinued. Where this was correctly interpreted, the patient involved was elderly and had multisystem failure and was not responding to maximum treatment, so it is conceivable that death was expected imminently.

Discontinue ventilation

10 (21.3%) nurses said that the ventilator was turned off, 7 of whom were talking about situations involving babies. The approach in SCBU's is different from that in adult ICU's and generally a treatment-withdrawal decision involving a ventilated premature neonate would result in the ventilation being discontinued and the baby being allowed to die in the parents' arms, free from the machinery and attachments.

Of the remaining 3 where ventilation was discontinued, 2 were diagnosed brain-stem dead which involves the doctors in carrying out a series of tests to establish the certainty of the diagnosis, including testing for an absence of ability to breathe, and it is usual to leave the patient off the ventilator having completed the second set of tests for brain-stem death, unless the patient is to be a transplant donor.

The other situation in which a patient's ventilation was discontinued, involved a middle-aged person who had cancer and treatment-withdrawal was in two stages, oxygen being reduced initially, then ventilation later.

The remaining two babies whose ventilation was not discontinued, had other treatments reduced or stopped which would have accelerated death, for example, the oxygen concentration reduced, sedation increased and inotropic support drugs reduced or discontinued.

Reduce oxygen concentration

These very sick patients will all be receiving supplementary oxygen through the ventilator, often at a high concentration. Once a decision to withdraw has been made, a reduction in oxygen concentration will usually be considered as continuation would only prolong the dying process in some situations. In this group, 23 (48.9%) of nurses said that the patient's oxygen was reduced.

Increased sedation

Another aspect of the change in the patient's treatment would be a need to consider whether the patient is adequately sedated, particularly if other treatments are being reduced or discontinued, which may cause the patient to begin to struggle and look uncomfortable. The aim will certainly be to ensure that the patient is pain-free and comfortable and if necessary, sedation is likely to be increased to ensure this. 29 (61.7%) of nurses said that sedation had been increased.

Cardiac support drugs discontinued or reduced gradually

Drugs which are widely used in ICU's to support the heart and circulation - inotropes - are likely to be important in the treatment of very sick people. Very often, it is a failure to respond to such drugs which prompts discussion about whether the patient's condition is reversible. In this study, responses to question 2 indicated that a failure to respond to maximum inotropic/cardiac support had prompted discussions about treatment-withdrawal in 26 (55.3%) of situations.

Once a decision has been taken to withdraw treatment, these drugs would probably be considered inappropriate and a plan made to discontinue them, either by stopping them immediately or by reducing the doses gradually. What action is taken depends on factors such as the patient's clinical condition, the family's feelings about the withdrawal decision and opinions within the health care team about the pace of treatment withdrawal. There may well be a feeling among team members that gradual withdrawal is kinder to families because it generally gives them time to adjust to the change in approach, contact other family members and have the opportunity to say their 'goodbyes'.

Among the group of patients under study, in 18 (38.3%) situations, the inotropic drugs were stopped and in 16 (34%) these drugs were reduced gradually.

Antibiotics and other drugs

Antibiotics and other drugs were both discontinued in 11 (23.4%) of cases.

Renal replacement treatment

Renal replacement treatment was discontinued in 11 (23.4%) of cases.

The person who explained to the patient's family about the treatment changes

This question asked about the person or people who explained to the family about the decision taken and the changes proposed in the patient's treatment. Within the team, this is often a shared responsibility between the doctors involved and the nurse taking care of the patient. A common scenario would be that a doctor and nurse together would see the patient's family, with the doctor giving the initial explanations but with the nurse then providing the continuing information and support subsequently, while the patient's condition worsens. Sometimes the patient's own doctor or another doctor, and the ICU doctor would see the family together.

Data in this survey indicated that:

in 36 situations, both a doctor and nurse or Sister, gave the explanations together;
in 1 situation, the nurse gave the information on his/her own;
in 9 situations, a doctor gave the information on his/her own; and
in 1 situation, no-one explained.

Opportunities for doctor-nurse communication

These questions asked whether the doctors explained to the nurse reporting why they felt that the decision was appropriate and whether the nurse had the opportunity to tell the doctor how he/she felt about the decision.

In the majority of situations, the doctors and nurses involved had communicated their opinions and feelings. What perhaps is of concern is that in 5 (10.6%) situations, the doctors did not give an explanation to the nurse, and in 4 (8.5%) situations, the nurse was not given the opportunity to explain feelings to the doctor, particularly when the role of the nurse during the treatment-withdrawal process is considered.

In two situations, the nurse had the opportunity to explain his/her feelings to the doctor but the doctor did not explain his/her reasons, and in one situation, the doctor explained to the nurse about the decision but the nurse did not have the opportunity to speak to the doctor. In two of these three situations, the nurse involved was unhappy about the circumstances and two-way communication would have been helpful in resolving conflicts and difficulties. Similarly, in three other situations, where explanations had not been given by either side, nurses had some concerns about the patients involved and their treatment. Further reference is made to this area in the later section covering troubling aspects of situations.

Reasons given in support of agreement or disagreement with decision to withdraw

"I felt that the decision itself was the right one because ..."
or
"I was unhappy about the decision because ..."

Of the 47 respondents, two disagreed with the decision. One of these felt that the decision was premature. The situation involved an elderly person and the nurse stated,

> "... the patient was only 12 hours post-op.. I felt that she should have been given longer. She had a good quality of life with a healthy husband. I found it difficult to understand how 12 hours previously she had been given every opportunity but only a short period later this was withdrawn".

In the other situation where the nurse was unhappy about the decision, the concern was associated with the dose of analgesia prescribed during the withdrawal process.

The vast majority of respondents therefore supported the decision, whether or not they had been involved in making it, and they gave reasons for this support which the researcher has divided as follows:

Failure to respond to maximum treatment
Treatment of elderly people
Quality-of-life issues
Irreversible acute medical problems
Family support of treatment withdrawal

Many respondents gave more than one reason in support of their agreement with the decision and there was considerable overlap in the themes derived.

About a third of respondents cited a failure to respond to maximum treatment and a similar number mentioned the anticipated poor quality of life in the event of recovery.

Failure to respond to maximum treatment

This theme is important in decision-making because it conveys the fact that despite the maximum treatment being offered over a reasonable period of time, the patient is not showing any signs of improvement, and there is an acceptance that continuing the high level of support is futile and inappropriate.

Nurses used phrases such as '...she had failed to respond to numerous treatments', '... no response to inotropes, ...unable to get oxygen saturations above seventy percent', '...all avenues of treatment/support had been exhausted and the patient failed to respond to maximum inotropic and other drug support', and ' ... every chance had been given'.

The time factor was mentioned by a number of nurses, and all implied that they felt that sufficient time had elapsed with the patient on maximum treatment for the patient to show some improvement if this were possible. One nurse commented that ' ...the patient had shown no improvement over a week despite maximal therapy', another said that '...although treatment continued for one week, patient continued to deteriorate', a third talked about the patient having been 'unresponsive to drugs/treatment and stimuli for some days', and a fourth said that '... the patient's condition was continuing to deteriorate despite maximum treatment for more than ten days'.

Another aspect which was mentioned by some nurses was that the patient had been given treatment opportunities and a chance to respond even though the prognosis seemed poor at an early stage. For example, one nurse had said that '... the patient had a hopeless prognosis but had received maximum invasive treatment prior to the decision' and another included overlapping themes in the statement,

> "... the patient had a chronic chest history and cardiac history and therefore already had reduced coping mechanisms. Every chance had been given with no sign of improvement. He had limited mobility pre-operatively and would most likely be more incapacitated if he survived."

One nurse expressed misgivings about the high level of treatment given to the patient in the statement,

> "...there was no chance of survival and felt that the patient should not have been aggressively treated in the first place"

whereas another nurse, talking about a baby, seemed to be more satisfied because '...all options and therapies had been tried'.

Treatment of elderly people

Six nurses specifically mentioned the word 'elderly' in their reasons for supporting decisions, although 21 of the situations described, concerned elderly people. For some nurses, it was apparent that if a patient were elderly this was a relevant factor, particularly when coupled with other facts about the poor current clinical situation and previous state of health. In this context then, nurses mentioned that, for example, '...the patient was elderly, living on her own and had been in pain for many years', '...the patient was very elderly, had cancer for five years and this was the third operation associated with the disease', and another said '...the gent. was 80+, his kidney damage was irreversible and his abdominal haematoma could not be removed due to a frail aorta', this last implying to the nurse that if the person is elderly, it reduces the chances of successful surgery.

One nurse supported withholding of active treatment because the patient 'was subjected to high tech. intervention, elderly, with heart, lung and kidney failure'. In a situation involving an elderly person who 'had previously been very active' the nurse supported the decision to withdraw because of the 'significantly lowered quality of life if they recovered'.

Quality of life issues

The anticipated poor quality of life should the patient recover was cited as a reason for agreeing with the withdrawal decision by one third of respondents which again draws attention to the importance of assessing current and anticipated quality of life.

In most of the situations involving babies, nurses felt that it was appropriate to cease support where there was a poor outlook. One nurse talked of 'the very poor quality of life the baby had, and was expected to have', another talked of the child being desperately sick and the outlook 'being very bleak', a third said that '...the baby would have been unable to survive without ventilatory support...', and a fourth, having given some clinical details indicating the severity of illness, commented that there was 'an abnormal head scan' and that 'his quality of life would have been very poor if he had survived', with another nurse talking of the infant having 'no quality of life at all'.

With adult patients, nurses again considered the future in their reflection on the withdrawal decision, and said, for example,

> "I could see that the quality of life he would have been left with would have been appalling".

A nurse commented,

> "... the patient had multiple organ failure and a newly-diagnosed malignancy. Her survival was highly-unlikely and if she did survive, her quality of life would have been so poor, given her diagnoses."

Another nurse said that '...the quality of life would be very poor ...EEG indicated minimal brain activity'. In one situation, the nurse said that 'the perceived quality of life would have been too drastically reduced'. This nurse also commented that 'it was felt to be fair to her and her family', and in another situation, involving a patient with a severe, irreversible brain injury, the nurse felt that the withdrawal decision 'was the most humane for the patient'.

Many nurses talked about the relevance of the patient's previous quality of life to the anticipated one in the context of decision-making, and comments were made about chronic health problems as well as social factors. For example, one nurse talked about 'the patient's history of chronic lung disease and painful arthritis ... and any future quality of life the patient may have had, would have been reduced due to the irreversible cardiac problems which developed during this admission'.

In a situation involving an elderly patient whose additional diagnosis of cancer was made during the ICU stay, the nurse said that the 'previous quality of life prior to admission was very poor'.

One nurse agreed with the decision to withdraw because of the patient's chronic respiratory disease, saying that 'he lived at home but was dependent on oxygen and only able to walk up and down two stairs a day without needing rest'.

On a number of occasions, nurses felt that the poor quality of life being endured currently by the patient and family, in combination with other factors, was relevant to the decision to withdraw.

In many situations involving babies, nurses talked about features of the clinical situation which indicated that the infant's quality of life was poor. For example, one nurse said that the baby '... had been on a ventilator for four months with no improvement', another talked about the child being 'desperately sick and had been fitting uncontrollably for a very long time (nearly two days)' and a third commented that 'the baby was suffering and no improvement was being made... she was struggling and it was very distressing for the family'.

With other patients, different concerns were expressed. One nurse talked about the 'physical distress of a gastric bleed causing frequent regurgitation of blood' as an additional problem to a situation where the patient was being treated maximally for other conditions. A nurse, talking about another situation where the patient was receiving maximal treatment, said that 'the patient had been in the Unit for many weeks and the family were distressed by his plight'.

In a situation involving a young person with multiple injuries, all treatment and rehabilitation options had been considered and were not possible, and the nurse talked about how devastated the patient was, and how 'he wanted to die sooner, rather than go through the indignity of a protracted death'.

Irreversible acute medical problems

About one third of respondents cited the irreversible nature of the patient's illness as being a reason for supporting the decision to withdraw. Many nurses gave detailed clinical information about the number of body systems failing or the severity of illness/injury, which confirmed their feeling that the illness was irreversible.

For example, one nurse talked about surgery showing that 'the patient's entire bowel was ischaemic and necrosing', and another said,

> " ... the baby had multisystem failure, abnormal clotting, so it was not possible to

> perform surgery for the clot or the NEC and he was too sick to withstand surgery'.

A nurse spoke of a patient's 'renal function poor, ...and no bowel function and was unlikely to survive major surgical intervention' and of an elderly patient 'with heart, lung and kidney failure'.

Some nurses spoke with certainty about patients who had 'no chance of survival', a hopeless prognosis', of 'clinical outcomes being considered but would continue to be unsuccessful'. In two situations involving patients who had brainstem death, nurses again knew that there was only one option under the circumstances, one nurse saying that the 'brain damage went beyond recovery' confirmed by brainstem death tests. In the other such situation, the nurse said,

> "...my knowledge of the patient's condition enabled me to realise that this was a logical progression and the only one available to this severely damaged and eventually brainstem-dead person".

Family support of treatment withdrawal

In about one sixth of the situations described, nurses thought that because the patient's family felt that treatment was inappropriate, this supported their own feeling, based on clinical data, that the decision to withdraw was the right one.

A situation involving a middle-aged person with three body-systems failing following surgery, led the nurse to say,

> "His family had expressed wishes that he not be put through 'unnecessary' treatment".

In another situation, the nurse commented that the 'patient's family were concerned that he was suffering and did not wish to prolong this'. Where an elderly patient had a hopeless prognosis, but had been given a trial of 'maximum invasive treatment prior to the decision', the nurse said that the 'patient's family were fully aware of the situation and felt that treatment should be withdrawn'.

The situation involving a patient who had acute, irreversible cardiac problems in addition to some chronic health problems, led to the nurse saying about the withdrawal decision that '... the family felt happiest with this option. The patient was given his dignity and nature was allowed to take its course'.

A nurse reflecting on a withdrawal decision involving a middle-aged person with a newly-diagnosed malignancy, said,

> "... it was what the family wanted and said the patient would want. The prognosis was poor and any treatment would affect the psychological well-being of the patient".

Under similar circumstances, this time involving an elderly person with a newly-diagnosed malignancy, the nurse felt that the 'partner was strongly in favour of withdrawal'.

In another situation involving a middle-aged person who had severe brain injuries and other problems, the nurse felt that by withdrawing treatment, 'it allowed the family to begin/progress through the grieving process, instead of building up false hope ...'.

In summary then, there was overwhelming support from nurses for these withdrawal decisions and there was a great deal of consistency in the reasons given for this agreement. It was obvious from the responses that nurses felt that quality of life for patients from all age groups was an important consideration and that, together with the knowledge that patients had been given the maximum treatment possible and failed to respond, was the major determinant in nurses' feelings about withdrawal decisions.

Feelings associated with decisions

This question sought further information about the nurse's feelings about the decision to withdraw, and the subsequent events, looking at whether there was agreement or conflict within the nursing team about the decision and exploring the nurse's ability to cope with the treatment changes and the care of the patient and family.

Some nurses qualified their responses, giving short explanations supporting their choice. There was a great deal of agreement in this group, the vast majority having agreed with the decision and feeling able to cope.

Additional comments made by nurses in relation to the question about coping with the family included,

> "We had built up a good relationship with the family and withdrawal of treatment had been discussed already".

This same nurse also commented that 'once treatment had been withdrawn, the patient died within an hour. This was hard on the family and I needed help to support them'. The majority of nurses,38 (80.9%), agreed with the decision and were able to cope with the patient's family, however the need for team support was apparent, 23 (48.9%) of nurses having said that they needed the support of colleagues to cope with the demands made.

One nurse said that 'I felt I could cope but it is nice to have support from other professionals', and another echoed this, saying,

> "I felt able to cope and have a lot of experience in this area. I always, however, value the support and help of colleagues".

One nurse felt that 'all staff need support in the ICU environment. Sharing experiences and thoughts enhances team cooperation and understanding'.

Another nurse added the statement,

> "I felt I needed support but it was not met at the time. Usually it is not until I go home that I realise that I need support and debriefing"

which has implications for the organisation of the support network in the team.

Disagreement within the nursing team was rare. 4 (8.5%) agreed with the statement that 'I felt that the decision was right but some of my nursing colleagues thought that the decision was wrong' and 36 (76.6%) disagreed with this. Two nurses disagreed with the decision and they both indicated that although they had reservations about the decision, some of their nursing colleagues thought that it was the right decision, therefore implying some differences of opinion within the nursing team.

Where nurses added comments to their responses, they generally said, for example, that 'all colleagues involved were happy with the decision' or that 'all my nursing colleagues present thought that this was the right decision'. Another similar comment was that 'discussion with nursing and medical staff always occurs in this situation. All relevant parties were considered'. One nurse added that 'a few nurses, for religious reasons, felt that withdrawal was wrong' and this was in connection with a situation involving a premature baby with an irreversible illness who had lived for three months.

In response to the statement, 'it was the right decision but I was unhappy about my role in the patient's treatment afterwards', 38 (80.9%) disagreed, so the majority were able to support the changes made. One experienced nurse, talking about a middle-aged patient with multisystem failure added,

> "I fully understood the patient's outcome and treatment being offered and was in full support of decisions being made".

Another (junior) nurse was less happy about one aspect specifically, saying,

> "I was unsure how to approach when turning off the ventilator once the patient had passed away".

Both the nurses who disagreed with the decision to withdraw had reservations about the treatment changes made. The opposite viewpoint was expressed by one nurse who said,

> "If anything, I mediated changes in treatment by communicating family wishes to medics".

In response to the statement about whether the views of the nurse were considered, only two nurses agreed and said that their views were ignored, and 38 (80.9%) disagreed. There were some qualifying comments including,

> "I thought it was the appropriate decision in the circumstances"

and another said that she was 'happy with the way this was managed'. A third nurse felt that 'all grades of staff should have the potential for input' as it 'aids acceptance due to participation in a stressful situation'.

"The worst thing(s) about this situation was (were)..."

Respondents were asked to reflect on the specific situation in which they had been involved and identify what they felt were the worst aspects of the situation. Predictably, there were many reports of the helplessness, the sadness and the sense of failure felt by nurses in these situations and this does have implications for the organisation and the support structures necessary in ICU's and SCBU's to enable staff to cope properly with repeated experiences of this nature.

Themes which arose from the responses were labelled by the researcher:

Helplessness
Technology and aggressive treatment
Professional roles
Personal factors
Moral issues

Helplessness

Helplessness was a core theme of many respondents' reports and reatured in nurses' reflections on the sadness associated with the sense of failure over the patient's death, and was also used by nurses to describe how the families felt. There was helplessness too associated with events beyond their control.

Loss and sadness

No nurse who deals with such situations can avoid the feelings of loss and sadness associated with them. The closeness of the relationship between the ICU or SCBU nurse and the patient and family inevitably means that the nurse is likely to empathise with the feelings and experience of the family. The patient may have been cared-for over a period of days to weeks or even months and although there may be a feeling of relief that a decision to discontinue treatment has been made and that the uncertainty is ending, the nurse may also experience the 'sense of failure after days of intensive treatment' as one respondent said.

Where the patients are babies, parents have problems unique to these situations which affect the feelings of their nurses. For example, one nurse commented,

> "...baby was one of twins and the parents were terrified of losing the other twin"

and in another situation, the mother had difficulties conceiving, and the nurse reported,

> "... it was a very much wanted baby and we were desperate to help these parents."

One nurse talked of the sadness of being 'unable to save this lovely baby' and 'what a pity it was that the mother had had to wait until the baby had died before being able to bath her'.

The word 'helplessness' was used by a number of nurses, both about their own feelings and those of the family members. One nurse talked of 'empathising with the family's feelings of helplessness', another talked about 'a feeling of helplessness as despite the knowledge and technology, the (patient's) condition was irreversible'.

Witnessing the grieving, sadness and distress of families was mentioned by some nurses, exemplified in the comment about an irreversibly-ill person,

> "... the loss of a young life and the overwhelming distress of a loving wife and family",

although only one nurse, for whom this was the first such experience, said,

> "I found the episode very stressful and upsetting".

If the patient seemed to be distressed at all, this again evoked comments about the feelings of helplessness experienced by nurses in these situations, because with the drugs now available, the expectation would be that there is no need for people to have pain or distress. One nurse mentioned seeing the patient have 'some physical distress and being unable to do anything about it' and another said that 'the baby did appear to be distressed and it took a little while for the baby to die. A third said that 'despite extra sedation, the baby gasped and cried for about fifteen seconds'.

There was helplessness implicit in the comment,

> "Admitting there is nothing more that can be done"

and this related to a baby where the nurse had also commented that 'it was difficult for parents to understand the medical situation'.

In a situation where the patient had such severe injuries that any future life would have been of an unacceptably-poor quality in the patient's opinion, the nurse talked about the frustration because 'the patient wanted to die but we couldn't just switch him off' and 'the feeling of being cruel in treating him'.

Another nurse expressed these feelings of helplessness when there was concern about the adequacy of medical care in the early stages which might have meant that the patient 'could have had a better chance of survival'.

A nurse who was trying to support a man on his own whose partner was dying, said,

> "I felt very inadequate in my ability to support him. I felt I could empathise, but I felt I didn't have the right words to express this."

Unexpected turn of events

In four of the specific situations, patients had become irreversibly-ill totally unexpectedly due to complications following elective surgery. Nurses wrote, for example, that the patient prior to surgery had been a 'fit, busy person who had an excellent quality of life' but went on to say how difficult it was for families to accept the contrast between the expected plan and the reality of facing the death of the person. One nurse talked of the family being 'very distraught about the sudden deterioration in health' and another spoke of the incident 'coming as a great shock to the family because they had expected the patient to go home the following day'. Again, ICU nurses under these circumstances must have felt helpless in situations where they had no control over events prior to the ICU admission.

Control limitations

An inability to organise and control events was a theme which came up many times in nurses' reports of situations. One area of concern involved treatment reductions made following the decision to withdraw support. It is not always made explicit to families that such decisions usually involve a shift in emphasis from full supportive measures, including drugs and mechanical assistance for failed body systems, to a promotion of comfort, peace and lack of distress, which commonly means a reduction in support drugs, withdrawal of some treatments, and an increase in analgesic and sedative drugs. The difficulties are associated with wanting to give the families time to come to terms with the change of plan, but at the same time, not wanting to prolong the suffering unduly. Ultimately, however, there can be no control over when the person dies, and some nurses expressed sadness about the timing. For example, one junior nurse commented,

> "... although permission had been given to turn off inotropes (support drugs) completely, it had been decided that because the relatives were present, to do things gradually. However, as soon as ... the adrenaline was weaned by two millilitres, this elderly patient passed away. I wished that the patient had died more slowly for the family's sake to give them longer to come to terms with things".

Another nurse had a very similar experience with an elderly patient who died within five minutes of the treatment reductions being started.

In other situations, nurses commented on the problem of 'explaining to the family about the uncertainty of how long the patient would survive for and coping with their fears of leaving in case they were not present at the time of death'.

The presence of family members with the patient at the time of death often carries a great significance for both nurses and families, and it is reflected in such comments as,

> "... the inability to predict when the inevitable outcome would take place to aid relatives"

and two nurses commented that they felt that one of the worst things about the situations in which they had been involved was that the family was not present at the time of death, with one nurse regretting an inability 'to speak to/ support the family as they had gone home as soon as the decision was made'.

This lack of ability to end a situation properly was also expressed by an experienced nurse who said,

> "I had become deeply involved with the care of this infant and family but was not actually present when he died, and because of this, I felt cheated in many ways because I had not seen the experience to its conclusion".

Practical as well as emotional problems were also an issue for some nurses. For example, one nurse described the difficulty of coping with a very large family, 'all of whom were understandably distressed and tearful'. Another nurse mentioned that 'even though the family knew we were withdrawing treatment, I still found it hard to reduce infusions and dismantle haemofiltration with the family present'.

Technology and aggressive treatment

Intensive care treatment always involves the use of technology for diagnostic purposes, monitoring the effectiveness of treatment and for supportive or replacement therapy, and in many situations, this technology is life-saving. In practice, this means that patients will be linked to, and often surrounded by, a variety of equipment, some of which will emit noises or display lights when operating. Such equipment can be intrusive in circumstances when patients are dying or have died, and nurses make efforts to clear unnecessary machinery away and make the physical environment more peaceful and pleasant for patients and families. Two nurses expressed unhappiness with this technology, one for example, said that one of the worst aspects of the situation described was that 'the (elderly) patient was still surrounded by technology at the end'. In SCBU's, babies are disconnected from ventilators and other equipment when treatment is withdrawn, so that the baby can die peacefully in its parents' arms.

Another aspect of dealing with technology is its discontinuation. A nurse clearly had misgivings when she said,

> "I was also asked to withdraw part of the treatment (CVVH) before the partner arrived and who was unaware of our decision. I refused, saying I felt it would look as if we had already withdrawn, before he had been told the bad news".

Aggressive, high-tech. treatment which proved to be ineffective and futile caused some nurses disquiet. One nurse talked of 'seeing elderly patients being subjected to high-tech.interventions' and another was unhappy about aggressive treatment being given to a patient whose injuries were so severe that survival was impossible, where treatment was not indicated, because of the 'false hope being given to the next of kin' and the resulting 'extended length of time that both the nurses and the family had to deal with a difficult situation'.

Professional roles

There were a number of references to professional activities and the importance of them to nurses, who were therefore unhappy when roles could not be adequately fulfilled. Reference was made earlier to a situation where a nurse had been thwarted in an attempt to 'speak to/ support the family as they went home as soon as the decision was made'.

Treatment withdrawal situations may be more upsetting if the nurse is unsure about the professional role due to inexperience and one nurse said that 'it was the first time I had had to participate in this course of action since joining ICU ... the episode was very stressful and upsetting'.

One nurse felt that 'having to be strong for the family' was one of the worst aspects.

For some senior, experienced nurses, the lack of participation in the decision-making process and any opportunity for nursing advocacy on behalf of the patient, was troubling, one nurse saying that an opinion was offered but 'to a large extent it was ignored' and another nurse who had to deal with a very difficult situation, was not involved in treatment decisions and the rationale for them, as they were not discussed with staff. One nurse felt that there was a 'failure to recognise the need for more nursing staff involvement in all decision-making processes, if the nurse is the carer'.

Nurses have a major role in supporting families through these difficult situations and have to give explanations about what is happening to patients. One nurse felt that one of the worst aspects was 'explaining to the family about the uncertainty of how long the patient would survive for', another talked of 'the distress of the family of losing their relative following what was considered a fairly straightforward operation'.

Where the decision-maker, the ICU consultant, 'seemed unsure of the decision afterwards' it caused the nurse involved some disquiet, and in another situation, the nurse felt that the doctor, because of uncertainty about a decision, seemed to be seeking support and reassurance from the nurse for the course of action taken. Other troubling aspects mentioned by nurses were conflicts between doctors over decisions, and the failure of the doctor to be available for consultation or to write decisions in the case-notes, were also cited. One nurse said that there was a 'difference of opinion between consultant and nurse in the amount of analgesia which was going to be administered'.

Personal factors

Where a close personal relationship had developed between nurse and patient, withdrawing treatment was hard. One nurse commented that '... we had all got to know the baby as an individual, so switching off the ventilator was difficult, even though I agreed with the decision'. Another nurse 'had become deeply involved with the care of this infant and family, but was not present when he died'. In one situation, the patient's family was known to the nurse because their children had gone to school together.

Moral issues

Some nurses experienced moral difficulty in the situations in which they were involved. One mentioned earlier was unhappy about the prescribed dose of analgesia which the nurse felt was inappropriate. A nurse talked about the patient's condition being irreversible, 'but I still felt that life was very precious and you should have what was given'. This same nurse also questioned what was meant by the 'dignified death' which the patient's family had said it wanted for the patient. Another nurse who was caring for a patient who wanted to die, felt that 'we were being cruel in treating the patient or were we just treating ourselves? '

"The best thing(s) about this situation was (were)..."

This question asked what the nurses felt were the best things about the situations they described.

Of the 46 respondents, six gave no answer to the question and four of these did not complete any sections of this part of the questionnaire. The remaining two who did not give answers about the best aspects, both gave answers about the worst aspects of situations. In one case, the situation involved a young patient with a devastating condition and the nurse talked about 'the loss of a young life and overwhelming distress of the family'. In the other case, the patient involved was elderly and the (experienced) nurse was apparently very concerned about older people being subjected to prolonged treatment and the suffering and distress associated with attempts at weaning from support.

There was a great deal of consistency in the responses to this question from which the researcher derived four main themes:

Rewards for nurses
Peace for the patient
Decision - right decision, right time
Family memories of situation

Rewards for nurses

To be able to continue to work in this speciality, particularly where these situations are being dealt with quite frequently in the department, nurses have to be able to derive, on reflection, some satisfaction, some rewards, from sad and difficult circumstances. Satisfaction can be gained from relationships with others, from feelings of trust and support which the nurse has developed with families, and from situations where the family has expressed thanks for what has been done for them. Satisfaction can also be gained from the relationships with team colleagues and the support obtained from them.

Nurses spoke frequently about the satisfaction they gained from knowing that, as a result of their efforts to build 'rapport with the family and create an atmosphere of trust', families felt supported through difficult and distressing situations. One nurse commented that 'the grieving family gained support when they needed it', and another said,

> "... as I had come to know the family so well, I felt I was able to support them through the experience,"

and a third talked about 'making a distressing situation as comfortable and free of bad memories as possible for relatives'.

The importance of being able to care for the patient properly was expressed by a number of nurses, who made such comments as,

> "... the patient was comfortable and well-cared for... and the family (members) were happy with treatment decisions and also the care given,"

and another nurse said,

> "... the subsequent death of this patient was dignified as much as it could be and the family were encouraged to spend as much time with a degree of privacy with their relative. They expressed their gratitude for everyone's efforts in making the patient comfortable and for giving them the time they needed."

This feeling of having been able to organise events sympathetically, and with compassion, recognising the family's needs as paramount at such times, was very important to nurses. One nurse, in talking about a baby's death, said,

> "... he died peacefully with his parents on the balcony in the sun. This is what the parents wished. It was beautiful and the parents expressed that their wishes were fulfilled,"

and another nurse commented that the family 'felt it was handled beautifully.' A nurse, talking about the death of an elderly person, derived pleasure from the fact that 'the family were with us. They stayed around his bedside. They held him and told him they loved him and were with him when he died'.

One nurse said (about a situation involving a baby) that 'the situation was controlled,' having said that '... the infant was able to die with dignity and the parents were able to have quality time with their infant alone,' and another nurse was pleased that 'the baby was being extubated while being held by mum and dad, closely surrounded by their parents - a very supportive situation'.

Nurses also derived satisfaction from situations where not only had time been allowed, but also the opportunity given to families to give their opinions. One nurse said that 'everyone was consulted' and another that there had been 'a multidisciplinary approach to the withdrawal of treatment and a presentation of all the facts to the family within the time allowed, to express views and feelings'. It was also satisfying to know that '...his family were absolutely certain that he would not want to live unless he was as well as he was before surgery'.

Support from team colleagues was also important when nurses reflected on the best aspects of situations and one nurse said that 'support from colleagues, including consultants, was excellent' and that 'the team worked well together'.

Peace for patient

The words 'peace', 'suffer' and 'dignity' were used frequently in nurses' comments about the best aspects of situations and it was obviously very important to nurses that patients were, in the end, allowed to leave any suffering behind and die with dignity in peace. The way the word 'dignity' is used by respondents, seems to imply that nurses felt that patients were not put through further intrusive treatments and that they were not given the 'respect for persons' on which nurses and others place high value.

Nurses made comments such as,

> "...the baby was no longer having to suffer"

and "... the baby at peace finally"

and the fact that the patient died 'whilst very well sedated', 'able to be pain-free and died with dignity' was satisfying and reassuring to nurses. One nurse reported that 'the parents felt that his suffering had gone on long enough and were relieved it was over' and this idea of the extended suffering of patients, the 'prolonging of suffering in an inevitably-poor situation' was echoed by a number of number of nurses. One nurse mentioned the importance of 'seeing his family realise that he clearly wasn't suffering' and another reported that 'the family felt in control and were able to allow their father/husband to die with dignity by his standards, rather than ours', and a nurse spoke of the '...sense of relief...' and that the 'family were not going to suffer any more than they had already. The patient would not suffer any more..' and went on to say that 'I felt that it was the most humane solution'.

One nurse commented,

> "The patient did not suffer and we did not have to continue treatment in what was quite clearly a hopeless situation."

Right decision, right time

Many nurses made positive comments about the treatment-withdrawal decision and talked about the timing of it, the relief of suffering which it brought and the process by which it had been made. Nurses expressed satisfaction with consensus decisions where all team members had participated and the patient's family understood the situation, gave their views and accepted the outcome. For example, one nurse in reflecting on a situation involving the unexpected deterioration of an elderly person following routine surgery, said that 'the decision to withdraw was timely and carried out with compassion and consideration'. The patient's family had been fully aware of the patient's condition and treatment and 'appreciated what was done, ... accepted the situation' and supported the decision to withdraw. In another situation, the nurse spoke of the patient's family having 'no doubts that he would rather die 'than live on with a very poor quality of life'.

Nurses also spoke of the 'correct decision being made', 'the multidisciplinary approach to the withdrawal of treatment' with the decision 'finally from the team', and the 'sense of relief that the right decision had been made'.

Two nurses reflecting on situations involving babies, commented on the wide consultations about the decision. One said that 'everybody was consulted and the decisions made throughout the child's admission were all joint with parents, medical and nursing staff'. Another nurse spoke of 'the agreement to withdraw being unanimous'.

On a number of occasions, nurses made comments about the timing of the decision. For example, in one situation, the nurse commented that 'the decision was made quickly without the patient having to suffer any longer' and in another, the nurse said that 'the right decision was made at the right time with no extended suffering of the patient'. A comment was also made that 'once the decision was made, support was withdrawn fairly quickly, supporting the case for judging the timing of the decision but also for regulating as far as possible, the withdrawal process.

Family memories

For the professionals involved in these sad situations, there will be some satisfaction obtained from aspects of what has happened and some memories of a 'job well done' but for the families of these patients, there will be a need to cope with the loss, the distress, the tiredness and the bereavement. Families have to live with these decisions for ever and it is essential that wherever possible, they derive some comfort from memories of events.

Many nurses commented about some of the happier memories which they felt families had taken with them. One nurse, talking about the death of a baby, spoke of 'mum and dad actually having happy memories about this situation and felt it was handled beautifully' and another nurse, again about a baby's death, said that 'mum held her, bathed her and had a normal cuddle before placing her in the moses basket'.

In many of the situations cited earlier in the section describing the rewards for nurses, there was satisfaction for the nurse because the family was enabled to have some happier memories. For example, the death of a baby who 'died peacefully with his parents on the balcony in the sun' which was what the parents wished, would have left the parents with some happier thoughts after this poignant situation.

The importance of the presence of the family at the time of death of the patient was commented on and was thought to be a source of satisfaction for families. One nurse, for example, said that 'the patient died quietly and peacefully with family present' and in another situation, the nurse commented,

> "They could see that the patient was not going to survive. They stayed around his bedside... and were with him when he died".

This opportunity to end a situation, and say goodbye, was perceived to be very important when nurses considered what happier memories families would take with them. Memories of the satisfaction with the treatment given were spoken about. One nurse reported that 'the family were at least present and were happy that we had tried everything and given the patient every chance'. Another nurse said that ' the family had been kept fully informed throughout the patient's stay and had been told that the treatment could be limited. They were also aware of the deteriorating condition and were anticipating our request that this (treatment withdrawal) may be the best and most appropriate thing for the patient'.

Time and privacy were also important and one nurse spoke of the family 'being encouraged to spend time, with a degree of privacy, with their relative' and of the family's gratitude for this and for making sure the patient was comfortable'.

On a number of occasions, nurses said that they felt that families would have been happier because their wishes were considered. One nurse said that 'family requests were listened-to' and in another situation, that the 'relatives had input and felt in accordance with the situation'.

Sources of support for families were also a subject for comment when nurses reflected on positive memories of these situations. Nurses were a source of support, comfort and information for families, but, of course, in many situations, the family members supported one another. One nurse, for example, commented that 'the family were very supportive to each other and were happy to care for their physical/psychological needs at the very end' and another nurse, reflecting on a situation involving a very large family, said that 'as there were so many, they were able to support one another'.

In conclusion then, nurses' feelings about the best aspects of situations depended to a large extent on whether it had been possible to give the patient and family the level of care, and create the environment, which they needed to enable them to cope with difficult and sad situations. Although the word 'advocacy' was not used by respondents in this section, the concept of advocacy was pervasive through these data. For nurses to be satisfied with situations often meant not only that they had been able to participate in discussions, but also that they were able to put the needs and interests of the dying patient first during the treatment-withdrawal process. Examples of this included resisting intrusion, ensuring adequate pain-relief and sedation, manipulation of the situation and creation of a peaceful environment, ensuring appropriate respect and dignity, and facilitation of the best possible circumstances in an ICU environment.

Reports about other troubling situations

This question asked whether the nurse had ever been involved in another situation which was remembered because some aspect had been upsetting or troubling.

Of the 47 respondents, 32 answered 'Yes' to this question, 12 said 'No' and there was no answer from 3, so 68% of those who gave an answer, had answered in the affirmative.

Of the 32 who answered 'Yes', 3 nurses said that they disagreed with the decision to withdraw treatment and in one situation, this disagreement was expressed and the decision was reversed. 8 nurses talked about the opposite situation and said that they felt that the life of the patient had been inappropriately prolonged. 12 nurses had misgivings about some aspect of the decision-making or the mode of treatment-withdrawal, of whom 5 were unhappy about the timing of the decision, generally because they thought that the time allowed for families to come to terms with what was happening, was too short.

The responses certainly addressed questions about which factors or features about specific situations were key in determining nurses' feelings, in terms of what made nurses have doubts or feel uneasy, the relative powerlessness felt by nurses many times, and personal factors about nurses themselves which affect how they feel.

There were seven themes apparent in nurses' responses, labelled by the researcher as:

Doubts
Discomfort
Dispute and conflict
Lack of discussion
Time
Personal
Inexperience

Doubts

The doubt nurses cited related mainly to some disturbing aspect of a patient's treatment and care, where perhaps a decision to withdraw was made which was supported by the nurse, but in following through the treatment-withdrawal process, the nurse experienced disquiet.

This theme was reflected in a situation where a nurse had doubts about the adequacy of care of a patient prior to the ICU admission, and commented,

> "...decision to discontinue treatment, although probably the right one, was very hard to follow through."

Another nurse who had discharged a patient from ICU, apparently recovering, only to re-admit the patient, now brain-dead, expressed a feeling of doubt, possibly about his or her role in the decision to discharge the patient, saying,

> "I was very involved during both ICU stays and the ward transfer."

Doubts about whether a family member really understood a medical definition sufficiently well to make a decision to allow organ donation were expressed by another nurse who had spent many hours caring for the patient and family member. For a nurse who has to deal with a patient who is to become an organ donor, any doubts perceived by the nurse about the level of understanding of the patient's family, must cause disquiet. This nurse stated,

> "Despite all efforts, I do not feel he ever really understood, although he consented to organ donation. He asked me regularly how the patient could be dead yet still breathing. The patient, of course, was mechanically-ventilated."

The doubts which nurses had related to the problem of assessing a patient's future, the anticipated quality of life if the patient were to survive, were expressed by some nurses. So much of the decision-making depends on this assessment and it is an area of great concern, because it involves the decision-maker forming a judgement about what value the patient and family place on life; what the (statistical) probabilities indicate about recovery from illness; and what constitutes an acceptable quality of life.

Although it is unclear whether the nurse is talking in general or specifically about one situation, the comment was made,

> "... we 'feel' that the patient will not recover, and obviously the investigations and results are conclusive that treatment is not helping, or maintaining a state that is preserving life - but how do we know what future state someone will recover from?"

Two nurses cited specific examples giving clinical details in which decisions to withdraw had been made on medical and quality-of life grounds, only for those decisions to be subsequently reversed because of a change of events, and for the patients to recover. Any involvement in such situations must reinforce the doubts which nurses may have about treatment-withdrawal.

On a related issue, one nurse had doubts about such a decision where a major influence in the treatment-withdrawal decision had been the opinion of a relative of the patient, making a judgement about the future quality of life of this (alcoholic) patient.

Discomfort

An allied theme was the discomfort felt by nurses about aspects of specific situations. This discomfort related to, for example, the scenario, to some aspect of the timing of the withdrawal, or to the drug dosages prescribed. In some situations, the discomfort was associated with possible mistakes made in judgements, care and treatment.

Discomfort was felt by the nurse when following the treatment-withdrawal decision, the patient took longer to die than expected. Examples of this were expressed by a nurse describing a patient who continued to be ventilated who 'became so cold he felt like marble', and another nurse who described a patient being 'taken off a ventilator and took two days to die', commenting that this was very distressing. The scenario where the parents of a patient could not accept the situation and refused to allow withdrawal, so that the inevitable death was delayed, was described by one nurse who commented on the difficulty of watching a cyanosed, bradycardic, dying patient but having to continue ventilation.

The opposite situation in which a patient died unexpectedly quickly was exemplified in a situation which left the nurse feeling very sorry and guilty. This nurse says,

> "I was asked to extubate a patient who had been put onto air and his inotropes withdrawn. It was put to his family that we were prolonging his death and they

> agreed to this decision. I was not convinced that the patient would maintain his airway but he was breathing sufficiently. ... I extubated the patient who died almost immediately. This appeared to be a great shock to the family in that he had died so soon. I felt terrible. There is a subtle difference between prolonging death and ending it and I felt as if I had participated in euthanasia rather than aiding the patient to a peaceful and dignified death. I will not agree to such a procedure in future."

Discomfort was also associated with procedures being carried out which were of dubious, debatable value under the circumstances, particularly when the nurse thought that the patient had been through enough already. The ability to advocate effectively on the patient's behalf would have been very important to the nurses involved in these situations. One nurse commented,

> "... felt patient should be left in peace despite medical request for (a medical test) for research purposes"

and another disputed the need for invasive procedures, feeling that their necessity was debatable. One nurse strongly expressed discomfort with the prolonged use of modern technology for a baby where the situation seemed hopeless, commenting that 'it was a degrading situation and the baby should have been allowed to die sooner with dignity'.

Where a withdrawal decision has been made, but external factors have impinged on the decision and process, nurses again expressed discomfort with this aspect. An example of this was where there was a problem of availability of ICU beds, and the nurse stated,

> "I felt that the family members were not given enough time to come to terms with the situation before treatment was withdrawn."

Two examples were given of situations where the medical opinion was that the outcome was hopeless and that treatment should be withdrawn, then later, when an alternative plan had been suggested or a further additional form of treatment had become available, the decision was reversed. Another similar example involved a situation where the nurse felt that the patient should perhaps have been given a chance to prove the decision-makers wrong.

Some discomfort was also expressed by nurse with the drug treatment prescribed following the treatment-withdrawal decision, one nurse feeling the amount of analgesia prescribed exceeded that needed by the patient to maintain comfort, and another nurse expressing misgivings about the large amounts of analgesia/sedation required.

Dispute and conflict

Dispute featured in some nurses' reports of situations remembered because they found them troubling. Sometimes the dispute was between nurse and doctor, sometimes between doctors from different specialities, and at other times, it was reportedly between the patient, or the patient's family, and the medical team.

Some of the situations cited above causing doubts and discomfort also involved disputes between doctors and nurses. For example, nurses disputed one decision to withdraw because they felt that there had been treatment options not explored, and insufficient time or opportunity had been given to the patient to establish certainty about the clinical condition of the patient and the potential outcome.

Dispute and conflict occurred between the doctors involved in a patient's care, where there was a difference of opinion about outcome and therefore the decision to withdraw. One nurse gives an example of 'conflicts between surgeon and ICU doctors' which led to delayed decision-making regarding treatment withdrawal, despite family requests to do so. Another nurse comments that on several occasions,

> "... treatment was very prolonged and the surgeons were reluctant to let the ICU consultant withdraw treatment."

Another area of dispute was exemplified in the situation cited by one nurse of a patient who was 'demanding not to be fed, and to be left to die' but where treatment continued until the diagnosis of a terminal illness was made, when 'he was transferred to a hospice'.

Lack of discussion

Dispute can only be resolved if there is discussion and a number of nurses were troubled because of a lack of discussion. One nurse commented,

> "There was no discussion with colleagues as to what would happen. Doctors made the decision which I think is unacceptable without nursing input".

Another said simply that there was no discussion. Where time or space were at a premium, this must have discouraged debate. In one situation, the nurse felt that the decision was inappropriate, but although the nurse's views were listened-to, they were 'not taken into account', implying that the nurse felt that there was no true debate. The nurse who supported the need for debate the most strongly, gave a detailed description of the clinical state of the patient where a treatment-withdrawal decision was made then reversed twenty-four hours later. This nurse said,

> "Although this patient did not die, the decision to withdraw was made without full discussion. After objections from nursing staff at its hastiness, the decision was changed (to allow more opportunity to assess the patient's condition). This shows that everyone involved should be allowed to express their views on this emotive subject".

Time

Time was mentioned by a number of nurses in connection with situations remembered as upsetting. In some cases, nurses commented on the shortness of time between the implementation of the decision and the death of the patient. This was illustrated by one nurse saying that 'we are not always able to give parents the time to say goodbye properly' before the baby dies. Others were concerned about not being able to give families enough time to come to terms with the situation and decision, with one nurse mentioning that the changeover of medical teams had been a factor in the timing of the withdrawal decision.

Time was also a factor in situations where treatment had been unduly prolonged and there had been delays in making a decision. These prolonging-life, delaying-death situations can be very stressful, and one nurse commented that 'if the prognosis is hopeless, patients should be allowed to die with dignity'. Two other nurses mentioned time in this context, one of whom commented,

> "The time it takes to withdraw treatment prolongs the waiting for stressed relatives."

Personal

Personal factors also had an influence in the reasons for situations to be troubling or upsetting. Examples of this include situations where the nurse identified with the patient or family in some way, such as where the nurse said that 'the patient was the same age as myself' and another said that the situation involved 'caring for the patient soon after my father had died'. Two nurses who were employed in ICU's rather than SCBU's at the time of the project, mentioned situations involving children as being upsetting.

Inexperience

Allied to these personal factors is the lack of experience of the nurse at the time of the remembered situation. One nurse commented that she remembered something 'simply because it was the first time I was ever involved in this type of situation' and another was 'inexperienced' in a situation where 'the patient's life appeared to be (artificially) prolonged and was requiring large amounts of sedatives', and this nurse went on to comment about the discomfort felt by the nurse and doctor while this patient was dying.

Analysis of this section then does indicate a number of factors which cause disquiet for nurses who are caring for patients where such decisions are being taken.

Questions arising

1. How does what happens in ICU's differ from euthanasia?

2. Who is the best person to represent the incompetent patient?

3. Who is the best person to make judgements about the patient's quality of life?

4. What should happen when the nurse knows that a family member is making an important decision about treatment withdrawal and does not really understand the nature of the situation?

5. What should happen when shortage of resources impinges on decision-making about treatment withdrawal?

6. Is truth-telling important when treatments are being reduced?

7. Who should participate in discussions and be influential?

8. What should happen when the patient or family refuse further treatment?

9. What should happen when nurses dispute the mode of withdrawal?

10. How should interprofessional conflicts in this context be resolved?

11. What should happen if nurses dispute the decision to withdraw?

12. What should happen when nurses feel that a proposed investigation on a dying patient is being carried out for research purposes, and is intrusive and not in the patient's interests?

Report of findings from questionnaire two

Note about qualitative data

Respondents were asked to reflect on the situations portrayed in each of the vignettes, then consider firstly, from what aspects they might derive satisfaction and secondly, what they felt might be the worst aspects. The intention was to draw some parallels between the data collected in the first phase and these replies to the questions about the hypothetical situations.

It was apparent that respondents had reflected on these hypothetical situations as if they were real, and to many respondents, the situations portrayed closely resembled ones in which they had been involved, so they identified strongly with aspects of them. It is possible that respondents were giving their true feelings associated with the real cases rather than their projected feelings about the hypothetical ones.

Demographic data

The respondents (n = 33) were drawn from two centres, (17) were from centre one and (16) from centre two. Both centres were general ICU's of 8 - 10 beds. Centre one staff had taken part in the first phase of the project and agreed readily to participate in the second phase. Centre two staff had access to a clinical ethicist, the development of whose role had been part of an earlier study in the department, and 'ethical issues' had quite a high profile amongst nurses.

Years experience in nursing

Range:	3 to 22 years
Mean:	11.05 years
Median:	10.50 years
Mode:	10 years

Years experience in ICU nursing

Range:	0.25 to 15 years
Mean:	6.07 years
Median:	5.00 years
Mode:	5.00 years

Education level

EN(G)	4	ENB 100	22
RGN	27	ENB 124	1
RN (Adult) /Dip.HE	8	ENB 125	2
Diploma in Nursing	7	ENB 148	0
BSc/ BA (Nursing)	6	ENB 249	1
BSc other	1	ENB 998 or similar	12
BA other	2	ENB 934	2
MSc	1	ENB 928	2
MA	0	ENB 920 (Paediatric)	4
		ENB 870	1

73% had a post-Registration qualification in the speciality, (8) from C1, (16) from C2

All (4) Enrolled nurses had further education in nursing. (3) of these also had the RGN qualification and (1) had the Diploma in Nursing

(12) respondents had completed a 'teaching and learning' course (ENB 998 or similar)

(9) respondents had undertaken a variety of short courses, for example, in the principles of ICU nursing; diabetes; introduction to research; and counselling.

Education in Ethics

Included as a topic in an ENB course	20
Included as a topic in RGN course	13
Included as a topic in Diploma/ Dip.HE course	14
Included as a topic in Degree course	8
Included as a major element in Degree course	1
Have completed a Diploma/Degree level module on Ethics/Law	4
Have an interest in the subject, so have read journal articles/books on ethical issues	17
Is of particular interest to me, so have written for journal/book on ethical issues	0
Is of particular interest to me, so have done some formal teaching/speaking on ethical issues	4
Have attended study day(s) where it was included as a topic	19
No specific education in ethics	3
Other: religious teachings, topic in Masters programme	4

One respondent said that although he/she had no specific education in ethics, he/she was very interested in the subject, and another nurse in this category, held EN, RGN and ENB 100 qualifications, so was likely to have had the topic addressed at some point.

One respondent said that he/she was currently enrolled on a Masters programme in which Law and Ethics was a topic.

Two respondents said that education on ethics had been obtained from 'religious teachings'.

With the dilemmas experienced by nurses in ICU's, the ability to debate knowledgeably is necessary if nurses are to avoid some of the concerns raised in the first phase of the study. To be able to fulfil the mediating and advocacy roles confidently, nurses need to be appropriately prepared.

Vignette 1

Mr.F. is 74 and has a diagnosis of abdominal sepsis, secondary to bowel perforation. This is day 7 in ICU and Mr.F. has had maximal treatment for sepsis, including ventilation, inotropes, antibiotics, fluid resuscitation and haemofiltration. Today, Mr.F.'s B/P is falling despite high-dose inotropes, and he is not responding to further manipulations of the drugs. The doctors feel that Mr.F. is irreversibly-ill and you know that with three body systems now failing, there is very little chance of recovery. The situation is explained to Mr.F.'s family and they accept that everything possible has been done and that Mr.F. is likely to die within 24 hours. The doctor suggests that you start reducing the inotropes gradually, although the family is not told about these reductions.

1.1 Truth-telling

Respondents were asked how important they felt it was to tell the truth to the family about the plan to reduce inotrope support. All respondents felt that telling the truth was important, and two-thirds of respondents indicated that it would be very important to them under these circumstances.

There would inevitably be conflict for these nurses if they were put in this position because the action of reducing drug doses, involving the alteration of settings on infusion pumps, would have to be done covertly. Equally, nurses may feel that confronting the family with the physical act of altering treatment should be avoided, in attempt to protect the family from more hurt and sadness.

In comparing the responses of the two centres, there was no significant difference, with the same number feeling that truth-telling was quite important, (5) from centre two (C2) compared with (3) from centre one (C1) feeling that it was moderately important, and rather more (12) from C1 than (9) from C2 feeling that it was very important.

1.2A Reduce inotropes

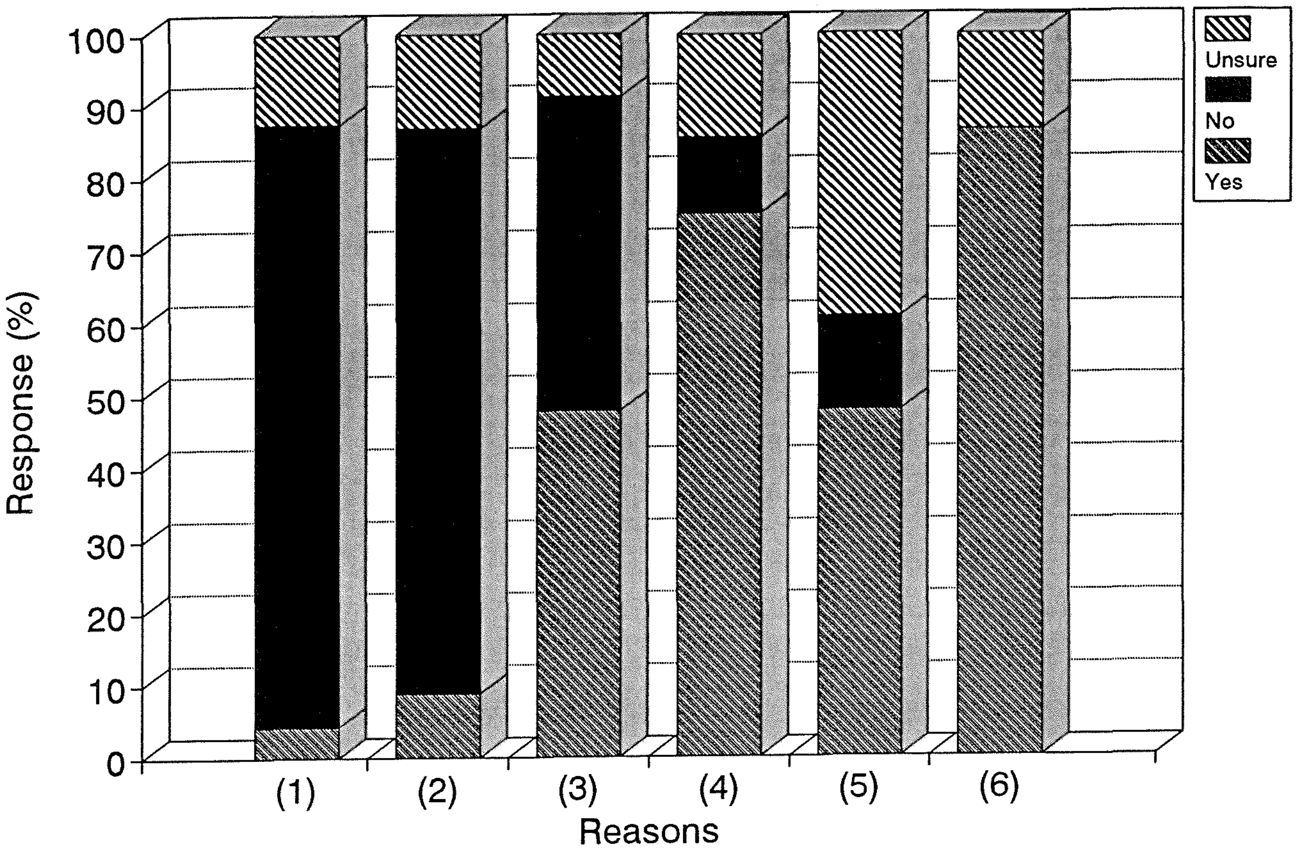
Respondents were asked whether they would normally be prepared to reduce the inotropes under these circumstances and three quarters of them said that they would, equally (12) divided between the two centres, with (7) saying that they would not. The validity of the responses to this question is debatable because respondents who answered 'yes' sometimes qualified their replies by saying that they would only reduce the inotropes if the family were told of the plan, and similarly, some respondents answered 'no' because of the lack of honesty with the family, so rather than testing whether or not respondents would be prepared to reduce inotropes under the clinical circumstances set out in the vignette where a patient had received maximal treatment which had proved hopeless, it was interpreted to some extent as a question of whether or not nurses would reduce inotropes when they could not be honest with the family.

1.2B Reasons

In this question respondents were asked to consider the reasons for supporting, or otherwise, treatment-withdrawal, and were given six possible options, each of which drew on material from the first phase. Nurses were able to give more than one reason (as many had done in the earlier material). There was little difference between the two centres in these responses.

See fig.1.2B

1.2.B Reasons for support of withdrawal decision



1. On religious grounds
2. On the clinical grounds that there is still a (remote) possibility of recovery
3. On personal grounds
4. On the clinical grounds that with three systems failing, the chances of making a good recovery are nil
5. Because medico-legally, they constitute futile treatment
6. Because I think it is in the best interests of the patient

On religious grounds

(1)	(from C2)	answered 'yes'
(21)	(10 from C1, 11 from C2)	answered 'no'
(3)	(2 from C1, 1 from C2)	were unsure
(8)		gave no answer

so as in the responses in the earlier phase, religious reasons played a very small part. The one nurse who cited religious reasons, said he/she would be prepared to reduce the inotropes in this situation.

On the clinical grounds that there is still a (remote) possibility of recovery

(2)	(1 from C1, 1 from C2)	answered 'yes'
(19)	(8 from C1, 11 from C2)	answered 'no'
(3)	(from C1)	were unsure
(9)		gave no answer

so more than half of the respondents felt that recovery was not possible on the clinical evidence cited in the vignette.

On personal grounds

(12)	(5 from C1, 7 from C2)	answered 'yes'
(10)	(6 from C1, 4 from C2)	answered 'no'
(2)	(1 from C1, 1 from C2)	were unsure
(9)		gave no answer

Respondents who cited personal grounds were likely to be expressing some moral difficulty associated with the decision in this patient context, and may perhaps have doubts about outcome, or may have concerns about the suggested mode of withdrawal. Some insight is gained from reports about the best and worst aspects of this situation (see later).

On the clinical grounds that with three systems failing, the chances of making a good recovery are nil

(21)	(9 from C1, 12 from C2)	answered 'yes'
(4)	(2 from C1, 2 from C2)	answered 'no'
(4)	(from C1)	were unsure
(4)		gave no answer

thus the nursing views coincided with the probabilities indicated by APACHE scoring (see later).

Because medico-legally they constitute futile treatment

(12)	(6 from C1, 6 from C2)	answered 'yes'
(3)	(2 from C1, 1 from C2)	answered 'no'
(9)	(4 from C1, 5 from C2)	were unsure
(9)		gave no answer

Once it is felt that the patient has not responded to maximum treatment and because of the number of organ system failures, it is certain that the situation is irreversible, treatment which is useless, in that it cannot help the patient to get better and will only prolong the dying process, can be withdrawn.

Because I feel that it is in the best interests of the patient

The majority of respondents answered in the affirmative to this, and so this was the reason cited most often in support of nurses' replies on whether they would discontinue inotropes under these circumstances.

(27)	(14 from C1, 13 from C2)	answered 'yes'
(4)	(1 from C1, 3 from C2)	answered 'no'
(2)		gave no answer

The term 'best interests' is used often in ethical decision-making and would be familiar to nurses working in ICU environments. It was used by respondents in the earlier phase when they were asked to justify their reasons for supporting a withdrawal decision.

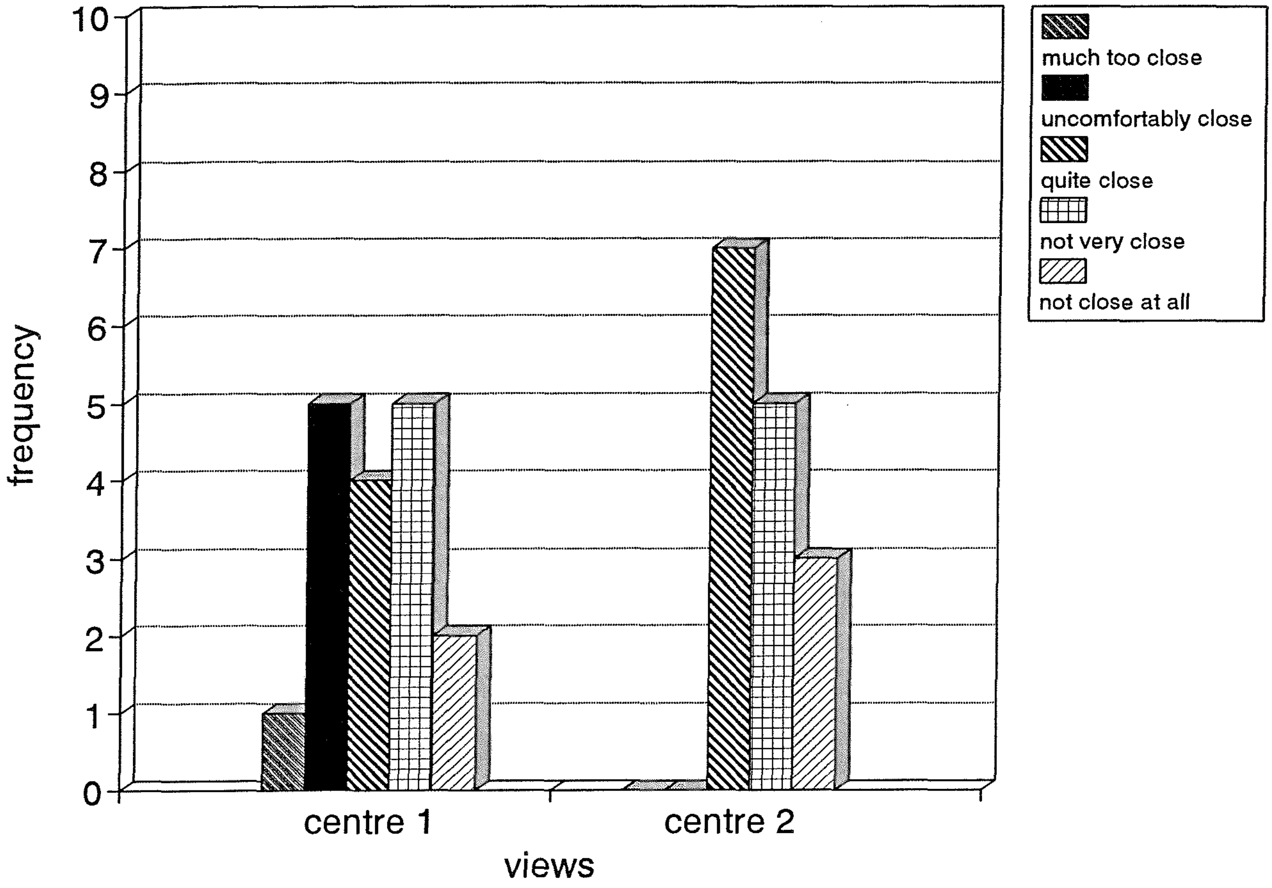
As the responses from the two centres throughout this section were very similar, no further statistical analyses were carried out.

1.3 Proximity to euthanasia

Respondents were asked for their views on how close they felt the situation described, in which the patient had died very quickly after the inotropes had been reduced for the first time, was to euthanasia.

See fig.1.3

1.3 Proximity to euthanasia



No nurses from C2 then felt uncomfortable with the possible proximity to euthanasia described in this vignette, although (7) from C2 felt that it was quite close. Just over half of respondents from C1 implied some uneasiness under these circumstances. This may indicate that nurses from C2 where 'ethics' has a high profile, are more certain about definitions of active and passive euthanasia or it may reflect satisfaction with the way that this type of decision would have been made in this centre.

Analysis of the difference in responses from the two centres using the Mann-Whitney-U test was carried out:

$U = 93$ Exact $P = 0.1214$ (2-tailed)

This indicates that any differences were not significant and possibly attributable to random error.

Projected sources of satisfaction

Respondents suggested a variety of possible sources of satisfaction from which four main themes have been derived. The core theme was the projected satisfaction from knowing that the patient received the best possible care both during the active phase of treatment and during treatment-withdrawal.

Peace

A theme which was mentioned by almost all respondents concerned the maintainance of sedation, peace and comfort for the patient and an end to the suffering of both patient and family. This theme was exemplified in a statement by one nurse who said,

> "I would take comfort from the fact that I had given Mr.F. excellent standards of nursing care and helped towards giving him the best possible chance of making a recovery and as that was not possible, at least his, and his family's suffering at his ill health was now over".

Dignity

A number of nurses felt that in some ways it was better that the patient died quickly, thus avoiding a protracted period of dying 'prolonging the agony' or as another nurse said, 'restricting a potentially drawn out and traumatic stay on ITU for the patient and family'. One nurse used the word 'dignity' in this connection, commenting that 'the patient had been given every possible chance of recovery but was also allowed some degree of dignity' which, to the researcher, implies that the nurse feels that a protracted dying process involves a loss of dignity, and another respondent commented that 'Mr.F. would have had a quick dignified death'. Another respondent in a similar vein, felt that satisfaction could be drawn from 'the fact that Mr.F.'s life was not prolonged without quality unnecessarily' implying that a protracted death is not only undignified, it lacks a desirable quality of life, and it may involve 'putting the patient through unnecessary pain'.

The preservation of the patient's dignity was mentioned by the majority of respondents and this generally appeared to mean that nurses could take satisfaction from being able to give 'the best possible standards of care' to the patient, so that he was well cared-for and had been given the maximum chance of recovery, if possible. To some nurses, a peaceful and dignified death meant not being subjected to 'CPR etc.'but being allowed to die quietly, 'hopefully with relatives present'. The maintainance of dignity to one nurse also meant that '...he did not go through unnecessary distress in a futile attempt to 'wean from the ventilator and then to die anyway'. One nurse felt that satisfaction would be obtained under these circumstances from 'creating a situation which maximises dignity and harmony for Mr.F. and his family'.

A number of respondents made comments about the fact that the patient had died so quickly, which confirmed, they felt, the severity of the patient's illness, the futility of continued and prolonged treatment and that it was reassuring to have confirmation of the correctness of the withdrawal decision.

Correct decision

These ideas were exemplified in a comment from one nurse who said,

> "A speedy end highlighted even more so how futile his treatment had become. Also he was probably only moments away from death given the rapid deterioration post-inotropic reduction. This reinforces that the right decision was made."

Another nurse said that 'the fact that the patient died so quickly would indicate how dependent he was on the inotropes and therefore confirm how severely ill he was'. One nurse commented that the consequences of reducing the inotropes 'highlighted how reliant Mr.F. was on the inotropes and that we were artificially keeping him alive', and another said that 'if treatment continued, you would unnecessarily be prolonging the patient's death, this being unfair to patient and his family'.

The satisfaction of feeling that 'Mr.F. would have had every possible treatment and chance for such treatment to work', that 'all was done' and then 'he was able to die with some dignity and peace', again conveys the idea of confirmation of the correctness of the decision. One nurse mentioned the importance of the decision being made by the team, saying that 'the team caring for Mr.F. were in agreement with the decision/ future treatment' again reinforces the feeling of support to the nurse in the withdrawal decision.

One nurse thought that there would be satisfaction about the correctness of the decision, in commenting that the family accepted the decision; the patient had received full treatment for seven days; he was aged 74 years; and that death occurred quickly.

Some of the comments which respondents made, implied that nurses felt they had to justify themselves in taking the actions they had, firstly by providing evidence that proved that the decision had been correct, then by saying that they felt they had acted in the patient's best interests, giving reasons in support of this. One nurse, for example, said that 'the fact that he died so quickly would indicate how ill he had been' and added,

> "I would hope I would know I acted in the patient's best interests".

Family

Being able to care for and support the patient's family was another aspect which nurses felt would give them satisfaction. More than half the respondents mentioned the family in their answers, focusing on different aspects. A number of nurses talked about the preparation of the family for the death and of supporting the family through the process. This preparation would include 'explaining fully to the family', informing the family of the intentions to reduce inotropes, giving reasons for this action, and one nurse talked of 'knowing the family were informed of the likelihood that the patient would die'. A number of nurses mentioned that the fact that the death happened so quickly, meant that there was an end of futile suffering and that the death was not 'drawn out for the family'. Nurses felt that it was important to the family to know that the patient appeared peaceful, comfortable and pain-free, and that 'his hair was brushed and his teeth cleaned'. Nurses felt that they would draw satisfaction from being able to 'allow the family to be with Mr.F.' and 'he was able to die with some dignity and peace with his family'.

The importance to nurses of being able to effectively manage these situations was exemplified in one nurse's comment that satisfaction would be gained from ensuring that the family 'have time to be together' and 'creating a situation which maximises dignity...' for Mr.F. and his family. It was also important that families 'accepted the clinical decision made' if nurses were to gain any satisfaction from this situation.

Three nurses made reference to the omission of informing the family of the inotrope reduction. One said that no satisfaction could be gained from this situation because 'honest communication with the family is the only acceptable communication' and that not telling the family about the drug reduction 'was dishonest'. Another nurse had a different view on this, feeling 'glad they weren't told initially as it is far too close to euthanasia'. A third nurse commented that 'if the family weren't aware why he died suddenly, then they may feel better that they didn't switch him off'.

Worst aspects

Nurses' views about the worst aspects of the situation described, fell generally into three main areas, firstly aspects concerning the family; secondly, admitting that there was nothing else to be done for the patient; and thirdly, the moral problem over the consequences of treatment-reduction.

Family

When nurses are caring for patients whose treatment is being withdrawn, it is usually possible to have some control over the pace and timing of events. In the situation described, the patient unexpectedly died as soon as the support drugs were reduced and eight respondents identified this as being the worst aspect for them, primarily because the 'family did not have time to prepare' and one nurse added that this would be even worse if the nurse did not know the family very well and had not had the opportunity to develop any rapport with them.

Many respondents linked their sorrow over the fact that the family had no time to prepare with concerns about the failure to inform the family about the inotrope reductions, feeling that if there had been full discussions about the situation and the withdrawal process, the family would have been better prepared. One nurse, for example, felt that the worst aspect was 'that the family were unaware that treatment was effectively already being withdrawn and that they should therefore expect the patient's death imminently'. Another commented that 'the family was not fully informed of the situation, therefore when he died, I feel that they may have been deprived of the few hours they may have left with him...'.

An aspect of this unpreparedness which concerned one nurse was the lack of time to 'ensure that religious needs were met' and another nurse was concerned because the family may not have been able to be present at the time of death because of the timing. Three nurses mentioned the limited time to bid farewell, one nurse saying, for example, 'that he died too quickly for the family to say a proper goodbye'. Ten nurses mentioned their unease over the failure to fully inform the family about the withdrawal process.

Six nurses felt that the worst aspect would be dealing with the sadness and grief of the family members and coping with their reactions to the death, 'dealing with upset relatives' as one nurse termed it, and another talked of the 'anguish of the relatives'. One nurse felt that the worst aspect would be 'if the patient was awake, aware and distressed'.

Four nurses mentioned another theme which involved the reactions of the family, concerning the mode of withdrawal. One nurse commented that a worst aspect would be 'dealing with the family and their reactions, particularly if they attribute death to the change in drugs' and another on similar lines, said, 'relatives feeling you have contributed to reducing inotropes (blame you)'. One nurse felt that a failure of the family to accept the situation where 'we actually reduced treatment prior to their knowledge' would be difficult.

Reconciled to failure

Respondents expressed their sorrow about being defeated in their attempts to get the patient better, for example, some nurses talked about 'the fact that the patient had to die at all' and of 'finally having to give up and admit that there is nothing more you can do'. Three nurses expressed concerns about the actual procedure of having to tell the family about the end of treatment and the sudden death, or accompanying the doctor while he did this. One nurse was concerned that the patient's views on withdrawal were not known.

Moral problems

Four respondents expressed moral difficulties with the process of treatment withdrawal in the vignette. One talked of 'coming to terms with the fact that the alteration in treatment contributed in a major way to allowing an earlier death' and asked '...morally how right is that?' Another nurse talked of 'feeling that I had killed him' and a third commented,

> "If anything went wrong, you were the last person to manipulate the drugs".

One nurse mentioned 'feeling responsible for the death if I hadn't challenged/ discussed the drug decision with the doctors'.

Finally, some respondents felt that the alternative scenario of not withdrawing treatment and of prolonging the dying process as being the worst aspect, one nurse commenting that 'it had taken seven days to get to this point' and another that 'maybe treatment had gone on too long' with the 'patient lingering on' as one nurse said.

Vignette 2

Mrs.S. is 70 and has a diagnosis of having had a cardiac arrest at home, presumably secondary to an MI.

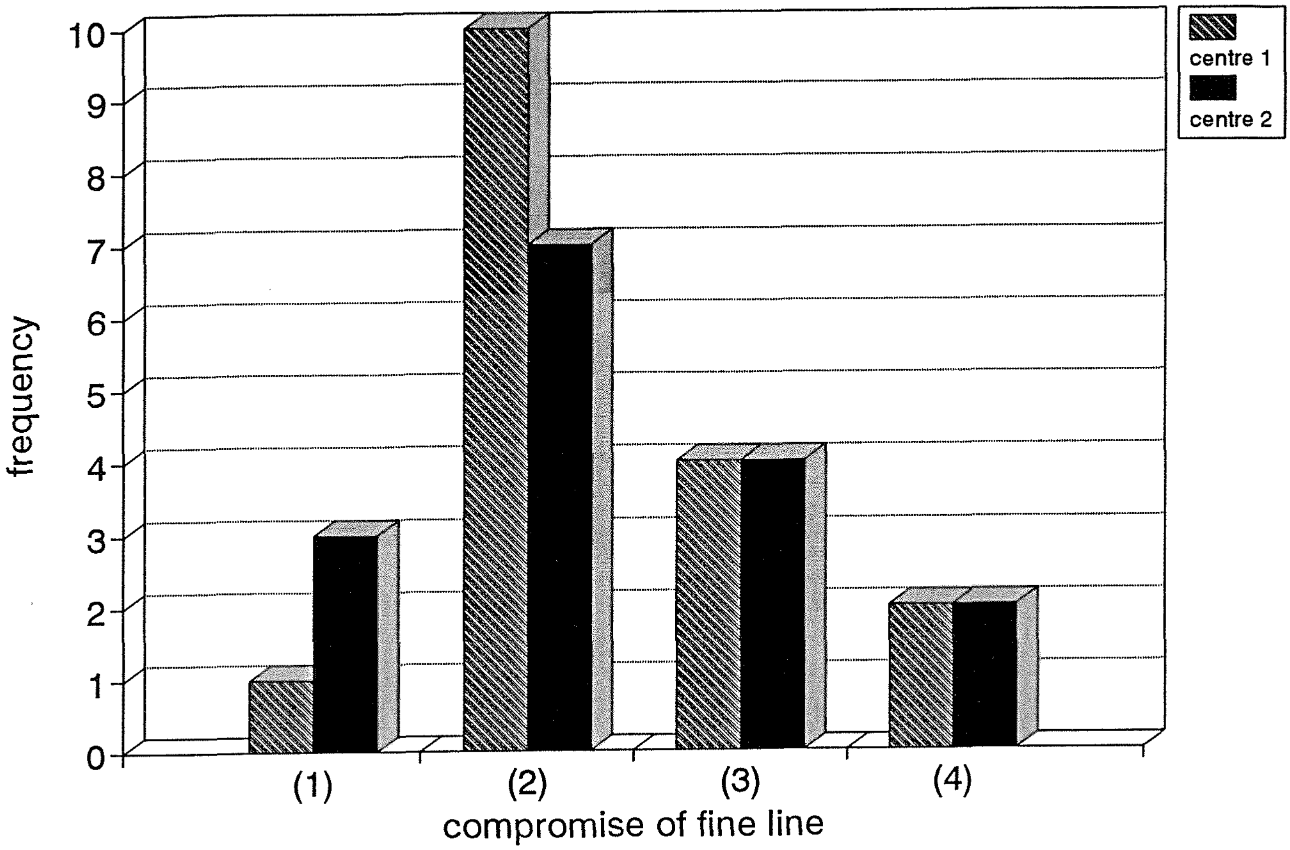
This is day 5 in ICU and it is apparent that despite the sedation having been off for the past 4 days, Mrs.S. has not woken up at all. The conclusion must be, from the clinical picture, that there has been irreversible brain damage. Mrs.S. has been off the ventilator for 24 hours and has breathed adequately, spontaneously, though is still intubated.

The situation is reviewed by the doctors involved, and the feeling is that the situation is hopeless, and that further treatment is futile, so Mrs.S. should be discharged to a medical ward for terminal care. You and the ICU consultant talk to the family about the situation and they accept that there is nothing more that can be done to help Mrs.S. to get better. They also agree that any medical treatment should be discontinued. The ICU consultant tells you to extubate Mrs.S. and make arrangements to discharge her. You are not certain that Mrs.S. will maintain her airway, but decide to do as the doctor suggested and take out the ETT. Within minutes of the ETT coming out, Mrs.S. dies and you feel awful about it happening so quickly, before the family has really had time to come to terms with what is happening. You know that the family did not expect this to happen and can see that they are shocked.

2.1 Under these circumstances, to what extent would you feel that the fine line between euthanasia and helping the patient to a peaceful and dignified death has been compromised?

(4) answered ’not at all’
(17) answered ’to some extent’
(8) answered ’to quite a large extent’
(4) answered ’to a very great extent’
(33) total
See fig.2.1

2.1 Compromise of fine line between euthanasia and helping a peaceful death



1. not at all
2. to some extent
3. to quite a large extent
4. to a very great extent

The justification for removing the endotracheal tube would be that it is no longer of benefit to the patient and certainly, the patient who was breathing spontaneously may have been able to maintain her airway without the tube in her throat. It may be preferable to families to have the patient as free of tubes and other features of the ITU technology as possible, once there is no longer a need for them.

The responses to this question indicated that there was greater unease among respondents over the circumstances described, which supports the view of the respondent in the earlier phase who described this type of situation, and was very unhappy about it. One nurse from this phase, for example, said,

> "I would never extubate a patient under these circumstances, though I might be prepared to let the doctor do it, though I may not. I feel that this action is unacceptable and the patient should not have been extubated. This is tantamount to active killing"

and another,

> "If I was concerned about her ability to maintain her airway I would challenge the decision to extubate".

It is apparent from fig.2.1 that there is no significant difference between the two centres. This was confirmed using Mann-Whitney-U test:

$U = 127.5$ Exact $P = 0.7595$ (2-tailed)

Vignette 3

Mr.R. is 55 and has a diagnosis of a GI bleed from oesophageal varices, secondary to alcoholic cirrhosis of the liver.

This is day 10 in ICU and despite the maximal treatment which has been carried out, Mr.R. continues to bleed intermittently. He has some renal dysfunction, but, so far, has not needed haemofiltration. Surgery could be offered to relieve the portal hypertension, but this would lead to Mr.R. having to be ventilated for possibly a week or more, as his condition is poor generally. This is Mr.R.'s third admission to hospital in the last year for the same condition, but his first admission to ICU. Mr.R. is now confused, disorientated and irrational, and cannot give a reliable indication of what he wants in terms of treatment. Mr.R.'s brother, the next of kin, says that nothing further should be done and no surgery or haemofiltration should be attempted, because he feels that Mr.R. would not want treatment which would only offer limited benefit, particularly when, in his opinion, Mr.R.'s life was already of very poor quality and he would inevitably start drinking again.

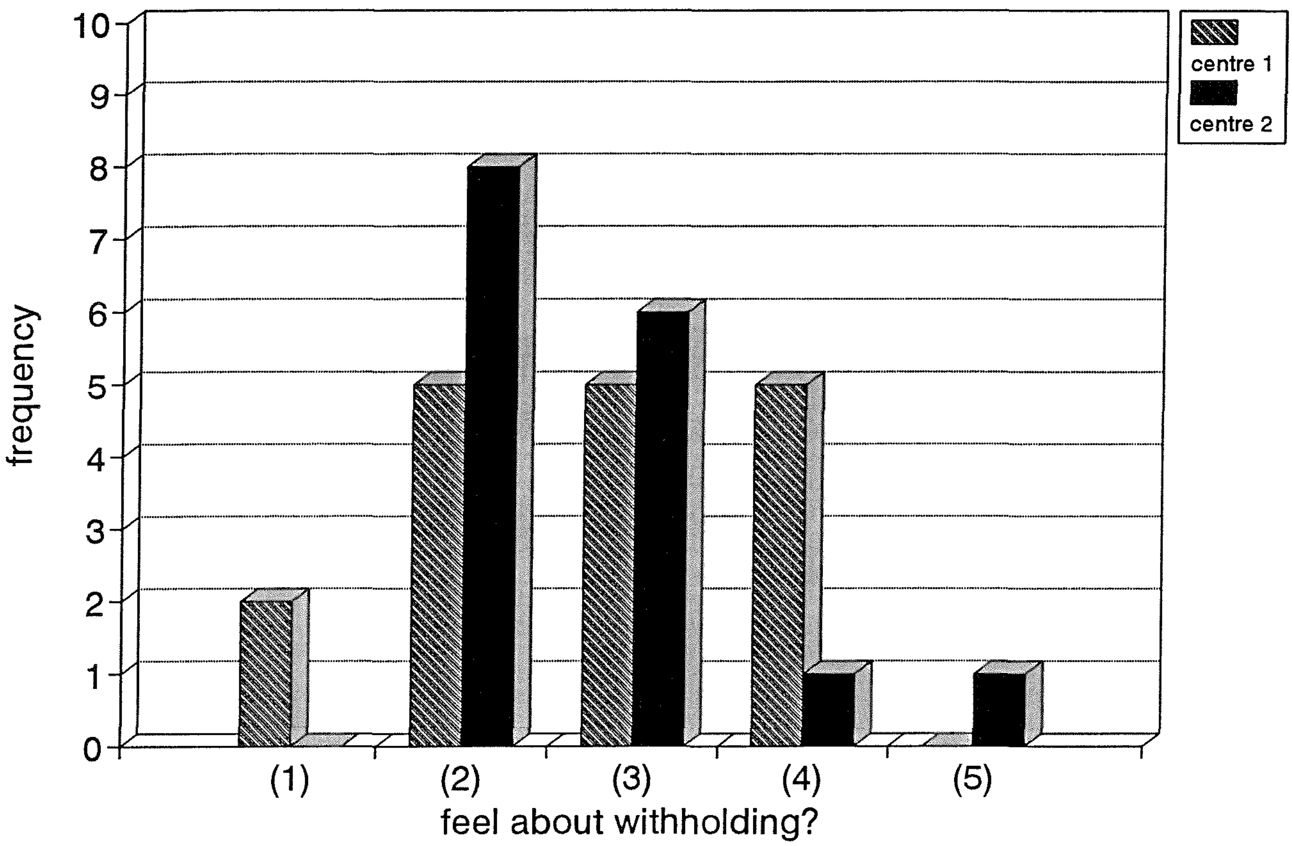
Mr.R.'s doctors review the medical situation and the treatment thus far, and, influenced by the brother's views, decide to maintain conservative treatment with drugs and fluids, but to withhold surgery, withhold haemofiltration, withhold resuscitation in the event of cardiac arrest, and to place a limit on the number of units of blood to be given, if a further transfusion is required.

3.1 Feelings about this withholding situation

Respondents were asked how they felt about the decision to maintain conservative treatment but withhold further new treatment from a patient whose condition was likely to deteriorate further, given the clinical features depicted in the vignette which would indicate increasing hepato-renal failure and intermittent bleeding from oesophageal varices.

See fig.3.1

3.1 Feelings about
withholding treatment



1. strongly disagree
2. disagree
3. unsure
4. agree
5. strongly agree

(2) strongly disagreed
(13) disagreed
(11) were unsure
(6) agreed
(1) strongly agreed
(33) total

This division would indicate that respondents were very uncertain about the correctness of a withdrawal decision. Almost half disagreed or strongly disagreed with the decision and a third of respondents were unsure. In the situation from the earlier phase, on which this vignette is based, the nurse involved did disagree with the decision to withdraw and felt that the patient should be given another chance, 'the chance to prove us wrong'.

Analysis using Mann-Whitney-U test indicated no significant difference between centres:

U = 124.5 Exact P = 0.6787 (2-tailed)

3.2 Who should have the most influence in making the withholding decision in this situation?

Respondents were next asked who they felt should have the most influence in making the withholding decision among a list consisting of the nurse, physician, ICU consultant, the patient's brother, the patient himself and the patient's GP,

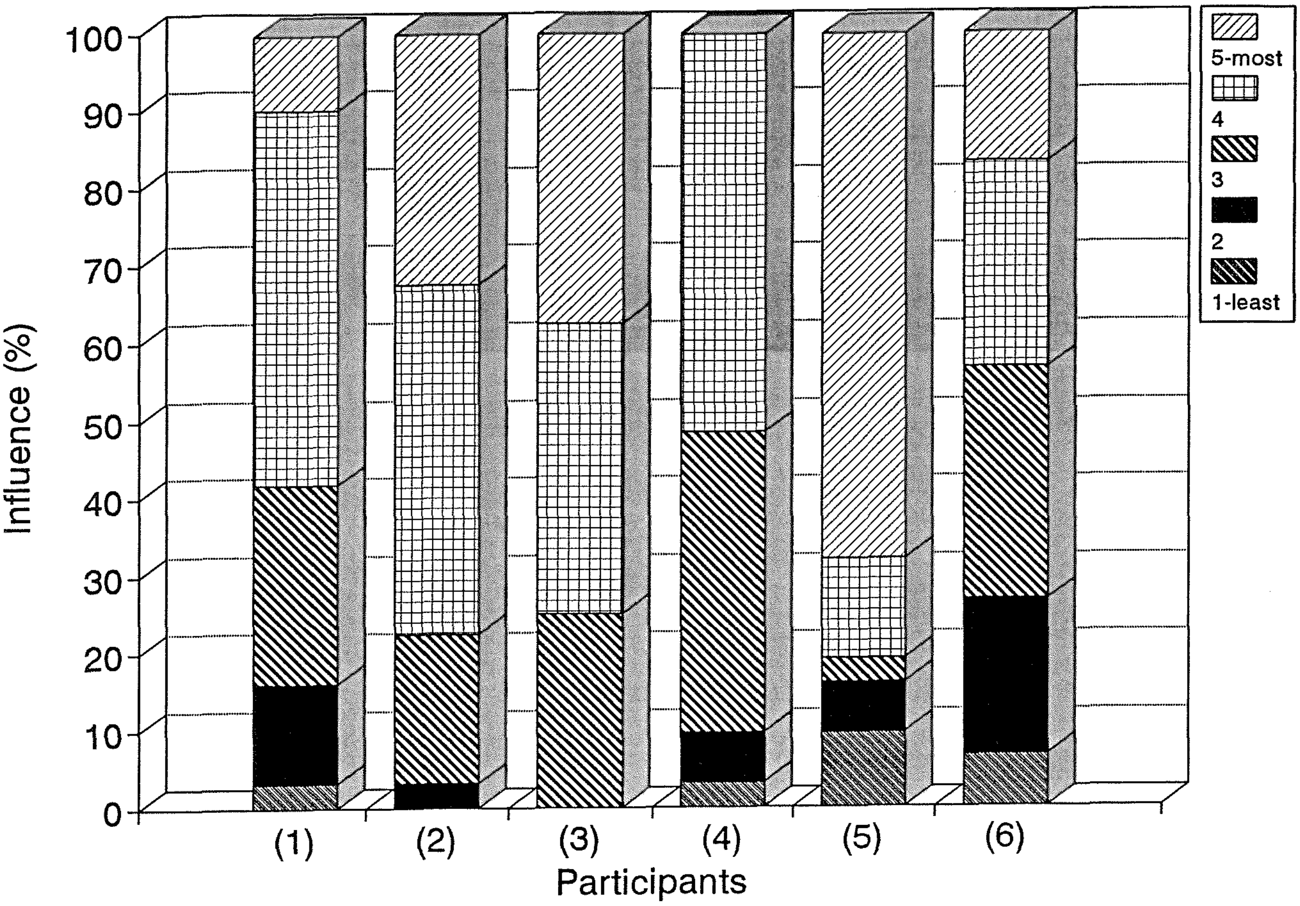
where 1 = should have the least influence and 5 = should have the most influence

Category	1	2	3	4	5	Mean	Median
Nurse (n=32)	1	4	8	16	3	3.500	4
Physician (n=32)	0	1	6	14	11	4.094	4
ICU consultant (n=33)	0	0	8	12	13	4.152	4
Brother (n=32)	1	2	13	16	0	3.375	3.5
Patient (n=32)	3	2	1	4	22	4.250	5
GP (n=31)	2	6	9	8	6	3.323	3

Total n=33, missing data indicated.

See fig.3.2

3.2 Projected influence of participants



1. You, Mr.R's nurse
2. Mr.R's Consultant Physician
3. Mr.R's ICU Consultant
4. Mr.R's brother
5. Mr.R., the patient
6. Mr.R's GP

Nurses felt that the patient should have the most influence in this decision-making process, although as depicted in the vignette, the patient's opinion would have been difficult to ascertain because he was confused and irrational. This highlights the importance of holding discussions with the patient early in clinical contexts like this one, as this will greatly assist later decision-making, and it is really the only way to enable the patient to have autonomy and have influence.

Respondents felt that the patient's consultants should be very influential in making the decision. Under these circumstances, the ICU consultant is likely to know of the patient's history and would know details of the current situation. The physician is likely to have known the patient and his history and may have detailed knowledge of, and insight into, the patient's illness and the prognosis. This correlates with findings from the previous situations where consultants, particularly ICU consultants, did have the greatest influence in the earlier phase.

One implication of these responses is that nurses do not feel that they should have as much influence as the doctors, which could mean that nurses may not agree with the decision taken but could not exert enough influence to alter it. This would create moral difficulties for the nurses who may find that they have to participate in the withholding of care from the patient when they disagree with the approach.

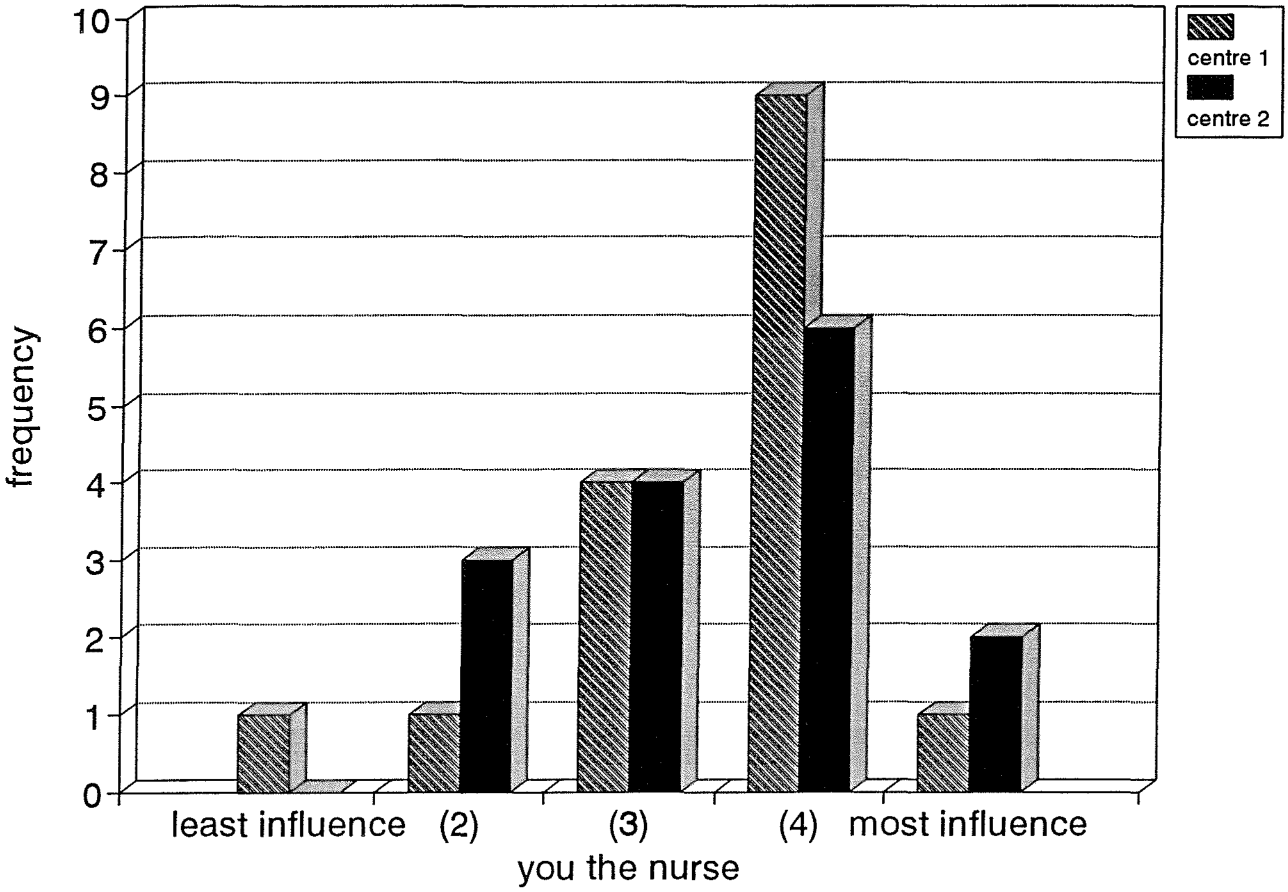
There is little difference between the two centres on the amount of influence which the nurse should have under these circumstances which was confirmed on analysis using Mann-Whitney-U test:

$U = 125$ Exact $P = 0.9100$ (2-tailed)

Similarly, there was no significant difference on analysis between the two centres for each of the other participants.

See fig.3.2.1

3.2.1 Influence of nurse



3.3 and 3.4 Do you feel that anyone else should have been involved in making this decision

Two-thirds of respondents felt that people other than those mentioned should be involved in the decision-making. Suggestions made by respondents included:

Family members who knew him well	-mentioned by 11 nurses
Ward nurses, his primary nurse	-mentioned by 8 nurses
Friends who knew him well	-mentioned by 7 nurses
Clinical ethicist	-mentioned by 6 nurses (out of the 16 respondents who work in a centre where there is an ethicist)
Vicar	-mentioned by 3 nurses
Social worker, if one involved	-mentioned by 4 nurses
Other members of the multidisciplinary team	-mentioned by 2 nurses
Community nurse	-mentioned by 2 nurses
Hepato-renal consultant (if own physician is not one)	-mentioned by 2 nurses
GP	-mentioned by 1 nurse
Psychiatrist	-mentioned by 1 nurse
Surgeons	-mentioned by 1 nurse

Many added a proviso to their suggestions of others who should be involved, saying that they should already have been involved and have known him well. One respondent, for example, said,

> "Any other family or friends who are close. Ward nurses or named nurse who knew his feelings on future care and treatment".

3.7

A little later after this withholding decision has been taken, you are told that the doctors want to obtain an EEG for research purposes.

How do you feel about the EEG request under the circumstances?

Reasonable, because something positive may be gained from it, so I would ensure that the brother was able to sit comfortably at the bedside while it was done, if this were what he wanted.

	Centre 1	Centre 2	Total
Yes	5	3	8
No	3	9	12
Unsure	4	0	4
Did not reply	5	4	9
Total	17	16	33

Of the respondents who gave an answer in C1, opinions were quite evenly distributed. In C2, respondents were much more positive in rejecting this statement, just over half of them saying 'no', with one fifth saying 'yes'.

Analysis using Mann-Whitney-U test revealed no significant difference:

$U = 66.0$ Exact $P = 0.7290$ (2-tailed)

Reasonable, but I would insist on the doctors asking the brother for permission to do it

	Centre 1	Centre 2	Total
Yes	9	4	13
No	3	8	11
Unsure	1	2	3
Did not reply	4	2	6
Total	17	16	33

Respondents from C1 were more likely to agree with this statement than those from C2, and analysis using Mann-Whitney-U test indicates a trend towards a significance in the difference:

$U = 55$ Exact $P = 0.0806$ (2-tailed)

Obtaining consent is problematic under these circumstances, as the brother cannot give consent on the (adult) patient's behalf, although he should be informed about it and consulted. Under these circumstances, if the patient cannot give consent, doctors must take the decision in the best interests of the patient, weighing up harms and benefits.

Unreasonable, but I could do nothing about it

	Centre 1	Centre 2	Total
Yes	2	0	2
No	8	8	16
Unsure	1	2	3
Did not reply	6	6	12
Total	17	16	33

Half of respondents disagreed with this statement, implying that they felt that if they did feel the test was unreasonable, then they could speak up and do something about it. There was agreement between the two centres.

Unreasonable, because I would feel that it was an unnecessary intrusion under the circumstances

	Centre 1	Centre 2	Total
Yes	7	9	16
No	4	3	7
Unsure	3	0	3
Did not reply	3	4	7
Total	17	16	33

Just about half of all respondents agreed that they felt the EEG request would be an unnecessary intrusion under the circumstances, although just under a quarter disagreed with this. There was agreement between the two centres generally.

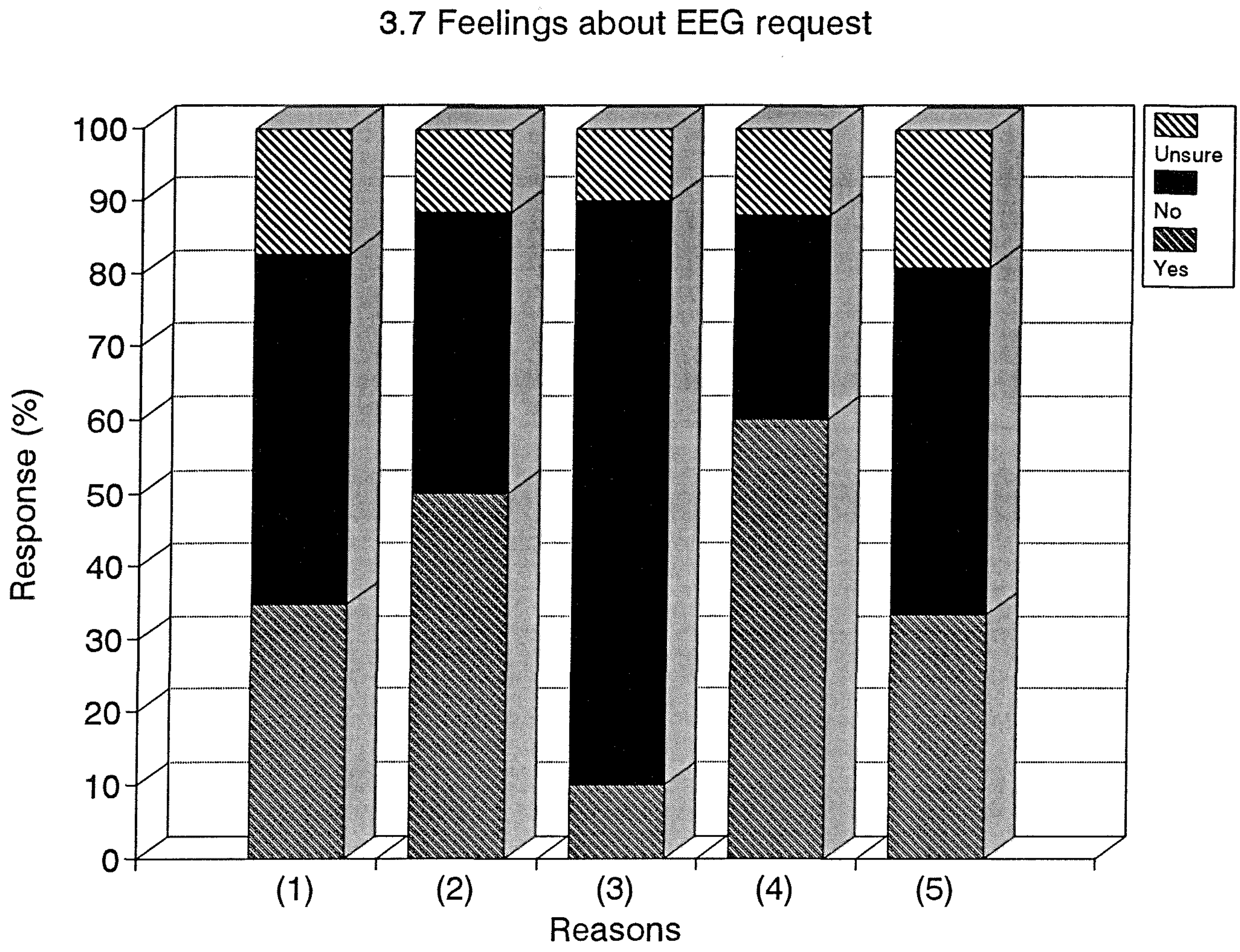
Unreasonable, because it is not possible to ask for the patient's consent

	Centre 1	Centre 2	Total
Yes	4	4	8
No	5	5	10
Unsure	2	2	4
Did not reply	6	5	11
Total	17	16	33

There was agreement between the two centres.

See fig.3.7

Uncertainty was expressed by respondents throughout this series of questions. Some indicated that they were unsure, but many more gave no reply, perhaps indicating that they lacked knowledge in this area, or did not feel that the statements were applicable.



1. Reasonable, because something positive may be gained from it, so I would ensure that the brother was able to sit comfortably at the bedside while it was done, if this were what he wanted
2. Reasonable, but I would insist on the doctors asking the brother for permission to do it
3. Unreasonable, but I could do nothing about it
4. Unreasonable, because I would feel that it was an unnecessary intrusion under the circumstances
5. Unreasonable, because it is not possible to ask for the patient's consent

Projected sources of satisfaction

Respondents suggested a variety of potential sources of satisfaction from which four main themes have been drawn, however, four nurses indicated that they would not gain any satisfaction from this situation and a further three had left the answer blank or said that they were unsure.

Not an arbitrary decision

One area concerned the process of planning and decision-making and a number of nurses felt that they would derive satisfaction from the fact that the decision was not taken arbitrarily but that there had been discussions about the whole situation, a reasoned decision taken and a definite plan for future care established.

One nurse commented that satisfaction would be drawn from 'the fact that the situation was discussed before haemofiltration was commenced; that things hadn't gone on longer that ten days; and that the medical staff are being realistic'. Other nurses also appreciated the timing of the decision and the avoidance of procedures and treatments which would prolong death, one saying for example, that I may prevent him from receiving invasive procedures which will not affect his quality of life and just prolong his death' and another, that if the inevitable death 'is not prolonged through unnecessary procedures... and he dies peacefully, that may give some satisfaction'. Placing 'limits of resuscitation and treatments so not prolonging how long you can give conservative management' was another aspect mentioned by one nurse and a nurse commented that there would be satisfaction because 'the patient will not suffer any long-term treatments'. One nurse felt that satisfaction may result from realising that there was 'the prospect of saving him from an even worse quality of life should he die'.

High standard of care

Eight respondents commented that satisfaction would be derived from being able to give a high standard of nursing care to the patient, with particular reference to managing the process of dying, so that the patient's death could be 'dignified, peaceful, comfortable and painfree'. One nurse felt that he/she would be 'comforted by the fact that Mr.R. would have received excellent nursing care' and another comments that satisfaction would be obtained from ensuring that all care was given 'to the best of my ability to provide maximal comfort for my patient', giving 'the best care I could', and from taking care of physical needs 'to maintain comfort, hygiene and adequate pain control'.

The mediation role of nurses was exemplified in one nurse's comment that satisfaction may be obtained from 'the opportunity to suggest medication (sedation) which might relieve his anxiety/ agitation'.

Family

Five respondents mentioned the care of the patient's family in connection with sources of satisfaction, particularly in the decision-making process. One nurse talked of 'appropriate involvement of the family' and another of 'some discussion with the next of kin, honouring what the family wants' and a third, of the fact that 'the next of kin had been listened-to and not ignored' and 'the brother's views have been considered'.

Patient's best interests

The theme which features in, and underpins, most respondents' answers is the primary concern of the patient's welfare and best interests. In connection with the situation portrayed in this vignette, nurses are anxious to ensure that 'every effort has been made to improve his condition; that the correct decision is made; that the suffering of the patient is not prolonged unnecessarily; and that the patient is allowed to die peacefully and comfortably if a withdrawal decision is taken.

Two nurses expressed concern that the patient's views should be considered, one of whom said that on reflection, it would have been better to 'initiate discussions with (the) patient sooner when more appropriate'. The other nurse said that he/she 'would hope if the patient wasn't confused that this would be in accordance with his wishes'. The nursing role in mediation, and in protection of the patient was expressed by one nurse in the comment,

> "I may prevent him from receiving invasive procedures which will not affect his quality of life and just prolong his death".

Worst aspects

There were essentially four main themes derived from respondents' views of the worst aspects likely to be associated with this vignette. These included aspects of the decision itself, concerns about not giving the patient the opportunity of having surgery, disquiet about the brother's role and fourthly, a category of comments where respondents had been cryptic and their meaning had to be surmised.

Decision

The first major area of concern related to the making of the withdrawal decision. Many respondents apparently would have disagreed with this decision, and for them, the worst aspect would have been an inability to prevent its enactment. For example, one nurse felt that the worst aspect would be 'if I strongly disagree, but I am not involved or influential in the decision' and another continued this theme by saying 'coming to terms with a decision that I didn't agree with', then 'acting on that decision' and 'being supportive to the relatives in an unbiased manner'. One nurse was concerned 'that he would have died and I never acted as his advocate appropriately ie. more aggressively'. Another nurse felt that the worst aspect would be 'disagreeing with the medical decision' and added 'conflict among the multidisciplinary team members'.

Doubts were expressed by some nurses. One, for example, said that with the type of limited-treatment decision made, it might indicate uncertainty, 'so if we weren't sure, then should we withhold treatment?' Disquiet about whether the decision taken was in the best interests of the patient, was expressed by some nurses. One, for example, was anxious 'that treatment would be changed before consultation with the patient's physician or liver specialist - these would hopefully give indications as to long term outcomes and whether or not to change the direction of treatment' and another said specifically that he/she would have 'uncertainty that this decision may not have been in the patient's best interests as I had little understanding of what the patient may have wished for'. Concern and doubts about the decision were also expressed by one nurse who said that 'the worst thing might be the worry that today's decision might be overturned by a different ICU consultant next week'.

A number of respondents disputed the decision taken because it was a 'halfway house' one, saying it was 'the worst situation to be in' as it was 'neither one decision or the other'. This nurse felt that 'they should either treat fully or withdraw everything except fluids and drugs for pain control and sedation'. Another nurse felt that the decision was 'prolonging death by doing nothing to speed it up or treating patient ie. I feel that this scenario would be sitting on the fence', and a further concern was expressed by one nurse feeling that the worst aspect would be a 'belief that (we are) only prolonging suffering if only conservative treatment is offered'.

Denying treatment

Many respondents expressed disquiet about the decision because the patient was not offered the chance of surgery and possible improvement. One nurse felt that the worst aspect would be 'letting him die without having a chance to have surgery' and goes on to ask 'how do we know if it wouldn't increase his quality of life?' Unease was expressed about the 'feeling that this decision has been made on social issues and not possible surgical intervention'. Concern was also mentioned by some nurses about the fact that the patient had a potentially reversible condition, and 'liver transplant may be possible' and another expressed regrets that 'active treatment was not given and an attempt to help was withheld'. This last nurse also talked of the 'difficulty on my part (of knowing) what the best treatment is - a feeling that it may have been our own feelings we satisfied'.

One nurse was concerned that 'the fact that he is confused disallows him from having surgery' implying that had the patient been capable of giving his opinion, he would have opted for surgery.

Brother's role in supporting autonomy

A quarter of respondents were anxious about the uncertainty over what the patient's wishes would have been, one saying that perhaps 'his brother's opinion was thought more of than his own'.

One nurse regretted 'the fact that the patient had become so ill that he could not make the decision for himself - or at least let his wishes be known' and another nurse suggested that 'some relative or close friend that could give some explanation for his drinking bouts' could be found. A nurse felt 'that it's a shame people have no way of telling us prior to becoming confused, of their wishes' and another was concerned because of 'never really being sure of his wishes, his quality of life or his desire to live longer as he would have chosen'. Because of these doubts about the patient's wishes, some nurses suggested that other people should be sought who could give a view about the patient, his quality of life and what his own opinion might have been. One nurse, for example, said that 'Mr.R should have been more involved despite his confusion'. This nurse went on to suggest that 'the GP should be involved as we are acting on his brother's information about his home situation' because Mr.R. may have a great will to live and have a satisfactory lifestyle prior to hospitalisation in his opinion.

Another area of concern to respondents was the role of the brother in the decision, whose motives they doubted.

One nurse was concerned about the 'strong influence the brother appears to have had over the medical team' and this nurse continues,

> "He may not have had his brother's best interests at heart, perhaps the GP could shed some light on their relationship".

Another nurse also felt that the relationship between the patient and his brother 'may not be good'. One nurse commented,

> "I think it very sad that his next of kin did not want any active treatment".

An alternative anxiety was expressed by one nurse who said that the worst aspect would be the medical team 'not honouring what the family wants.

Moral problems

Cryptic comments made by some respondents included,

> "Age 55"

which the researcher would interpret as the fact that the patient was relatively young to be deemed as having an irreversible illness. Another nurse questioned the moral stance taken, saying that the team was judgemental about alcoholism, adding that 'it's not up to us what a person may or may not do on discharge'. A third nurse felt that the worst aspect might be 'using up the last unit of blood', presumably implying that it would feel awful to realise that the end had been reached and the patient may then die of a failure to replace blood loss. One nurse commented that 'dying of liver failure was one of the worst deaths'.

Vignette 4

Mrs.A. is 60 and has a diagnosis of acute exacerbation of chronic respiratory disease. This is day 24 in ICU and Mrs.A. has received maximal drug treatment and ventilation and has had a tracheostomy to facilitate weaning. There have been a number of attempts to wean Mrs.A. using a variety of techniques, but on each occasion, she has made some progress and, at best, has come off the ventilator for up to an hour, then has begun to struggle, so has had to return to the ventilator.

This is her second admission to ICU within six months, but on the first occasion she was successfully weaned from the ventilator during her three-day stay, and went home. At home, she was not ever well enough to do her own shopping or cleaning, and she spent most days resting in bed or in an armchair. She is widowed, and depends on her sons and daughters for help to manage on a day-to-day basis.

You have cared for her through a large part of her ICU stay and have got to know her quite well. She has said to you more than once recently during weaning attempts that she 'has had enough' and has lost any motivation to try to get better. Today, her heart failure is worsening, her blood oxygen is falling, her blood carbon dioxide is rising and her level of consciousness is deteriorating.

The ICU consultant, the patient's own physician and the junior doctors all visit and there is a discussion about Mrs.A.'s treatment. The ICU doctors are keen to start more aggressive treatment for the heart failure, but the physician feels that although this may be helpful in the short-term, the longer-term outlook is very poor.

The first four questions associated with vignette 4 attempted to establish each respondents threshold for treatment withdrawal under these circumstances and ascertain how respondents felt about using diamorphine for a patient who does not have pain, although diamorphine does offer other beneficial effects, such as relief of anxiety and fear, and possibly some reduction in the development of pulmonary oedema.

4.1 How would you feel about a decision to start more aggressive treatment?

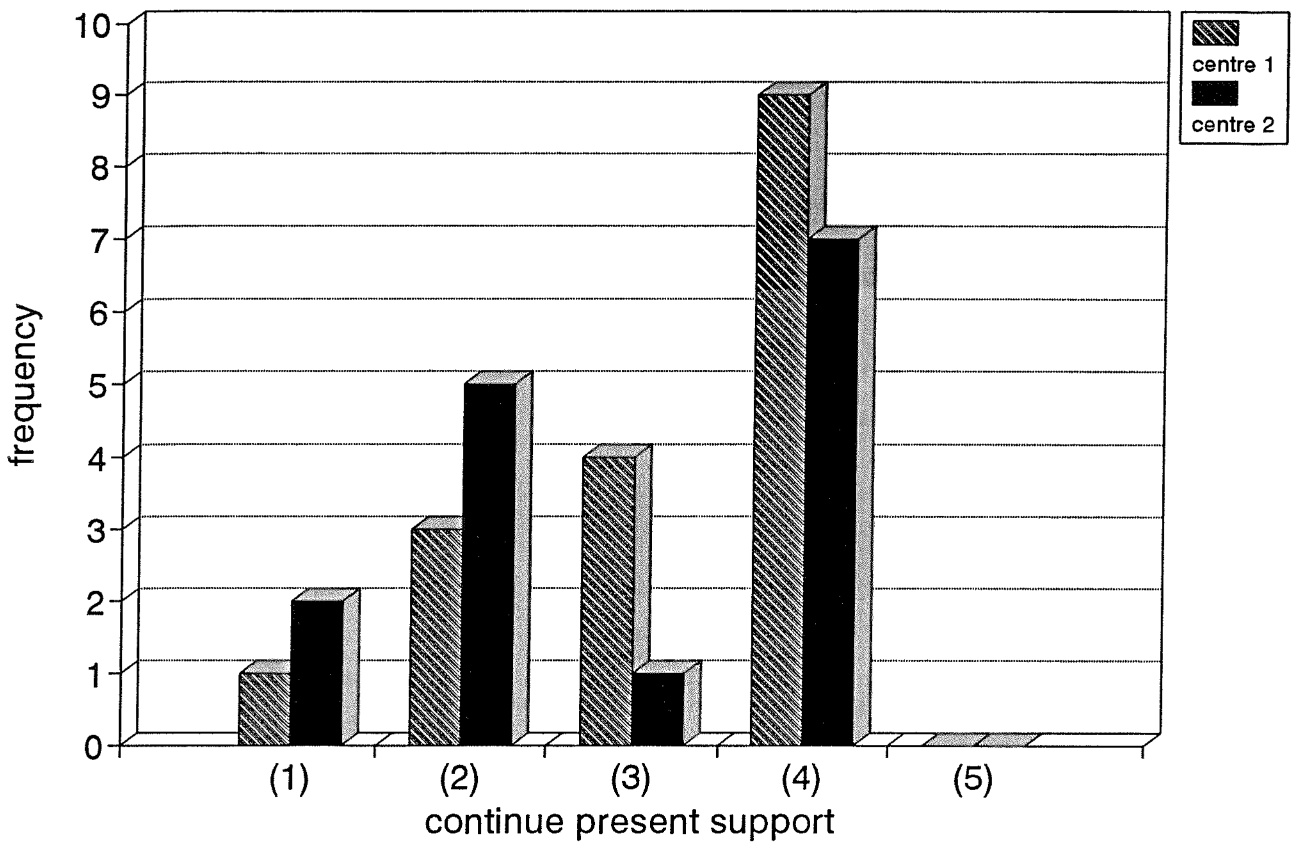
	Strongly disagree	Disagree	Unsure	Agree	Strongly agree	Missing	Total
Frequency	12	18	2	0	0	1	33

(30) of the (33) respondents disagreed with the decision to start more aggressive treatment, of whom (12) strongly disagreed, so the strength of feeling of the nurses who replied is quite obvious. (2) respondents were unsure.

4.2 How would you feel if a decision were made to withhold the further aggressive treatment for the heart failure, but to continue the present level of support?

(16) respondents agreed that further aggressive treatment should be withheld but that the present level of support should continue. (11) respondents disagreed with this, (3) of them strongly disagreeing. (5) were unsure. There was little difference between the centres.
See fig.4.2

4.2 Feelings about continuing present level of support



1. strongly disagree
2. disagree
3. unsure
4. agree
5. strongly agree

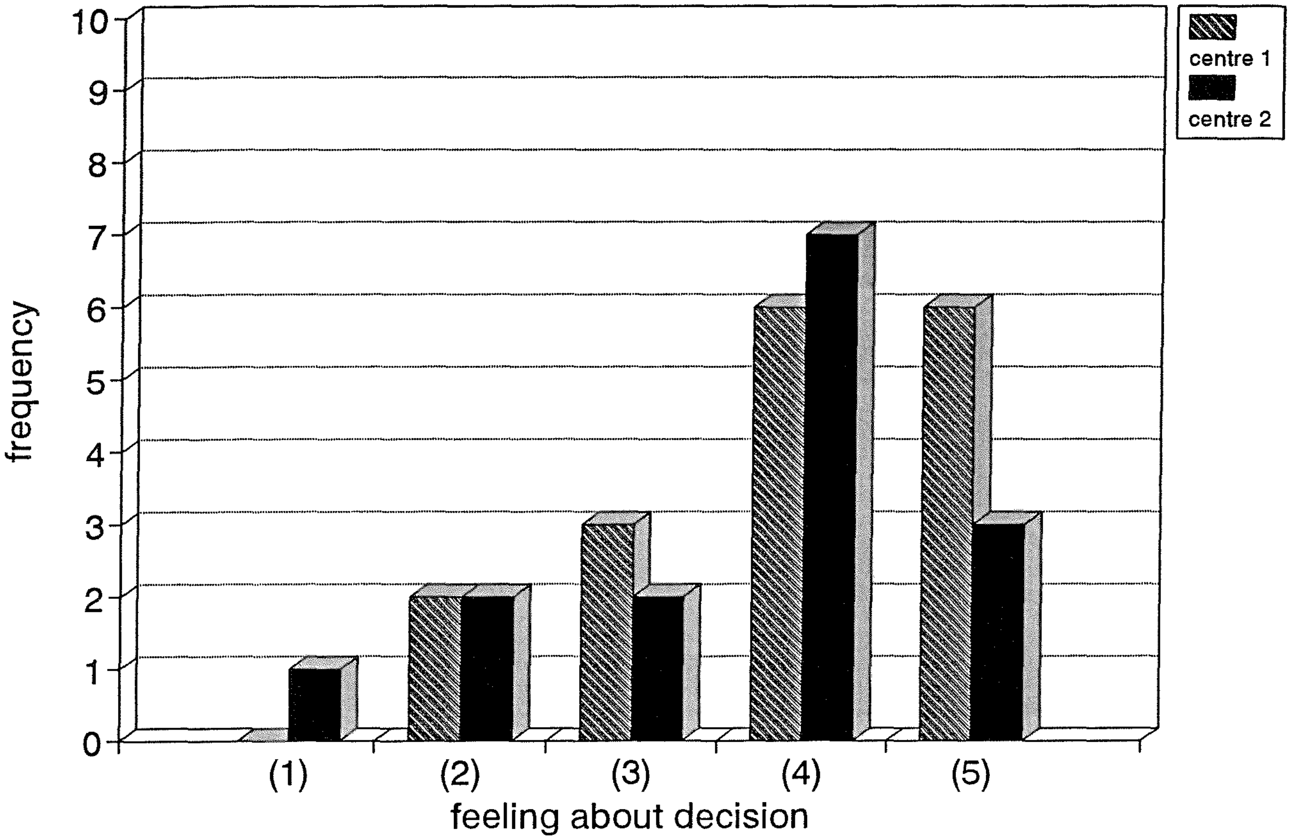
4.3 How would you feel if the decision were made to withhold further treatment and reduce the present level of support?

Again there was largely agreement between the centres. Just over half - (18) respondents agreed that further treatment should be withheld and the level of support reduced and (6) disagreed with this, (1) strongly. If this approach were taken, the patient would probably die quite quickly of cardiorespiratory failure under the circumstances described.

4.4 How would you feel if the decision were made to withhold further treatment, reduce the present level of support and start a diamorphine infusion, to ensure that Mrs.A. is comfortable during the withdrawal process?

See fig.4.4
As can be seen, (22) respondents, two-thirds of the group agreed with this approach, with (9) strongly agreeing with it. There was some disagreement though, (5) respondents disagreeing, (1) strongly.

4.4 Feelings about reducing support and and starting a diamorphine infusion



1. strongly disagree
2. disagree
3. unsure
4. agree
5. strongly agree

4.5 Who do you think can best represent the views of Mrs.A.?

Respondents were asked who they felt could best represent Mrs.A.'s views, where 1 =worst at representing Mrs.A's views and 5 = best

	1	2	3	4	5	Mean	Median
Sons, daughters	0	0	2	11	20	4.545	5.000
You	0	2	9	15	7	3.818	4.000
Mrs.A.'s physician	1	2	9	14	7	3.727	4.000
ICU consultant	2	5	14	10	2	3.152	3.000
Another person	0	0	0	8	10		

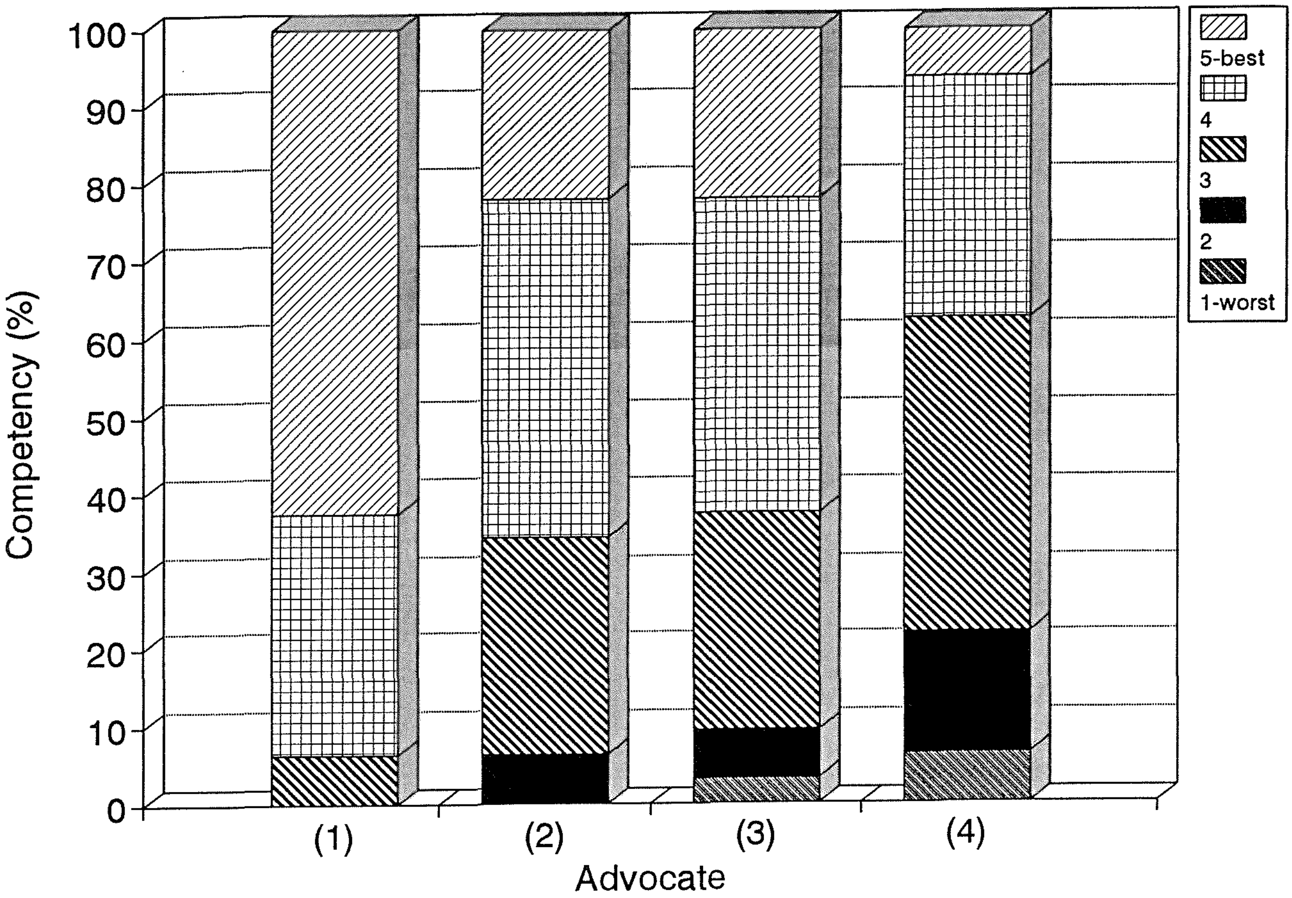
Of the eighteen respondents who mentioned another person, (8) said that Mrs.A. was the best person to represent her views, or perhaps under the circumstances, the implication is that the views she has previously expressed should be accepted.

Other people suggested were the GP by (4) respondents who felt that this person would be the best or almost the best for giving the views, and the vicar, a close friend and the physiotherapist were each mentioned by (1) respondent as being able to represent Mrs.A.'s views well.

It is clearly shown that respondents felt that the patient's family should be the best people to give the patient's views about treatment, so for this group of nurses, it would be important to include the family in discussions. Nurses, too, felt that they would have an insight into the patient's views over time, as would the physician, and therefore would be able to speak for the patient in discussions. Respondents were less confident about the ICU consultant's ability in this respect.

See fig.4.5

4.5 Best at representing views



1. Sons and daughters
2. You, the nurse
3. Mrs.A's Physician
4. ICU Consultant

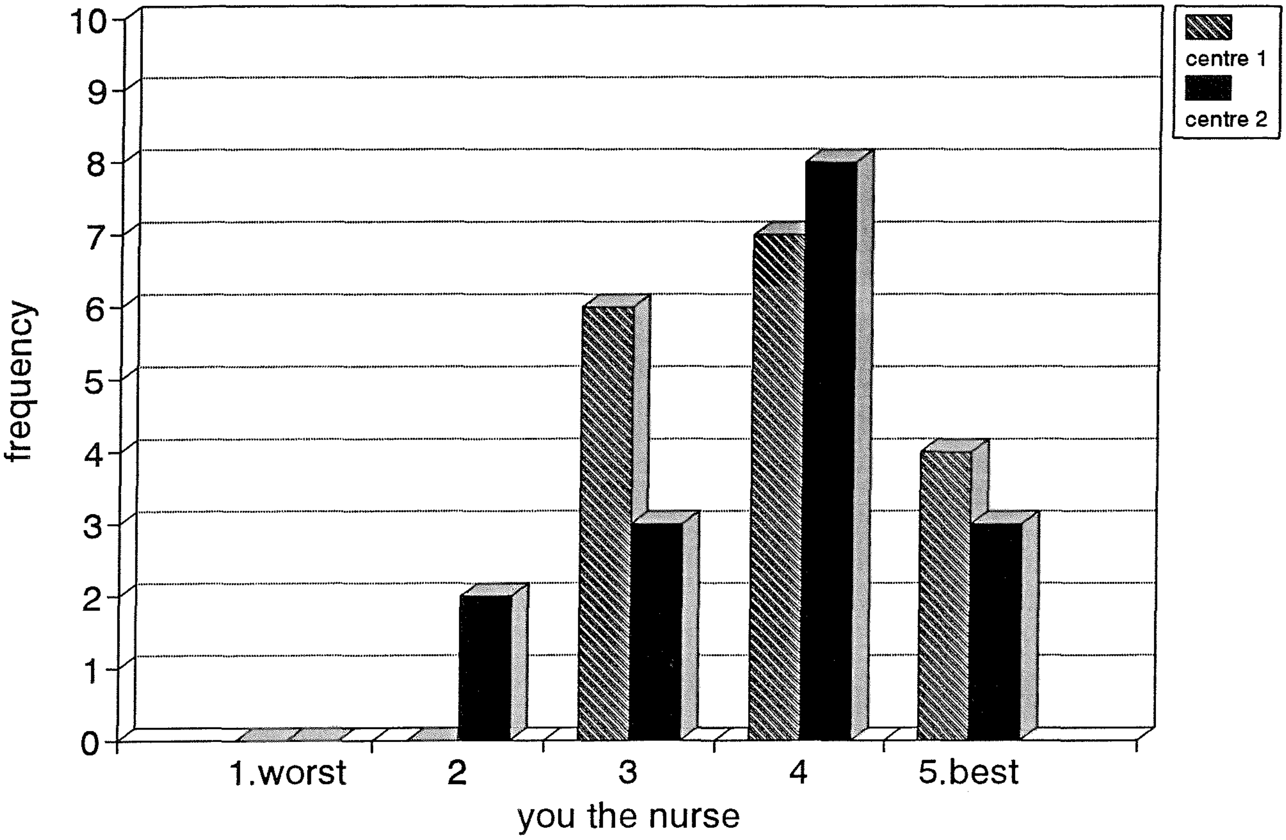
There was largely agreement between the two centres about the extent to which nurses could represent Mrs.A's views.

See fig.4.5.2

Mann-Whitney-U tests carried out for each category revealed no significant differences:

Category	U	Exact P (2-tailed)
Sons and daughters	100.5	0.2010
You	130.0	0.8289
Mrs.A.'s physician	120.5	0.5766
ICU consultant	105.0	0.2641

4.5.2 Projected extent to which nurses represent patients' views



Projected sources of satisfaction

Advocacy

In this vignette, the nurse had formed a close relationship with the mechanically-ventilated patient over a period of time during the stressful weaning attempts, and the patient had expressed the view when capable of doing so, that she wished the process to be ended. The advocacy role of nurses, representing the views of the patient in discussions about future treatment, was significant in the projected sources of satisfaction for the respondents. The majority of nurses, approximately 70%, mentioned this aspect and for many nurses there were two elements, firstly, having had the opportunity to get to know the patient well, having 'gained a rapport and bonding with her' and built up a relationship with her, and then secondly, 'being able to express her views'. One nurse, for example, commented that satisfaction would be gained from 'an opportunity to represent Mrs.A's views' because,

> "I would have got to know her and be able to judge whether she was rational or confused when making such requests".

One nurse mentioned that satisfaction would be gained from knowing that Mrs.A. was sufficiently comfortable with the close relationship which had developed that 'she was able to express her views to me' and another talked of 'meeting her as a person, knowing that she herself thought her quality of life was poor'.

A number of nurses talked about advocacy specifically, one nurse saying that satisfaction would be gained from 'knowing that Mrs.A's views were being taken into account' and from 'the ability to use one of our most important roles as ITU nurses, advocacy'.

Many nurses talked about the satisfaction to be gained from 'acting on the patient's wishes' and that if treatment were withheld, 'the patient has been part of the decision-making process'. One nurse said that he/she would have been 'glad to have acted on the patient's wishes', another 'that it was what she wanted' and a third, that 'I would like to respect the wishes of Mrs.A. which she has vocalised'. One nurse talked of the satisfaction of knowing that the patient had actually stated that 'enough had been done'.

Another aspect mentioned by some nurses was that of 'being patient advocate, creating discussion, and getting the doctors to discuss what the patient wants' and as one nurse stated,

> "To involve all pertinent people in a meeting to ensure that Mrs.A's feelings were known to the doctors".

Optimum care

A second theme mentioned by about a fifth of respondents concerned the care and comfort of the patient, having 'given the best possible chance to wean and get out of the Unit' and 'done my best to make her comfortable' to then aiding the patient to a peaceful and dignified death. This would involve, as one nurse said, 'caring with compassion and sympathy'.

Another said that 'the diamorphine would have ensured comfort during the withdrawal process and reduced potential anxiety levels'.

One nurse talked of 'helping Mrs.A. to a peaceful and natural death' and another of 'being the patient's advocate and if necessary, facilitating in her dignified and peaceful death'.

An allied theme mentioned by one nurse, was that of 'having gained a rapport and bonding with her', feeling that 'she had someone present (apart from family) who she knew and got on with'.

Significant deterioration

The fact that the patient's condition had already deteriorated markedly, despite active intervention, was mentioned by two respondents, one of whom felt that it would be satisfying to recognise 'that nature might take its own course anyway and obviate the need for further suffering'. Another aspect of this theme was an acknowledgement of Mrs.A's situation and if 'they did pull out, if she deteriorated and died quickly, it would show how reliant she was on the support which was maintaining her life', implying a need to this nurse to have some confirmation that if treatment were withdrawn then the correct decision was taken.

Worst Aspects

Phrases used by respondents to illustrate the worst aspects of the situation described in vignette four included:

personal knowledge
attachment
distress and sadness
frustration
team conflict
aggressive treatment
euthanasia
helplessness

Themes derived from respondents' answers generally fell into four main areas and centred on the personal relationship which had developed between patient and nurse, and the sadness when the patient died; the helplessness felt by the nurse if the doctors made a decision which went against Mrs.A's views and the possible ensuing conflicting feelings among team members; concern over euthanasia; and dealing with the patient's family under these circumstances.

Sadness

A number of respondents reflected on the situation where a patient whom they had supported through a series of difficult weaning attempts, 'seeing the patient distressed and struggling', became irreversibly-ill and died. Nurses talked of 'being part of her frustration and distress at not improving' and of 'admitting that there is no more to be done'. When the nurse has felt close to the patient over a period of time and has 'got to know Mrs.A. on a personal level', her death is 'harder because of that'. Another nurse commented that 'having cared for her for a long time, it would be a sad occasion when she died'. One nurse talked of the sadness of 'watching her die as she had been through so much' and another, of the fact that 'there is nothing that can be done to restore Mrs.A. to a quality life, by me or by others'. One nurse felt that the worst aspect would be,

> "The death of the patient. The pain I would feel. I think however a good ICU nurse should feel emotion when performing this on a patient they knew well. It makes you human and offer better support, although it can be difficult".

Helplessness

A feeling of helplessness was mentioned by about a quarter of respondents in connection with a decision to actively treat Mrs.A. against her expressed wishes. For example, one nurse projected 'a feeling of helplessness if the doctors did not listen to Mrs.A's views and continued an aggressive approach to care', another talked of a decision to continue with aggressive treatment 'knowing that the patient did not want it' and a third 'that the decision of the medics. contradicts Mrs.A's wishes'. Doubts over any decision were expressed by one nurse who asked,

> "Is this really what she wanted?"

One nurse expressed helplessness and frustration in her comment about the worst aspect which was 'that ICU was too active in treatment, playing God in keeping a patient alive when she should have been at peace', and goes on to questions the team's treatment motives, saying,

> "Basically treatment could have gone on and on, but the achievement would only have been for ICU not for the patient".

This same nurse is concerned 'that I may have to carry out care which I feel is wrong for that patient, because of the doctor's decision'.

Another nurse was concerned about 'the fact that though Mrs.A. has made her feelings clear, the ICU doctors have chosen to disregard her wishes'.

A nurse also mentioned concerns about the process of dying from LVF and felt that the worst aspect would be in allowing 'the heart failure to increase in severity would be like watching her drown which would be inhumane'.

There was also some concern about any 'prolonged indecision' or a 'half-way house' decision, prolonging the process of dying.

A different aspect of helplessness was expressed by one nurse who spoke of the implied difficulty of 'enabling the (multidisciplinary) team to understand frustrations, both personal and those of Mrs.A. to the length of ICU stay and the long-term quality of life'. One nurse was concerned 'how we can label patients within ICU of being clinically-depressed, then take away their decision-making powers'. This same nurse went on to say that after reflecting on patients nursed in similar situations, the very worst thing is 'that we can become focused on the ICU care of the patient and aim for discharge (from ICU) rather than focusing on the long-term aims of treatment and future prognosis'. For one nurse, the difficulties inherent in a situation where the 'ICU consultant/physicians and nurses (were) not all in agreement as to the patient's treatment'.

Euthanasia

Euthanasia was mentioned by two respondents. One talked about how LVF can be an awful way to die' but that 'diamorphine may be the answer in small doses, not euthanasic doses', with the aim of 'comfort, not unconsciousness'. The other nurse was concerned about the possible use of diamorphine under these circumstances, saying,

> "To commence a diamorphine infusion when there was no clinical need for it (ie.pain). I would feel this would certainly be classified as euthanasia (active) and possibly be liable for prosecution".

Family

Finally, concerns about dealing with the family were also expressed. For example, one nurse felt that 'dealing with the family if they hadn't had a chance to come to terms with the situation' would be the worst aspect, another that the family did not seem to have been involved in the decision-making, and a third, 'how the family will feel considering her age and situation'.

Vignette 5

Mrs.B. is 58 and has had an elective repair of an abdominal aortic aneurysm. This is day 5 on ICU. Mrs.B. has had an unexpectedly stormy post-operative course and she is still ventilated and sedated because of surgical complications which have necessitated two return visits to theatre to try to restore the circulation to her legs. Presumably the grafts to the legs have blocked and despite treatment, both legs are ischaemic and are not viable. Mrs.B. is also today beginning to appear quite 'toxic' and she now has other problems, including a change in heart rhythm from sinus tachycardia to rapid atrial fibrillation and she has some renal dysfunction.

The surgeons say that the only treatment is to do a bilateral, high-level amputation, but this would be very disfiguring surgery.

Mrs.B. cannot give her views. The sedation would take too long to wear off and Mrs.B. would have severe pain if allowed to wake up. Mrs.B.'s family says to you that this surgery would be totally unacceptable to her and that they know that she would rather die than endure such an operation and the resulting change in her way of life.

You can see from Mrs.B.'s ward admission profile that she is a very active person in the village where she lives. She takes part in amateur dramatics, sings in the church choir, is a voluntary driver for the senior citizens' community bus and generally helps anyone in need.

The issue here is Mrs.B.'s future quality of life.

5.1 Who do you think is the best judge of the acceptability to her of the future quality of her life?

Respondents were asked to indicate who, they felt, would be in the best position to judge, where 1 = the worst judge of acceptability and 5 = the best judge

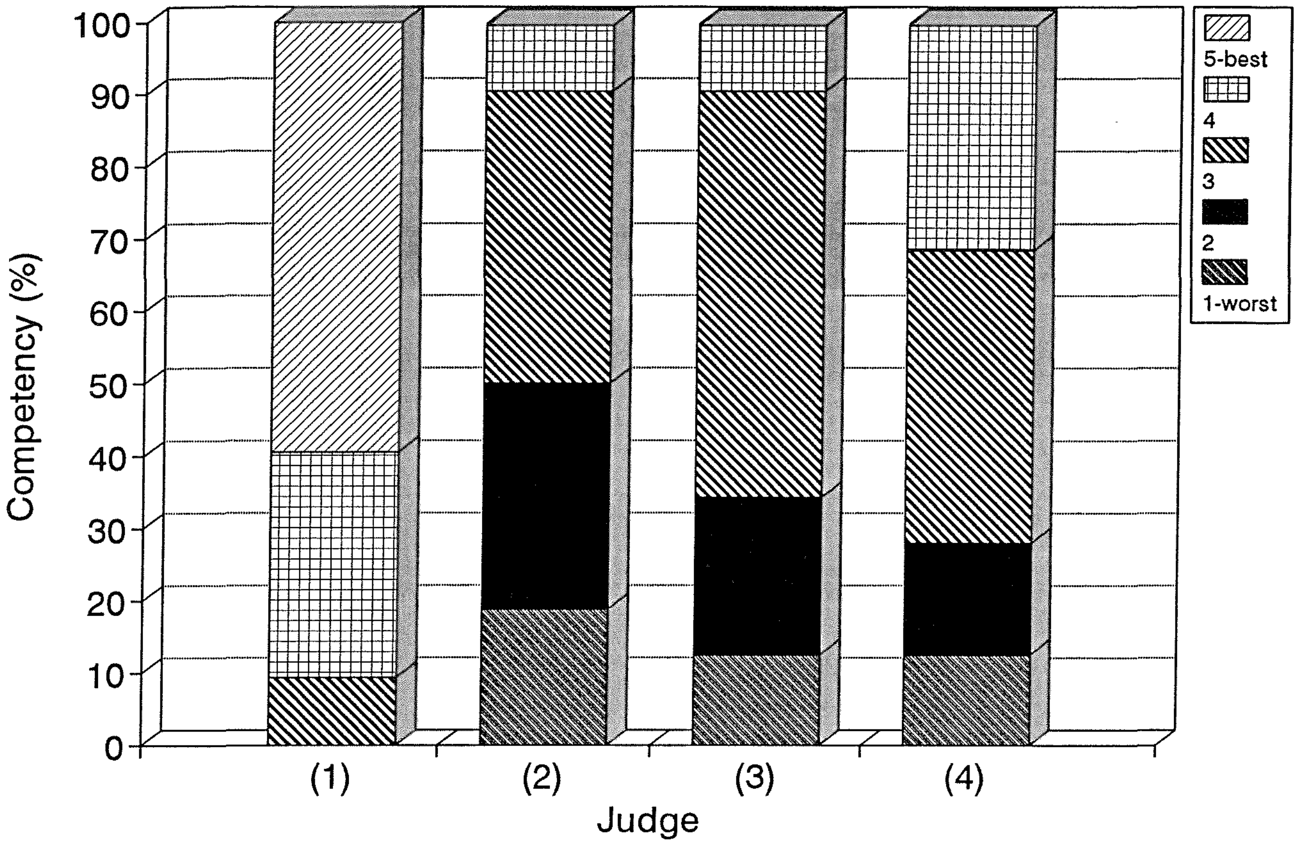
	1	2	3	4	5	Mean	Median
Family	0	0	3	10	20	4.515	5.000
Surgeons	6	10	14	3	0	2.424	3.000
ICU doctor	4	7	19	3	0	2.636	3.000
You	4	5	14	10	0	2.909	3.000

The majority of respondents felt that the patient's family was the best judge of the acceptability of Mrs.B.'s future quality of life, should she survive the surgery. Of the doctors, the ICU one was rather better than the surgeons, in the respondents' views, and the nurses themselves felt that they were better judges than either group of doctors. Certainly under the circumstances described, the nursing team would have had close contact with Mrs.B. and her family over the five days in ICU, and would have been in a position to collect relevant information from the patient, possibly pre-operatively, the patient's family and also from the ward nurse who carried out the admission procedure. Again, there was largely agreement between centres on the nurses' ability to judge acceptability to the patient.

Analysis using Mann-Whitney-U test to explore any differences between centres revealed no significant differences.

See fig.5.1

5.1 Best judge of acceptability of future quality of life



1. Her family
2. The surgeons
3. The ICU doctor
4. You, the nurse

5.2

The surgeons want to try surgery, although there are obvious risks associated with anaesthetising Mrs.B. as she is now so ill.

How would you deal with this? Which statement best describes your probable actions?

	Frequency	%
I would support the surgeons' decision	1	3
I would strongly try to dissuade them, because I do not think that surgery should be carried out	0	0
I would present the family's views because I think that this is an important part of my role, although I disagree with them and would say so to the doctors	2	6
I would present the family's views because I think this is an important part of my role, and give my own views in support of theirs	3	9
I would ask for a meeting between us, the nurses, all the doctors involved, the family and some other people, probably...............to discuss the issue	27	82

Overwhelmingly, the respondents felt that their action would be to ask for a meeting with all involved to discuss the matter. Respondents mentioned that people such as 'an active amputee'(1), clinical ethicist (4), GP (5), Chaplain (5), physiotherapist and other multidisciplinary team members (3), friends (2), ward nurses (1), and anyone else suggested by the family, as well as the doctors, family and nurses. In a situation like this where there is not a clear indication of outcome and where a decision has to be made on whether or not surgery should be offered, discussion is vital. One major problem would be that if surgery were to go ahead and the family did strongly disagree with this approach, it would be very difficult to deal with the consequences. The one respondent who said that his/her most likely action would be to support the surgeons' decision, felt that the most satisfying aspect in this situation would be 'if there were a positive attitude to her rehabilitation'.

Projected sources of satisfaction

Advocacy

The theme which assumed the greatest importance was the advocacy role of nurses which was mentioned by the majority of respondents and included not only the task of speaking for the patient and family, representing their views, but also a mediating, liaising role in ensuring that a meeting of all team members concerned, was convened, in order to discuss the dilemma fully.

Nurses talked of 'acting as patient's advocate', 'trying my best to advocate for the patient', being her advocate and stressing her opinions as relayed by (the) family', and of trying 'to get patient's quality of life seen as an issue and fulfilling my role as best possible'. This theme of advocacy, where the nurses felt this was an important role and also that carrying out that role on behalf of the patient, would be a source of satisfaction, featured frequently in responses.

The other aspect of this advocacy role was in the nurses seeking appropriate channels for all involved to be able to express opinions. Nurses saw this as 'facilitating reaching a decision made by thorough discussion with everyone involved'. One nurse talked of 'being able to discuss with the team and family the best way forward for the patient' and a number of nurses spoke of 'liaising with a multidisciplinary team to reach an appropriate solution', or of 'reaching a decision having liaised with the family and the multidisciplinary team'.

Two nurses implied some uneasiness with the situation, one saying that 'I would feel happier that all people involved were contacted and able to discuss the situation and comment as able', and the other, that 'I would be pleased because I would have asked for everybody to get together and make a joint decision rather than such an important decision being made by one party alone'.

The necessity for 'ensuring all involved were as well-informed as possible' was mentioned specifically by one nurse and another commented that 'if everyone had had their say (it) would be satisfying', and a third thought that there would be satisfaction derived from 'maybe the benefits or outcomes of organising a meeting between interested parties and family to discuss the problem'.

Best care possible

Another theme mentioned by about a quarter of respondents was linked with the caring aspect of the nursing role in 'giving as good care as possible' to her and family and friends, to ensure that the patient was 'comfortable and pain-free'. Satisfaction would be derived from 'believing I am doing my best', 'in caring' and from 'one-to-one nursing, comfort, reassurance and analgesia'. One nurse talked of gaining satisfaction from 'offering support to patient, family and colleagues'.

Disfigurement

An area of concern about the situation, and the decision made, was another theme, and nurses spoke of the difficulties inherent in this dilemma where '..she is going to be so disfigured'. Five nurses were doubtful about any sources of satisfaction in this situation, one saying that there would be none, and the others leaving the answer blank or saying that they were unsure. One nurse said, again expressing doubts and unease,

> "This is a very difficult situation and the only satisfaction I may get is hoping the family knew Mrs.B. well enough to know her decision and could convince me."

Positive thoughts

The fourth theme identified was that of gaining satisfaction from aspects which were positive and hopeful about the situation. One nurse, for example, cited previous experience with a similar patient to that described in the vignette 'who survived to make a good recovery' and that this knowledge 'gives hope for other patients'. One nurse talked of 'saving her life, although disfigured' and another of 'helping the patient come to terms with the operation when awake'. Satisfaction would come from the situation 'if there was a positive attitude to her rehabilitation' and from, as one nurse said,

> "Recognising Mrs.B. is a strong, independent lady who may cope very well in any physical circumstance ... giving her the opportunity to survive".

Worst Aspects

In responding to the request to identify the worst aspects of the situation portrayed in vignette five, nurses were forthcoming about the dilemma and many replied at length.

One encapsulated many aspects of the difficulties by saying,

> "That one person's views would influence more that others ie. family without thinking about whether patient with a positive outlook could adapt to a new lifestyle. Alternatively, the surgeons without thinking of long-term outlook for patient ie.numerous operations and how successful operation will be in view of overall condition,"

and one expressed her regrets and sadness, saying,

> "The fact that the surgery was unsuccessful and that it had come to this awful decision. What a waste of a life. What a tragic shame..."

The themes derived could generally be divided into four areas but aspects were interdependent and a number of nurses linked themes together.

Patient's values

A major area of concern for respondents was whether the patient would cope with the situation if she were to survive, and nurses gave evidence for and against her coping successfully, citing the clues they would use under these circumstances to form their own opinions of what the patient's values and views would be. For example, nurses talked of the patient being 'a contributor', of her being 'only 58 and active' and of the fact that she was 'normally active, and her Christian views might allow for life with disability'.

One nurse said that 'it is not possible to guess if someone would place losing their legs above losing their life' and another was concerned about 'not really knowing if she wanted to live without her legs as her life was precious to her'.

Anticipated quality of life

Some nurses talked of the difficulties of 'predicting future quality of life for someone who is unconscious' and one nurse defined the dilemma in saying,

> "The difficulty in trying to make the best possible decision for the patient's interest - no-one can assess quality of life accurately except that person as it is purely subjective. It's possible she may cope very well with a lot of support from the villagers and family".

The worst aspect projected by a number of respondents concerned how they might feel if Mrs.B. were to survive the bilateral amputation and they had to 'explain to Mrs.B. what had happened' and they speculated on 'being told by Mrs.B. and her family that they wished it had never happened'. One nurse was concerned about 'Mrs.B's reaction' and another about the patient 'surviving the operation and being very distressed after the news' and a third, about Mrs.B. having surgery and of 'her survival to regret her new life'.

Difficult decision

One nurse was concerned that 'the wrong decision might be made' in not carrying out the surgery, but wondering whether 'Mrs.B. might have come to terms with the situation' and have 'been happy ' and some nurses felt that Mrs.B. should be 'given a chance'.

The very great difficulties in making this decision were mentioned by a number of respondents. About a quarter were concerned that the surgeons would 'disagree with the family and operate', would 'ignore the reality of her future life', 'the surgeon's insistence', and the 'decision to allow surgery to go ahead and its consequences' would be the worst aspects for some nurses. One nurse expressing this last view said,

> "That the surgeons insisted on surgery and the amputation was performed - I would feel that the role of patient was compromised by the patriarchal doctors"

and another, that the worst aspect would be 'that they took Mrs.B. to theatre, knowing the risks, against the family's better judgement, and she died. It would have been a totally uncaring, unnecessary action'.

Supporting patient autonomy

For many nurses, the major problem was the inability to obtain the patient's views and the necessity of having to rely on the views and wishes of the family. About a third of respondents mentioned the lack of knowledge about the patient's opinion being the worst aspect. Nurses talked of 'allowing the amputation without the patient's views', of 'making a decision without consent', and of 'not knowing what the patient wants' with 'no certainty about whether the team was 'doing the right thing'.

Nurses were worried because 'families can be mistaken' and that the 'family's impression of the patient's lifestyle may be wrong' and an incorrect decision might be made. Some nurses were also sad for the family having to be in this position, expressing 'distress at the family having to make (the) decision' and one nurse talked of having 'a distressed family to deal with if surgery goes ahead'.

Summary of results from vignettes

Vignette 1

This vignette was representative of the largest diagnostic category of patients described in phase one. During the hypothetical patient's 7-day stay, nurses would have had time to establish trusting relationships with the patient and family, so it is not surprising in this context that all nurses would have wished to tell the truth to the family, not only about the irreversible nature of the situation, but also about the withholding of support drugs. On balance, this group of nurses felt that it was preferable to tell the truth, rather than withdraw treatment covertly.

In phase one, 34% of respondents reported that the plan in the real situations they described was to reduce inotropes gradually during treatment withdrawal. The majority of phase two respondents indicated that they would have been prepared to reduce inotropes in the situation portrayed in vignette one.

The options listed for the grounds on which respondents based their support of treatment withdrawal were drawn from those cited by phase one respondents. In response to the vignette one situation, respondents were in agreement with the views of nurses in phase one in similar situations, citing the irreversibility of the illness, and therefore the futility of treatment as the most important, so as a consequence, the withdrawal decision was felt to be in the best interests of the patient.

The proximity to euthanasia made 6 (18%) of respondents uncomfortable, with a further 11 (30%) feeling that the events in vignette one were quite close to euthanasia.

Projected sources of satisfaction for the nurses caring for this patient included:

1. The delivery of excellent nursing care, with the objectives of maintaining dignity, peace and comfort for the patient while dying, together with relieving the patient and family's suffering.

2. Confirmation of the futility of treatment as evidenced by the rapid demise of the patient immediately after the reduction in inotropes.

3. Knowledge that the patient had received maximum treatment, even though this had been unsuccessful.

The worst aspects were:

1. Regret that it was not possible to manipulate the situation so that the family had a little more time to come to terms with what was happening and prepare themselves for the patient's death.

2. Regret that the patient's treatment had not been successful.

3. Concerns about the mode of withdrawal, partly because of the lack of honesty, and partly because of feelings of culpability associated with the patient's death following-on closely after reduction of inotropes.

Vignette 2

This vignette explored the issue of causation in relation to the patient's death, where the death followed immediately after the nurse's action. Findings from respondents in phase two largely supported the views of the nurse in phase one who described this situation, with the majority (88%) feeling that the fine line between helping the patient to a peaceful and dignified death and euthanasia, had been compromised, to some extent at least.

Vignette 3

This vignette described a patient with a chronic medical problem associated with alcohol abuse, and primarily explored nurses' views about a withholding decision influenced by the opinion of a family member. The situation portrayed indicated that there were doubts about the reversibility of the illness, the patient's views about treatment, and the quality of life of the patient.

Because of these doubts, respondents largely disagreed with the withholding decision, did not feel that the brother should have so much influence, and felt that the patient's treatment should continue, particularly if this then gave an opportunity for the patient's condition to improve sufficiently that he was able to express his own wishes. Nurses themselves seemed doubtful about their own knowledge, and felt that they should have less influence than the doctors.

As a consequence, nurses would have encountered a moral dilemma if they were instructed to withhold treatment when they disputed the decision. This problem was raised in nurses' descriptions of the worst aspects, in which they talked about the difficulties when there were disagreements within the multidisciplinary team. The other major area of concern was that there was uncertainty about the patient's outcome, so on balance, nurses felt that the decision taken was not in the best interests of the patient, because other treatment options were not pursued.

Question 3.7 sought nurses' views about obtaining consent from incompetent patients to participate in research, particularly when it involves an intrusive test at a time when nurses would have wanted to leave the patient in peace. A nurse in phase one had objected to such an intrusion, and about half of the respondents in phase two agreed.

Sources of satisfaction for some nurses included appreciation for the fact that if the patient were not going to survive, it was preferable to withhold further invasive procedures and avoid a protracted period of dying. Again the primacy of the caring role of nurses was an important element in how nurses felt, and their main concern was for the welfare and best interests of the patient.

Vignette 4

Again in the situation portrayed, the patient's outcome was uncertain, but this time, the nurse had cared for the patient over a period of time, and knew the patient's views on the continued struggles with weaning from the ventilator, and had some insight into the patient's current and previous quality of life.

Respondents felt that under these circumstances, they would be much more knowledgeable about the patient, and they therefore rejected plans for further aggressive treatment, with the majority recognising the irreversibility and supporting the use of diamorphine to relieve the patient's distress. Respondents thought that the opinion of the family about the patient's views under these circumstances should be very influential in decision-making.

Sources of satisfaction centred on:

1. The ability of the nurse to be the patient's advocate.

2. Being in a position to 'give care with compassion and sympathy' as one nurse said.

The projected worst aspects were:

1. The sadness about the patient's situation with the patient perhaps dying after a series of distressing attempts at weaning.

2. The helplessness associated with the doctors' rejection of the patient's views, with the resultant conflict between team members.

3. Two nurses expressed anxiety with the use of diamorphine in the circumstances described.

Vignette 5

Again in vignette five the nurses' views on the role of family members in decision-making were explored, and respondents clearly indicated that the family's opinions about how the patient would feel about further treatment, should be accepted, which would then lead to a treatment-withdrawal decision. Nurses overwhelmingly felt that when the surgeons proposed more surgery, a meeting should be arranged between all relevant people to ensure that a considered decision was taken which was in the patient's best interests.

Sources of satisfaction:

1. Advocacy on the patient's behalf was an important projected source of satisfaction for nurses.

2. The knowledge that the patient and family had received the best care possible under

these very distressing circumstances.

3. Respondents also talked about the satisfaction to be gained from helping the patient to adapt to a new way of life, if she were to be given the opportunity to survive.

In considering the worst aspects, respondents expressed the doubts and uncertainties in this situation:

1. Firstly about how positive the patient might feel about life with a severe disability, were she to survive.

2. Secondly, with the enormous difficulty associated with trying to make some judgement of the values held by the patient about life.

3. Thirdly, about the right course of action to take.

Conclusion: phase two

Support of the incompetent patient's autonomy

This issue was explored in three different contexts, and it was of paramount importance to nurses who felt that the best person to make judgements about values and the acceptability of the anticipated quality of life was the patient him- or herself. Whether nurses felt that the family members could support the patient's autonomy varied with the context. Where nurses themselves were uneasy about the withholding decision in vignette three, they questioned the judgement of the patient's brother. Nurses welcomed the involvement of other participants in decision-making, where that meant that the patient's rights and interests were better served by doing so (vignettes three, four and five).

Nurses recognised the value of the insights which families could provide, and did support the involvement of families in decision-making, although they also wanted the family protected from any burden of guilt, if there were any likelihood of family members feeling responsible for the death of the patient (vignette one) by agreeing to treatment reductions.

Quality of life

Quality of life was an issue in all the vignettes. In vignettes one and two, the patients were not aware of their present situations, although to the families, continued treatment would have been increasingly burdensome, and lacking 'quality'. Past, present and future quality of life were relevant in the remaining three vignettes, and nurses supported efforts to gain evidence about what patient's lives had been like previously, and how the patients might view the anticipated quality of life were they to survive.

Nursing care

The quality of nursing care was very important to nurses who felt that even when patients were irreversibly-ill, if events could be managed well, and nurses were consistently able to give optimum care to patients and families, then these were sources of satisfaction. The nursing care included advocacy for the patient, and when nurses felt that they were successful in this role, again this was a source of satisfaction.

Moral difficulties

Some qualms were expressed by nurses about their roles in treatment withdrawal in all the situations portrayed. In vignettes one and two, unease was associated with causation in connection with the patient's death, In vignette three, unease was expressed about withholding treatment when the nurses themselves disputed the decision. In vignette four, unease was expressed, both with giving further aggressive treatment if prescribed, when nurses felt that the patient should be allowed to die, and, for a minority, with giving diamorphine, when they felt it was not indicated on clinical grounds, and was being used to shorten life and possibly procure euthanasia.

Summary

In summary, the vignettes did enable further exploration of some specific instances prompted by respondents in phase one. It was possible to pose questions raised by a small number of phase one respondents, for example, on the larger group, and to compare responses. Vignettes three and four enabled a comparison to be made between nurses' feelings about two chronically-ill patients, in one of which nurses strongly supported treatment withdrawal, but in the other, the majority were uneasy about it. The vignettes allowed some exploration of the distinguishing features between the two, and the reasons nurses gave to support their decision in each situation. Proximity to euthanasia was also explored in the vignettes, and findings were indicative of the circumstances under which nurses become concerned about their actions in relation to the death of the patient.

Review of research questions

Review of research questions

1. *How is the treatment-withholding or treatment-withdrawal decision made?*

This area was explored in general in phase one, with some specific questions about participants in decision-making, and the influence they should exert, raised in vignettes three, four and five, in phase two.

Respondents gave examples of satisfying aspects of decision-making, in which all team members were included in the process, and support was available for participants during, and after, withdrawal. Situations were also cited, particularly in the 'worst aspects' and 'still-troubling' sections, where no discussion had taken place with the nurses involved. These then felt aggrieved at their powerlessness, and were unhappy about their inability to fulfil their professional roles adequately, especially regarding advocacy and the provision of optimum care to the patient and family at a very stressful time.

In phase one, specific questions directed at exploring how decisions are made included establishing the context, in terms of the patient's diagnosis, complications and age-group, and data on adults indicated a preponderance of middle-aged and elderly patients who had abdominal sepsis, with prematurity, and a variety of conditions associated with it, affecting the babies.

Other information about how decisions are made was obtained from data about clinical factors which prompted the initiation of discussions about treatment-withdrawal, and foremost among these were organ system failures and a lack of response to maximum cardiac support, with family requests to cease treatment also being important.

Other factors were also sought, and data indicated a recognition that the anticipated quality of life for the patient if he/she survived, as the most important, with the age of the patient also being pertinent.

Data were not obtained about the mode of decision-making in this study, so for this group it is not known whether discussions were part of the usual daily clinical review on ward rounds, or whether meetings had been set up specially to discuss the issues.

In phase two, presented with the very difficult situations portrayed in vignettes three and five, nurses sought a meeting between all the people who could contribute evidence about the patient's previous life, the current situation and the projected quality of life, together with the patient's probable views, primarily with the purpose of ensuring that the patient's interests were protected.

Nurses wanted to be involved, not necessarily because they felt that they should be the most influential, but mainly because they had relevant information to contribute, and would need to be well-informed about the facts included in discussions in order to support families through the subsequent events. Data also indicated that nurses needed to have a role in determining the pace and mode of treatment-withdrawal, especially regarding the timing of treatment-reductions, and also the use and dosage of analgesic and sedating drugs. It was essential, then, that nurses were confident in their knowledge of ethics and ethical decision-making to enable them to participate effectively, and be satisfied with their contribution and the outcome. Evidence to support this assertion comes from nurses' reports of the best and worst aspects of situations.

Family members were also frequent participants in discussions. From the nurses' perspectives, they were seen as important and influential contributors, who provided the insights about the patient which were not readily available to the professionals involved, particularly regarding the ability of the patient to cope with potentially a very different, and usually worse, quality of life, if they were to survive. In vignettes four and five, nurses very much supported the role of families in this area, although where nurses did not support treatment-withdrawal in vignette three, they mistrusted the motives of the hypothetical patient's brother, and felt that the patient's interests would be better served if he could be made well enough to be consulted himself.

The grounds on which these decisions were based were the acknowledged failure of treatment in a patient with multisystem problems, the futility of continued treatment under such circumstances, and a recognition by the nurses that treatment-withdrawal was in the best interests of patients. There were some notable exceptions identified in phase one.

In summary, respondents cited factors which prompted discussions, and commented on the influence of participants. Whether or not respondents were satisfied with the process of decision-making, they largely supported the decisions taken. Nurses under these circumstances did express concern, both with personal and professional issues, and with their limited ability to intervene on behalf of the patient. Nurses expressed satisfaction with the multidisciplinary approach to decision-making in which all views were considered within a supportive team framework, where this happened.

2. *What objective data about the patient's illness and outcome are explicitly used in the decision-making process?*

Respondents were able to identify clinical features about patients which were likely to prompt discussions but did not cite any specific scoring methods used in their place of work. Nurses were able to give evidence about patients' conditions which indicated probable irreversibility of illness, such as a further organ system failure and a recognition that all treatments possible were being administered, although ineffective.

Four patients were recorded as brainstem-dead, a diagnosis based on objective criteria. Objective evidence also came from nurses in phase one in reasons for supporting the treatment-withdrawal decision, including a failure to respond to maximum treatment for a week or more; a recognition that an elderly patient had an acute illness, with a background of a number of chronic medical problems; an acknowledgement of the life-threatening problems associated with prematurity; and evidence of clinical conditions such as malignant metastases or inoperable bowel conditions. Objective clinical evidence was also cited in the two situations where nurses disputed the withdrawal decisions which were subsequently reversed.

3. *Who participates in making such decisions?*

Respondents in phase one gave information about the actual participants in decision-making in the situations they described, and in phase two, they were able to project into these situations and suggest who they felt would be the most appropriate participants to represent, and protect the interests of, the patient.

The ICU consultant was involved in all situations, with the patient's own consultant involved in the majority. Family members were usually involved, including partners, parents, grandparents and sons/ daughters where appropriate.

One or more nurses were usually involved, perhaps the patient's own nurse plus the Unit Sister, but in four situations in phase one, no nurse was involved.

Other multidisciplinary team members, such as the physiotherapist and chaplain were involved in a minority of situations in phase one. In phase two, vignettes three and five, respondents suggested those participants they thought should be involved in decision-making, and these included other family members, friends, social workers, ward nurses, clinical ethicist, the GP and specialist doctors, where appropriate.

4. *Who has the greatest power and influence in the process?*

Nurses were usually involved, but were generally less influential than medical participants. The ICU consultant was likely to be the most influential, with the patient's own consultant also playing a major part. Family members did participate in most situations, having at least some influence.

When nurses were asked their opinions about power and influence of participants in relation to the situations in vignettes three, four and five, they generally identified the people who would be best be able to give the views of the patient, if the patient were incapable of doing so. In vignette three, where the hypothetical patient could not give his opinion, nurses thought that the consultants should have the most influence, but that they themselves should also have a role.

Regarding vignette four, in which the nurse knew the hypothetical patient quite well, respondents felt that the patient's family should have the most influence, but that they, the nurses, should have more influence than the doctors involved, particularly because in the situation portrayed, the patient had stated her views about continued treatment to the nurse.

In vignette five, too, respondents proposed that the patient's family should be the most influential, with nurses again more influential than the doctors.

The conclusion to be drawn from these data is that nurses want to ensure that the person best-placed to represent the views of the patient is involved, and is influential, in decision-making, but that this person will vary with the context. Nurses invariably want to be involved, and in situations where they are not, or where their views are ignored, they feel powerless and helpless in making the best decision for the patient.

5. *Where patients are incapable of participating in decision-making, is any evidence sought about what their opinion would have been, were such a situation to arise? Have they prepared an advance directive or appointed a proxy?*

No evidence was obtained about this in the first phase, but it was an issue explored in three vignettes in the second phase. Respondents expressed anxiety when the hypothetical patients were incapable of giving views in situations where it was difficult for others to determine a course of action which was in the best interests of patient.

Where it seemed feasible to do so, in vignette three, nurses supported actions which might have given the patient a chance to improve, when his opinion could then be sought. Some respondents regretted that the situation had not been anticipated earlier, when the possibilities could have been discussed with the patient.

6. *Where patients and families do not participate in decision-making, how is the decision conveyed to them?*

In phase one, respondents said that in 36 of the 47 situations described, the doctor and nurse together explained to the family about the decision, and in most of the others, the doctor talked to the family, with just one nurse saying that in the situation described, no-one explained. The implication of these data is that although families were consulted during decision-making, the decision was taken by the professional team, and the changes in treatment then explained to the family.

7. *Does the timing of such decisions seem appropriate to the nurses involved?*

The timing of decision-making was quite an important issue for respondents, who, in most of the situations described, felt that the timing was appropriate, however misgivings were expressed when the dying process, as respondents saw it, was unduly protracted.

There were many references in phase one to the problem of maintaining peace and comfort for the patient when treatment was continued, and nurses expressed dissatisfaction with situations in which the dignity of the patient was threatened by the intrusive nature of interventions, especially if viewed as experimental, when they felt that the patient's condition was irreversible. There was reference too, to the difficulties for nurses when they were caring for patients in these delaying-death situations because of the false hope being given to families.

In phase two, vignette one, respondents supported the timing of the withdrawal decision because they recognised the futility of continued treatment after a week of full support. Concern was expressed however about insufficient time being available for families to come to terms with what was happening, which echoed respondents' earlier comments in phase one.

With vignette three, those nurses who supported a withdrawal decision felt that the timing was appropriate, before interventions such as renal replacement treatment were begun. One conclusion to be drawn is that it was easier for nurses, in considering this situation, to accept withholding of a treatment not yet commenced, than it was to stop something already in progress.

In situations where the timing of the decision might have been acceptable, misgivings were occasionally expressed about the mode or pace of withdrawal, and where nurses felt that deaths were hastened as a result of actions taken, concerns were raised about the proximity to euthanasia. This issue was explored in phase two, in vignettes one and two, and data confirmed anxiety amongst nurses.

8. *Are there occasions when nurses feel that active treatment is being inappropriately prolonged and that treatment withdrawal should be considered?*

This issue was further explored in vignette four, in which the hypothetical, chronically-ill patient had deteriorated and there was a difference of opinion between team members about whether treatment should be discontinued or stepped-up. Because, in the situation portrayed, the patient had expressed the view that she had 'had enough', the majority of nurses felt that the time had come to withhold further aggressive treatment, with most supporting the administration of diamorphine during treatment-withdrawal.

9. *In the nurses' opinions, what has prompted consideration of treatment withdrawal?* *See 1 above.

Nurses were able to identify clinical and other factors which prompted consideration of treatment-withdrawal. Usually nurses accepted that the patient's condition was irreversible as a result of chronic and acute problems, and were able to give reasons for this. Family requests to discontinue treatment also played a part. The other important factor, was the anticipated poor quality of life if the patient survived.

10. *If nurses are not included in the decision making process, is this acceptable to them?*

This was a source of concern and dissatisfaction for nurses, who felt that they could usefully contribute to discussions, particularly in advocating for the patient, and were therefore unhappy when this was denied. Data from these studies strongly support the involvement of nurses in decision-making with many nurses giving cogent reasons for including them in discussions. The main reasons cited were the insights they had into the patient/family situation, amidst concerns about important and relevant facts being overlooked, particularly by doctors. Nurses demonstrated their breadth of knowledge about such clinical situations in their responses, and they were anxious to be given the opportunity to give their own views. The importance of advocacy was mentioned by respondents in both phases, and although nurses did not always feel that they were the best people to speak for the patient, (the evidence from replies to vignettes four and five supporting advocacy by families to a greater extent), they still felt that involvement was essential to avoid the powerlessness and frustration mentioned earlier.

11. *Do nurses feel adequately prepared for the roles required of them throughout the process?*

While many nurses, particularly the more-senior, experienced ones, were confident in their knowledge about ethical matters, concerns were raised, and a need for further education was identified. The roles of nurses throughout the withdrawal process were explored and nurses were able to identify sources of satisfaction and distress associated with these situations. Key professional roles, such as clinical debate, mediation, advocacy and provision of support, were identified, and one of the most important areas for nurses was their role in the preservation of peace and dignity for the patient and family. It was apparent that for nurses to feel satisfied with the care they gave to patients and families, they needed to be assertive in their ability to negotiate an appropriate mode of treatment-withdrawal, create the peaceful environment required, and resist unwanted intrusions.

12. *Are channels available for nurses to participate in decision-making?*
*See 1 and 10 above.

13. *Are nurses prepared to share and accept responsibility for the decisions and actions taken?*

This group of nurses clearly wanted to be able to participate in debate. Although some misgivings were expressed about aspects of treatment-reduction and withdrawal, the majority of nurses accepted that it was humane and appropriate to discontinue treatments when they were futile, and were therefore prepared to follow the revised treatment plan. It was not apparent from these data whether nurses were explicitly asked-to, or were prepared-to, accept responsibility for decisions taken.

Reference was made by some nurses in phase one to their willingness to mediate with doctors on behalf of families who were requesting treatment-withdrawal from the patient. In the hypothetical situations in phase two, nurses indicated that they were willing to take responsibility for mediating on behalf of patients. Some respondents, in fact, commented that they would have felt that they had let the patient down if they had not spoken-up in the patient's defence. These comments were made both in connection with actions contributing to treatment-withdrawal, and those involving disputing withdrawal decisions or the mode of reductions proposed by doctors.

In situations where nurses felt they were very much part of the team involved in decision-making, they appeared willing to share in the group's responsibility for actions taken.

14. *Do nurses experience disquiet about some decisions which are taken, and if so, what is the nature of these concerns?*

Many sources of disquiet and concern were raised, particularly in the section where nurses were asked to reflect on situations which still troubled them. Disquiet was expressed where the decision had been taken to withdraw without exploring all the possible avenues of treatment. One nurse was concerned about a withdrawal decision taken when the patient's father could not grasp the concept of brainstem death. There was unease, too, associated with withholding-decisions taken when the patient's earlier care had probably been mismanaged. Frustration and disquiet were expressed when nurses felt that decisions were taken to continue treatment in the face of apparent futility of these interventions, and there was uncertainty created by indecisiveness of consultants after decisions were taken. Disquiet was caused by conflict within the team which impinged on the ability of the nurse to give the best care to the patient. For novice nurses, dealing with these situations for the first time was a very stressful experience.

15. *Once a withdrawal decision has been made, what is the likely course of events subsequently? What instructions are likely to be given to the nurses taking care of the patients? What do the nurses feel about these instructions?*

Respondents identified treatment reductions made and talked about problems such as dismantling equipment with the patient's family watching. The intrusiveness of technical equipment when patients are dying was a source of frustration and sadness for nurses, as was the lack of control over the timing of events, making it harder to care-for and support patients and families.

Some of these issues were explored further in phase two, for instance, the question of inotrope-reduction was raised in vignette one, to which the majority of respondents replied that they would support this action under the circumstances described, provided that the family knew about it. A great deal of concern was expressed about the removal of the endotracheal tube from the hypothetical patient in vignette two because of the issue of causation in connection with the patient's death.

Concerns were also expressed about the treatment-limiting decision taken in vignette three, mainly because almost half the group of nurses disagreed with the decision taken, and one third were unsure. Nurses projected into their roles under these circumstances and imagined their feelings, for example, when giving the last unit of blood available, particularly when it was felt that the patient was being denied potentially-helpful treatment. Nurses also projected into the situation in vignette five and considered how they might feel in breaking the news to the patient that bilateral amputations of her legs had been carried out, especially if she would have refused consent.

16. *What specific responses and reactions from patients' families cause anxiety and distress in nurses?*

A major source of satisfaction for nurses was the ability to provide a high standard of care for patients and families. Anxiety and distress in nurses was caused by a feeling of letting people down in some way, adding to the hurt and sadness being experienced. Where nurses felt that situations were being rushed, and too short a time was available for families to adjust to the change in plan and accept the inevitable, there were regrets expressed. The shock experienced by families, especially that associated with unexpected events, such as patients who died immediately following the withdrawal decision, or when patients became irreversibly-ill following relatively-minor procedures, was distressing to nurses. They also wanted to protect families from seeing the patient experiencing discomfort, such as that associated with bleeding or inadequate sedation. Refusal by the family to accept the irreversibility of illness, was upsetting to nurses, especially where this meant a protracted period of waiting for the inevitable death of the patient. Witnessing the distressing scenes associated with the deaths of many patients, together with experiencing the likely helplessness, were also sources of sadness and regret for the nurses involved.

17. *How do nurses cope when they are involved with these situations?*

Evidence from the study demonstrated that a supportive, multidisciplinary team is essential if staff are going to cope well with repeated experiences of this kind. Many nurses commented on the value they placed on colleagues' support. Where nurses are able to give unhurried, excellent care, and carry out their professional roles to a high standard, then they draw satisfaction from this and are able to cope more readily.

With experience, nurses were more likely to recognise the features of clinical situations where patients' conditions were no longer reversible, and so could accept that a withdrawal decision was in the patient's best interests. Experienced nurses, too, were more confident about their knowledge and their ability to intervene on behalf of patients and families. They were likely to have the satisfaction of being able to advocate effectively and manage situations well, so that patients were able to die in peace, in the presence of families.

Discussion

Discussion

Preface

> "...aspects of the patient's problems which are accessible to scientific intervention and analysis will take priority, while those aspects which are less well comprehended (emotions, spirituality, social well-being) are likely to be ignored. This results in doing what is technologically possible, rather than in doing what may be in the best interests of the patient, all things considered."
>
> (Hewa, Hetherington,1990)

A number of ethical dilemmas emerged from the data, concerning the care and treatment of patients in ICU's and SCBU's.

1. A need to preserve dignity and respect for patients whose illness and complex treatment necessitated total dependence on others, not only for meeting the most basic physical needs, but also for making the most important 'life and death' decisions.

2. A need to provide humanitarian care and appropriate privacy for patients and families in the highly-technical and busy environment of an ICU.

3. Medical requests to provide treatments for which nurses felt there was not sufficient justification, which appeared therefore to be causing a protracted dying process.

4. Decisions taken which were counter to the views of the nursing team, or about which nurses felt uncertain, but where no opportunity had been given to debate the issues.

5. Perceived conflicts among the medical teams leading to ambiguous, or non-existent, decision-making, with the result that nurses experienced dissonance between the values they held about the care of patients and those 'powerful' others.

6. Threats to the welfare of families because of insufficient time and opportunity being allowed during the treatment withdrawal process for them to be helped to come to terms with the reality of events and the radical change in treatment plan.

7. Threats to the autonomy of the patient in decision-making.

8. Threats to the advocacy role of nurses, which was perceived then as inhibiting consideration of the wider health, social and psychological needs of the patient in decision-making.

9. Caring for elderly people who are dying surrounded by all the technology typical in ICU.

10. Whether the criteria used for the assessment of future quality of life are adequate and reliable, and whether the judgements made reflect the values likely to be held by the patient.

Moral dilemmas were associated with interventions which may accelerate the death of the patient:

1. Excessive prescription of opiates.

2. Removal of an endotracheal tube (artificial airway).

3. The proximity to euthanasia felt by some nurses, associated with actions taken during treatment-withdrawal.

4. Denial of medical treatment when nurses felt that this jeopardised the patient's chance of recovery.

Dignity

A recurring theme of major importance in the data was the desire nurses expressed to maintain peace and dignity for the patient, and this was part of a general need to preserve humanity in the technological environment of ICU.

Loss of dignity often means dependence on others for assistance with activities which adults expect to be able to carry out independently, particularly in connection with hygiene needs and eating.

Murphy (1984) talks of the problem of identifying what is a 'harm' to the patient and goes on to comment that with the availability of technology it becomes more difficult to preserve human dignity and show respect for life unless it is first possible to determine the best way to recognise it. This same author was describing a patient-advocate model of nursing care, under which 'when patient's rights and interests were in conflict with the physician or institution', the nurses felt that their function was 'the enhancement of the decision-making capacity of the patient and the patient's family' in the context of ethical dilemmas.

Zorb and Stevens (1990) speculate on the root of disputes between professionals, and feel that the problem lies in the fact that values differ, citing the example of a nurse who values a dignified death for the patient and who concludes that 'invasive techniques would destroy that dignity and are not warranted'. Dignity, then, for the nurse in this oncology setting, was associated with a lack of disruption and interventions which the nurse felt were not essential to the patient's welfare.

In one situation, the patient himself, once he knew that he had irreversible injuries, wanted to be allowed to die sooner rather than 'go through the indignity of a protracted death'. On many occasions, nurses cited the fact that patients had been able to die with dignity, without further invasive treatment, as a source of satisfaction.

For many nurses, dignity is associated with the ability to keep the patient clean, tidy and appropriately dressed, and Wilson-Barnett (1986) talks of a student nurse who was distressed because a terminally-ill patient, whose active treatment had been discontinued, became 'generally malodorous' and the student felt that the comfort of the patient had been neglected.

In the current data, a nurse, for example, derived satisfaction from knowing that the patient was 'comfortable and well cared-for' and that the family were happy with the treatment decisions and the care given. Other nurses talked of the patient's family expressing 'their gratitude for everyone's efforts in making the patient comfortable' and of feeling 'that he had received excellent care', with a nurse in the second phase projecting that he/she would 'take comfort from the fact that the patient had been given excellent standards of nursing care' and another 'that the patient would have one-to-one nursing care, with her hygiene needs, skin integrity and comfort all considered', themes echoed by many respondents about these hypothetical situations.

In a case-report involving a brain-injured patient who had been in coma for 18 months, the family wanted her to die 'with dignity' in contrast to 'existing in a state of living death' which was the description given in court during a hearing about discontinuing treatment (Bale,1997).

> "We all want to live but maybe we can envisage circumstances in which we would not want to live"
> (Mitchell, 1990, in Byrne)

and this theme was echoed by one respondent who felt that the patient had been 'allowed to die with dignity by his standards, not ours'.

Twenty years ago, Henderson (1980),in an essay on preserving the essence of nursing in a technological age, asserted that the unique function of the nurse was 'to help persons, sick or well, from birth to death, with those activities of daily living that they would perform unaided if they had the strength, will and knowledge' and the objectives of this care were 'to help people to regain independence, and when this is impossible, to cope with handicaps and irreversible disease, and when death is inevitable, to die with dignity'. Nurses in the current study drew satisfaction from being able to carry out the care of patients in an exemplary manner, and were aware of the importance to families of the patient receiving the best care possible, not only the advanced, sophisticated treatments, but the basic care, given with attention to detail. One nurse felt that this was the worst aspect when this was not achievable in a situation involving a patient in 'physical distress from gastric bleeding' when she was unable to do anything to help. Family members are able to observe the behaviour and attitudes of nurses towards other patients, as well as their own relative. Some nurses' comments in the current study reflected how appreciative families were of the respect shown to patients and the attention paid to the comfort of all.

Privacy for patients and families in ICU's can be difficult to achieve because of the close observation required on safety grounds of anyone connected to the multiplicity of equipment now in common use, and it is this aspect of technology which some nurses in the current study resented and found intrusive, particularly with older patients. One nurse, for example, expressed unhappiness at 'seeing elderly patients being subjected to hi-tech interventions, trying to wean off ventilation, with very slow progress'.

Miller (1987) in a debate about whether there are circumstances under which doctors have a duty to hasten death, feels that when 'physicians and surrogates ...see the autonomy and dignity of patients threatened' they should not intervene in the dying process. In fact, he goes further, saying that 'with sincerest respect for human dignity that he believed that physicians must be willing, on occasion, to take an active role in the process of death' with the purpose of relieving suffering. This author feels that where incompetent patients are involved, rights, duties and obligations must be considered, because patients have 'a right to die as dignified, thinking human beings' (Miller,1987) and what he is opposed-to, as were some respondents in this study, is arbitrary and excessive use of technology, beyond the time when its use can potentially save the life of the patient.

In the context of CPR, the lack of dignity in situations where there is no hope of a successful outcome ultimately, is a clear reminder to all potentially involved in such situations to anticipate, and make appropriate withholding decisions, in order to avoid 'the mayhem of CPR' because 'a procedure less dignified and peaceful could hardly be devised' (Saunders,1992).

Dignity was a core theme derived from a study by Soderberg et al (1997) investigating the feelings of nurses about ethical dilemmas in ICU and this author cited examples of situations narrated by her respondents which illustrated three concepts of dignity:-

1. Dignity means transforming disrespect into respect for the inviolable value of human beings.

2. Dignity means transforming an ugly situation into a beautiful one.

3. Dignity means transforming the discord of death into togetherness (allowing a dignified farewell to the dead).

Examples drawn from the current study emphasise respondents' agreement with the importance of these areas. In one situation, a patient's family requested cessation of treatment because there had been no improvement over a week of maximal therapy and they were anxious not to prolong the patient's suffering. In another situation involving an elderly patient who had acute, irreversible cardiac problems in addition to chronic health impairment, the nurse supported the withdrawal decision, saying that the family wanted this option, so 'the patient was given his dignity and nature was allowed to take its course'. It was notable that the examples from SCBU's frequently illustrated the second point above where there were satisfied comments about being able to create a private and peaceful situation for babies to die in a supportive and pleasant environment. Many nurses in this study talked about their satisfaction from enabling families to be together at the end, giving them whatever time and opportunity there was to reconcile themselves to what was happening, to grieve, to comfort one another and to 'say goodbye'.

Families' needs have been explored in a number of studies (Molter,1979; Daley,1984; Coulter,1989; Wilkinson,1995) and consistently through these, the need for retention of hope has featured strongly. To a large extent, this desire focused on hope for recovery, but in the context of patients who will not survive, this may change. Coulter (1989) in her study of families' needs, reports,

> "Even in cases where hope of recovery had gone, a more generalised hope for a peaceful and painfree death for the critically-ill person replaced specific aspirations for recovery".

Technology and the preservation of humanity

In a review of the historical development of ICU's and the impact on nursing patients, Fairman (1992) talks of the work of the intensive care nurses in the early days 'providing a model for a better way of caring for critically-ill patients, setting the tone for patient-centred care, characterised by watchful vigilance', but that this was gradually 'obscured by enthusiasm for machines as ICU's became a technologic repository'.

There have been great benefits from the developments in equipment and the parallel advances in the knowledge and skills of the users in their application, enabling earlier and more-accurate diagnoses, detection of potential complications, life-saving treatments and prevention of problems through immediate access to measurements of clinical parameters.

The advent of some forms of technology has altered patterns of treatment, and in a cardiac setting, for example, increasingly 'diagnostic and therapeutic procedures are performed endoscopically or microscopically, which affects rates of complications and lengths of hospitalisation' (Pelletier et al,1996) thus benefiting patients by enabling earlier access to treatment to relieve symptoms and also avoidance of an ICU stay.

Ashworth (1990) comments that 'well-designed and reliable computers and other technology can remove much of the repetitive, monotonous, yet concentrated work which usually falls to intensive care nurses' suggesting that one reason for having such equipment is to free nurses from some tasks to enable more time to be spent in other activities. It is very obvious too, to any intensive care nurse, that the regulation of complex treatments such as multiple drug and fluid infusions or modes of assisted breathing, has created opportunities not only to deliver regimens safely and accurately, but also to promote comfort for the patient.

In this study, some measure of the technology used can be obtained from nurses' reports of treatments discontinued, for example, out of the 47 patients, (11) had their renal replacement treatment stopped, (10) had mechanical ventilation discontinued, (29) had sedation increased (using infusion pumps), (34) had inotropes reduced or stopped (using infusion pumps), and the treatment of all patients would have involved the use of cardiovascular monitoring, specialised beds and other equipment.

Nursing tasks associated with technology which were identified in a literature review by McConnell (1990), include:-

1. making a decision to use a machine
2. explaining machinery to patients and families so that they understand, accept and feel secure about it
3. using machines knowledgeably
4. having an input into the design of machines
5. functioning as the interface between patient and machine
6. dealing with the potential hazards of innumerable connections involving tubing, cords and wires.

Working with machinery creates pressures on nurses and McConnell (1990), in her study into the impact of technology, found that 'a sense of mastery' was essential and this came with 'an understanding and familiarity with the machine's operations', because then nurses could use equipment more effectively as an adjunct in care and were freed to focus on the patient.

In a study of a group of nurses who work in a technologically-intense area, ambivalence was typical when they were asked about whether technology freed-up time for them to spend with patients and families, because sometimes nurses felt that all they did was to work with machines, not people, and that 'the technology detracted from ministering to a patient as a person with needs other than physical ones' (Wichowski,1994).

McConnell (1990) comments that regardless of the advantages provided by technology, 'the machines required the nurse's time just as patients did...and the issue became quantity of patient time versus quality of patient time, with machines competing with the patient for nursing time'.

A number of authors (Pelletier et al,1996; Ashworth,1990; Henderson,1980) suggested that in earlier days of high technology ICU's, the result was fragmentation of care, increased non-responsiveness to human needs, and that nurses were concerned about feelings of powerlessness, and the fears associated with the introduction of technology. Ashworth (1990) and Pelletier et al (1996) talk about nurses using the technology as a psychological defence against the emotional stress and demands in an acute environment, even having a preference for technical tasks, 'nursing the machines'. Hawthorne and Yurkovich (1995) feel that 'care' for individual human needs is jeopardised by increasing reliance on computerised information, which can lead to 'people being labelled as numbers or codes'.

The evidence from the current study provides support for the views of Pelletier et al (1996) who feel that there has been a shift in emphasis towards thinking that technology is an essential part of care, as it extends the ability to provide care, and that there is a need to skilfully blend technology into sensitivity to the needs of the patient'.

In this study, there were many references to technology, both the positive and negative aspects of it, but the pervasive impression from respondents was their concern for the preservation of humanity in the highly-technical environment of ICU's and SCBU's.

A number of respondents made reference to the intrusiveness of technology and the barriers which were created by it when patients were dying, so that in situations where the nurse was trying to create a peaceful environment in which family members could be close together, the machinery and its attendant noises, militates against the creation of such an ideal. One consequence when patients have multisystem failure is that their active treatment is likely to involve the greatest amount of equipment.

Some nurses made particular reference to the use of technology in the care of elderly people, partly because the intrusion was resented when the person was dying, but also where the use of technology was inappropriately-prolonged in older people, denying them the dignified death which nurses wanted for their patients.

One nurse very much resented the use of the available technology for a middle-aged person whose injuries were such that there was little real hope of reversing the situation. The decision to treat had been taken without consultation with the nursing team, and the nurse respondent felt very strongly that they had been left to deal with the difficult situation, raising the obvious question of whether it is always appropriate to use the technology available.

Kennedy (1988,p.289) talks of the benefits of technology but adds a cautionary note about the price of the benefits:-

1. the increasing cost of technology, in terms of development, purchase and service, the training of staff, and its operation;
2. the potential or real imbalance in expenditure which technology introduces into the allocation of resources in health care. Money spent on machines or intensive care units is money not available for other services;
3. the possible distorting effect that technology has on attitudes to, and the availability of, other forms of health care - for example, preventive care and the often forgotten possibility of not doing anything;
4. the fostering of an impersonal approach to health and medical care, where the machine intrudes between the patient and the doctor, and may thereby affect deleteriously the development of caring, personal relationships.

Another problem area in this data, associated with the use of technology, occurred when one ICU nurse felt that a test for research purposes which was carried out on a dying patient, was an intrusive and unnecessary disturbance, and in a similar situation in SCBU, a nurse felt that a baby's treatment was unreasonably protracted to test the efficacy of equipment. Both these situations perhaps illustrate the difference in attitudes between doctors and nurses in their views about the use of technology.

When nurses in phase 2 were asked about a test for research purposes being carried out on the hypothetical patient with liver failure, 16 (48%) thought it was unreasonable because it was an unnecessary intrusion, and 8 (24%) because it was impossible to obtain the patient's consent, with 11 (33%) not replying and 4 (12%) unsure, indicating uncertainty about the issue of consent under these circumstances.

Historically, according to Hewa and Hetherington (1990), the orientation of medicine has been to 'seek solutions to the suffering of mankind through technical advances which concentrated on viewing the body as a mechanical system in need of repair' leading to priority being given to aspects of patients' problems which are 'accessible to scientific intervention and analysis' and possibly those aspects less well understood, such as 'emotions, spirituality and social well-being' being ignored.

Practical problems raised by nurses in this study included the difficulties with 'dismantling the haemofiltration equipment with the patient's family at the bedside, after the withdrawal decision was made' and there would be other similar concerns about removal of equipment and infusions, or altering dosages on infusion pumps. One nurse experienced the opposite dilemma when asked to discontinue treatment and remove equipment before the patient's family was told about the change in direction of the plan of care. A junior nurse in this study expressed uncertainty about what should be done with the mechanical ventilator once the patient had died, because having the machine continue to work after the patient's heart had stopped, would be intrusive and inappropriate, but she did not know whether she was permitted to switch it off.

Many respondents expressed satisfaction, on reflection, with the fact that patients had been given maximum treatment because although it had failed, at least the patient had been given the opportunity. The benefits of this maximum treatment would not be achievable without the use of technology, however the theme of this study has been the issues surrounding its discontinuation and the ethical dilemmas which arise. Prominent among the responses was the importance of respect for the person which involved concern for the humanity of people, despite the technological environment. This respect is exemplified in the many situations where the nurse expressed satisfaction with the decision-making process about treatment-withdrawal, where decisions were not taken in an arbitrary way, but had reflected the concerns of all involved, offering opportunities to give views and feelings, nurses were much more reconciled to the decision and its consequences.

The themes arising from the data reflect the general acceptance of science and technology forming the basis of modern medicine but an acknowledgement in this post-modern era, that the total care of patients has other dimensions too. Nearly twenty years ago, Henderson (1980) proposed that hospital administrators can help to 'preserve the essence of nursing ... by providing settings in which nurses can 'practice both the art and science of nursing'.

Post-modernism, as defined by Parsons (1994, in Burnard, Millar, p.309) refers to an 'age... where the values of Western science, scientific medicine and technology no longer dominate society' and it is 'characterised by a plurality of values drawn from a wide range of very different academic disciplines and cultural experiences'.

The problems associated with 'pressures to implement a mechanistic model in nursing which tend to undermine the basic values of the nursing profession and lead to job dissatisfaction, stress, frustration and confrontation between nurses, physicians and health care administrators' were discussed by Hewa and Hetherington (1990) who felt that there was a need to return to the original paradigm of 'humanitarian caring for the sick with no distinction between the physical, psychological, social and spiritual aspects' of treatment. These authors referred to Weber's concerns about the potential consequences of an emphasis on scientific rationality, characterised by calculability, predictability, freedom of choice and practicality, because the process would have adverse effects on human values by eliminating the sense of duty based on values which bind people together (cited by Hewa, Hetherington, 1990).

Respondents in this study generally portrayed concerns for not only the scientific basis of care but also for the physical, social, psychological and spiritual aspects, thus demonstrating perspectives beyond technological nursing. A SCBU nurse illustrated this well in saying that 'the baby was extubated while being held by Mum and Dad, closely surrounded by their parents... a very supportive family situation... the parents felt his suffering had gone on long enough and were relieved it was over'. Some of the worst aspects for nurses occurred when the satisfaction of achieving peace and dignity were denied, such as 'seeing the patient have some physical distress and being unable to do anything about it' as one nurse said, and another described the frustration associated with 'false hope being given to the next of kin in aggressively treating the patient', and a third, of the 'inability to withdraw some support measures that were going to extend suffering'.

The advent of science and technology have provided us with an understanding of many disease processes, and from that, a real chance of cure, but it is likely that the healing in its widest sense results from attention to the human aspects of care. Other issues, reflected by respondents, relate to concerns over prolonging life which is of poor quality, or postponing death, such as the length of time taken to make the decision - about three weeks - despite family requests, especially as there were conflicts between surgeons and ICU doctors'.

Technology has also had a major effect on society. Weber (1978,cited by Parsons, 1994, p.293) predicted that 'advanced technology might make society economically more comfortable but people would find their lives empty and spiritually bleak... and certainly not more meaningful' and Cohn (1988) talks of 'the paradox of high-tech. health care' asking whether our technology has outstripped the ability to be ethical, cost-effective and timely in its delivery.

Another author, Cooper (1993) also uses the term 'paradox' in connection with technology, but the focus of her paper is on the 'intersection of technology and care in ICU' and other authors (Ashworth,1990; Mann,1992; Wilkinson,1992; Halm and Alpen,1993) discuss the influence of technology on the care given by nurses in ICU's. Within the past ten years, the nursing literature has reflected an increasing concern with the problem of preserving humanity in these highly-technical environments. Respondents in this study echoed the theme, and it was apparent that in the context of treatment-withdrawal decisions, the primacy of respect for the humanity of the patients was foremost in the minds of this group of nurses.

Much of the literature in this area covers not only the potential problems created by technology but also the means by which nurses may attempt to preserve humanity.

Hawthorne and Yurkovich (1995), for example, question whether science and technology are compatible with professional caring, because in environments where they are valued highly, it may be to the detriment of care, and Cooper (1993) talks about technology 'alienating' nurse and patient under these circumstances, thus inhibiting the nursing care.

Some of the problems cited by Ashworth (1990) are that machinery can be seen by patients (and families) as 'inhuman, potentially dangerous and frightening' and possibly leading to helplessness and enforced dependency, but this author feels that if viewed through a 'nursing lens' (assuming that nurses do not share the patient's fears), people can be helped to regard the visible aspects of technology differently. One of McConnell's participants (1990) spoke of these explanations being 'a positive kind of interaction with patient and family'.

Nurses, in contrast to machines, provide an expert ability to respond to cues and clues in clinical signs and measurements, and also an intuitive ability to perceive changes and understand the significance of them, but these attributes are also reflected in humanitarian aspects of care, where nurses, because of their closeness and constancy of presence, detect and sense needs and feelings of patients and families, and are in a unique position to respond to them. Nurses need to have sensitivity to the feelings of isolation and hopelessness which are associated with people in these situations.

The therapeutic relationships which are central to care may be difficult to establish where patients cannot communicate easily (or at all), and Nolan (1993), talking about an elderly-care context, asks 'if therapeutic reciprocity is essentially dyadic, how can it be sustained with individuals who cannot provide adequate reciprocation?' yet this is the daily challenge in ICU too. Nolan (1993) goes on to ask 'how, in such circumstances, can staff create and sustain meaning for their interactions with patients?'. The answer from respondents in this study was that families are seen as an extension of the patient, and that satisfaction for nurses was derived from establishing meaningful relationships with the family group generally and with the patient in particular wherever that was possible, but where reciprocation was impossible, this was a source of anxiety to respondents when patients could not express views about the continuance of treatment.

The companionship and presence provided by nurses plays a major part in 'humanising' the technological environment, and Benner (1984) and Pettigrew (1990) cite examples of meaningful experiences where a nurse by 'being there' when a patient needed this, helped people through situations when they were in despair. The 'skilled companionship' (Ashworth,1990) is characterised by more than just the nurse being physically present. it requires attention to detail, a concentrated focus on the needs of the patient, and a sensitivity to the feelings of vulnerability and loneliness. One aspect of inhumanity would be indifference to these feelings being experienced by the patient. Pettigrew (1990) refers to the 'ministry of presence' and comments that 'the nature and essence of presence is that it is understood and discerned through an intangible sense of knowing', but this author reminds us that as it involves exposure of pain, fears and anxieties, trust and respect are an essential component of this interaction.

There is a need to recognise that this willingness to share in the suffering of patients and families, to provide a caring presence in order to give 'the faith and strength needed to find meaning in a moment of crisis', takes its toll on nurses, and Lanara (1988) asks,

> "Can the nurse afford a sharing of feelings of loneliness, anxiety, fear of death, suffering? Can she afford the anguish and prolonged suffering of the dying patient? Such care implies giving one's time, energy and self".

The demands on nurses who work with patients and families in crisis, whatever the context, are high, and there were many references to the sadness and distress of families, and for one nurse, the worst thing was 'empathising with the family's feelings of helplessness'. One nurse, when asked about the projected worst aspects associated with the patient in vignette 4, said that this would be 'her actual death, if I had become close to her', and another nurse talked about the 'death of the patient and the pain I would feel if a close, personal relationship had developed'.

In the parallel setting of palliative care, Randall and Downie (1996,p.57), in discussing 'caring for each other', talk about '(E)motional exhaustion or 'burn out' being not uncommon in those involved ... due to a strong motivation to do one's best for the patient no matter what the personal cost, or to frustration at not being able to do the job as well as one would like, usually due to resource constraints'. They feel that the martyrdom which some professional carers are driven to has the result of 'experienced, effective and compassionate carers having to leave this specialist work as a result of emotional exhaustion' (Randall, Downie,1996,p.57) Evidence from this study of the willingness to care for, and support people, came in nurses' comments about satisfying aspects, such as the nurse who said that the best thing was 'developing a rapport with the family and trying to make a very difficult situation a little easier to understand and cope with' and the SCBU nurse who said she had come to know the family so well, she felt she was able to help support them through the experience'. These themes were also apparent in nurse's comments about attempts to create some happier memories of these situations.

In ICU's, despite the compelling, insistent alarms resulting from the technology, nurses can give the human touch, literally, and 'help family members past the equipment so they can be close to their loved one' (Halm, Alpen,1993). The importance of being able to create this environment where patients and families can be close; where privacy can be provided; where the intrusive presence of equipment was minimised; and where there was a dignified, caring atmosphere, was expressed repeatedly by respondents in this study, with satisfaction being expressed when this was achieved for these dying patients. This evidence refutes a statement made by Dean (1967, cited in Hewa, Hetherington,1990) that nurses 'are not able to respond to the suffering of the needs of patients' ... and are 'forced to respond to the needs of physicians and mechanical systems' which are dominating the approach to health care and illness, although this early paper perhaps reflects the prevailing view at the time of the adverse effects of technology on nursing care.

Wilkinson (1995) reporting on her findings in a study of families' needs, cites the importance to families of the happy and welcoming atmosphere created by ICU staff, and the high standard of care offered, and refers to the 'competency in caring' which was of great value and comfort to families. Awareness of this adds to the fears and pressures for inexperienced nurses, and novices provided evidence in the current study of anxieties about, for example, 'how the family is going to react when the patient dies', and how they will feel. There were also indications that juniors, in particular, sought confirmation and reassurance that the correct decision had been taken. Experience in nursing generally was beneficial to nurses in their ability to cope, it did not have to be solely ICU experience, and one nurse with less than one year in ICU but ten years nursing experience, was able to demonstrate good insight into problems, and was thoughtful in responses to the questions in phase 2.

The culture of the department is also crucial to the welfare of patients, families and staff. Where nurses are working in a supportive, caring environment, in which the needs of the staff are also respected, and opinions and feelings valued, then sensitivity and humanity will characterise attitudes towards colleagues. In the current study, 23 (49%) of nurses said that they needed the support of colleagues to help them to cope with the demands made on them during the treatment-withdrawal process, with one commenting,

> "I felt able to cope and have a lot of experience in this area. I always, however, value the support and help of colleagues",

and another felt that 'all staff need support in the ICU environment, ...sharing experiences and thoughts enhances team co-operation and understanding'. The SCBU nurses too illustrated the importance of professional teamwork to enable optimum care of babies and their families.

Advocacy

There were some situations in the current study in which the nurse's opinion was not valued when given, and in some, was not even sought, and these featured in descriptions of the worst aspects and still-troubling aspects of situations.

Nurses may see advocacy for the interests of patient and family as a major part of their role, and certainly their advocacy role was of key importance to many nurses in both phases of this study. Nurses may feel that because of the differing values among the health care team members, opinions may vary about what is in the best interests of the patient. An example of a situation involving a very sick neonate, from whom treatment was withheld after consultation with specialists and discussion with family, illustrated graphically the difference in values held by the nurse from those of the doctor (Morray,1995). The nurse was concerned that the baby was suffering during the withdrawal process, and repeatedly asked the doctor to increase the prescription for morphine, but the doctor disagreed. It was discovered subsequently that the nurse had increased the dose in the three hours before the baby died, without an order to do so, and was disciplined for the offence. Morray (1995) says that the nurse knew that the mother was concerned about the child's pain, so the frustration would have added to the distress which the nurse must have experienced.

There was some evidence of the differing values between doctors and nurses, where perhaps the scientific rationality of doctors was allowed to dominate the process, and either inappropriately-excessive investigations or treatment were given in the nurse's view, despite other evidence about the suffering to be endured for little or no gain. For example, nurses described situations in which treatment withdrawal was delayed unduly, one SCBU nurse talked of a situation in which 'a baby had been kept alive purely to see how long it could survive with modern technology'. Another nurse talked of 'the patient being the same age as me' and went on to question the necessity for performing invasive procedures on this rapidly-deteriorating patient.

Differing values and views of doctors also caused difficulty, and some reference was made to this by respondents, who talked, for example, of the 'conflicts between surgeon and ICU doctors', 'the surgeons being reluctant to let the ICU consultant withdraw treatment', and 'conflicts between consultants' in their reflections on the worst aspects of situations. Viney

(1996) too, in her study into ethical decision-making, found 'moral dissonance' between clinicians from different specialities, which was 'centred around power and control'.

This theme was pursued in vignette 5, where respondents were presented with a scenario in which surgeons and ICU doctors had potentially differing views about the appropriateness of surgery for the critically-ill patient, but nurses too had difficulty with deciding on which action would be in the best interests of the patient and very much empathised with the doctors' dilemma, because ultimately, this type of decision would have to be made by the doctors, when the patient is incapable of giving or denying consent. Nurses expressed fears about taking the 'wrong decision' and of denying patients the opportunity of possibly getting better. Some advocated an element of risk-taking in trying to act in the patient's best interests, offering a trial of maximal, aggressive treatment, and nurses cited some of the clues they might use about the patient's coping ability, to support this plan, feeling that it would be wrong to deny her the opportunity to survive. Nurses demonstrated how their judgements were influenced by other similar experiences, so, for example, where a nurse had previously cared for a well-adapted patient who was a bilateral amputee, this made her feel much more strongly that surgery should be attempted, despite the family's views to the contrary.

Other nurses felt equally strongly about not intervening, and expressed the likely dissonance and conflicts if they did encounter these types of situations. One nurse worried about having 'to carry out care which I feel is wrong, because of the doctor's decision', and another of 'coming to terms with the decision then acting on it', with a third, of a 'feeling of helplessness if the doctors did not listen to the patient's views and continued aggressive treatment'. One nurse thought that the worst thing would be 'that they took Mrs.B. to theatre, knowing the risks, against the family's better judgement, and she died,...as this would be a totally uncaring, unnecessary action'.

In this situation, nurses felt that the best approach would be to ensure that a debate took place between all the relevant people, to try to create a forum where views about the wider aspects than just the clinical, scientific ones, could be considered.

The need for this type of discussion was perhaps best illustrated in the two situations in which nurses talked about doctors indicating uncertainty after the decision had been taken, one saying that 'the consultant became indecisive following the actual withdrawal of treatment and appeared to need reassurance from myself and other members of the multidisciplinary team regarding involvement in the process'.

The context in individual situations is of great importance. One nurse, when asked about the proximity to euthanasia, said that at different times, she had felt that actions were too close to euthanasia and that the 'fine line had been compromised' under these circumstances, yet where the hypothetical patient in vignette 4 had said that she did not want further treatment, the nurse felt comfortable in withholding this, and she also supported withdrawal when the patient in vignette 3 was incapable of expressing his views.

Although the focus of this study has been on the effects on nurses, the impact on doctors is also very great, and although objectively their stance is different, they too share some of the sadness and hurt involved, and Viney (1996) found that two of her doctor respondents experienced 'moral distress' associated with 'saving patients at the cost of a poor quality of life and treating patients against their wishes'.

In Viney's (1996) study, views of senior doctors and nurses were compared, and she concluded that nurses can accept the inevitability of these decisions more readily than doctors, saying that,

> "As nurses did not take responsibility either professionally or legally, nor take an active part in the decision-making process, then withdrawal was easier to accept than it was for medical staff",

and she goes on to suggest that 'a passive acceptance of the medical domination regarding withdrawal decisions may also be a way of coming to terms with withdrawal'.

Reckling (1997) in her study of the roles of participants in ethical decision-making in North America found that,

> "...the person with responsibility for making the decision often did not have the responsibility to carry it out; that is, the physician, in concert with the patient's family, often made a decision and another person, often the nurse, carried it out, sometimes without accepting responsibility for actions".

She comments that nurses said that they often felt powerless to change these kinds of situations, even when they thought that the decision was not what the patient wanted, and concludes that 'the apparent passivity of nurses may be the result of a combination of their professional expectations and situational constraints they face,' where these might include fear of legal action or physician dominance (Reckling,1997). In interviews, nurses discussed their reluctance to risk the anger of other health care professionals, especially doctors with whom they had to work, and worried aloud about 'jeopardising their jobs' (Reckling,1997).

Sherblom et al (1993) too comment that nurses 'feel professionally and institutionally constrained and must make their moral decisions in contexts in which they do not always feel free to act', thus drawing a distinction between what they feel is the moral action required and their possible actions within their professional role.

Norrie (1997) warns that nurses must be aware of the dangers to themselves of speaking out and advises that '... they must have further training in dealing with ethical issues which will make them convincing and authoritative advocates'.

Reckling (1997) concludes from her findings and the literature that '...nurses find the role of advocate problematic in their restrictive work environments'. Sherblom et al (1993), in a study of nurses' ethical decision-making, feel that,

> "Advocacy concerns express an overall commitment to a patient's well-being, weaving rights and needs together. Advocacy is sometimes articulated in justice terms or in care terms, but ultimately the nurses conception of advocacy transcends and integrates justice and care perspectives".

In the current study, the reasons cited by nurses in support of the withdrawal decision often gave indications of the nurses' knowledge about their patients in terms of their pre-ICU quality of life, the clinical details which pertained to the potential reversibility of the patient's illness, and nurses' understanding of the ethical difficulties in balancing benefits and burdens of treatment. This evidence would support the contribution which nurses could make to decision making, and provided that they could articulate the facts and insights about the patient and family situation, it is clear that they would feel frustrated if denied the opportunity to speak. Advocacy on behalf of the patient would therefore be of crucial importance to the nurse who felt that some aspect was being overlooked.

One nurse, for example, commented that 'the (patient's) family had expressed wishes that he not be put through unnecessary treatment', and another talked about insights into the patient's lifestyle, as although he lived at home with his wife, he was dependent on supplementary oxygen, only able to manage two stairs a day, and that it was unlikely that he would wean successfully from the ventilator. One patient was described as having a 'chronic chest and cardiac history ... with limited mobility pre-op. ... and likely to be more incapacitated if he survived'.

It would have been imperative for the nurse caring for the patient who 'was devastated by his treatment ... because he wanted to die sooner rather than go through the indignity of a protracted death' to participate in discussions and fulfil an advocacy role where he/she felt it necessary, in order to minimise the moral distress inevitable in such a situation.

Two nurses specifically cited examples of situations in which they were dissatisfied with their abilities to advocate for patients, one of whom saying that an opinion was offered but 'to a large extent it was ignored', and the other feeling that the 'aggressive' treatment given was not warranted and gave false hope to the next-of-kin, but as there was no discussion with staff, 'no rationale was given', it left the nurse powerless in this difficult situation. Another nurse talked about the importance of the role of advocate, adding that 'whether doctors want to listen to us or not, we must make our views heard'.

Because the nurse may feel that the patient should be defended against unwanted medical interventions, there are personal risks in expressing views, and Lindahl and Sandman (1998) comment that 'even if the moral urge to advocate is strong, the authority to do so is weak, ...' so the role of nursing advocate 'often evokes feelings of loneliness and vulnerability' especially if met by medical 'arbitrariness or an arrogant attitude'.

In the reports in the current study of unhappy memories about such situations, most nurses cited examples of dilemmas in which it would have been important for them to express their concerns and perhaps speak for patients and families. One, for example, 'felt that the patient should have been left in peace despite a medical request for an EEG for research purposes' and another expressed concern about the lack of certainty about reversibility in a situation.

In many situations, it was apparent that the views of nurses differed from those of the doctors, but that the medical opinion determined the actions taken. In one situation which still troubled a nurse, the withdrawal decision was reversed because the nursing team objected to its 'hastiness', so illustrated well the need for consultation.

Whether or not these examples represent advocacy by the nurse on behalf of the patient is contentious. The nature of these situations is such that a nurse is rarely able to ascertain the patient's own views, so can really only share insights obtained in the course of caring for the patient. In this study, it seems that what nurses meant by their role as advocates, was that they themselves had an opinion, based-on, and informed-by, their knowledge of situations about what was in the best interests of patients, all things considered.

When this issue was pursued in the case-study vignettes, the autonomy of the patient was very important to nurses who tended to feel that where there was uncertainty about the outcome for the patient, as well as doubts about the likely views of the patient, then it was better to err on the side of caution. Where the anticipated outcome was poor, the patient had expressed a reluctance to continue treatment, and the nurse knew the patient quite well, respondents were much more certain about speaking for the patient, indeed the majority of respondents felt that doing this would be a source of satisfaction for them.

Lindahl and Sandman (1998) present an enlightening perspective on nursing advocacy in ICU's based on their study of six nurses narrating episodes of care with which they had been satisfied or dissatisfied. They identify the components of the role of the nurse as an advocate as:

> to build a caring relationship,
> to carry out a commitment,
> to empower,
> to make room for, and interconnect,
> to be a risk-taker,
> to be a moral agent, and
> to create a trusting atmosphere conducive to recovery.
> (Lindahl, Sandman,1998)

For Lindahl and Sandman (1998), these descriptors of advocacy arise because the critical care nurse, 'who is in a unique position to meet, support and protect the patient and family', is aware of the patient's powerlessness and dependency, and recognises the threat to patient autonomy, then acts on it by reflecting, arguing critically and acting independently, in order to present alternative strategies. There are striking similarities between the concept of advocacy as described here and that found in this study.

Evidence from the current study indicates that nurses, particularly the more senior ones, do perceive a responsibility to participate in discussions, and to advocate on behalf of their patients and families, but there was also evidence that nurses, even more senior ones, had doubts about the adequacy of their knowledge of ethical matters. They feel dissatisfied if they are thwarted in attempts to participate, and may continue to question the decision taken, fail to come to terms with withdrawal, and are troubled about aspects of situations. Simpson (1997) talks of the distrust which nurses may experience when there are 'ambiguous decisions' taken, and 'hidden agendas' are suspected, which can only be resolved when meaningful dialogue takes place involving the whole team. This theme was pursued in vignette 3, and nurses talked about the 'halfway-house' decision proposed, because of the 'belief that we are just prolonging suffering if conservative treatment is offered', and one nurse said that the doctors 'should either treat fully or withdraw everything except fluids and drugs for pain control and sedation'. Simpson's (1997) respondents indicated that for trust to occur, 'the nurse required a mature insight into the difficulties the medical staff might have' in making these decisions, and that if they themselves had the absolute responsibility, 'they too might err on the side of caution' and delay decisions until there was greater certainty.

In a study of nurses working in neonatal ICU's, Portell Elizondo (1991) found that 93.3% of her 60 respondents stated that they 'experienced conflict related to their participation in ethical decision-making' and 46 (82.1%) said that this conflict was with physicians, 33 (58.9%) with parents, 28 (50%) with their own ethical beliefs and 22 (39.3%) with nursing colleagues, and analysis of respondents' comments indicated that a major concern was 'frustration resulting from the lack of involvement in decision-making' and a 'lack of consideration given to nursing input', thus endorsing the views of some of the ICU nurses in this study.

Where all viewpoints are valued and respected, then conflicts do not occur, and the impression gained from evidence in this study is not that this is the result of decisions being left to the doctor totally, and everyone else falling in with the plan, but rather that the multidisciplinary team is sharing responsibility for achieving consensus in these inevitably-sad situations. The positive aspects were exemplified in a SCBU nurse's comment,

> "I feel particularly lucky in the area in which I work because when there are incidents involving withdrawal of care, there is always consultation, with all members of the team and the families involved, and there is so much peer support. We always have the opportunity to reflect on decisions after the event and we are always able to talk through the situation with all grades from consultant downwards".

The influence of nurses in such discussions was explored in the current study, both in the amount which nurses felt they had in the specific situations described, and, in the second phase, the relative amount of influence they felt they should have in the contexts portrayed in the vignettes. In the first phase, nurses mostly reported that they had some influence in decision-making (15) (32%) with (6) feeling that they had quite a lot, but (5) saying they had none, although in the sub-group of (19) Sisters/Charge Nurses, in (8) situations they felt they had quite a lot of influence and in (1), the most.

In vignette 3, nurses were asked to choose who, among a group of participants, should have the most influence in the dilemma involving a man who had alcoholic liver disease. Mean scores indicated a rank order of the patient having the most influence, and the patient's brother, the least, with nurses scoring a little higher than the brother. Nurses felt that of the professionals involved, the ICU consultant should have the most influence in making a decision about treatment withdrawal. As the patient under these circumstances usually cannot give an opinion (in phase 1 of this study, only one patient was able to indicate a choice), the consequence is that the decision rests with the doctor, acting in the best interests of the patient, who may, in coming to a decision, consult others about their own views and the probable views of the patient. It is essential that the doctor engenders the trust of the patient's family and the team members, and Simpson (1997) talks of the distrust which develops 'when the nurses felt that social judgements were influencing treatment decisions'.

The issue of the person who can best act as advocate was explored in vignette 4, in which a patient who was well-known to the nurses, had said during the course of her protracted treatment that she had endured enough of the stressful weaning attempts and did not want to try any longer to get better. In response to this scenario, 30 of the 33 respondents disagreed with a decision to start further aggressive treatment, and two-thirds agreed with a decision to withhold treatment, reduce support and give diamorphine to relive distress during the withdrawal process. When asked about representing the patient's views, nurses felt that the patient's family was best-placed to do this, with the nurses themselves next best, and the doctors, the worst.

An important difference between these two situations is that almost half of the nurses disagreed with the withdrawal decision, and a further one third were unsure about it, when asked about the patient in vignette 3, in contrast to the overwhelming majority in favour of withholding further treatment from the patient in vignette 4. Perhaps one inference to be drawn from this is that where nurses have been close to the patient through a series of distressing episodes, and the patient has been 'able to express her views to me' as one nurse said, then nurses feel more strongly that they can represent the patient. Comments indicated that nurses felt that they had to advocate for the patient to ensure 'that her views were taken into account' and to support her autonomy and respect her wishes. Some nurses made reference to the evidence they would draw on to support their view that withdrawal was appropriate. For example, one nurse said that because of the closeness which had developed, 'she would have got to know her and be able to judge whether she was rational or confused when making such requests' and another spoke of 'meeting her as a person, knowing that she herself thought her quality of life was poor'. Because of the uncertainties about outcome for the patient in vignette 3, and as he was not able to give an indication of what he would want, nurses felt less able to be influential than the doctors, even though they disagreed with the decision themselves.

Models for ethical decision-making

In both medical and nursing literature there have been references made to the use of ethical decision-making models or grids as one solution to ensuring that appropriate debate takes place and important areas are not overlooked. Proponents of this approach feel that models 'assist the moral reasoning process' (Seedhouse, Lovett, 1992,p.99) because they enable a logical method of selecting the most important and pertinent components of the dilemma, the primary considerations, which can then act as a reminder in discussions for 'reasoning and justification'.

Models may include a variety of principles and issues from which selections are made according to the priority in relation to the clinical situation under review. Models are likely to consist of sets of prompt questions or instructions which can be worked through systematically, beginning with the facts about the clinical case, application of the ethical principles, balancing the relative risks and benefits, sources of conflict, and then ultimately arriving at a decision which can be justified. Within the process, judgements have to be made about the availability of options, the chances involved, desirability (in terms of likely outcomes) and the strategy for integration of all the aspects into a coherent plan which can be articulated, so that comparisons can be made between derived options (Dowie, 1994, in Gillon, p.421).This author feels that this approach imposes burdens on the medical decision-makers because of the need to expose, and make explicit, differences in beliefs and values, however, it does mean that issues cannot be resolved covertly or ambiguously, and this may be particularly useful in considerations of support of patient autonomy (Dowie,1994, in Gillon, p.430).

Nursing authors have also proposed the use of models by nurses in critical care who face ethical dilemmas frequently.

Rodney (1991) feels that in order to 'enact their role as advocates, nurses need to be able to implement a process of ethical decision-making in practice' and use of a model may enable this. Given the closeness of ICU nurses to their patients and families, it is very likely that nurses will be best-placed to identify ethical conflicts and dilemmas associated with the care being given to patients, and it is essential that nurses are then able to mediate on behalf of others and raise concerns. In this study, a number of such issues were highlighted, such as where family members requested cessation of treatment for the patient; where the nurse was worried by the lack of understanding of a family member about brain death and organ donation; where the patient was deemed irreversibly-ill but nurses dissented from this; and where investigations and treatments were being proposed which nurses felt were not indicated.

These situations raise ethical problems because the nurse's primary responsibility is to ensure safe, quality care to the patient and 'where this responsibility conflicts with others, nurses must choose which obligation to honour' (Wlody,1990). Ethical problems faced by nurses may involve 'discomfort and dehumanisation of a patient who will die' (Rodney,1991) and there were echoes of this theme in data from respondents.

Use of an ethical decision-making model under these circumstances may enable nurses not only to identify the dilemmas arising, but also to clarify and organise the components of the problem, to initiate discussions, and preparatory to any debate, to ensure that the appropriate participants are present, thus reinforcing the pivotal, mediation role played by nurses on occasions, as well as protecting the patient from harm and providing support for those involved (Wlody,1990). Nurses in phase 2 of the current study were able to identify other potential participants in decision-making about the hypothetical patients in vignettes 3 and 5, and gave examples of the contribution they might make.

For the nurses in this study, the use of such tools may have provided the appropriate prompting of a multidisciplinary debate and therefore greater assurance that a thorough exploration of the issues has been undertaken.

Models have also been advocated as learning tools to enable nurses to 'develop skills in the cognitive process' necessary (Greipp,1992) which involves progressing through the stages from problem identification to resolution. The purpose, then, is to strengthen the ability of nurses to participate effectively in discussions in their day-to-day clinical practice. These skills also have a wider application in nursing involvement in department or institutional policy development regarding ethical matters.

Spirituality and religion

Acknowledgement that there is a spiritual dimension to the care given to patients implies that people have needs beyond the physiological, psychological and social. These spiritual needs relate to the desire to make sense of, and find meaning in, life, and help to 'give purpose and direction' (Hawthorne, Yurkovich, 1995), and O'Brien (1982, cited by Labun,1988) defined spirituality as 'that which inspires in one the desire to transcend the realm of the material'.

Caring and compassion are expressions of spirituality, and the descriptions respondents gave of the relationships they had developed with patients and families, illustrated nurses' concerns with the significance of these close, personal contacts in which hope and comfort were given. The reality in treatment-withdrawal situations is that hope for recovery has been abandoned, and alternative, positive aspects have to be sought, such as the desire for a peaceful, dignified death and an end to suffering, so that as respondents said, 'families could have some happier memories of events surrounding the death'.

Sensitivity to the values of patients and families is part of the nursing role, and respect for personal and cultural values is very important around the time of death. Nurses in this study expressed satisfaction when they were able to achieve this by, for example, ensuring that families could be with the patient, in the best-possible surroundings under the circumstances, but were sad and frustrated when the time available was too short (the patient died as soon as the drugs were reduced or tubes removed) or too long (where the patient was subjected to unreasonably-protracted treatment in the view of the nurse). In one situation in the current study, a nurse was concerned that because there had been little time between the decision to withdraw treatment and the patient's death, there was no opportunity to address the religious needs of the family.

Ashworth (1987) talks about the need for spiritual health, whether or not people have a religious faith, which involves utilising their customary sources of support, meaning and purpose in life, and part of the role of the nurse is to seek and explore this, mediating as necessary between the family and others, where the nurse recognises limitations in his/her understanding of the beliefs (Labun,1988).

"...if they do have such a faith, it is likely to become even more important to them

> in a critical care situation, and if they do not, they may begin to think more deeply about life, death, suffering, their meaning to the person and God as a source of supernatural support".
> (Ashworth,1987)

Gordon (1982, cited by Labun,1988) agreed with this, commenting that 'the nurse who understands the client's spiritual beliefs may be able to support coping strategies of this type'.

The importance of both the interrelationship between physical, emotional and spiritual aspects of health, and the relational aspects within spirituality were discussed by Labun (1988) who summarised her conclusions as follows:-

Spirituality

1. is an aspect of the total person which is related to, and integrated with the functioning and expression of all other aspects of the person;
2. has a relational nature which is expressed through interpersonal relationships between persons and through a transcendent relationship with another realm; and

3. involves relationships and produces behaviours and feelings which demonstrate the existence of love, faith, hope and trust, therein providing meaning to life and a reason for being.

Spirituality may be expressed as institutionalised religion, with needs channelled through 'prayers, rituals, religious communities and worship' or may be demonstrated in meaningful work or creative expression in writing, or by being able to 'explore feelings, values and an understanding of life with another person' (Labun,1988).

Patients in the situations described in this study were not able to communicate their needs in this area, and it is likely that most, if not all, were unaware of any spiritual distress caused by a failure to address these needs, however the families and friends would have been only too aware, and the efforts of nurses were directed at providing relief for these people. Burnard (1987) feels that spiritual distress results from 'a total inability to invest life with meaning' which can be 'demotivating, painful and cause anguish to the sufferer' and there were a number of echoes of this description in respondents' descriptions of treatment-withdrawal situations which were not managed well or where nurses felt that such decisions should have been made, but were not, leaving families with 'feelings of despair, distress and emptiness' (Frankl,1959, cited by Burnard,1987) and with hopes which could not be sustained.

Nurses who described situations where the patient had become unexpectedly very ill as a result of complications following surgery, for example, would have been dealing with families who would have had great difficulty accepting the change in treatment plan. One nurse spoke of 'the patient being fit and well prior to admission' and then that the family was 'distraught about the sudden deterioration', and talking of another patient who had a routine operation but suffered complications following a fall, the nurse commented that the patient had been expected to go home the next day and that ' the incident came as a great shock to the family'.

One nurse talked about a very premature baby whose parents 'had a low IQ and were unable to understand the situation', and described the frustration and distress in trying to deal with this because the parents would not allow treatment to be withheld from the 'cyanosed and bradycardic baby', although the grandparents supported the decision to withdraw.

The counsel of perfection which Burnard (1987) describes as being necessary in order to intervene in these situations, involving 'total commitment and immersion on the part of the nurse, utilising intuitive, empathic listening', may be hard to attain in a busy ICU, and perhaps this is what some respondents meant when they said that families did not have enough time, or were not given the opportunity, to come to terms with events. It is important to aspire to this, because as Mitchell (1990, in Byrne) says, 'respect is due not only to what we can comprehend and assess in people, but also to what eludes, and indeed transcends our understanding ... as there is a mystery about human existence'. Pettigrew (1990) too states that 'nursing care that ignores or fails to recognise spiritual needs as a vital part ... becomes unethical and violates the principle of fidelity', so nurses must be able to identify these needs and respond to them.

Evidence from families was sought by Coulter (1989) in her study of families' needs, and she comments that where the prognosis was poor, relatives hoped that the patient would be comfortable and pain-free, and 'that they would have religious and spiritual peace'.

Institutionalised religion played a major role in nursing development and evolution because nursing 'was influenced by Judaeo-Christian values and shaped the occupational goals of the profession ... as the majority of nurses in the early 19th century were Roman Catholic nuns and their services were regarded as a humanitarian gesture towards the poor, sick and disabled on the part of the Church' (Hewa, Hetherington,1990). This influence persisted through Florence Nightingale's reorganisation of nursing as she was a student of a Lutheran Minister in Germany (Bradshaw,1997) and had a strong commitment to religious beliefs which inevitably pervaded the ministry to the sick advocated by her. Pettigrew (1990) also uses the term 'ministry' in her discussion about how important a nurse may be, in 'being with' a person in need, and she uses the biblical reference 'My soul is overwhelmed with sorrow to the point of death ... stay here and keep watch with Me' (Matthew 26:38) to illustrate the point.

Bradshaw (1997) feels that 'the spiritual dimension of care is inextricably tied to the ethic of nursing ... and is the fundamental expression of care ... not so much talked about, but lived out' as a service to those who needed it. This view could be challenged not only by the technical, mechanistic approaches to treatment, but also by the increasingly, scientifically-dominated nursing programmes and Bradshaw (1997) feels that some of the traditional values of nursing have been 'devalued and replaced by the philosophical theories of the new profession'.

While acknowledging that spiritual needs could be overlooked by the new practitioners, many authors assert that the caring dimension of nurses does encompass a spiritual component (Ashworth,1987; Carter, in Millar,Burnard,1994; McGilloway, Myco,1985; Watson,1990) and Watson (1990) talks about nursing having 'caring knowledge that enriches the soul'.

Where suffering patients' needs make demands on the nurses, Lanara (1988) asks from what source can nurses gain strength, then goes on to say that, 'faith is a resource from which the nurse may draw power to transcend the difficulties associated with suffering in the delivery of care'.

The focus of the above discussion has been the spiritual needs of the patient, but spirituality and religion may be of great importance to the members of the health care team, and in the context of treatment-withdrawal, religious doctrines, principles and convictions may have a major influence on the views of professional carers about the sanctity of life. In a study exploring the attitudes of critical care professionals, Sprung et al (1992) noted, with surprise, that 'a higher percentage of Jewish respondents reported that they had withheld or withdrawn therapies compared with Catholics and adherents to other religions', because of the importance in Jewish law of preserving life. These authors suggest as an explanation for this anomaly 'that some respondents belonging to a particular faith may not necessarily adhere to its teachings in these matters' although it would be expected that religious beliefs would influence beliefs about treatment withdrawal.

The values of staff are very important in this context and one respondent in the second phase commented that 'life was precious, and you should have what was given' and was concerned that it was impossible to know what value the hypothetical patient in vignette 5 would have placed on her life with, potentially, very severe disabilities. Another respondent, about the same hypothetical situation, said that 'the patient's Christian views and therefore values, may allow for life with disability'.

Religion did not play a large part in respondents' views in the current study, although its influence was sought in both phases.

For one nurse in the first phase, the religious beliefs of a health care team member did influence the treatment-withdrawal decision and, on religious grounds, this nurse objected to the prescribed dose of analgesic which, she felt, exceeded the dose required to keep the patient comfortable. The 'double-effect' principle under which drugs are prescribed in these circumstances states that in giving drugs with the objective of relieving pain and distress, health care staff accept that the patient's life may be shortened as a result of the secondary, side-effects of this treatment. This nurse felt that the doctor's prescription for analgesia went too far towards a deliberate intention to hasten death and she objected on moral and religious grounds. Another nurse commented that some team colleagues, because of their religious beliefs, objected to treatment-withdrawal on principle, and in this nurse's view, could adversely affect appropriate decision-making.

Within the data in the second phase, religious teachings were mentioned by two respondents as a source of education in ethics, and religious grounds were cited by one respondent as having an influence on views about treatment-withdrawal from the hypothetical patient portrayed in vignette 1.

It may be viewed that 'life is a divine gift (bestowed, sustained and finally reclaimed by God)' although as Kuhse (1987) says, this is harder to maintain now in this age of technology when life can be supported for prolonged periods and some control is possible over the time of death. Kuhse (1987,p.2) raises the pertinent questions about when such support should be offered, and whether it should be permissable to shorten life by direct means under some circumstances. Kuhse (1987,p.5) offers a qualified, 'Sanctity of Life' principle to guide us, saying that,

> "...whilst it is always absolutely prohibited to terminate life intentionally on the basis of quality of life considerations, it is sometimes permissable to refrain from preventing death and let a patient die,"

but goes on to present inconsistencies in adopting this absolutist approach in practice.

The position taken by the Roman Catholic Church on this matter was recently restated by Cardinal Basil Hume (The Times,27.11.97,p.20) reasserting the principles included in the Vatican's Declaration on Euthanasia (1980, cited by Kuhse,1987). In a warning against the proposed Bill on 'Doctor-assisted dying', Hume (1997) feels that if the law were to be changed to allow 'intentional termination of life by withdrawal or denial of treatment', then active euthanasia 'could enter by the back door'. The concerns which Hume (1997) has relate to possible termination of life when the person's life is judged by others to be no longer worth living; secondly, a decision could be taken that it would be kinder to 'dispatch patients by swift lethal injection rather than subject them to a lingering death by disease or thirst'; and thirdly, that 'the human motive to develop compassionate and effective approaches to the care of the suffering and dying would be undermined'.

The importance of this last point was exemplified in a letter (Moore,The Times, 06.12.97, p.23) from a woman whose husband had just died, in which she said that had euthanasia been available, her husband's life would have been shortened by eight days, and they, herself and their young children, would have been denied the opportunity 'to nurse him, and show him love and care, and fully to realise that the time had indeed come, and were all at peace with it'.

The proposer of the current Bill, Joe Ashton, MP for Bassetlaw (The Times,01.12.97,p.23) rejects these concerns, feeling that the Bill is not advocating euthanasia, but instead is 'giving the right to terminally-ill patients to shorten their life by choice' because he felt that the law at present lacked clarity and was ambiguous.

Searle (1997), a medical doctor and Anglican priest, supports Hume's (1997) warnings about the possible dangers associated with adopting the Dutch approach to euthanasia, but does feel that when it is obvious that treatments are prolonging dying of an irreversibly-ill patient, then they should be discontinued, stating that this approach does not 'undermine the Christian belief in the sanctity of life'.

The opposite view was held by a representative of Islamic Concern, Suhaib Hasan (The Times,06.12.97,p.23) who strongly supports the principles and philosophy underpinning the hospice movement, but states,

> "Only God, the Creator of all, is the owner of life and only He will decide about its end".

This view was echoed in a recent case report in which the mother of a child who had a fatal disease and was irreversibly-ill said,

> "We are all Orthodox Jews and live our lives by those values. One of the principles fundamental to our religion is that life should always be preserved",

and this was the basis on which the parents were objecting in court to the withdrawal of mechanical ventilation from the 16-month old girl. The ruling by Sir Stephen Brown (Wilkins, The Times,20.11.97,p.12) went against the parents' views on the grounds that it was in the baby's best interests to let doctors withdraw treatment, stating,

> "Whilst the sanctity of life is vitally important, it is not the paramount consideration".

The origins of the view that human life is valuable and worthy of respect are from Judaism and Christianity, but Humanists, too, believe that 'man is a person of dignity and worth and should be respected' (McGilloway,Myco,1985,p.34).

Some of the concerns over moral issues which were expressed by respondents could lead to a question of whether the conscience clause in section 4 of the Abortion Act,1967 (cited by Morgan, Lee, 1991,p.177) which states,

> "No person shall be under a duty, whether by contract or by statutory or other legal requirement, to participate in any treatment authorised by this Act to which he has a conscientious objection"

should be adapted to cover treatment-withdrawal situations, in order to protect the staff involved.

Euthanasia and manslaughter

A theme which arose from the data in the first phase and was followed-up in the second, was nurses' concern about the proximity of their actions during the treatment-withdrawal process to the patients' deaths. The most cogent example of this from the earlier data was the situation in which the nurse, somewhat against her better judgement she implied, had removed a terminally-ill patient's endotracheal tube at the doctor's suggestion, and the patient died almost immediately. The nurse said that she 'felt terrible...felt as if (she) had participated in euthanasia rather than aiding the patient to a peaceful and dignified death'. When the 33 nurses in the second phase were asked how they might feel under these circumstances, how close they would feel this was to euthanasia, their replies were as follows:
(4) not at all, (17) to some extent, (8) to quite a large extent, and (4) to a very great extent, with one nurse commenting,

> "I would never extubate a patient under these circumstances, though I might be prepared to let the doctor do it, though I may not. I feel that this action is unacceptable and the patient should not have been extubated. This is tantamount to active killing".

In virtually all the situations in the first phase, nurses supported the treatment-withdrawal decision and so were reconciled to accepting treatment changes which would include reduction or discontinuation of cardiovascular support drugs, reduction of supplementary oxygen, withholding of renal-replacement treatment, and withholding of other therapeutic measures where the previous intention had been restoring the health of the patient. Despite acceptance of the decision taken, reservations were still expressed by two respondents about what they felt were 'inappropriately-high' doses of opiates being prescribed, and in the situations where patients had died within minutes of the reductions in treatment, there would have been an obvious association between the actions of nurses in collaboration with doctors' instructions, and the consequences. Again, when nurses in the second phase of this study were questioned about such situations, concern was expressed, with (1) saying that it was much too close to euthanasia, (5) saying that it was uncomfortably close, (11) saying that it was quite close, (11) saying that it was not very close, and (5) saying that it was not close at all, although to some, the immediate death was reassuring because it confirmed the severity of illness of the patient, and the level of dependence on the support drugs.

Pace (1996,in Pace, McLean, p.52), when discussing the reasons for deciding to reduce supplementary oxygen levels rather than discontinue ventilation, feels that,

> "It could be that doctors may be deluding themselves into believing that it is acceptable to withdraw oxygen but not ventilation because the patient does not die immediately when ventilated with air. The immediate causal link between the death and stopping ventilation makes intensivists much more wary. It is perceived as directly killing the patient, since the patient dies within a matter of minutes".

It is obvious from this statement why nurses may have concerns about their actions under these circumstances.

Reservations were also expressed by one nurse about the use of an opiate, diamorphine, for the hypothetical patient dying of chronic respiratory disease in vignette 4, saying,

> "To commence a diamorphine infusion when there was no clinical need for it (ie.pain). I would feel this would certainly be classified as euthanasia (active) and possibly liable for prosecution",

and four respondents disagreed with the approach suggested which included withholding further treatment, reducing the current level of support and starting a diamorphine infusion. This reluctance perhaps also ignores the benefits obtained in the reduction of distress associated with pulmonary congestion and heart failure when such drugs are administered. One respondent referred to this, saying that 'diamorphine might be the answer in small, not euthanasic doses', to relieve the distress associated with dying of heart failure, which another respondent felt would be 'like watching her drown'.

Why some nurses are now feeling more uncomfortable with these situations needs to be considered.

There have been two nurses convicted, one of murder and one on a count of serious assault on an ICU patient, while this project has been in progress. Both nurses had personality disorders.

The first, Allitt (Clothier,1994) was convicted of murdering four children, nine attempted murders and nine counts of grievous bodily harm with intent. The second, Jenkinson (Duce,1997) was convicted on grounds of 'tampering with a patient's life support equipment to discredit a colleague on the Unit'. The cases were followed by inquiries (Clothier,1994 - the Allitt case; Bullock,1997 - the Jenkinson case) resulting in recommendations being made about recruitment and selection procedures and managerial practices, in order to protect the public. Both of these cases were reported widely, and it is possible that nurses now feel more vulnerable to accusations of misdemeanours, given the consequences of actions they are taking during treatment-withdrawal.

The other aspect implied by respondents when they said, for example, that 'the family did not expect this to happen', 'were shocked' by events, was the betrayal of trust between families and the health care team. Patients' families, although their views are listened-to and respected, ultimately have to accept the expert view from doctors about the irreversibility of the patient's illness, and it is the 'doctors who carry the legal responsibility for the treatment and outcome, whereas the nurse may have expressed opinions about the nature of treatment' (Melia, 1996, in Pace, McLean,p.137).

Melia (1994) points out, however, that 'nurses have power by virtue of their knowledge and familiarity with the system, whereas patients are, in general, vulnerable' so the result is 'benevolent paternalism on the part of the nurse and trusting acceptance on the part of the patient' (and family).

Nurses exert a great deal of power when reinforcing the opinions of doctors that further treatment is futile, then taking actions to discontinue these treatments, and Melia (1994) goes on to say that 'nurses may simply have to live with the moral uncertainty which accompanies their attempts to act in the best interests of the patient'. The findings of this study do not indicate that nurses feel they have much power and influence in the decision-making though, and reference was made to this earlier in the discussion about the values and influence of health care team members.

Nurses do have increased autonomy in clinical decision-making, working within parameters, making judgements, and they increasingly expect to be heard now, given their knowledge of situations and perhaps particularly because of the tasks assigned during the process of treatment-withdrawal.

Downie (1996,in Pace, McLean,p.4) also makes reference to this saying,

> "...group decision-making involves group responsibility. If the nursing profession wants equal claim to be heard, then nurses must be willing to be held responsible for their decisions",

and during the treatment-withdrawal process, a great deal of the responsibility for the pace and timing of support-drug reductions and sedation increases, devolves to the nurses involved as illustrated in the reports of nursing activities in the situations described in this study.

Randall and Downie (1996,p.52) feel that it is appropriate that all professionals play a part in decision-making, but they go on to say,

> "The price that nursing staff will have to pay for greater respect for their professional autonomy leading to a greater ability to influence decisions is a greater degree of accountability, and from the legal perspective, this unfortunately means that they can and will be exposed to litigation".

Manslaughter

Another reason for some of the feelings of vulnerability and culpability may be associated with the medical cases of attempted murder and manslaughter reported in the past eight years in Britain, and also the cases where doctors, either individually or through their employers, have gone to law to ensure that they will not be charged as a result of their actions in giving or withholding treatment.

Two doctors 'were convicted of manslaughter arising from their treatment of a 16-year-old patient with leukaemia, whom they accidentally injected intrathecally with vincristine' and the patient had died (R v Prentice,1991, in Korgaonkar, Tribe,1994). They were convicted on the basis that 'as the doctors had failed to give any thought to the possibility of their actions amounting to a serious error, in circumstances where an ordinary, reasonable doctor would be expected to have recognised that there was a serious risk, the test for reckless manslaughter had been met' (Korgaonkar, Tribe,1994).

Subsequently, these convictions were overturned in the Appeal Court on the grounds that a 'recklessness' test was 'inappropriate in manslaughter trials when the death was caused by a breach of the duty to care' (Brahams,1993). This Court stipulated that certain conditions had to be met for manslaughter by breach of duty to be proved:

1. the existence of the duty;
2. breach of that duty, causing death; and
3. gross negligence, which the jury consider justifies a criminal conviction,

and Brahams (1993) goes on to say that proof of the following states of mind may properly lead a jury to make a finding of gross negligence:

a. Indifference to an obvious risk of injury to health.

b. Actual foresight of the risk coupled with the determination nevertheless to run it.

c. An appreciation of the risk coupled with an intention to avoid it but also coupled with such a high degree of negligence in the attempted avoidance as the jury consider justifies conviction.

d. Inattention or failure to advert to a serious risk which goes beyond 'mere inadvertence' in respect of an obvious and important matter which the defendant's duty demanded he should address.
(Brahams,1993; Korgaonkar, Tribe,1994)

A series of manslaughter cases were reported from New Zealand, involving the convictions of two anaesthetists and a radiologist (Blair,1994) and all resulted from 'simple negligence or carelessness' which, according to this author, 'would not qualify for a criminal conviction in Australia, Canada or England'. Reflecting on these cases, Blair (1994) feels that the 'threatening and hostile environment has subtly affected capacity to deliver health care...'. In a letter refuting an accusation that 'doctors are scared' and 'want to water-down the criminal law or be exempt from it' Clarkson (1994) contends that the problem is that there is no distinction in New Zealand law between 'simple human error on the part of the practitioner and gross negligence or recklessness', and both may attract criminal charges if the patient dies.

The New Zealand Nursing Organisation (NZNO) responded to these cases and other subsequent ones, with advice to nurses to contact them, or a lawyer, if they were 'working at the time of a death which may relate directly to nursing practice' and quoted the appropriate section (155) of the Crimes Act,1961, which says,

> " Everyone who undertakes (except in cases of necessity) to administer surgical or medical treatment, or to do any other lawful act the doing of which is or may be dangerous to life, is under a legal duty to have and to use reasonable knowledge, skill and care in doing such an act, and is criminally responsible for the consequences of omitting without lawful excuse to discharge that duty",
> (Cronin,1994)

and in a submission asking for a review of this position, the NZNO said that 'application of the ability to prosecute ... was unfair' and gave examples of how potential liability for manslaughter was concentrated in areas of nursing such as intensive care, post-operative recovery, neonatal intensive care ...or caring for the acutely-ill or dying (Cronin,1995).

In Britain, prior to the Bland case (Airedale NHS Trust v Bland [1993] 1 All ER 821,880-3) when some doctors asked the coroner about 'withdrawal of artificial feeding from a comatose accident victim', the response was that there would have to be a referral for criminal investigation (Pace,1991) however the precedent set in Bland has established the principle in law that treatment-withdrawal is appropriate in situations where people are in PVS.

The situation in intensive care is different and Pace (1991) expresses concern that 'the judiciary uses a 'blind eye' approach for many medical matters'. This was in reference to an ICU patient's case where treatment was withdrawn from a severely-ill, elderly man who had chronic respiratory disease, which Dr.Pace (an anaesthetist and intensivist) had reported to the Procurator Fiscal's Office, but no action was taken. Pace (1991) says that he does not like this approach because 'one never knows when the judicial eye is going to open', thus expressing the uncertainty perceived by health care team members. Branthwaite (1996) too asks,

> "...if it is morally wrong to kill, does the withdrawal of intensive care lay the practitioner open to a charge of homicide?",

but goes on to explain that this charge could only succeed 'if it can be shown beyond reasonable doubt that the actions of the accused caused the death and that there was an appropriately-guilty state of mind, an intention to kill...' with causation in fact (proof that the death would not have occurred but for the act) and in law (proof of an uninterrupted sequence of events leading from the original event to the fatal outcome) both established.

Branthwaite (1996) states that 'on analysis, withholding and withdrawing intensive care are morally and legally defensible in appropriate circumstances... but that when decision-making is particularly difficult, it is both prudent and practical to seek the authority of the courts'. If this were to become necessary to safeguard everyone's interests, then it is inevitable that these stressful situations would be protracted, with the consequent need for measures to be taken to support all involved.

Uncertainty may have underpinned the recent situation where a patient went to law to ensure that her doctor would legally be able to give her whatever doses of drugs she required to relieve her distress during the terminal phase of her illness (reported in the Guardian 29.10.97,p.3). Montgomery (1997,p.441) in a discussion about mercy-killing, expresses the same uncertainty where non-professionals are involved, feeling that 'the fact that mercy-killing is a criminal offence encourages secrecy' and that it is possible that cases of it 'often do not reach the courts because the authorities decide not to prosecute'.

In English law, the principles are that murder involves an intention to kill or cause serious harm, and manslaughter, other causes of unlawful killing, and Goff (1995) says that,

> "If a doctor deliberately brings life to an end and does so unlawfully, then however extenuating the circumstances, however merciful the motives, he is liable to be charged with the crime of murder".

This was the basis on which Dr.Cox was convicted of attempted murder because he administered a drug with the intention of relieving the patient's suffering by causing her death.

The law 'accepts that doctors may give pain killers in acceptable doses at the end of life to relieve the distress of terminal disease, the legal basis for this being no causation, since causation cannot be proved' and the aim is no longer to extend life but to make the life remaining as comfortable and meaningful as possible (Pace in Pace, McLean,1996,p.64). The crucial difference between the action of Dr.Cox and the latter principle, is the intention to hasten death because 'expert evidence showed that the potassium chloride used had no pain-relieving properties, and it was clear that the dosage given would be fatal' (Montgomery, 1997,p.440).

Another important issue is the duty of care owed to the patient. Health professionals have such a duty of care and 'are at risk of being prosecuted for manslaughter if their patients die after a negligent failure to treat them' (Montgomery, 1997,p.437) however,

> "...the doctor is under no duty to continue treatment once it had proved ineffective, thereby introducing the concept of futility and the distinction between proportionate and disproportionate treatment".
> (Pace in Pace, McLean, 1996,pp.59-60)

Treatments therefore have to be assessed in terms of their proportionality in relation to the patient's condition.

Proportionality, in a rather different sense, was a problem for two respondents in the first phase of this study, who were concerned about the 'excessive' dose of opiates prescribed. The appropriate dose is the one which relieves the pain or distress being experienced by the patient, but the problem involves situations 'where drugs are used at a dosage which will have the result of bringing the patient's death nearer' (Montgomery, 1997,p.439).

When this principle was established in case law (R.v.Adams [1957] CRIM.LR 365, cited by Montgomery, 1997,p.440) the judge's direction was based on the arguments that the doctor's actions would not cause the death, the death resulted from the illness itself, and also that the doctor did not have a criminal intention in prescribing in this way.

The principles established that 'the administration of drugs which hasten death will be lawful providing that three tests are satisfied:

1. *The patient must be terminally ill.* It is unclear how close to death the patient need be, and this is not always known with any certainty, however the patient must already be dying if it is to be argued that the illness, not the drugs, was the cause of death.

2. *Prescribing the drugs must be the 'right and proper treatment'.* This appears to mean that it must be treatment accepted as proper by a responsible body of the profession.

3. *The motivation for prescribing the drugs must be to relieve suffering,* otherwise the shortening of the patient's life would not be incidental to the prescription, but its primary purpose.
   (Montgomery,1997,p.440-1)

The situation in intensive care though is still complicated in this respect and Branthwaite (1996) feels that 'it is far more difficult to rely on the doctrine of double effect to justify the withdrawal of intensive care than to condone or commend the administration of opiates to those suffering otherwise unrelieved pain'. Reference has been made to situations in both phases of this study where nurses have been concerned about the use of opiates.

Cessation of mechanical ventilation would be 'regarded as a letting-die type of omission, because if the doctor has no legal duty to provide care, then such an omission would not be regarded as a cause of death', so under these circumstances, this, too, would be lawful (Pace in Pace, McLean,p.60).

The dilemma for members of the health care team is the element of uncertainty regarding acts which are likely to hasten death, so even under the circumstances where the decision to withdraw treatment is felt to be correct and in the patient's best interests, some nurses still have personal misgivings, despite the legal principles recounted.

The dilemma is potentially greater in ICU's than in many other areas of health care because these decisions involve actively discontinuing life-supporting therapies, including possibly respiratory support, as opposed, perhaps, to taking more passive decisions not to commence treatments or to withhold them in the event that they become necessary. The other comparable, and very difficult, situation which occurs in other areas is that of cessation of administration of food and fluids, where the dilemma is associated with actively stopping a very-basic supportive measure.

An attempt has been made in this study to explore aspects of situations which do cause nurses to feel uncomfortable about the process of treatment-withdrawal. The conclusion from these data is that it is essential for all team members directly associated with individual patients to be involved in the decision-making, so that concerns are expressed and debated. To alleviate some fears about actions, the purposes of treatment changes need to be made explicit. Nurses have to know this in order to support the need for truthfulness which was advocated by all respondents in dealing with the situation in vignette 1. It is also necessary for nurses in particular to understand the ethical basis for the decisions, and the legal principles governing their activities.

Some nurses in phase 1 mentioned the need for education in ethics, although 32 (68%) felt that they had sufficient knowledge to enable them to take part in such discussions, most of these being in the more senior and experienced group. Looking at the data supplied in the second phase, most nurses obtained this education in post-registration, clinical specialist courses, but the reality is that little time could be allocated in the crowded curricula of such courses. In order to achieve the objective, nurses would need, at minimum, theories and principles, but they must also have the opportunity to learn to reason and debate.

Resources

While there were very few direct references to the resource implications of ICU care in the current data, resources do play a major role. Firstly, resources are essential in the provision of intensive care for those who could benefit from it; secondly, in the promotion of humanitarian care for patients and families; and thirdly, in concern for the welfare of staff, particularly in the context of treatment-withdrawal.

In the first phase of the study, three respondents cited bed shortage as a factor which had some influence in the treatment-withdrawal decision, and two cited 'cost of treatment' related to the situations being explored.

In response to being asked about aspects which continued to be upsetting or troubling, a nurse cited the example of a patient whose treatment-withdrawal had been expedited because of an ICU bed shortage, saying,

> "I felt that the family members were not given enough time to come to terms with the situation before treatment was withdrawn".

Support

There are resource implications, too, in the need for support of colleagues when nurses are going through what can be an emotionally-draining experience in caring for patients and families through the withdrawal process. In the first phase, 23 (48.9%) of nurses said that they needed the support of colleagues to cope with the demands made, saying, for example,

> "I felt able to cope and have a lot of experience in this area, ... however I always value the support and help of colleagues,"

and another felt that 'all staff need support in the ICU environment' and that 'sharing experiences and thoughts enhances team cooperation and understanding'.

A comment which does highlight the need for a supportive culture included reference to a requirement for support which was not met at the time, and the nurse went on to say, "Usually it is not until I go home that I realise that I need support and debriefing".

Outcome and the use of scoring systems

The purpose of intensive care, according to Searle (1996) is 'to provide monitoring and organ support for patients with critical illness from which recovery is possible'. The very great difficulty though is determining at an early stage whether or not a patient will benefit from such care, and once intensive care has begun, for how long it should be continued, particularly when doubts about a positive outcome are arising. The relevant issue then is whether there are prognostic indicators available to enable accurate predictions of the likelihood of success or failure. A major consideration is resources, both in terms of the availability of staffed ICU beds and the costs of intensive care, which are inevitably high relative to 'ordinary' care. Because there are finite restrictions, choices have to be made about which patients should be offered intensive care, and rationing then becomes an issue.

Smith et al (1995) also raise the problem of variability of provision across Britain, which leads to greater pressures in areas where the resource is inadequate, with the result that over a two-year period, 'operations (mainly for aortic and oesophageal surgery) were cancelled on at least 205 occasions ... and 58 patients were transferred to other ICU's' because of the lack of beds in the ICU of which he is the director.

Other costs of inappropriate intensive care are also a consideration and Jennett (1984) summarised these as,

1. unnecessary, because the same end could have been achieved by simpler means;
2. unsuccessful, because the condition is beyond influence;
3. unsafe, because the risks of complications outweigh the probable benefits;
4. unkind, because the quality of life afterwards is unacceptable; and
5. unwise, because resources are diverted from more useful activities.

A fundamental problem, then, is determining the likely outcome for an individual patient with and without intensive care.

In the current study, just one nurse mentioned that the predicted outcome from a scoring system influenced the decision, but had the doctors been asked for their evidence to support a withdrawal decision, it is very likely that most would have cited indicators from such scores, in combination with experience. Nurses too need to understand the data underpinning scoring systems so that they have insight into the reasoning based on these data.

The methods available for predicting outcome 'enable patients to be placed in risk groups' (Searle, 1996) and the scoring system utilised and cited by many authors is the APACHE II score (Knaus et al,1985; Palazzo and Patel,1993) and more recently, the APACHE III score (Seneff et al,1997).

The APACHE (acute physiological and chronic health evaluation) score is widely used as a measure of defining illness-severity, because it reflects the extent of deviation from normal using a number of clinical, physiological measurements, including a score ascribed to the level of consciousness. It also encompasses chronological age and indicators of chronic health problems which have a compounding effect on the acute physiological disturbance. Searle (1996) cites studies to support his assertion that there is a clear relationship between the APACHE II score and the risk of death.

Serial measurements of APACHE scores can also be employed to detect trends, and such scoring methods have been used in computerised systems developed to increase accuracy in predictions, but Searle (1996) concludes that the systems are not very sensitive when assessing individuals, although 'they are useful tools for audit within and between ICU's'. Seneff et al (1997) however believe that individual daily prognostic estimates (using APACHE III) are useful as indicators, when used in conjunction with other informative data about the patient, and can be relied upon to prompt appropriate discussions about treatment limitation. These authors also promote the use of APACHE III to improve quality in intensive care, for example, to justify nursing ratios and make more-rational decisions about patient care.

Bion (1993) feels that while these scoring systems 'predict the risk of a particular outcome, they do not predict the outcome for a particular patient and therefore they cannot be used as a substitute for clinical judgement', but even with expert judgements, mistakes are possible, resulting in cases such as the head-injured man whose doctors had told the patient's parents, after three weeks of intensive care, that there was irreversible damage, only for the man to recover subsequently after being transferred to another hospital, because the parents did not accept the prognosis (reported in The Times,11.03.94,p.6).

Two respondents in the current study gave examples of troubling situations which had involved patients for whom treatment-limiting decisions had been made, only for those decisions to be subsequently reversed. In both cases, the patients had survived. Experiences of this type inevitably lead to misgivings and uncertainty among team members.

When the computerised system used by Bihari (Hawkes,1994) was publicised in the media under the heading 'Doctors debate the ethics of a machine which pulls the plug', one criticism was that the 'computer was making the decision' rather than the doctor using clinical judgement. As Bion (1993) says,

> "A predicted risk of death of 50% identifies a critically-ill population but it also tells us that for any patient in that mortality band, the outcome could not be more uncertain".

Seneff (1997) too, comments that when the mortality risk, derived from APACHE score, is 30 - 70%, then this range indicates uncertainty about outcome, and the estimate will 'often be used to justify maximal aggressive intervention'.

Kirton et al (1996) in a study of the significance of APACHE scores of 65 acutely-injured patients, found that scoring

> "...did not meaningfully stratify patients in terms of risk, but rather serves to identify patients who must receive sufficient interventions to achieve a normal cardiovascular function as quickly as possible. If stability was not achieved quickly, continued therapy became futile".

These authors advocate giving maximal treatment to those who respond to interventions, so that these patients are offered the best chance of survival, but also to recognise the non-responders and avoid 'continuing useless interventions that only prolong dying', and they comment that 'continuing futile care is not ethically desirable and is economically imprudent' (Kirton et al,1996).

The influence of outcome predictions on treatment decisions about severely head-injured patients was demonstrated in a study reported by Murray et al (1993) where a computerised prediction system had been devised for this setting, and the results showed that with knowledge of the outcome score, doctors were significantly more likely to offer aggressive, supportive treatment to patients whose chances of survival were better, and withheld this from patients with a predicted poor outcome. The consequences of this approach would be better use of expensive resources and a withholding of futile care, and as the actual outcomes of the group were very similar to another group whose predicted outcome score was not known to the medical team, it would indicate that the system was helpful in making appropriate decisions.

In a survey of 600 respondents (registrants at an annual Society of Critical Care Medicine meeting), the importance of the need to consider the unique aspects of each potential treatment-withdrawal situation as opposed to insensitive scoring methods, was apparent. Sprung et al (1992) comment that 'paternalistic attitudes were also influential' demonstrated in concerns about chances of survival, the reversibility of both acute and chronic disorders. Interestingly, this committee also explored views of the least important aspects in decision-making, and these included 'social worth, previous medical history and financial costs to society'. Sprung et al (1992) conclude that 'critical care practitioners give greater import to their responsibility to their patients than to their responsibility as gatekeepers for society'.

The main question, of course, is whether ICU care benefits patients, and this is very difficult to demonstrate because of the great variation in the nature of illness of the patients. For example, in a report of the outcome for patients in a surgical ICU (Bams, Miranda, 1985) where it could be surmised that more than 60% of the patients were undergoing elective surgery, the in-Unit mortality was 5.4%, whereas in a review by Raffin (1989) of the mortality in ICU's, he quoted an average mortality of 15-25%, and Knaus et al (1985,cited by Raffin,1989) conclude from their work that when the number of organ system failures are reviewed, and the duration of failure, then with three or more organ system failures, mortality is 80% after one day, rising to 100% after five days.

McAllister and Fee (1997) comment that most intensive care research has used in-Unit, severity-adjusted survival as a measure of outcome when auditing activity but 'there is little evidence that what we do improves either survival or morbidity', and yet in a study by

Metcalfe et al (1997), examining the outcome of patients refused admission to intensive care when they had been appropriately referred, found there was 'a higher rate of attributable mortality in patients who were refused', particularly among emergency patients.

Comparisons between Britain and the USA are sometimes difficult because where admission APACHE scores are examined, 62% (Knaus et al,1986, cited by Metcalfe et al,1997) are in the lowest score band (less than 15) in the USA, compared with 24% (Rowan,1992, cited by Metcalfe et al,1997) in Britain, indicating that patients who do receive intensive care here are much sicker in general than those in the USA.

Bams and Miranda (1985) defend the heavy costs associated with intensive care for their patients by citing the low mortality rate and 'high degree of rehabilitation of survivors' so that the 'earnings of the successfully-treated patients balanced the costs involved'. These findings were not supported in a study of quality of life after intensive care by Ridley and Wallace (1990) who found that of the 385 patients discharged from ICU over a two-year period, 129 (34%) had died, and amongst the survivors, 'patients who had previously been fully employed suffered a significant decrease in their employment category'. They also found 'significant decreases in quality of life in younger patients', and that 'trauma patients and patients whose admission APACHE scores had been in the middle or higher bands, were more likely to be disabled subsequently (Ridley, Wallace,1990).

Not only must ICU care be directed at those patients who can benefit from it, but it must be withheld from patients for whom such care is futile, if money and other resources are to be used most cost-effectively, but, as has been discussed above, making decisions about individuals is difficult. One source of error in terms of prognostication, identified by Bion (1993), was the point in the patient's illness at which the APACHE score was estimated, because, if prior to estimation, resuscitative and other support measures had been carried out, and the patient had responded positively to this treatment, then the score would be lower, indicating a less severe illness than the true situation. Palazzo and Patel (1993) recommend that the influence of the location of the patient prior to ICU is included in estimates using the updated APACHE III score.

The likely consequence of denying admission to a person whose estimated risk of mortality was 70% or more, would be the death of the patient. Metcalfe et al (1997) reported that of the ICU referrals studied in a British national project, 80% were appropriately referred, and that 'the numbers of deaths attributable to refusal could be between 2100 and 2500 each year'.

Another issue here is the need for staff, patients and families to have the satisfaction of knowing that attempts have been made to reverse the illness, and there were echoes of this throughout the current data where nurses felt that they and the families could be reconciled to treatment-withdrawal because 'everything had been done and maximal treatment offered'. Equally, nurses were concerned about the inhumanitarian approach of offering treatment where there was no hope of survival, because 'false hopes are raised for the relatives as well as drawing out their anxiety and distress' (Searle,1996).

Interpretation of the data of the risk of mortality associated with the number of organ system failures and the duration of failure (Knaus et al,1985, cited by Raffin,1989) leads to the conclusion that a mortality risk of 68% or more is not reached until there have been two or more organ system failures for seven days, although once there are three organs failing, the mortality risk is more than 93% after two days. The implication of these data is that where doubts about outcome exist, treatment should be commenced, and with the type of support involved, this will necessitate an ICU referral. Of course, the nature of the acute illness and chronic health problems, together with the age of the patient, are all relevant to the decision-making.

Futility

The approach clinically then, is, depending on the availability of the ICU resource, to offer support where it is considered of benefit to do so, but then to withhold treatment subsequently if, following maximal attempts, the patient fails to respond, and further treatment is deemed futile.

In a recent paper, Luce (1997) reviews the incidence of treatment-withdrawal decisions in two North American ICU's and reports a substantial increase from 51% of the deaths in 1987/8 to 90% of the deaths in 1992/3 having been preceded by a treatment-limiting decisions. Further examination of these results indicated that 'in 56% of cases where futility was cited, physicians judged that patients had no chance of leaving the ICU' but of the remainder, the concept of futility was applied 'despite an estimate of ICU survival of between 1% and 50%', and Luce (1997) explores this in reviewing other recent studies which demonstrate a great deal of variability from Unit to Unit in the likelihood of treatment-withdrawal decisions being taken, which he attributes partly to differences in illness-severity, but mostly to 'differences in the beliefs and behaviour of physicians'.

Because 'it is assumed that futile treatment consumes significant health care resources', Halevy et al (1996) reported a study in an ICU of the number of patient-bed-days used by patients meeting definitions of medical futility'. Futility was categorised as *imminent demise* (APACHE score giving risk greater than 90%); *lethal condition* (eg.metastatic cancer, severe heart failure); or *qualitative* (conditions resulting in unacceptable quality of life, such as a prior vegetative state, or severe neurologic impairment secondary to an anoxic episode) and the study was carried out in a 16-bed medical ICU over a 6-week period, involving 129 patients and a total of 614 patient-bed-days. Results showed that 2 bed-days (0.3%) were used by patients with >90% predicted mortality; 22 (3.6%) were used by patients with a poor prognosis secondary to hypoxic, ischaemic coma; and 101 (16.4%) by patients in the 'lethal conditions' category, and Halevy et al (1996) conclude from these data that 'there are not many patients receiving futile and expensive care', so the potential for saving resources would be limited. These authors feel that treatment-limiting decisions should not be made 'under the guise of futility', if, in reality, decisions are being influenced by pressure to introduce a 'formal rationing process'.

Policies

The need to ration ICU services has resulted in recommendations being made about restricting 'marginally-beneficial care' but that 'decisions to limit care should be made only by explicit institutional policies that reflect a social consensus in support of such limitations' and that 'patients and the public should be informed of financial incentives for limiting care by physicians or health-care institutions' (American Thoracic Society Bioethics Task Force, 1997).

In expressing concerns about decision-making in this area being determined by physicians' 'personal notions of futility', Luce (1997) advocates the use of multi-institutional policies, and comments,

> "Although their input is desirable, administrators, even if they are physicians, should not be allowed to impose futility policies that serve primarily to protect their businesses' bottom lines".

It has become increasingly evident from the North American literature in the past two years that, driven primarily by resource-limitations and health-insurance costs, policies are being developed to guide health care teams in decision-making about treatment-withholding.

The Society of Critical Care Medicine's Ethical Committee (1997) issued a consensus statement with the objectives:

1. to provide a definition of futility that will enable a clearer discussion of the issues;
2. to identify principles that are useful in the ethical analysis of cases in which treatment may be considered futile or inappropriate; and
3. to identify processes and procedures that may help in the resolution of cases in which life-sustaining treatment may be futile or inadvisable;

and the need for this statement had arisen because of increasing pressure on resources and some insurers 'prospectively denying coverage for certain controversial and expensive treatments that they label futile without critical examination of what the term means'.
The committee found it necessary to classify treatment into four areas:

1. treatments that have no beneficial physiological effect;
2. treatments that are extremely unlikely to be beneficial;
3. treatments that have beneficial effect but are extremely costly; and
4. treatments that are of uncertain or controversial benefit,

then defined (1) as futile and the remainder as 'inappropriate and hence inadvisable, but not futile' (Society of Critical Care Medicine, 1997).

The values of all involved in decision-making are of crucial importance and may be the cause of conflicts between families and team members, particularly when policies about treatment-limitation are in place which do not allow any variation for specific individual features, beliefs or desires, and the committee advised the establishment of appeal mechanisms, with the courts being used as the ultimate arbiters.

There was evidence in the current study of dispute and conflict between different teams of doctors over whether treatment withdrawal was appropriate; between nurses and doctors over commencement of treatment or its continuation when no reason for this was apparent; between nurses and doctors when treatment withdrawal seemed premature and questionable; and between families and doctors where there was disagreement over the course of action to be taken.

The findings of a study by Asch et al (1995) give some indication of the extent of differences of opinion between intensive care patients, their families and the doctors, showing that, for example, 294 (34%) of physicians had declined requests from the patient or surrogate to withdraw mechanical ventilation in the previous year. Reasons given by doctors included that they believed that the patient had a reasonable chance of recovery; the family might not be acting in the best interests of the (incompetent) patient; concern over illegality or malpractice litigation; family opposition to the (competent) patient's wishes; and that the doctor felt that this mode of withdrawal was unethical in general or that this was counter to the usual practice. The opposite situation also occurred in which 726 (83%) of doctors had reported withholding treatment on grounds of futility 'without the written or oral consent of the patient or family (25%), without the knowledge of the patient or family (14%), and despite the objections of the patient and family (3%), and these authors felt that their findings suggested the need for guidelines in these matters, and greater use of resources such as ethics committees or bioethicists for resolution of dilemmas (Asch et al,1995).

Luce (1995) concludes from a review of the literature that the 'refusal of physicians to provide futile or unreasonable care is supported by ethical principles, and particularly by the need for distributive justice in 'the current climate of health care reform' which involves access to basic health care for all and reduction in costs overall, and thus rationing. Demands that doctors demonstrate benefit in treatments offered may threaten the care of critical care patients because their care may be 'expensive and of unproven long-term benefit' (Luce,1995) and he advocates the development of consensus policies on decision-making and perhaps the use of a concept of 'reasonableness' rather than futility, with its connotations of a purely-physiological definition, as the basis for guidelines.

The point of view of Civetta (1996) is that 'society should use distributive justice to define access to health care, but that once begun, treatment should be continued while there is a reasonable expectation of success', although this is based on a belief that patients and families have reasonable expectations about what treatments are offered. The difficulty is that faced with critical illness, patients and families differ in their views about what is reasonable. They may value a life which others would consider to be of poor quality, and they may be in 'denial', that is, are unable to accept the diagnosis and prognosis given. Civetta (1996) offers an enlightened and practical approach to situations where there is conflict about continuation of care, and cites examples of family members who have presented unreasonable opposition to treatment-withdrawal, with the likely explanations for their views.

Increasing concerns about cases where either families (surrogate decision-makers) are requesting discontinuation of medical overtreatment or where families are requesting aggressive treatments which the attending doctors 'believed were inappropriate or futile' resulted in the creation of a multi-institution futility policy in the Houston area, reported by Halevy (1996).
This policy,

> "...affirms both the traditional goals of medicine and the moral value of physician and institutional integrity in discerning the limits of medical interventions. Respect for this integrity provides the basis for the right to refuse to provide medically-inappropriate intervention. It complements the right of patient determination that must be given both voice and effect in any forum for medical decision-making. This appeal to integrity is generally rooted in a combination of concerns such as avoiding harm to patients, avoiding provision of unseemly care, and just allocation and good stewardship of medical resources".
> (Halevy,1996)

It is followed by the procedures to be carried out in the event of dispute, which include involvement of nurses, the chaplaincy, ethics committees and patient representatives in discussions, and also the option of transfer of the patient's care to another doctor for terminal care, if, for example, the patient's own doctor believed that treatment should be continued in opposition to the consensus decision taken. This would obviate the situation where a doctor was obliged to withhold treatment but was opposed to it on moral grounds (Halevy,1996).

Policy developments would avoid doctors having to rely on their own definitions of futility and may enable a more-equitable approach to decision-making following utilitarian principles. The important implications of such policies are that the patient's interests may be better-protected but that the care of critically-ill patients may be unduly protracted by the need to follow time-consuming procedures.

Nurses will continue to be involved in these difficult situations, providing the support which they have traditionally given, but they may find themselves increasingly having to mediate in disputes and resist others' attempts to undermine the primacy of concern for the best interests of patients.

Justice

Justice and the allocation of resources is then an issue, and there have been some high-profile cases reported in the media, for example, the case of child B (Duce,1995) whose father brought court action to try to obtain treatment for his daughter when the health authority said that it could not justify the cost of treatment when the girl had only a 2.5% chance of survival. Sir Thomas Bingham, in the Court of Appeal, was reported to have said,

> "In a perfect world, treatment would be provided ... but difficult and agonising judgements have to be made as to how limited budgets can best be allocated to the maximum advantage of the maximum number of patients" (Duce,1995).

In response to this case, Hopkins (1995) wrote that there is 'an absence of a defined system with accountability, for allocating resources for the care of individual patients', and said that clinicians may need to press for resources from managers of NHS Trusts, to enable the support necessary, then continued,

> "Patients and their doctors are partners in care in a relationship based on trust, a trust which takes into account the proven effectiveness of treatment and the costs to society of an individual's treatment in terms of other opportunities lost".

In another letter in response to the child B case, Paxton (1995) wrote that because her regional centre for paediatric oncology had 'the vision and courage' to try some treatment for her baby whose prognosis had been deemed hopeless by another hospital, she now had a son who was 'a healthy teenager, growing normally, doing well at school'.

The elderly in ICU

In this study, the majority of patients about whom treatment-withdrawal decisions were being made, were elderly, and due to the demographic changes in the population, it is inevitable that there will be increasing numbers of older people needing treatment in acute-care settings.

Rationing on the basis of age was the topic of an article reported in the media by Rogers and Driscoll (1994) in which they said that decisions about limiting the care offered to older people 'until recently rested solely on the doctor's clinical judgement' but now, finance plays a major role. It was reported that 'the simplest way round the problem is to class everyone over sixty-five as geriatric, ... then keep them ticking over as cheaply as possible ... so that arbitrary age restrictions bar access to high-technology treatment' (Rogers,Driscoll,1994). These authors explain that in 1901, less than 5% of the population reached the age of 65; currently, 16% do; and it is projected that by the middle of the twenty-first century, 25% will, and these pressures are already felt throughout the health-care services. In an ICU context, age is considered a relevant factor when estimating illness-severity, and Raffin (1989) concludes from a review of a number of papers, that 'advanced chronological age increased the probability of developing organ system failure and also the probability of death once the organ failure had occurred'.

In two studies, however, (Rockwood et al,1993; Chelluri et al,1992) examining the outcome of elderly patients who needed intensive care, the conclusion from one was that 'age does not have an important impact on outcome from critical illness, which is most strongly predicted by severity of illness, length of stay, prior ICU admission and respiratory failure' (Rockwood et al,1993) and from the other, that 'age alone may be an inappropriate criterion for allocation of ICU resources' (Chelluri et al,1992).

If the objective of age-related rationing is to enhance health care available to younger people, Pabst Battin (1994,p.63) raises the problem that because older people typically 'have more complex medical disorders, compounded by a decline in function of many organs and by reduced capacity for healing', more treatment has to be invested in the elderly to achieve comparable benefits.

In terms of cost-effectiveness then, greater benefits are likely to accrue from using the most expensive diagnostic and treatment modalities for younger people. The corollary of this approach though is that the quality of life for elderly people will decline, because as Pabst Battin (1994,p.65) says, there is a 'substantial difference in the character of life for a person who remains ambulatory as a result of a hip replacement, pacemaker or coronary artery by-pass surgery' and people who do not receive appropriate treatment do not die, but instead 'suffer their illness and disabilities without adequate aid' and may not receive the best palliative care. Nolan (1993) describes some of the deficits now in the provision of care for increasingly-elderly, frail people, so it would seem to be a false economy to deny patients the treatment which enables them to remain self-caring in the community, apart from the humanitarian concerns about the alternative of low-standard residential care in which the quality of life for residents is poor. Demographic changes in the population will dictate that expenditure must increase in order to provide residential and respite care for elderly people, and Nolan (1993) discusses this issue and describes a model which promotes high-quality care and enhances satisfaction for both patients and carers.

Regarding the elderly in ICU, Raffin (1989), having examined evidence from a number of studies, feels that because elderly people have an increased mortality with systemic illness, and a significant number have a decreased quality of life after intensive care, biologic age (chronologic age plus consideration of chronic health problems) should be taken into account when making these difficult decisions.

Quality of life

Quality of life was an important issue to nurses in this study. In the first phase, 75% of respondents cited 'anticipated poor quality of life if patient survives' as a factor influencing the withdrawal decision, and many nurses made reference to it when giving their reasons for supporting the decision, such as the nurses who felt that prior to admission to hospital, the patient's life had not been of good quality, usually secondary to chronic health problems in an elderly person. It was also mentioned when even though previously the patient 'had an excellent quality of life', it was obvious that there would be such a radical change in the person's lifestyle that this would be unacceptable to the patient. With babies it was also an issue, and SCBU nurses gave evidence of brain and lung injury and other irreversible problems which would lead to a life of very poor quality, to support their decisions.

Given the importance attached to the issue, it was followed up in phase 2, in vignettes 3, 4 and 5.

The projected outcome for the patient in vignette 5 required a judgement to be made by nurses about this patient's quality of life. Nurses felt that in decision-making, the family members would be the best judges of the patient's views, and in the vignette, it was said that the family did not support a decision to try further surgery, as the resulting change in the way of life would be unacceptable to her. Nurses, in considering this situation, felt strongly that they should advocate for the patient and family and have a major liaising role under these circumstances, and in the course of the discussions, which 82% of respondents wanted, they would 'get the patient's quality of life seen as an issue' as one nurse said.

Use of resources

The question of rationing and the appropriate use of resources when there is a moral issue about an 'undeserving patient who is the author of his own misfortune ... because he is obese, or a heavy smoker or drinker' (Newdick,1995,p.288) arose in the first phase of the study when a respondent expressed concern with a withdrawal decision which involved an alcoholic. The patient had alcoholic liver disease, and the nurse disagreed with the decision taken because the doctors seemed to have been strongly influenced by the views of a relative in making a judgement about the patient's future quality of life. The nurse felt that the patient should have been 'given a chance'. This scenario was explored in vignette 3 of the later study, and 15 (45.5%) of the respondents disagreed or strongly disagreed, 11 (33.3%) were unsure, and 7 (21.2%) agreed or strongly agreed with the withholding decision described, demonstrating the strength of feeling of this group of nurses. When reflecting on what the worst aspects would be, nurses were concerned about their lack of power in acting as the advocate for the patient in influencing the decision. They were anxious about following the instructions arising from the withholding decision, such as 'letting him die without a chance of surgery', and had misgivings about whether the doctors' decision had been in the best interests of the patient, perhaps because of the moral judgement being made about the patient's alcoholism.

The problem, discussed by Newdick (1995,p.289) is that it is very difficult to isolate the clinical grounds (which are the basis on which these decisions should be made) from the judgemental or social. The principle of justice is relevant, and, to further penalise people by depriving them of treatment, when their socioeconomic circumstances, for example, have led to the problem, seems unfair, but equally, faced with a resource crisis, decisions in the best interests of all patients do have to be made about the benefits to be obtained from treatment. Choices have to be made throughout the health care system about who should receive treatment, and about the nature of that treatment.

Ridley et al (1993) conclude from the findings in their detailed cost-benefit analysis of intensive treatment that this type of review does enable comparisons to be made between patients, giving the example,

> "... treating one extra patient with sepsis (57% ICU mortality and a cost per one year survivor of £11,000) may deny treatment of 3 or 4 patients admitted for respiratory observation and monitoring (ICU mortality 16% and cost per one year survivor of £3,000)".

Newdick (1995,p.274) suggests that in attempt to improve the NHS and promote greater effectiveness, it may be necessary to introduce measures to regulate decision-making, but the effects of this will be to diminish important aspects of care such as 'clinical priority, candour between doctor and patient, and choice'.

In attempting to define the notion of justice, Kennedy (1988,p.291) talks about community values, and how being a member of a community carries 'obligations and duties to others' and goes on to state that justice

> "is that which tells us that we ought to seek a society in which each person is accepted as of equal moral worth and has equal opportunity to enjoy an equal share of the total sum of society's goods".

Kennedy (1988,p.291) draws attention to the result of this approach which would involve 'caring for the weak and most vulnerable first ... which may have important implications for the allocation of scarce resources'.

In ICU's, the resource theme is pertinent in three main areas. Firstly, the availability of beds when a request for admission is made. Secondly, in determining the course of treatment offered, for example, prescribing practices are likely to be influenced by the costs of drugs. Thirdly, there is pressure to ensure the cost-effectiveness of treatment, which could then become an influence in the determination of futility of treatment, about which there may be uncertainty.

The high costs associated with intensive care are recognised universally, and titles of papers on the subject, such as 'Outcomes and costs' (Bams,Miranda,1985), 'Futile care:confronting the high costs of dying' (Coppa,1996), 'CPR: what cost to cheat death?' (Lee et al,1996), 'The economics of intensive care' (Shiell,Griffiths,1991), and 'A cost-benefit analysis of intensive therapy' (Ridley et al,1993) reflect the nature of some of the concerns.

Intensive care is an expensive commodity, but Rennie (1996a) quoted an estimated shortfall in Britain of about 700 beds, and surveys have demonstrated that 'too many Units have too high a level of bed occupancy' (Rennie,1995) which results in denial of admissions, and interhospital transfers of patients to obtain an ICU bed over distances of up to the 130Km quoted by Smith et al (1995). Rennie (1995), in supporting the need for a 33% increase in ICU and High-dependency (HDU) beds, says that one in four of requests for admission are refused.

It is difficult to envisage any foreseeable change in the number of requests for ICU admission, so these pressures are likely to continue. Marsh et al (1994) indeed suggest that 'recent changes in the community care of schizophrenic patients may have produced an increased requirement for intensive care after deliberate self-harm' and go on to cite an increase of such admissions from (9) patients in 1990 to (51) in the first 11 months of 1993, an increase of 566% over three years.

In a recent letter, Smith, a psychiatrist, (1998) says that 'there have been too many homicides and suicides' since the changes in policy towards people with severe mental illness, and questions whether 'the idea is fundamentally flawed' or whether it has failed 'because it was implemented badly and underfunded'. He goes on to state that the funding of mental health services has fallen from 15% to 12% of the overall health budget, and concludes that the changes 'were undertaken by managers whose primary goal was saving money' (Smith,1998). Pritchard (1995,p.170) questions the patient-centredness of the new managers in the health service, who have yet to provide the proof of their fidelity, and comments that

> "...unlike medicine, social work and nursing, whose rationale is the primacy of the

> patient above everything else,... 'management' gives us little confidence that it will defend the defenceless, or take risks on behalf of an individual patient, as doctors, nurses and social workers do when they make palliative care decisions which ensure a 'good death'".

Costs of intensive care

The issue of costs of intensive care will now be explored.

Bams and Miranda (1985) reported from their study of a surgical ICU in the Netherlands, that '52% of the total hospital costs for patients were spent on their ICU care, although the time spent in ICU accounted for only 17.5% of their total admission time'. In this study, the mortality rate quoted was 5.4% in ICU, which is very much lower than the 15-25% (Raffin,1989) quoted for general ICU's, in which 80% or more of the patients are emergency admissions.

Costs of intensive care are particularly relevant when the difference between survivors and non-survivors are examined. Ridley et al (1993) carried out a detailed study of the ICU costs of ninety patients in 1989 and found a mean daily cost for survivors of £550.00 (range £262 - £1017) whereas for non-survivors, (there was a 23% mortality rate) it was £816.00 (£349-£1238) and this disparity has been demonstrated in other studies in Britain and the USA. Ridley et al (1993) cite Detsky et al (1981) who say that patients with a chance of survival of less than 50% incurred costs which were twice as high as those with a risk of mortality of less than 50%.

In a study of patterns of resource consumption in a medical ICU (Oye,Bellamy,1991), the 8% high-cost patients used as many ICU resources as the low-cost 92% remainder, and 'over 70% of the high-cost patients died'.

Ridley et al (1993) note that while there were wide variations in the daily costs in their study, conditions such as septic shock and metabolic disorders (usually renal failure) which carried the highest ICU mortality, also had the highest daily costs, and non-survivors continued to incur higher costs throughout their stay, whereas for survivors, costs declined. From this evidence, Ridley et al (1993) conclude that widespread use of scoring systems which enable 'early identification of eventual non-survivors, may contribute to better use of resources'.

The costs of intensive care are four- to five- times higher than general ward care, and Searle (1996) questions whether this is just use of resources. Shiell and Griffiths (1991) conclude from their review of the economics of intensive care that 'intensive care medicine reduces morbidity and mortality for some conditions (but) for others, the benefits are less certain'. The problem, as discussed earlier, is that denial of admission will lead to some avoidable deaths. Another problem is that 'for patients on the borderline, only a trial of intensive care will determine whether or not they may benefit from intensive treatment' (McTurk in Pace,McLean,1996,p.174). Many nurses made reference in phase 1 to the fact that everything had been tried, 'maximal treatment had been given' without any response, in giving support for the withdrawal decision, and it was apparent that this was a factor in nurses' acceptance that withdrawal was appropriate.

The question then is whether instead of the different areas, such as intensive care and mental health competing for resources, there should be a greater proportion of money to support the health service in attempt to reduce the pressures, and potential injustices, in allocation.

In a review of the percentage of gross domestic product (GDP) spent on health, Pritchard et al (1997) compared British expenditure with other Western world countries over the period 1980 to 1993, and quoted, for example, 5.8% in 1980 and 7.1% in 1993 for Britain against 9.3% and 14.1% for the USA in the same years. Even with these relatively small increases in Britain, Pritchard (1997) cites evidence for greatly-increased efficiency in terms of bed-availability and episodes of care, but states that 'the majority of other countries also needed to increase expenditure even more than the UK in order to meet the needs of a modern health service'.

With the demographic changes in the population, the expectations of the public, the great advances in the development of techniques and treatments, and the desire to offer patients therapy which will benefit them, it is inevitable that pressures on resource allocation will continue, if there is no increase in provision.

In attempt to address the problem of differing values amongst health care team members, Cook et al (1995) feel that

> "...in this era of increasingly constrained resources, the ultimate goal must be to develop guidelines for use of scarce resources that reflect the values of society, and that, when implemented, will minimize the impact of individual idiosyncratic values of health care workers on life and death decisions"

and one respondent in the current study expressed exactly this concern in saying that some people are against treatment withdrawal in principle and would therefore not support it under any circumstances, leading to unduly prolonged treatment in hopeless situations.

The approach advocated by Cook et al (1995) does not, however, give recognition to the responsibility which doctors have, to administer treatment which is determined by the best interests of their individual patients. The term 'best interests' was used by respondents in their support of decisions taken, and in vignette 1, 27 (82%) of nurses gave this as one of their reasons for discontinuing inotropes in the treatment of this hopelessly-ill patient.

Considerations of treatment withdrawal can only be made in relation to each patient's unique set of circumstances, but Cook et al (1995) made their recommendations because they felt that doctors' own 'ethical, social, moral and religious values influence their decision-making' and perhaps they would appreciate the support and endorsement obtained from consensus views on these issues.

McTurk (in Pace,McLean,1996,p.172) suggest that to have consistency and attain a 'rational and fair allocation of resources, where difficult choices have to be made, a hierarchical model should be used, considering firstly, medical indications, then patient autonomy, patient's best interests, and lastly, external factors such as relatives' wishes and resource-allocation issues. A difficulty with this hierarchical approach is the paternalism involved. Savulescu (1995) argues for 'non-interventional paternalism' in which there is a broad and detailed discussion of the issues, so that a decision is arrived-at 'all things considered', and although the doctor will have given an opinion about what appears to be best, the patient has the option of accepting or rejecting this viewpoint. This approach, while reasonable, is rarely applicable to treatment-withdrawal situations, because patients are unable to participate, and so it is left to families and friends to express their own views and those of the patient, as far as they are able. Decisions, largely, have to be made therefore by doctors and accusations may be made by other team members about the inherent paternalism, unless the approach advocated by

Savulescu (1995) in which doctors consider issues wider than just the purely- medical, is adopted.

There are important resource implications in this context for the provision of both medical and nursing staff, the former so that they have the opportunity to weigh up the facts, consult colleagues appropriately, and spend time discussing matters with families, seeking their views and helping them to understand all aspects of situations, and the latter, so that there are sufficient numbers of skilled and experienced nurses to deal in an exemplary manner with patients and families. Adequate resources would enable unhurried decisions to be reached, without the pressures created by bed- and staff-shortages, and would allow everyone involved to feel satisfied that the correct decision had been made. With adequate staffing levels, too, the supportive environment which respondents wanted, would be feasible. Unfortunately, in these constrained times, the response to a request for more resources may well echo that portrayed in evidence given by an ICU charge nurse in para.3.10 of the Bullock Report (1997),

> "G.R. had prepared a business case under which he would have received more staff which may have removed the need for him to work regularly on the clinical rota and given him freedom to address internal difficulties within the Unit. He was, however, told that this was not regarded as priority, and that executive weight and support had been given to Mental Health in preference to ICU".

Conclusion

Fear no more the heat of the sun,
Nor the furious winter's rages;
Thou thy worldly task hast done,
Home art gone, and ta'en thy wages;
Golden lads and girls all must
As chimney-sweepers, come to dust.

Fear no more the frown o' the great,
Thou art past the tyrant's stroke,;
Care no more to clothe and eat;
To thee the reed is as the oak;
The sceptre, learning, physic, must
All follow this, and come to dust.

Fear no more the lightning flash,
Nor the all-dreaded thunder stone;
Fear not slander, censure rash;
Thou hast finish'd joy and moan;
All lovers young, all lovers must
Consign to thee, and come to dust.

No exorcizer harm thee!
Nor no witchcraft charm thee!
Ghost unlaid forbear thee!
Nothing ill come near thee!
Quiet consummation have;
And renowned be thy grave!

William Shakespeare
from Cymbeline, Act 4, scene 2

If you are a family member sitting at the bedside of a patient dying in an ICU, these may express some of your thoughts as you reflect on recent events.

It is very likely that a decision has been taken to allow your relative to die now, rather than continue the struggle against the overwhelming problems associated with complications from surgery, injury, infection or metastatic disease. You may have the companionship of other relatives, and you can then sit together and support one another.

You will have a number of visitors. Doctors will come and go, and the most senior one will stop and spend time with you, explaining, answering questions where there are answers to be given. The hospital chaplain may come if you wish and sit and reflect with you for a time.

Your most constant companions, whom you may have come to know quite well over some days or weeks, will be the nurses assigned to care for your relative.

What you want, above all, is to know that you can trust the caring team to make the right decisions at the right time. You want to be able to think back at some point in the future and say that you were satisfied with the care you and your relative received; that appropriate respect was given and dignity preserved; that the manner in which staff worked conveyed caring and sensitivity, as well as technical expertise; and that when you or your relative needed help, someone was there to give it.

The focus for nurses throughout the study was on the care and welfare of patients and families around the time that a treatment-withdrawal decision was being considered and implemented. When nurses identified the best and worst aspects of situations, they frequently said that the worst thing was some inadequacy in the care of the family but this was balanced by a beneficial aspect for the family, such as the patient dying without pain, comfortably and peacefully, with the family present.

Nurses have a great desire to be kind to families, to reduce the hurt and sadness associated with these situations, to enable the patient and family to be comfortable, and to get the timing and circumstances of treatment-withdrawal and the death of the patient, as gentle and tolerable as possible. Nurses dislike seeing families rushed and not having enough time to come to terms with what is happening. There is a need for recognition from other team members that nurses are very close to the people involved in these situations and are likely to be closely in touch with how the family members are feeling, what they want, and whether something could be done to enable them to cope better.

One of the problems is that nurses need to be able to say to the families that everything has been done for the patient, all options considered and tried, and that the patient has received maximum treatment but has failed to respond. This is, however, difficult, if the nurse has some doubts about an aspect of the patient's treatment, perhaps earlier in the patient's stay in hospital.

A number of nurses in the study mentioned the difficulty of not being able to predict during the withdrawal process, when the patient might die. Being with the patient when he or she dies is very important to many family members, and nurses want to try to guide families in judging when to leave to eat or rest, but there is always uncertainty.

Not only do nurses want to get the timing right, they also want to create a pleasant environment for families, so that there are at least some happier memories, and this can be difficult to achieve when patients are still connected to the technology which has been used in attempt to get them better. Nurses also mentioned that despite all the technology, it still was not possible to help the patient, and expressed sadness because of this.

A problem mentioned by some nurses was where families were not able to grasp the facts about the situation and could not understand therefore why nothing more could be done to help. If family members cannot understand the concept of brain death or the facts about another irreversible medical condition, they cannot possibly accept that treatment withdrawal is an appropriate action. Not only are these situations very sad and difficult to cope with, the nurses have qualms about family members giving consent to donate organs, for example, under these circumstances.

There was a need expressed by a number of nurses to finish situations properly, to see a situation through to the end, to care for the patient and family through the withdrawal process and the death.

Emotional impact

The emotional impact on nurses was apparent through this study. Nurses carry the continuing responsibility for the care of the patient and family, so although the doctor is likely to have been involved in giving information with the nurse to the family, subsequently the nurse is left to manage the situation through the withdrawal process. This is an emotional drain on the nurse who is probably reducing the patient's treatment, dealing with a dying patient and caring for a family which is being bereaved. Although some nurses in the study said that where they knew the patient and family well, they were able to offer them better support through this process, it was also harder for nurses to withdraw treatment from patients they had got to know over a period of time.

There were particular problems also for nurses when they identified with some aspect of the situation, such as where the nurse knew the family socially, or where the patient was the same age as the nurse, or where the nurse had been recently bereaved.

Junior nurses

Junior nurses who were dealing with these situations for the first time had heightened sensitivity to feelings of inadequacy when dealing with these patients and their families. They were conscious of the need and desire to get everything right, but were uncertain of how this could be achieved. Even with the support of colleagues, junior nurses found the process very stressful and upsetting.

Teamwork

Throughout the study, the need for team support was mentioned by nurses, whether junior or senior. Colleagues were valued, and even if they were not actually needed, nurses said that they knew there was help and support available if necessary.

Conflict and dispute

There was some conflict and dispute mentioned by nurses. Sometimes there was disagreement between the consultants involved over the treatment of the patient. In other situations, there were differences of opinion amongst the nurses over decisions, where some had reservations and others had none. Communication was poor between doctors and nurses on occasions, and this led to unresolved problems and unhappy memories. Both groups needed to acknowledge the difficulties which arose, and debate would have enhanced understanding.

There is a great need for nurses to be able to trust the doctors involved in these situations to make appropriate decisions. Where there are doubts and disputes, or perhaps, as in one situation, a change of plan when the medical team changed, nurses expressed qualms about this. Doctors are the ultimate arbiters in many aspects of the care of the ICU patient, and nurses do need to feel that they can trust the judgements made about treatment, and be satisfied with the process in order to convey that certainty to families.

There were reservations expressed by some nurses over the treatment plan for patients, where the nurse had dissenting views about the withdrawal decision but these views were not taken into account. Another area of difficulty was where nurses felt that treatment was too aggressive or being unduly prolonged for some patients, but that these views were not being considered.

One nurse had particular concerns about a situation in which she felt that the line between 'aiding a patient to a peaceful and dignified death' and euthanasia, was breached, because she felt that her actions contributed directly to causing the death of the patient. When this aspect was pursued in the second phase in two different patient contexts, many nurses shared these anxieties.

Some activities undertaken during treatment withdrawal caused disquiet, even though the actual decision had been supported by nurses, so in situations where decisions were disputed, the concerns were greater.

There is a need for all members of the multidisciplinary team to acknowledge the roles played by nurses in these situations, and to respond to the issues highlighted in this study.

Debate

It was very important to nurses that they did have a voice in the decision-making process and were given the opportunity to talk about their views and feelings, as well as debate the ethical issues. Where there had been consultations, and all team members had been involved in the discussions, nurses expressed satisfaction with this. A need was also expressed for nurses to be involved in the initial debate over whether treatment was appropriate for some patients, because nurses had doubts over whether patients should be put through the aggressive treatment process and all this involves, if there is little or no hope that the patient will benefit, because it raises false hope in families.

Quite senior and experienced nurses had doubts over their knowledge of ethics, and some nurses mentioned the need for education in ethical decision-making to prepare them better for the roles they had to fulfil.

In summary then, it is inevitable that dilemmas will occur in this setting, but the manner in which these problems are resolved is the determining factor in how nurses will feel about the situations.

Hewa and Hetherington (1990) in their discussion of the difficulties associated with providing humanitarian care in highly-technical environments, talk of,

> "...the medical profession and health care administrators attempting to expand the utilisation of technological devices in medicine,"

which leads to nurses,

> "...not able to respond to the suffering or the needs of the patients, rather they are forced to respond to the needs of physicians and the mechanical systems in which they have become enmeshed".

The contrast between the above views and the reality depicted in the following comment from a SCBU nurse, could not be more marked.

> "I feel it is very important that we involve the whole family and give them time to adjust to what will happen. Some may find it hard to speak and we need to give them space and understanding. Some (most) nurses may find it very emotionally tiring and we need to give support and opportunity to debrief afterwards. I think that we need to give a dignified, peaceful end to the patient which takes the parents' wishes fully into account. The parents should be made to feel that the decision to withdraw is theirs, but that we, the professionals, have our experience and knowledge with which to guide and support them".

Recommendations

Because of the importance of advocacy and intervention on behalf of people in their care, nurses should be included in discussions, and their roles in mediating in these situations, in giving support to those involved, in providing insights about the patient and family, and in the discontinuation of treatment, should be recognised by the doctor(s) with whom the decision to withdraw ultimately rests.

Because of the importance to nurses of the autonomy of the patient in making decisions about their treatment, the promotion of discussions taking place at an early stage of a patient's illness about any limits they would place on treatment, should be encouraged.

Because even some quite experienced nurses lacked confidence in their knowledge of ethics, nurses must feel equipped to participate in such discussions and to give explanations and support to families during the whole process. This necessitates a higher profile being given to education in ethical debate, both from a theoretical perspective and from a practical, experiential one, as this will involve developing debating, as well as counselling, skills.

Because inexperienced, junior nurses feel particularly vulnerable and distressed about these situations, they must have education, guidance and support in areas such as ICU's during their orientation to departments, and subsequently.

Because of the frequency with which these situations are met in ICU's, the issue of treatment-withdrawal should be discussed with applicants for junior nursing posts in these departments.

Because all staff need support when making these decisions and in managing the events which follow, the culture and philosophy of the department must reflect the value placed by nurses and others of collegial decision-making and teamwork.

Because nurses are concerned about the proximity of their actions during treatment withdrawal to the death of the patient, and because of the nature of these decisions and the consequences of them, nurses and others in the multidisciplinary team must be aware of the legal implications of their acts and omissions.

Because there is a need to avoid the moral dissonance and distress, the repugnance, the regrets and resentments engendered in nurses and others by poorly-managed situations involving dying patients, it is important that all staff feel able to speak freely about issues which concern them, and any expression of a conscientious objection to a task or decision should be respected.

Because there is a need to facilitate ethical debate within the multidisciplinary team, where there are contentious issues and unresolved problems, the use of decision-making grids or frameworks should be promoted, and all potential users should have the opportunity to learn to use the selected instrument effectively.

Because there are problematic, contentious issues arising in some of these situations, anyone involved should be able to request the involvement of another person, possibly a clinical ethicist, acceptable to all multidisciplinary team members, who is seen as unbiased, and who can act as facilitator and mediator, where necessary.

Because of the context, in terms of pressure on resources, in which these decisions are being made, it is imperative that clinicians are able to make reasoned, unhurried evaluations and judgements in weighing-up the clinical aspects of situations, taking account of the wider social, psychological and quality-of-life issues.

Because of the importance of past, present and future quality-of-life for the patients, consideration should be given to the use of a formal assessment instrument, and the need to make any value judgements and assumptions explicit, so that they can be challenged by others, if necessary.

Because of the importance to nurses of being able to achieve dignity, peace and comfort for their dying patients, it is essential that staffing levels, the skills and experience of doctors and nurses, and the ICU environment, are all conducive to this.

Because of the endorsement given by the small group of SCBU nurses in this study, to the manner in which decisions were made and followed-through, further exploration should be carried out into the model adopted by SCBU's, so that the strengths can be identified and applied more widely.

Because of the distressing and difficult aspects of these situations, the nursing leadership and team structure should foster and promote the supportive and sensitive approach which is necessary to enable nurses to cope well, even when there are repeated experiences of this kind.

Appendix

Questionnaire one

Your experience of caring for a patient where a treatment-withholding or treatment-withdrawal decision was made.

When completing this questionnaire, **please focus on a recent, specific situation** in which you were involved, where a decision to withhold or withdraw treatment was taken. Many of the questions can be answered by simply ticking boxes, but please add comments and explanations, if you wish, as anything you can add will be welcomed.

To set the scene, please first answer these questions:

I am male ___ female ___

I have ___ years experience in nursing,

___ years in Intensive Care/Special Care nursing

The **specific patient** involved was:-

a baby	
a child	
a teenager	
a young adult	
a middle-aged person	
an elderly person	

and had a primary diagnosis of:-

complicated by:-

1. Who among the following participated in the **discussions** about treatment- withholding or treatment-withdrawal?

Patient	
Patient's partner	
Patient's parent(s)	
Patient's son(s), daughter(s)	
Patient's friend(s)	
Patient's own Consultant (eg.surgeon, physician, paediatrician)	
ICU Consultant	
Another doctor (own doctor's team)	
Another doctor (ICU team)	
You, the nurse	
You, the ICU Sister/Charge Nurse	
ICU Sister/Charge Nurse (not you)	
Other:-	
Other:-	

2. Which of the following **prompted these discussions** about treatment-witholding or treatment-withdrawal? (more than one may be applicable)

Diagnosis of brain-stem death	
Failure of an organ system eg. kidneys, liver, heart	
Failure to respond to maximum inotropic/ cardiac support	
Pathology report of metastatic disease	
Pathology report indicating irreversible disease	
Diagnosis of irrecoverable injury or illness from x-ray test or similar	
Diagnosis of new illness in presence of a number of chronic medical problems	
Patient requested cessation of treatment	
Patient's family, or appointed next-of-kin, requested cessation of treatment	
Other:-	
Other:-	

3. Do you think that any of the following factors had some influence in the treatment-withdrawal **decision?** (more than one may apply)

The age of the patient	
Bed shortage	
Cost of treatment	
Anticipated poor quality of life if patient survives	
Social factors	
Predicted outcome obtained from scoring system	
Patient's religious beliefs	
Religious beliefs of patient's family	
Religious beliefs of a health care team member	
Advance directive (living will) from patient	
Other:-	
Other:-	

4. Do you feel that you have sufficient knowledge about ethical decision-making to enable you to take part in such discussions?

Yes	
No	
Unsure	

5. How do you feel about the following statement?:

"The professionals' own ethical and philosophical views are irrelevant in these situations. It is the views of the patient and/or the family which are of paramount importance."

Agree	
Disagree	
Unsure	

6. How much **influence** did each of the participants have in the final **decision?** (Please put a tick in the appropriate box for each person listed)

	Did not take part	No influence	Some influence	Quite a lot of influence	The most influence
Patient					
Partner					
Parent(s)					
Sons, daughters					
Friends					
Own Consultant					
ICU Consultant					
Another doctor (own team)					
Another doctor (ICU team)					
You, the nurse					
You,the Sister, C/N					
Sister,C/N (not you)					
Other:-					

7. What happened to the patient's treatment after the **decision** was made? (More than one may apply. Please tick those which are applicable)

Treatment was continued as before but the patient was not to be resuscitated in the event of cardiorespiratory arrest	
The patient's ventilator was switched off	
The prescribed oxygen concentration was reduced	
The prescribed dose of analgesia/sedation was increased	
The patient's cardiac-support drugs were stopped	
The patient's cardiac-support drugs were reduced gradually	
The patient's antibiotics were stopped	
Other drugs were stopped	
Renal-replacement treatment was stopped	

8. Who explained to the patient and/or the family about these changes in treatment? (more than one may apply)

The ICU Consultant	
Patient's own Consultant	
Another Doctor	
You, the nurse	
You, the ICU Sister or Charge Nurse	
ICU Sister or Charge Nurse (not you)	

9. In this specific situation, did the doctors explain to **you** exactly why they felt that the **decision** was appropriate?

Yes	
No	

10. In this specific situation, did you have the opportunity to explain to the doctors how **you felt** about the **decision**?

Yes	
No	

11. How did you feel about this treatment-withholding or -withdrawal decision?
(Please complete whichever one of the sentences is closest to the way you feel)

a. I felt that the decision itself was the right one because

Please go to question 12(A)

b. I do not know whether it was the right decision or not because

Please go to question 12 (B)

c. I was unhappy about the decision because

Please go to question 12 (B)

12 (A).Please answer this question **only** if you **agreed with the decision** to withhold or withdraw treatment.

Please indicate how you feel about these statements, as they apply to you, adding further explanations if you wish.

	Agree	**Disagree**
a.I felt that it was the right decision, but some of my nursing colleagues thought that the decision was wrong		
b.I thought that it was the right decision, but I felt strongly about something and my views were not considered		
c.It was the right decision, but I didn't feel able to cope with the patient's family		
d.It was the right decision and I was able to cope with what was expected of me without help from anyone else		
e.It was the right decision, but I was unhappy about my role in the changes made in the patient's treatment afterwards		
f.It was the right decision, but I needed the support of my colleagues to cope with the demands made on me		

12 (B) Please answer this question **only if you had reservations** about the decision to withhold or withdraw treatment.

Please indicate how you feel about the following statements as they apply to you, adding explanations where necessary.

	Agree	**Disagree**
a. I had reservations about the decision, but I know that some of my nursing colleagues thought it was the right decision		
b. I was unhappy about the decision and I felt quite strongly about something, but my views were not considered		
c. I had doubts about the decision, so I did not feel able to cope with the patient's family		
d. I was unhappy with the decision, so was uneasy with my role in the changes made to the patient's treatment afterwards		
e. Although I had doubts about the decision, I was able to cope with what was expected of me without help		
f. I was unhappy about the decision and I needed the support of my colleagues to cope with the demands made on me		

13. The worst thing(s) about this situation was (were):-

14. The best thing(s) about this situation was (were):-

15. Have you been involved in other situations like this, where treatment-withholding or -withdrawal was considered?

Yes	
No	

16. If you have been involved in other such situations, was there one in particular which you remember because some aspect upset or troubled you a great deal?

Yes	
No	

Why, please?

please continue over page

17. Have I forgotten to ask you something which you think is important? Please use this space for any comments you wish to add.

Thank-you very much for your time and patience. RRS.

Questionnaire two

Please read through each vignette and give the answers which correspond best to what your decision or feelings would be under the circumstances.

Vignette 1

Mr.F. is 74 and has a diagnosis of abdominal sepsis, secondary to bowel perforation. This is day 7 in ICU and Mr.F. has had maximal treatment for sepsis, including ventilation, inotropes, antibiotics, fluid resuscitation and haemofiltration. Today, Mr.F's B/P is falling despite high-dose inotropes, and he is not responding to further manipulations of the drugs. The doctors feel that Mr.F. is irreversibly ill and you know that with three body systems now failing, there is very little chance of recovery. The situation is explained to Mr.F's family and they accept that everything possible has been done and that Mr.F. is likely to die within 24 hours. The doctor suggests that you start reducing the inotropes gradually, although the family is not told about these reductions.

1.1

How important do you think it is to tell the truth about reducing the drugs under these circumstances?

1.Not important	
2.Quite important	
3.Moderately important	
4.Very important	

1.2.A

Would you normally be prepared to reduce the inotropes under these circumstances?

Yes	
No	

1.2.B

What would your reasons be for your answer to question 1.2.A, please?

	No	Unsure	Yes
1. On religious grounds			
2. On the clinical grounds that there is still a (remote) possibility of recovery			
3. On personal grounds			
4. On the clinical grounds that with three systems failing, the chances of making a good recovery are nil			
5. Because medico-legally, they constitute futile treatment			
6. Because I feel that it is in the best interests of the patient			

Mr.F. unexpectedly dies within minutes of the inotropes being reduced for the first time.

1.3
Although this is not active euthanasia, how close do you feel that this process is to it?

1.Much too close	
2.Uncomfortably close	
3.Quite close	
4.Not very close	
5.Not close at all	

1.4
If you were the nurse actually involved in this situation, do you think that there would be any aspects of care which might give you some satisfaction, on reflection?

1.5
If you were the nurse actually involved, what might be the worst thing about this situation for you?

Vignette 2

Mrs.S. is 70 and has a diagnosis of having had a cardiac arrest at home, presumably secondary to an M.I.

This is day 5 in ICU, and it is apparent that despite the sedation having been off for the past 4 days, Mrs.S. has not woken up at all. The conclusion must be, from the clinical picture, that there has been irreversible brain damage. Mrs.S. has been off the ventilator for 24 hours, and has breathed adequately, spontaneously, though is still intubated.

The situation is reviewed by the doctors involved, and the feeling is that the situation is hopeless, and that further treatment is futile, so Mrs.S. should be discharged to a medical ward for terminal care. You and the ICU Consultant talk to the family about the situation and they accept that there is nothing more that can be done to help Mrs.S. to get better. They also agree that any medical treatment should be discontinued. The ICU Consultant tells you to extubate Mrs.S. and make arrangements to discharge her. You are not certain that Mrs.S. will maintain her airway, but decide to do as the doctor suggested and take out the ETT. Within minutes of the ETT coming out, Mrs.S. dies, and you feel awful about it happening so quickly, before the family has really had time to come to terms with what is happening. You know that the family did not expect this to happen, and can see that they are shocked.

2.1
Under these circumstances, to what extent would you feel that the fine line between euthanasia and helping the patient to a peaceful and dignified death, has been compromised?

1.Not at all, because you did not intend to cause the death of the patient	
2.To some extent, because the death was related directly to the extubation, even if this was not what you intended	
3.To quite a large extent, because the action was likely to shorten life	
4.To a very great extent, because the intention was to accelerate the dying process	

Vignette 3

Mr.R. is 55 and has a diagnosis of a GI bleed from oesophageal varices, secondary to alcoholic cirrhosis of the liver.

This is day 10 in ICU and despite the maximal medical treatment which has been carried out, Mr.R. continues to bleed intermittently. He has some renal dysfunction, but, so far, has not needed haemofiltration. Surgery could be offered to relieve the portal hypertension, but this would lead to Mr.R. having to be ventilated for possibly a week or more, as his condition is poor generally. This is Mr.R's third admission to hospital in the last year for the same condition, but his first admission to ICU. Mr.R. is now confused, disorientated and irrational, and cannot give a reliable indication of what he wants in terms of treatment.
Mr.R's brother, the next-of-kin, says that nothing further should be done, and no surgery or haemofiltration should be attempted, because he feels that Mr.R. would not want treatment which would only offer limited benefit, particularly when, in his opinion, Mr.R's life was already of very poor quality and he would inevitably start drinking again.

Mr.R's doctors review the medical situation and the treatment thus far, and, influenced by the brother's views, decide to maintain conservative treatment with drugs and fluids, but to withhold surgery, withhold haemofiltration, withhold resuscitation in the event of cardiac arrest, and to place a limit on the number of units of blood to be given, if a further transfusion is required.

3.1
How do you feel about this withholding decision?

1.Strongly disagree	
2.Disagree	
3.Unsure	
4.Agree	
5.Strongly agree	

3.2
Who should have the most influence in making the withholding decision in this situation? Please circle the number which approximates how you feel,
where 1 = should have the least influence and 5 = should have the most influence

1.You, Mr.R's nurse	1	2	3	4	5
2.Mr.R's Consultant Physician	1	2	3	4	5
3.Mr.R's ICU Consultant	1	2	3	4	5
4.Mr.R's brother	1	2	3	4	5
5.Mr.R., the patient	1	2	3	4	5
6.Mr.R's GP	1	2	3	4	5

3.3
Do you feel that anyone else should have been involved in making this decision?

1.Yes	
2.No	

3.4
If so, who do you suggest?

1.
2.
3.

3.5
If you were the nurse actually involved in this situation, do you think that there might be any aspects of care which might give you some satisfaction, on reflection?

3.6
If you were the nurse actually involved, what might be the worst thing about this situation for you?

A little later after this withholding decision has been taken, you are told that the doctors want to obtain an EEG for research purposes.

3.7

How do you feel about the EEG request, under the circumstances?

	No, disagree	Unsure	Yes, agree
1.Reasonable, because something positive may be gained from it, so I would ensure that the brother was able to sit comfortably at the bedside while it was done, if this were what he wanted			
2.Reasonable, but I would insist on the doctors asking the brother for permission to do it			
3.Unreasonable, but I could do nothing about it			
4.Unreasonable, because I would feel that it was an unnecessary intrusion under the circumstances			
5.Unreasonable, because it is not possible to ask for the patient's consent			

Vignette 4

Mrs.A. is 60 and has a diagnosis of acute exacerbation of chronic respiratory disease. This is day 24 in ICU and Mrs.A. has received maximal drug treatment and ventilation, and has had a tracheostomy to facilitate weaning. There have been a number of attempts to wean Mrs.A., using a variety of techniques, but on each occasion, she has made some progress and, at best, has come off the ventilator for up to an hour, then has begun to struggle, so has had to return to the ventilator.

This is her second admission to ICU within six months, but on the first occasion she was successfully weaned from the ventilator during her three-day stay, and went home. At home, she was not ever well enough to do her own shopping or cleaning, and she spent most days resting in bed or in an armchair. She is widowed, and depends on her sons and daughters for help to manage on a day-to-day basis.

You have cared for her through a large part of her ICU stay, and have got to know her quite well. She has said to you more than once recently during weaning attempts, that she 'has had enough' and has lost any motivation to try to get better. Today, her heart failure is worsening, her blood oxygen level is falling, her blood carbon dioxide level is rising and her level of consciousness is deteriorating.

The ICU Consultant, the patient's own Physician and the junior doctors all visit, and there is a discussion about Mrs.A's treatment. The ICU doctors are keen to start more aggressive treatment for the heart failure, but the Physician feels that although this may be helpful in the short-term, the longer-term outlook is very poor.

4.1

How would you feel about a decision to start more aggressive treatment?

1.Strongly disagree	
2.Disagree	
3.Unsure	
4.Agree	
5.Strongly agree	

4.2

How would you feel if a decision were made to withhold the further aggressive treatment for the heart failure, but to continue the present level of support?

1.Strongly disagree	
2.Disagree	
3.Unsure	
4.Agree	
5.Strongly agree	

4.3

How would you feel if the decision were made to withhold further treatment and reduce the present level of support?

1.Strongly disagree	
2.Disagree	
3.Unsure	
4.Agree	
5.Strongly agree	

4.4

How would you feel if the decision were made to withhold further treatment, reduce the present level of support and start a diamorphine infusion, to ensure that Mrs.A. is comfortable during the withdrawal process?

1.Strongly disagree	
2.Disagree	
3.Unsure	
4.Agree	
5.Strongly agree	

4.5

Who do you think can best represent the views of Mrs.A.?

Please circle the number which approximates how you feel,
where 1 = worst at representing Mrs.A.'s views, and 5 = best

1.Sons and daughters	1	2	3	4	5
2.You	1	2	3	4	5
3.Mrs.A's Physician	1	2	3	4	5
4.ICU Consultant	1	2	3	4	5
5.Another person:-	1	2	3	4	5
6.Another person:-	1	2	3	4	5

4.6

If you were the nurse actually involved in this situation, do you think that there would be any aspects of care which might give you some satisfaction, on reflection?

4.7

If you were the nurse actually involved, what might be the worst thing about this situation for you?

Vignette 5

Mrs.B. is 58 and has had an elective repair of an abdominal aortic aneurysm.

This is day 5 on ICU. Mrs.B. has had an unexpectably stormy post-operative course and she is still ventilated and sedated because of surgical complications which have necessitated two return visits to theatre to try to restore the circulation to her legs. Presumably the grafts to the legs have blocked, and despite treatment, both legs are ischaemic and are not viable. Mrs.B. is also today beginning to appear quite 'toxic', and she now has other problems, including a change in heart rhythm from sinus tachycardia to rapid atrial fibrillation, and she has some renal dysfunction.

The surgeons say that the only treatment is to do a bilateral, high level amputation, but this would be very disfiguring surgery.

Mrs.B. cannot give her views. The sedation would take too long to wear off, and Mrs.B. would have severe pain if allowed to wake up. Mrs.B's family says to you that this surgery would be totally unacceptable to her, and that they know that she would rather die than endure such an operation and the resulting change in her way of life.

You can see from Mrs.B's ward admission profile that she is a very active person in the village where she lives. She takes part in amateur dramatics, sings in the church choir, is a voluntary driver for the senior citizens' community bus and generally helps anyone in need.

The issue here is Mrs.B's future quality of life.

5.1
Who do you think is the best judge of the acceptability to her of the future quality of life?

Please circle the number which approximates how you feel,
where 1 = the worst judge of acceptability, and 5 = the best judge

1.Her family	1	2	3	4	5
2.The surgeons	1	2	3	4	5
3.The ICU doctor	1	2	3	4	5
4.You	1	2	3	4	5

The surgeons want to try surgery, although there are obvious risks associated with anaesthetising Mrs.B., as she is now so ill.

5.2

How would you deal with this? Which statement best describes your probable actions?

1.I would support the surgeons' decision	
2.I would strongly try to dissuade them, because I do not think that surgery should be carried out	
3.I would present the family's views because I think that this is an important part of my role, although I disagree with them and would say so to the doctors	
4.I would present the family's views because I think this is an important part of my role, and give my own views in support of their	
5.I would ask for a meeting between us, the nurses, all the doctors involved, the family and some other people, probably ________________ ____to discuss the issue.	

5.3

If you were the nurse actually involved in this situation, do you think that there would be any aspects of care which might give you some satisfaction, on reflection?

5.4

If you were the nurse actually involved, what might be the worst thing about this situation for you?

Please give the following background information:-

1.Years of experience in Nursing:_____ 2.Years of experience in ICU Nursing:_____

3.Education

1.EN(G)		10.ENB 100	
2.RGN		11.ENB 124	
3.RN (Adult)/Dip.HE		12.ENB 125	
4.Diploma in Nursing		13.ENB 148	
5.BSc/BA (Nursing)		14.ENB 249	
6.BSc other:		15.ENB 253	
7.BA other:		16.ENB:	
8.MSc		17.ENB:	
9.MA		18.ENB:	

4.Ethics Education: Please indicate your sources of education in ethical issues by ticking in all the appropriate boxes.

1.Included as a topic in an ENB course	
2.Included as a topic in RGN course	
3.Included as a topic in Diploma/Dip.H.E. course	
4.Included as a topic in Degree course	
5.Included as a major element in Degree course	
6.Have completed a Diploma/Degree level module on Ethics/Law	
7.Have an interest in subject, so have read journal articles/books on ethical issues	
8.Is of particular interest to me, so have written for journal/book on ethical issues	
9.Is of particular interest to me, so have done some formal teaching/speaking on ethical issues	
10.Have attended study day(s) where it was included as a topic	
11.No specific education in ethics	
12.Other:	

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