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**MANAGEMENT OF DEATH, DYING AND EUTHANASIA : ATTITUDES AND
PRACTICES OF MEDICAL PRACTITIONERS AND NURSES IN SOUTH
AUSTRALIA**

by

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CHAPTER 1

INTRODUCTION

Euthanasia, and the issues surrounding withholding and withdrawal of medical treatment for the terminally ill have been debated for many years, but recently the nature of the debate has changed. New arguments, which acknowledge the dilemmas which confront the medical profession as a result of significant advances in medical knowledge and technology, are now put forward in support of changes to legislation. These advances have meant that the medical profession now exercises greater control over life and death processes, with the result that more people survive, and more people survive longer.

Medical advances have meant that the causes of death have altered radically in most developed countries, and death from communicable disease has now declined to insignificant levels. Chronic, degenerative diseases are more common causes of death. These generally occur later in life, and being progressive, lead to gradual deterioration in health over a long period. In countries such as Australia the survival rate amongst premature, low birth weight infants is much higher than in the past, but many of the survivors have serious life-long handicaps. It is also possible for infants born with congenital deformities such as Spina Bifida to survive into adulthood, but with varying degrees of handicap.

It is the very success of modern medicine which has produced moral and ethical dilemmas concerning treatment. The problem is that while it is now possible to sustain life so that through the use of a range of life-sustaining treatments and techniques the lives of infants, the elderly or disabled may be prolonged, the ability to maintain health has not altered as dramatically. While survival is more likely, those who survive may suffer varying degrees of pain, discomfort, chronic illness or disability, and the quality of life may vary from good to miserable in the eyes of individuals who live those lives.

There is therefore increasing tension between the aim and ability of medicine to sustain life and the requirement to relieve suffering, and in many situations the two objectives have become incompatible. Questions now increasingly faced by medical

practitioners revolve around when to forego, initiate, withdraw or terminate life-sustaining treatment. There is wide divergence of opinion as to when intervention or non-treatment should occur, and no unanimity on the moral and ethical status of decisions to forego treatment and actions taken to withdraw or terminate treatment. To some they may appear clearly immoral and unethical, to others necessary and appropriate, although their morality may be open to question. There is now considerable uncertainty about what constitute reasonable medical standards, and practices differ widely between individual medical practitioners and between medical institutions.

Medical practitioners also face the dilemma that the principle aim of medicine, the preservation of life is tied to philosophical and religious ideas of the sanctity of life. This concept together with the notion of the need to protect the lives of innocent humans, form the foundation of our political and legal systems. Decisions which therefore may or may not appear immoral, unethical, or may appear appropriate and necessary, may be clearly illegal or their legality may be questionable.

Given the medical ability to influence the manner and timing of death, people in the community wish to be protected against decisions which facilitate death, as well as those which delay it unnecessarily. Thus, the debate on euthanasia and the issues surrounding the withholding and withdrawal of treatment has intensified. There is greater community concern that the power to make decisions about the continuation or cessation of treatment should reside with the patient wherever possible and not simply with the medical practitioner. There is therefore public desire for increased participation in decision making in the field of health care delivery. New attitudes to authority have fuelled this trend. It is said that people have the right to self determination, and the right to refuse medical treatment when they are terminally ill. The locus of authority in medical decision making is no longer seen to be the sole prerogative of medical practitioners, especially where decisions appear to prolong the dying process rather than sustaining life. The problems of the locus of authority where decisions are required concerning cessation of treatment for incompetent patients and

the newly born continue, but increasingly it is suggested that greater decision making powers should reside with those affected by decisions. This group includes parents and relatives. However, it is also suggested that the community as a whole should have an input into decision making at some level, where financial costs are shared by the wider community. However, concern has been expressed about the criteria on which decisions for this group are made, and it is postulated that abuses are possible whether decisions are made by medical practitioners, parents, relatives or the community.

Medical intervention which requires the use of sophisticated technology to prolong or save lives is usually undertaken in institutions. This care is becoming increasingly expensive and costs in Australia are born by the entire community. A call for the re-evaluation of permissible medical practices is fuelled by the realisation that the community does not have unlimited ability to provide and pay for medical services (Robertson 1984; National Health and Medical Research Council 1988; South Australian Health Commission 1991). It is suggested that there is a divergence between what medical science can achieve in each individual case and the resources available for that care. High costs and finite resources preclude the ability to apply all available techniques and facilities to all cases. The question then arises as to how resources should be apportioned and who should be rationed. It is proposed that greater benefit may derive to the whole community if funds are used on health education programs rather than on expensive treatment for individuals for whom there is little chance of a successful outcome.

There is increasing awareness that existing legal sanctions against termination of life supports and medical interventions may no longer be tenable in the light of medical advances. The sanctions which were intended to protect life may now in fact have the opposite, albeit unintended effect of harming lives. On the other hand, the arguments against altering legislation which will permit community sanctioned termination of treatment and lives are still strong, for it is felt that legislative change could damage our fundamental regard for the sanctity of human life and the need to protect the innocent on which our law is based. Further it has been suggested that it is difficult to provide

useful criteria and procedures which will be properly defensive of human life, but at the same time be respectful of individual autonomy, attentive to the relief of pain and distress, and accepting of the process of death (Kirby 1986).

This study addresses these issues by examining the attitudes and practises of medical practitioners and nurses in South Australia towards the management of death, dying and euthanasia. The study aims firstly, to examine whether medical practitioners and nurses are ever asked to hasten the death of patients, and the ways such requests are currently handled; secondly, to investigate how medical practitioners and nurses consider such requests could be handled, and whether guidelines should be established to clarify the current legal position. It is anticipated that answers to these questions will inform debate on the issue of legislative change.

The monograph is divided into eight sections. Chapter two examines the ethical issues and different ethical positions on euthanasia and the main arguments both for and against its introduction. Chapter three outlines legal issues and examines current Australian legislation on death and dying. Chapter four reviews some of the problems and dilemmas which have arisen in the practice of medicine with recent advances in medical knowledge and technology. This chapter also considers current research on attitudes towards changes in medical practice. Chapter five details the methodology used in undertaking this study. In chapter six the research findings are described, and chapter seven provides a discussion of the implications of the findings for future legislation change.

CHAPTER 2

EUTHANASIA : THE ETHICAL ISSUES

INTRODUCTION

The arguments in favour of euthanasia have been reformulated recently and there has been a change in the language used to discuss death as a result of withholding, withdrawal or termination of treatment. The term "mercy killing" is an old alternative to "euthanasia", but it appears there is a move away from the use of the term euthanasia, to euphemisms such as "death with dignity", "allowing to die", "letting die", "treatment of choice", "proper care for the dying". The definition and meaning of euthanasia, which has never been unitary, has also undergone some revision over time and is still in the process of redefinition. The move to alternative terminology may be partly in response to the perceived need for legislative change and the need to establish new guidelines and codes in medical practice. The achievement of these aims may be hampered by the use of the term "euthanasia" which arouses strong emotions and which is identified in the minds of many with murder, the Nazis and eugenics. The term "mercy killing" appears to be unacceptable because killing is usually illegal. Thus it has become necessary for those who argue in favour of euthanasia to alter terminology and revise definitions so that actions which may once have been regarded as illegal or which may never have been necessary in the past, but which now seem morally and ethically acceptable to an increasing number of people, may now be incorporated within the lexicon of permissible acts. Several writers (Veatch 1976; Ramsey 1978) avoided the term euthanasia per se because of the emotional feelings and moral outrage it often engenders. Veatch (1976) preferred to concentrate on the important questions surrounding the termination of life, which he defined as: (1) is there any difference between killing and letting die? (2) is there any difference between stopping treatment and failure to initiate it? (3) is it acceptable to undertake treatment if one of its side effects is death? (4) is there any significant, absolute difference between "ordinary" and "extraordinary" treatments, and if so when is it permissible to use or discontinue the use of one or the other? Before dealing with these questions and the arguments both for and

against withholding, withdrawal and cessation of medical treatment for certain categories of persons, we will briefly consider some definitions of euthanasia.

DEFINITION

The word "euthanasia" has various and contradictory meanings which make its use problematic. While for some people the term simply refers to a good death, by whatever means, for others it may mean any humane assistance (which includes cessation of treatment) given to terminate a life which is, or is considered will be, unbearable. Alternatively it may only refer to direct action taken to terminate life. Interpretation of these meanings may vary from the perception that direct and indirect assistance and action are morally acceptable to perceptions that all such actions constitute murder and taking part in such acts is morally and ethically improper.

The Oxford Dictionary defines euthanasia as 1. "a quiet and easy death", 2. "the means of procuring this", and 3. "the action of inducing a quiet and easy death", a definition which derives from the Greek (eu) meaning well, and (thanatos) meaning death. This definition is very broad as it encompasses actions which are both active and passive, and deaths which are both voluntary and involuntary. Suicide can also be included in this definition. The Macquarie Dictionary defines euthanasia as 1. "painless death", and 2. "the putting of a person to death painlessly, especially a person suffering from an incurable and painful disease". This definition includes only the active act of terminating the life of another and excludes passive actions/inactions which allow a person to die, as well as suicide. The definition introduces the concept of intent, and specifies a particular category of person who dies, but does not exclude other reasons for terminating life or other categories of persons. The definition, does not require the permission of the person who is to die, and therefore includes both voluntary and involuntary deaths.

Generally suicide is differentiated from euthanasia in that the latter requires the involvement of a second or third person. Suicide is the taking of one's own life, while euthanasia is the taking of the life of another. According to Rachels (1986) the two are

linked because he considered that if it is permissible for a person to commit suicide, then it is also acceptable for that person to ask for assistance, providing the rights of the third party are not violated. The terms "medically assisted suicide" (Syme 1991) and "helping to die" (Davies 1988) demonstrate the linkage. In this way Rachels and others such as Kuhse (1986) and Nelson-Miller (1984) attempt to legitimise euthanasia by linking it with a legal act and therefore distancing it from the illegal. The argument is linked with the idea of a "right to die" for it is said, if a person has a right to die, then the medical practitioner has the right to perform active euthanasia at the patient's request. Sometimes this is phrased as a question (Hadding 1989) and sometimes as an assertion (Syme 1991).

A distinction is generally made between active and passive forms of euthanasia. The former involves a direct action taken to end life, "killing", while the latter usually involves refraining from taking actions so that death will come more quickly, "letting die". Many would suggest the differences between the two are not clear cut as it is difficult to separate action from inaction. An example of this problem is the difficulty of identifying cessation or withdrawal of life-sustaining treatment as an action or an omission. Lander (1984) questioned if switching off an artificial respirator is an act or an omission, an active or passive act. Further, the result of both action and omission is death, whether the person is killed or allowed to die, so it is argued there is no moral difference between killing and letting die (Kuhse and Singer 1988; Gillon 1988). The distinction has been drawn by many medical practitioners and others who believe that passive euthanasia is morally preferable to active euthanasia and legally acceptable. In fact many medical practitioners and others would argue that refraining from taking action and cessation of treatment are not euthanasia at all (South Australian Health Commission 1991, p. 8; Henley 1986; Pollard 1991). This distinction is made for two reasons. Medical practitioners are often required to make decisions which they know will shorten patient's lives and therefore there is a strong motivation to interpret those actions as "letting die" or "not prolonging death" rather than "killing". Persons with strong religious convictions make the distinction to enable those required to make such

decisions to absolve themselves of the unintended effects of their actions. So an action can be proper if the intention is good. However, the law is not so clear cut in resolving the legality of refraining from taking action or omissions and according to the Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research (1983, p. 34) "the omission of a duty to take protective action by someone obligated to do so, such as a physician or a parent, is regarded by the law in the same way that an action would be that led to the same result".

Where legislation to legalise euthanasia has been introduced or contemplated, euthanasia has been narrowly defined in order to exclude certain categories of actions which are still to be regarded as illegal. In the Netherlands it is described in the 1987 Euthanasia Bill as "the deliberate termination of the life of a person on his request, by another person" (Leenan 1989, p. 520). The Bill clearly distinguishes between acts and omissions and only the former falls within the definition. A number of situations are not defined as euthanasia which means that they are permissible and legal. These are: firstly, withholding or termination of medical treatment when treatment is pointless and where this results in the death of a patient; secondly, when a patients life is shortened as a side effect of the administration of pain killers; thirdly, when death results from refusal of treatment by a patient (Leenan 1989).

The volition of the subject is required in the Netherlands definition to ensure that the killing of patients against their wishes, or the killing of incompetent people and infants is not condoned. These would be regarded as cases of unlawful killing or murder. The Oxford and Macquarie Dictionary definitions do not specify consent of the person to die, but other writers suggest this is a critical factor (Davies 1988). Elsewhere a distinction is drawn between different forms of euthanasia on the basis of the consent of the subject (Lander 1984; Campbell and Collinson 1988). Voluntary euthanasia involves a situation where the subject gives consent to his/her own death. Involuntary euthanasia is the situation where a person did not consent to their own death, and non-voluntary euthanasia is the situation where the person had no capacity to request or refuse such action.

Euthanasia is said to be differentiated from murder because the killing is done for the sake of, or for the benefit of the one who is to die, whether the person consents or not (Kohl 1975; Campbell and Collinson 1988). Therefore the motives and intentions of the killer are the differentiating factor. However the law operating in Australia and in most other western countries does not recognise any difference between euthanasia and other forms of illegal killing.

Consent, deliberate action and specific intent could be seen to be critical defining criteria of euthanasia, but there is no unanimity of opinion on an acceptable definition. Diversity is partly the result of different ethical positions on withholding, withdrawal and termination of life supporting medical treatment as well as the need to resolve moral and ethical dilemmas raised by medical advances. There has been some attempt to redefine passive euthanasia in terms other than as euthanasia, thus removing it from the unethical and definitely illegal category. There has also been some attempt to alter the language used, thus making the situations and activities seem more acceptable. This is usually done by those who wish to influence community attitudes or press for legislative change. Refraining from actions which enable death to come more quickly have now been renamed as permitting "death with dignity" or allowing death to take its natural course. Active euthanasia has been referred to as "medically assisted suicide" (Syme 1991), and involuntary euthanasia has been called "beneficent euthanasia" (Kohl 1975).

ETHICAL POSITIONS

While it is difficult to separate ethical positions on euthanasia into completely discrete viewpoints, as there is overlap and qualification on many points, it is possible to define two principal directions from which the question is approached. These are the sanctity of life perspective and the quality of life position.

(1) The Sanctity of Life Position

Most societies regard life as sacred, but those derived from the Judeo-Christian tradition believe that only human life is sacred because humans occupy a special place in creation. Within this perspective little value is placed on non-human life, and therefore

killing animals requires almost no justification. Only the killing of humans is morally wrong, because human life is created in God's image and life is a trust from God. In essence, the sanctity of life position therefore holds that all human life is sacred.

To circumvent some of the problems which this position creates, a number of qualifications to the sanction against killing have been introduced. It is said that the killing of humans can be permissible under certain conditions, and a distinction is drawn between the innocent and others. Capital punishment and killing during war are justified by the rationalisation that those who are killed are not innocent. Another distinction is also drawn between intentional and unintentional killing and this means that killing in self defence is also a permissible act. Violence is permitted if it is performed with the right intention e.g. to end war. So it is only the intentional killing of innocent humans which is expressly forbidden.

A distinction has also been drawn between actions which result in the death of the innocent on the basis of the intentions of the perpetrator of the act. This is the doctrine of double effect. Under this doctrine it is permissible to perpetrate an act which has two effects, both positive and negative, if the good effect was the only intended effect.¹ So under certain conditions one need not be responsible for the negative effects of one's actions, which, although they may be foreseen, were not intended (Campbell and Collinson 1988). Although consequences or results of behaviour are important in this doctrine, intentions are vital.

Although this doctrine does not suggest whether failing to act is ever permissible, it is generally held that a person who fails to perform an action which would prevent evil consequences is morally less culpable than someone who performs an action which results in the same evil consequences. Thus a distinction is drawn between killing people and letting people die (Clayden and Mattar 1984; Slack 1984; Davies 1988). The

1 An action which has two effects - good and bad, may be done provided four conditions are satisfied,
 (a) the act itself must be of a type that is permitted,
 (b) the bad effect may not be aimed at or intended, only the good effect,
 (c) the bad result must not be used as a means of achieving the good result,
 (d) the amount of good accomplished in the good result must be great enough to outweigh the evil of the bad result.

latter is sometimes permissible, as we are not always required to use every available resource to prolong life, even the lives of innocent humans (Rachels 1986). To assist decision making, religious organisations and others distinguish between "ordinary" and "extraordinary" means of treatment. It is always said to be obligatory to give the former, but discretion may be exercised in giving the latter. Both these distinctions have provoked considerable debate.

(2) The Quality of Life Position

While this perspective may or may not accept that human life is sacred, regard and respect for human life are fundamental. It is the value which is placed upon human life that is critical from this viewpoint. What the determinants of value should comprise, and whether that value should be ascribed by beholders of those lives, or by those who live the lives themselves, are much debated issues.

The principles on which the quality of life should be determined are not fixed within this position. Kuhse (1986) argued that it is the human ability to choose or to exercise self determination and personal autonomy which gives special value to lives. While Rachels (1986) argued that the value of life is not the value it has for God, or because it has been assigned value on religious grounds, but it has value by virtue of the value it has for the beings who are the subjects of lives. Something has value for a person if its loss would harm him. Rachels (1986) drew a distinction between having a life in a biographical sense and merely being alive in a biological sense. He considered that the reason there should be a rule against killing of humans is to protect biographical lives, but not necessarily just biological lives.

Similarly, Pollard (1991) drew a distinction between physiological and spiritual life. He argued that human life consists not only of a functioning physiology, but also serves higher purposes of life, such as thinking, emotions, human relationships and spiritual experience. He went on to say that 'if it can be shown in an individual that these capacities have been permanently lost, life in its human fullness is already lacking'.

Upholders of this position suggest that quantity of life should not be given greater priority than quality. The difficult questions are firstly, how to measure the quality of

life, and what criteria to use, and secondly, how to distinguish satisfactorily between biological/physiological and biographical/spiritual lives.

Utilitarianism, a philosophy which focuses on the consequences of an action, provides the principle which forms the basis for such decision making. Briefly, utilitarianism states that the action with the most good effects and the least bad effects is the best action. Good effects can be measured in terms of benefit to the individual, net social benefit or maximisation of happiness for the majority of people. The problem with the application of this principle is there are several ways of determining the best action, but it is not clear what or whose interests should be given the greatest weight. In reality it is rarely clear what is the best course of action, and abuses of individual rights and injustice could be the result.

THE ETHICAL DEBATES

(a) Argument in Favour of Strict Interpretation of the Sanctity of Life Position

People who hold the sanctity of life position with no qualifications would argue that everyone who is born has a "right to life". This position commits the holder to the belief that all killing is wrong as it violates this right. It then follows that all available techniques should be available to maintain life (Slack 1984) and this includes nutrition and adequate shelter. Any deviance from this would be an abuse of the right to life.

(b) Argument in Favour of Modification of the Sanctity of Life Position

Many people find this unacceptable and maintain there is a difference between acts and omissions and killing and letting die. While it may never be permissible to actively kill someone, it may be permissible to act or fail to act when the foreseeable result will be the person's death. It is said to be permissible on a number of grounds.

Firstly, the doctrine of double effect (discussed above) permits an action or omission, if only the good effect of that action/omission was the intended result. So there is a difference between intended and merely foreseen deaths. It is argued that "proper care" for the dying involves relief from pain. If the drugs used for this purpose

also have the effect of shortening life, then that is acceptable, because it was not the chief aim of the treatment (Henley 1986).

Secondly there is a difference between acts and omissions, thus it is said there is a difference between not connecting a patient to a respirator and disconnecting a patient from a respirator even though death may result in each situation.

Thirdly, it is argued that it is not the act or the failure to act which causes the person's death, but the disease or disability from which the person suffers (Ramsey 1978).

Fourthly, it is stated there exists an obligation to use "ordinary" treatments only. "Extraordinary" treatments are not obligatory. It is therefore acceptable not to treat a patient in certain circumstances.

Fifthly, people have the right to refuse treatment, and therefore medical professionals have a duty to honour the decisions of their patients to forgo further treatment. This right is based on the belief that we have the right of moral autonomy and the right to control or determine the course of our lives. This right to self determination gives us the right to die when and in the manner we wish (Charlesworth 1986), but the death which results from the exercise of this right is not suicide (Campbell and Collinson 1988). It is argued that this right applies to the person who may have legal responsibility to make decisions about medical care on behalf of the patient (Ruark and Raffin and The Stanford University Medical Center Committee on Ethics (1988).

According to Campbell and Collinson (1988) allowing someone to die can be done actively or passively. Whether this amounts to killing depends on whether it was the intention that the person should die as a result of the act, or failure to act. If the death was merely foreseen but not intended, then the death was not the result of killing.

(c) Criticisms of these Modifications

Upholders of a rigid sanctity of life position, and those who wish to move to permit euthanasia have each levelled a number of criticisms at these arguments. The denial of a moral difference between killing and letting die has been used both by those

who oppose passive euthanasia, and those who would wish to condone active voluntary and involuntary euthanasia.

In response to the distinction between intentional and non-intentional termination of life, Rachels (1986) questions that if an act can be wrong with one intention, that it can also be right with a different intention. He says that transformation from wrong to right cannot be effected by simply purifying the intention.

In response to the concept that there is a difference between acts and omissions it is argued that this is not always clear. A number of examples of the difficulty have been commonly given and include the question of interpretation of turning off a respirator as omitting ongoing treatment or acting to disconnect. Similarly, when discontinuing dialysis, or deciding not to give the next in a series of anti-biotic doses, should these be interpreted as acts or omissions? Rachels (1986) maintains that it is not true that when a medical practitioner allows a patient to die he does nothing, - because he lets the patient die. Neither does the distinction itself determine what is morally acceptable. The only clearly acceptable omission is when a choice not to undertake/continue treatment has been made by a patient.

In response to the third qualification which suggests the person dies from their illness not because of the failure to act on the part of the medical practitioner, it is argued that there is a gap between believing that it is permissible to cease to treat a person who is going to die anyway, and believing that it is permissible to cease to treat a person who is only going to die because of the decision to cease treatment (Campbell and Collinson 1988). This brings into question "do-not-resuscitate" orders in hospitals, withdrawal of treatment, and "nursing care only" orders which involve failure to provide food to infants, actions which are all argued to be proper because they can be regarded as omissions or as "extraordinary" treatment.

In answer to the suggestion that there is a difference between "ordinary" and "extraordinary" treatments, and in the obligation to undertake each form of treatment, it is argued that these terms are vague and imprecise and are open to variable interpretation which may be conflicting. The terms have been used to denote usualness,

availability, usefulness, complexity, invasiveness, artificiality and expense. Questions arise concerning the definition of treatments such as artificial feeding and antibiotics. Lack of consensus allows subjective judgements about treatment to be made on the basis of expected quality of a life, while at the same time denying that this is the basis of decision making (Campbell and Collinson 1988). Thus the difference may lie in the persona of the patient rather than in the treatment itself. Rachels (1986) maintains that it is difficult to tell the difference between the two types of treatments, and further that differences may change over time.

(d) Argument in Favour of the Quality of Life Perspective

The quality of life position requires the establishment of criteria by which quality and value are to be measured. While utilitarian principles generally provide the basis of decision making, these can produce widely divergent opinions as to the best course of action depending on what and whose interests are given priority, and who participates in the decision making process.

In the report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research (1983) it was argued that "the best interests of the patient", defined as well being and self determination, should be the foundation of medical decision making. Parkin (1986) concurred, but felt consensus on "best interests" should be achieved by consultation as there are "no all embracing formulae". It has also been argued that compassion for the individual should be the primary concern, and decisions which involve selective non-treatment, withdrawal or cessation of medical treatment should be made on the basis of the benefit to that individual. Those who hold these opinions could argue for euthanasia, either active or passive, voluntary or involuntary, depending on their religious and moral views on the sanctity of life.

(e) Argument in favour of Euthanasia from the Quality of Life Perspective

There are two main arguments in favour of voluntary, active or passive euthanasia. Firstly, it is regarded as a kindness, and as people have an obligation to be kind, euthanasia is therefore an obligation (Kohl 1975). It is said that people should be

permitted to escape useless or unbearable suffering and to maintain dignity (Downing 1986). It is also argued that extreme suffering is degrading and inhumane (Barnard 1986). People should be permitted to be released from pain. Those who argue in favour of active euthanasia suggest that it is more cruel to allow to die than to kill as it takes longer (Kuhse 1986, Rachels 1986). Letting a person die often runs counter to their best interests.

The second argument in favour of voluntary, active or passive euthanasia is based on the concept of justice. It is said that laws which prevent people from dying who are afflicted with incurable and painful disease and who want to die quickly, are cruel (Flew 1986), because to deny the right to "die with dignity" is unjust (Kohl 1975). It is also argued that while the State has a duty to protect life, this only applies to protecting lives from being taken against someone's will (Leenan 1989). It is increasingly argued that people have the "right to self determination" (Presidents Commission for the Study of Ethical Problems in Medical and Biomedical and Behavioural Research 1983), the "right to refuse treatment" (Ruark, Raffin and The Stanford University Medical Center Committee on Ethics 1988), the "right to die" (Miller 1987), the "right to die with dignity" (Gibbs 1986).

Argument in favour of active rather than passive euthanasia centres on this issue of the right of self determination. It is said that passive euthanasia does not allow people to die in a manner or at a time of their own choosing (Kuhse 1986).

Arguments in favour of justice and kindness are also used in support of involuntary euthanasia but the concept of a "worthwhile life" is usually also added. It may be argued that not all lives are of equal quality and therefore in medical practice it should be permissible to undertake selective non-treatment when continued survival means a life with handicaps. It is argued that "it is also right to discontinue a medical treatment such as life-sustaining intensive care, for a person who will not recover meaningful life" (Gillett 1988, p. 67). It is therefore "kind" to end the life of someone who cannot express an opinion on this matter because they appear to be suffering, or lack a "dignified", "meaningful" life (Kohl 1975).

Others who argue from utilitarian principles wish to widen the number and types of people whose interests would be considered in medical decision making. Robertson (1984) argued that action should be decided on (1) the previous wishes of the patient, (2) distress caused to relatives by undignified behaviour, (3) distress caused to other patients by undignified behaviour, (4) financial implications for other groups of patients, (5) desire to promote patient dignity. This presupposes that decisions are made by persons other than the patient, and allows decisions on grounds other than the best interests of the patient.

Some have denied any difference between active and passive euthanasia. It is stated that as there is no moral difference between killing and letting die, if letting die is a good or permissible action, then it follows that it is permissible to kill (Kuhse 1986).

(f) Criticism of Arguments in Favour of Euthanasia from the Quality of Life Perspective

Arguments in favour of active and passive euthanasia which have as their rationale that persons do not or will not have a worthwhile, meaningful, dignified life, are criticised because of their reliance on using utilitarianism as a guiding principle. The problem with arguments in favour of death which are based on notions of dignity, kindness, meaning, worth, is that there is no necessary agreement on the precise meaning of these terms, or the way they are to be measured.

If considerations of harm and benefit are widened to include the interests of persons other than the individual, then this will tend to lead to decisions which favour death (Brooks 1984). This is because decisions are likely to be made either by or with the approval of those who stand to benefit by the death. As Brooks (1984) said in response to the criteria for decision making proposed by Robertson (1984), the problem is how much weight to give each factor. He enquired how many relatives must be distressed and to what degree. More importantly, one could question the criteria on which dignity or undignified behaviour are to be determined, and the determinants by which medical care is to be rationed.

The other main argument against decision making on the basis of perception of quality of life is that if total protectionism based on strict sanctity of life notions is abandoned, then there is no fixed, acceptable, alternative standard which can be adopted. It is argued that if it becomes justifiable to kill or allow to die in certain circumstances, there is no logical reason why the categories of persons to die should not be widened to include others who may seem a nuisance to themselves, their family or society. The categories deemed suitable for death will be extended. This is the "slippery slope" argument.

It is also argued that any change is open to other abuses, as people may be coerced or irrationally agree to die. People may feel an obligation to die, based on belief that not to do so would seem selfish or cowardly. They may feel themselves to be a source of trouble to others, or they may wish to save money for their families or society (Kamisar 1986).

MORAL AUTONOMY AND SELF DETERMINATION

The value of moral autonomy and self determination as distinctive and distinguishing human attributes are acknowledged by those who argue both from the sanctity of life position and the quality of life position, and they are said to be the basis of all other rights. What devolves from the right to self determination is debated. On the one hand it is argued that as we have a right to control the duration of our lives we should not be penalised for exercising that right. It is also said to be reasonable to ask another to assist in terminating one's life, and it need not be morally wrong for another to assist in this (Charlesworth 1986, Syme 1991). Rachels (1986) agrees but adds the qualification that such a request or action must not violate the rights of third parties. Campbell and Collinson (1988) consider that while someone may have the right to harm themselves, no one else has the right to harm them just because they ask to be harmed.

SUMMARY

There is considerable agreement on the moral acceptability of passive euthanasia both by those who argue from a modified sanctity of life perspective and those who argue from the quality of life perspective. The only real disagreement may be in using the term passive euthanasia itself, with all its negative connotations, for actions, behaviour and treatment which are seen to be appropriate by those coming from the sanctity of life position. Campbell and Collinson (1988) maintain that to regard passive euthanasia as not permissible would mean that all patients should be treated with all available medical resources up to the moment when all life ceased. Most would regard this as unacceptable.

The differences between the sanctity of life and quality of life perspectives on the issue of involuntary active euthanasia are also less than first appears. There is therefore no clear cut division between the two positions, and all, apart from those who interpret the sanctity of life position quite strictly, are on a "slippery slope", although some may be further down the slope than others. Fairbairn (1988) says it is a slope onto which we must step unless we are to cause unnecessary suffering. The critical issue is to determine the difference between morally correct and morally wrong reasons for ending life.

CHAPTER 3

LEGAL ISSUES

THE LEGAL POSITION

The sanctity of life position is the view that the law in most western countries reflects; thus

"when decisions about life and death and the integrity of life are directly at issue, legal theory appears to consider sanctity of life not just one factor among others in determining the prohibitions, responsibilities and sanctions - it is the conclusive and fundamental factor." [(Keyserlingk E.W. 1979, Sanctity of Life or Quality of Life P 3-4) cited in South Australian Health Commission 1991, P 12]

According to Gormally (1986) it is vital that the State upholds the concept of the sanctity of life for it would be destructive of the sense of security held by citizens if the State itself killed, or condoned the killing of the innocent.

While philosophers have argued that there is no moral difference between killing and letting die (Rachels 1986), some Christian organisations do not subscribe to this viewpoint and have erected a number distinctions and qualifications to point out a difference between the two categories of action. Thus actions are permitted which may seem contrary to the notion of the sanctity of life, or which may have negative as well as positive effects. Laws in most western countries are based on the idea of the sanctity of life, but the practice of those laws is tempered by Judeo-Christian distinctions concerning actions and omissions, and the notion of "double effect". This allows room for divergence between the law and its practice. As a result there are few cases of active euthanasia brought to trial. However, the law in relation to passive euthanasia is more complex and difficult to interpret, and legally a question exists as to when a medical practitioner may cease to provide life sustaining procedures.

There are dangers in not maintaining the notion of the sacredness of human life as the fundamental basis on which law is formulated, for if it is permissible to kill or let die in certain circumstances, it is also feasible for those circumstances be altered or widened. This could result in abuses of human life. It is difficult to conceive of an alternative value which would be sufficiently protective of human life.

On the other hand The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research (1983) considered that "slippery slope" arguments themselves are subject to abuse, because proponents rarely demonstrate that allowing one kind of action which may seem justified will increase the tendency for other unjustifiable actions to occur. It was stated that the cost of accepting this argument is defence of the status quo and continued prohibition of some conduct which is acceptable.

LEGISLATIVE CHANGE

In the past decade legislation has been introduced in Australia and other countries to permit the termination of treatment in certain situations. Generally legislative change has aimed to uphold and strengthen the right to refuse medical treatment. In so doing the rights of the competent have been addressed, but the rights of, or society's duties towards the incompetent or never competent, have not yet been satisfactorily resolved.

Changes in the law have not yet been sufficient to diminish the discrepancy between medical practice and the law. This is because there are inherent difficulties in framing legislation which will safeguard the interests of all persons, and which will be sufficiently flexible to encompass all cases and situations, but at the same time prevent the extension of the acceptance of killing or withdrawal or termination of treatment to ever widening categories of persons.

In changing legislation there has been no shift in the presumption of the overriding importance of the sanctity of life. Legislation has been framed to preserve this value, and to preserve and enhance the duty of the State to protect life, except in situations where a person is deemed to have forfeited their right of protection, and also to ensure that the moral underpinnings of State legitimacy are preserved. The legislation which has been enacted is not without its flaws, and in some countries has resulted in unforeseen problems for patients as well as a narrowing of patient rights.

In 1984 the Dutch Medical Association established guidelines to enable medical practitioners to terminate the lives of patients, but proposals to change the law were rejected by the Dutch Parliament in 1986. Despite this rejection there is de facto agreement amongst the judiciary in the Netherlands not to prosecute medical practitioners if they terminate lives within the guidelines prescribed by the Dutch Medical Association. The guidelines established in 1984 were: lives may only be terminated by a medical practitioner following consultation with another physician, on the repeated request of a competent patient, in a situation where the patient is in a state of unbearable pain and suffering, and where no measures could improve their condition (Pence 1988; Leenan 1989; Wanzer et al. 1989). Voluntary euthanasia is still officially illegal in the Netherlands and medical practitioners are in an uncertain legal situation when they terminate patients lives even within the guidelines prescribed. Recently Dutch medical practitioners and judges have relaxed the guidelines concerning categories of patients considered acceptable for mercy killing, and paraplegia, multiple sclerosis, and gross physical deterioration with advanced age have also been included (Pence 1988). Involuntary euthanasia continues to be forbidden and patients must request the termination of their lives. For some people the widening of categories is a logical development, for others it is an insidious slide towards involuntary euthanasia.

Legislation to permit living wills had been introduced in 40 American states by 1990 (Annas 1991). Most living will legislation in America is strictly limited and therefore has a number of drawbacks. Firstly, patients must be certified as 'qualified' to have their will respected, and only terminally ill patients qualify for such certification. In practice the legislation erodes the rights of others who may wish to make living wills regarding termination of treatment outside the ambit of the Acts. This is because common law rights, which permit patients to refuse or consent to medical treatment, are not specifically preserved. Where living will legislation exists, given the litigious atmosphere in America, the current interpretation of the law in the States is that all medical measures must be taken to save the life of a patient unless a valid living will is in place (Heintz 1988). The prior wishes of patients who are not certified are even less

influential once they become incompetent than before (Ranaan 1988). Secondly, the types of treatment which can be refused are limited to "artificial" or "extraordinary" treatment (Annas 1991). Thirdly, generally they make no provisions for power of attorney or proxy decision making (Annas 1991). Fourthly, even where an advanced directive exists this is no guarantee that medical practitioners will act upon it or implement it for fear of criminal charges. There are no penalties for not acting upon a living will (Wanzer et al. 1989; Annas 1991).

By 1992, 19 American states had enacted legislation to provide that a spokesperson/proxy can authorise the withdrawal of life support, (Kjellstrand 1992) although every state has general power-of-attorney legislation which permits a person to nominate another to act for them if they become incapacitated (Annas 1991). Proxy health care legislation is also limited as such powers are extended to competent adults only, but not to children, the mentally retarded and other incompetent adults. The US Patient Self Determination Act of 1990 also now requires hospitals and nursing homes to approach patients to find out their wishes regarding life-sustaining measures (Kjellstrand 1992).

In Britain the limits of treatment are not clearly defined legally and decisions are usually left to the discretion of medical practitioners. At the same time patients have the right to inform doctors of their wishes concerning treatment. In practice only some medical practitioners respect their patients' wishes, while others insist on absolute control of decision making (Ranaan 1988). The possibility of introducing living will legislation has been investigated but met with opposition from the British Medical Association. There have also been unsuccessful attempts to introduce legislation to legalize voluntary euthanasia in Britain in 1936, 1969 and again in May 1990 (Helme 1991).

Living will legislation was pioneered in two Australian states, with legislation in other states modelled on these precedents. In South Australia, The Natural Death Act, passed in 1983, provides that an adult person may direct that extraordinary measures are not to be used if they suffer from a terminal illness. In Victoria, The Medical Treatment

Act, 1988, and the Medical Treatment (Enduring Power of Attorney) Act, 1990, enable a mentally competent person of 18 or more years, or their appointed agent on their behalf, to refuse medical treatment generally, or for a current condition. The Victorian legislation, in permitting proxy authorisation and the power to refuse medical treatment generally, gives greater patient autonomy than the South Australian Act.

LEGISLATION IN SOUTH AUSTRALIA

The 1983 Natural Death Act had a long genesis in South Australia. A Bill was first introduced in 1979 and in 1980 it was referred to a Select Committee. The rationale given for its introduction was that the advances in medical knowledge had resulted in a qualitative change in the medical treatments available to the terminally ill. This meant that medical practitioners have the ability to use, and often feel pressured to utilize all procedures available to prevent death. This, it was stated, had resulted in death being regarded as unnatural, an event which is increasingly taken out of the hands of the dying and their relatives by "experts who claim exclusive rights to knowledge" (Hansard, 22 October 1980, p. 1280).

The legislation did not pass both houses, and one of the problems lay in the lack of general legal recognition of brain death at that time. It was considered that the definition of death in the proposed Bill was inconsistent with the definition under consideration by The Australian Law Reform Commission and in other Australian states at that time. Without a definition of death it was opined that withdrawal of treatment from people who were brain dead and artificially sustained on respirators, could be regarded as homicide (Justice Michael Kirby, Australian Law Reform Commission). Reintroduced three years later with reference to definition of death omitted, The Natural Death Act was passed in 1983 (see Appendix B). The passage of the Death (Definition) Act in the same year meant that it was unnecessary to include a definition of death in the revised Act.

THE SCOPE OF THE ACT

It was stated during the second reading that the principle purpose of the Act was to "provide for, and give legal effect to, directions against the artificial prolongation of the dying process" to "ensure that a terminally ill patient will be able, if he wishes, to issue a direction that extraordinary measures are not to be taken when death is inevitable and imminent" (Hansard, 23 March 1983, p. 550).

Adults have the right to refuse medical treatment under common law in South Australia, and this right ensures that no medical practitioner is permitted to treat a person against his known wishes. However two problems exist in the exercise of this right. Firstly, the right is not generally well known by members of the public. Secondly, the right can only be exercised when a patient is conscious. When a patient becomes unconscious, treatment is then undertaken at the discretion of the medical practitioner. It is then possible that the given treatment may not be in accord with the patient's desires. The Natural Death Act was therefore designed to ensure that the wishes of the patient concerning treatment would be respected if the person became unconscious, and to remove the responsibility for such decisions from the medical practitioner and the relatives of the patient.

The right to refuse medical treatment once a person became unconscious was not extended to all possible cases and situations, and the Act was limited in scope in three ways: (a) in the categories of persons it embraced, (b) in the nature of the medical states it covered, and (c) the type medical treatments it included.

The legislation was restricted to adults only, with the issues surrounding the treatment of terminally ill children excluded from consideration. Neither did the Act include reference to people whose condition could be described as "vegetable".

To come within the ambit of the Act, patients were required to be suffering from "terminal illness", which was defined as one from which death would be "imminent" if extraordinary measures were not undertaken, and from which there was no hope of temporary or permanent recovery.

The medical treatments encompassed by the Act included only "extraordinary measures". These were defined quite specifically as medical or surgical measures which prolonged life, or were intended to prolong life by supplanting or maintaining body functions that were incapable of independent operation. It was understood that there may be considerable variation in interpretation of the term in medical practice, but it was intended that only "useless measures in the case of a dying person" be included in the definition for the purposes of this Act (Hansard, 30 March 1983, p. 744).

Therapeutic medical measures were excluded from the scope of the Act. While it was recognised that people may have the right under common law to refuse ordinary or therapeutic medication for treatable diseases, it was felt that the Act should not attempt to codify that right. The legislation therefore dealt with "useless treatment" only.

To avoid misinterpretation in the minds of the general public, and to ensure that the Act was not seen as one which legalised euthanasia, it was stated that acts which cause or accelerate death were not authorised. Such acts were differentiated from those which simply permit "the dying process to take its natural course". Further, it was stated that non-application of, or "withdrawal of extraordinary measures from a person suffering from a terminal illness did not constitute a cause of death".

The Act provided that persons who wished to ensure that "extraordinary measures" were not undertaken when they were terminally ill, could make a declaration on a prescribed form, which must be witnessed by two witnesses.

Medical practitioners were required to act in accordance with the declaration, unless they believed that the patient had revoked or intended to revoke their declaration or that the patient did not understand the consequences of the direction at the time it was made.

LIMITATIONS OF THE NATURAL DEATH ACT

The South Australian Natural Death Act, 1983 was a strictly limited piece of legislation and did not attempt to address all problems surrounding death due to terminal illness. Through its use of narrowly defined terms, specific inclusion of only

particular types of persons, and the requirement that people make a declaration concerning their desire for treatment in a single type of situation, it attempted to avoid the pitfalls of being perceived as an Act which legalised euthanasia. In so doing, it did not address a number of issues. These included the position of the terminally ill child; the situation of persons who become comatose or who had entered a state commonly referred to as "vegetable" and who required treatment to remain alive, but who, given such treatment, might live for extensive periods; persons who were severely ill but who were not terminally ill within the strict definition of this Act; and patients with severe and irreversible dementia. In so doing the Act avoided pronouncement on some of the more difficult issues faced by medical practitioners.

Neither did the legislation address the issue of withdrawal of therapeutic treatment for treatable conditions where patients also suffered from incurable but not yet terminal disease, or those who were frail and elderly. In stating that decision making in these situations should be left "to the ethics of the patient/doctor relationship and to the common law" (Report of the Select Committee of the Legislative Council on the Natural Death Bill, 1980, p. 2), medical practitioners were left to continue to operate in a legally ill defined position.

With the definition of "terminal illness", the Act required that death be "imminent" and extraordinary measures be "useless", for the declared wishes of a patient to be followed. In such a situation a declaration would appear to be unnecessary, for given the medical evidence to the Select Committee, it would seem that such measures would not generally be undertaken in any case. The legislation was therefore almost superfluous.

One of the supposed benefits canvassed in parliament in support of the legislation (see Appendix C) was that people would be given peace of mind knowing they would not be subjected to unwarranted medical treatment in the terminal stages of illness. It could be suggested that the legislation would fail in this area because in attempting to prescribe limits and institute safeguards, the Act applied to so few cases and situations that it failed to address other, equally important community concerns

surrounding the termination of medical treatment. Every treatment avenue could still be pursued until there was no hope, and it is this prolongation of treatment which is the concern of many in the community.

The Act made a distinction between acts which cause or accelerate death, which were not permitted, and acts which permit the dying process to take its natural course, which were permitted (see clause 7 (2)). In so doing the Act attempted to distinguish between passive and active acts, in order to accentuate the dichotomy between legislating for greater patient control over how death occurs and permitting some form of euthanasia. It could be argued however that there is little difference between such acts. Both have the same effect, i.e. the death of the patient, and it is only in the intention of the act that the difference lies.

It was suggested during the parliamentary debates that few people would avail themselves of the opportunity to make declarations under the Act, although their ability to do so, and the resultant peace of mind that would ensue, were major benefits of the legislation. It could be suggested there are two other benefits of the legislation, one direct and one indirect. Firstly, the Act gives a legal affirmation that decision making is not the sole prerogative of the medical practitioner. Secondly, the Act makes some legal recognition that medical science has advanced so far that the issue is no longer simply a medical struggle to fight death and disease, but other issues are also important. Although not mentioned directly, the Act by its very existence acknowledged the ethical issues surrounding the debate on quality of life, and the economic issues related to the ability to pay health costs.

PROPOSALS FOR FURTHER LEGISLATIVE CHANGE IN SOUTH AUSTRALIA

A Select Committee on the Law and Practice Relating to Death and Dying was established in South Australia in December 1990 to examine (a) the extent to which health services and the law provided adequate options for dying with dignity; (b) whether there was sufficient awareness of pain relief and palliative care, whether there was adequate provision of such services; whether there was sufficient awareness of The

Natural Death Act; (c) to what extent, if any, the law relating to dying needed to be clarified or amended.

The Committee found that "the law should be reformed to clarify patients' rights, to reinforce sound medical practice and to reflect prevailing community attitudes that people should not be kept alive at all costs" (1992, p. 1). It also found that there was little understanding or knowledge of The Natural Death Act in the community, and further that the Act had a number of drawbacks. These difficulties included the fact that the living will must be made well in advance of the terminal illness, by which time advances may have been made in medical expertise. The views of the patient may have been different if they had been aware of the medical context in which the declaration would take effect. A medical practitioner when confronted with an unconscious patient is unable to present current treatment options. Living wills are only effective for terminal conditions. Finally, a person may be resuscitated if there is no knowledge of a declaration.

In its second interim report published in May 1992, the Committee made a number of recommendations. Among the most important of these were; (1) the right to refuse treatment be established by statute; (2) a medical power of attorney be established by statute; (3) the provision of normal palliative care (defined as "measures directed primarily at maintaining or improving the comfort of a patient who is, or would otherwise be, in pain or distress") administered without negligence and with the informed consent of the terminally ill patient is not to carry any criminal or civil liability even if it has the effect of shortening life; (4) the Natural Death Act should be repealed; (5) "do-not-resuscitate" orders be replaced by "good palliative care" orders, based on consultation with patient, family, or other significant persons and ward staff.

While the Committee felt that the proposed "good palliative care" orders, and the power to confer medical power of attorney would cover the needs of intellectually disabled people, and the elderly suffering dementia, no recommendations were made regarding the withdrawal or non-initiation of treatment to severely disabled or low birth weight infants.

The Committee specifically rejected any notion that the law should be changed to provide for medical assistance in dying, and further maintained the position that there is a moral distinction between allowing someone to die and bringing about a person's death. It was felt that this distinction should continue to be preserved in law.

CONCLUSION

If the recommendations of The Select Committee on the Law and Practice Relating to Death and Dying become incorporated into legislation in South Australia they will enhance patient rights and self autonomy and prevent the continuation of invasive or unnecessarily aggressive medical treatment where this is no longer desired by the patient. However, there are dangers in extending the right of self determination to incompetent patients through the use of proxies because of the inherent difficulty of ensuring that decisions are made on morally proper grounds. Among the criteria on which proxies must or will base decision making are the quality of life available to the person for whom they make the decision, and the emotional and financial costs to close relatives and society generally. The establishment of clearcut, fixed standards on such issues is essentially problematic.

CHAPTER 4

ISSUES IN MEDICAL PRACTICE

INTRODUCTION

In Australia a number of problems have emerged as a result of advances in medical knowledge and technology. Firstly, there is lack of consensus between medical practitioners on what are correct and desirable medical practices in the treatment of neonates, disabled babies, the terminally ill and the elderly. Secondly, there is a widening gap between the law and medical practice, for often, what appears to be the best ethical decision and action in a particular medical situation is either in conflict with the law, or the law is unclear. Thirdly, there is evidence of a lag between changing community attitudes and the attitudes of medical practitioners to treatment in such situations, and an even greater differential between community attitudes and what is permissible by law. Finally, questions have been raised regarding resource allocation given the increasing expense of many life sustaining medical procedures.

MEDICAL PRACTICE IN AUSTRALIA

It has become established medical practice to permit non-initiation of treatment and withdrawal of treatment in certain cases and situations in Australia. In the treatment of new born infants it has become accepted practice to withdraw or withhold medical treatment where an infant is dependent on medical treatment for survival, where death is inevitable regardless of treatment, where there is substantial probability of a major disability, and/or where continued treatment cannot relieve pain or suffering believed to be intolerable. It is also accepted practice for life support not to be given to extremely low birth weight infants (South Australian Health Commission 1991). It has also become established practice for decision making in these areas to be the responsibility of parents in consultation with health care providers.

It is also accepted practice for medical practitioners not to treat intercurrent, treatable diseases such as pneumonia in the frail elderly, and not to undertake aggressive resuscitation procedures where an elderly person experiences acute illness

and is also suffering from other chronic ailments (written submission to Select Committee on Natural Death Act 1980 from representatives of The Australian Medical Association). It has also become more common for medical practitioners to order doses of pain relief, the side effect of which may be death. The use of do-not-resuscitate orders has increased in nursing homes (Wanzer et al. 1989).

There is some evidence that medical practitioners and nurses also undertake active steps to terminate the lives of patients. Kuhse and Singer (1988) who conducted a survey of attitudes and practices to voluntary euthanasia amongst medical practitioners in Victoria found that 29% of the 369 doctors who responded to a question which asked if they had taken active steps to bring about the death of a patient when requested by the patient to do so, replied that they had. In a similar study among nurses in Victoria, Kuhse and Singer (1992) found that of the 333 nurses who had received a request to hasten the death of a patient by the use of "direct and active steps", 5% had complied with the patient's request, without having been asked by a medical practitioner to do so. Twenty five percent of respondents had been asked by a doctor to directly and actively end the life of a patient, and of these 85% had done so, and 80% had done so more than once (p. 22).

MEDICAL PRACTICE AND THE LAW

The existing legal prohibitions on the taking of life in most countries have led to an increasing distance between written law and medical practice, given the moral and ethical dilemmas posed by the rapid advances in medical knowledge, expertise and technology. These changes enable medical practitioners to maintain life almost indefinitely. However, increasing control over the length of life has not necessarily been accompanied by a concomitant ability to maintain health, and the quality of the additional life may vary from tolerable to miserable. No longer simply faced with the task of fighting disease, illness and death, doctors are required to decide when to use, and when to cease to use, life sustaining measures.

The position with regard to medical practices is not static, and change in medical practice has been relatively rapid in the past few years. Practices which were unacceptable a few years ago have become more commonplace. Moves to widen the range of acceptable, if not legal, practices are evident in medical journals, where there is a debate at present concerning the categorisation of life-sustaining measures. Some writers suggest that there is a growing perception that there is little difference between naso-gastric feeding or intravenous hydration and other life-sustaining procedures such as resuscitation, ventilation or dialysis, therefore it is ethical to withdraw nutrition and hydration from dying patients (Ruark & Raffin and the Stanford University Medical Center Committee on Ethics 1988; Steinbrook & Lo 1988). This was the position of the American Medical Association in 1986 (Steinbrook & Lo 1988). Regarded as the same as other medical interventions, it is therefore seen as ethical to discontinue feeding.

These practices are either not clearly legal or are clearly illegal. In a discussion paper on the ethics of limiting life-sustaining treatment, The National Health and Medical Research Council (1988) stated that contrary to popular belief and common practice, parents do not have the legal right to determine that their infant be refused medical treatment without which the infant would die. It is the legal view that life-sustaining treatment must be given except in exceptional circumstances where death is imminent, or where a child will suffer life-long pain and distress. Future mental handicap is not seen as sufficient grounds for withdrawal or non-initiation of life-sustaining treatment. It appears to be the legal view therefore, that quality of life is not a relevant criterion which doctors may weigh up when deciding whether to undertake aggressive treatment. Recognising that the legal position runs counter to medical practice, the document added that "in cases of extremely low birth weight babies and some infants with major congenital abnormalities, it is likely both doctors and parents make decisions which are not acceptable under present Australian laws." The problem was that while these decisions may be illegal, most Australians considered them to be reasonable. It was also the expressed opinion of Mr Justice Kirby that current practice runs counter to the law as he stated that, "the silent deaths of grossly deformed and

retarded babies, in the medical practice in a number of countries, constitutes murder or manslaughter, at least in its strict letter" (National Consensus Conference on Neonatal Intensive Care 1989).

The National Health and Medical Research Council (1988) discussion paper also stated that in a situation where a doctor fails to undertake routine medical treatment, and where that omission was the cause of death of a patient, the doctor may be charged with manslaughter. Further, where such an omission was deliberate, the doctor may be charged with murder. Acts of omission are seen in exactly the same light as acts of commission for the law is concerned with intent. On the other hand the document stated that the law does not require "heroic measures in all situations".

The problem for medical practitioners is that often the most ethical, appropriate or beneficial decision may be in clear conflict with the law, or there exists ambiguity or confusion in the way the law applies in a particular situation.

The failure of the law to keep pace with developments in medicine and medical practice, when combined with a lack of clear guidelines for current practices have resulted in wide differences in practice between individual doctors. In addition there are variations between the approaches adopted by different medical institutions on attitudes and practices in the treatment of non-viable infants born and the elderly.

ATTITUDES TOWARDS CHANGES IN MEDICAL PRACTICE

(a) Attitudes of Medical Practitioners

There is increasing awareness amongst members of the medical community of the need not only to change medical practices, but to alter, or at least specify clearly, the official guidelines to codes of practice. A number of discussion papers have been published on the ethical and legal issues surrounding non-initiation, withdrawal, and cessation of life-sustaining medical treatments both in Australia and overseas (Presidents Commission for the Study of Ethical Problems in Medical and Biomedical and Behavioural Research 1983; National Health and Medical Research Council 1988;

South Australian Health Commission 1991). Each of these reports has sought to delineate the desirable principles on which future decision making should be based.

There has been little published research on the attitudes of medical practitioners to issues of medical treatment for the terminally ill. A report on general practitioners' views and experiences in the care of terminally ill patients prepared for the South Australian Select Committee on the Law and Practice Relating to Death and Dying (1991c) suggested that the majority were reasonably satisfied with the care they provided for terminally ill patients at home. However 80% thought they would benefit from more training in the management of cancer pain, and 80% for the control of other symptoms (p. 8). The report highlighted the problems of establishing where the locus of responsibility in decision making lies (or should lie) in the care of the terminally ill. Once patients were admitted for institutional care (especially in public hospitals), many general practitioners experienced difficulties in communicating with hospital specialists, gaining access to patients and felt excluded from decision making, which was at that point apparently shifted to the hospital carers.

Neither has much research been undertaken on the attitudes of medical practitioners towards euthanasia, but the little which exists indicates that many believe it is acceptable to terminate the lives of their patients at their request. Kuhse and Singer (1988) found that 62% of doctors surveyed, responded in the affirmative to the question "do you think it is sometimes right for a doctor to take active steps to bring about the death of a patient who has requested the doctor to do this?" Thirty four per cent gave a negative response (p. 624). Only 16% of these respondents said their views were based on religious principles. In response to the question "do you think the law should be changed to allow doctors to take active steps to bring about a patient's death under some circumstances?" 60% replied in the affirmative and 37% in the negative (Kuhse and Singer 1988, p. 625). While a majority were in favour of change in both medical practice and legislation, there was a considerable minority who disagreed with these proposals.

In a survey of the attitudes of medical students, interns and specialists at Flinders Medical Centre, South Australia to active voluntary euthanasia Robertson and Tobin

(1989) made similar findings. In response to the question "do you think it is ever right for a doctor to take active steps to bring about the death of a patient who has requested the doctor to do this?" 70% responded in the affirmative (p. 35). Unlike the Kuhse and Singer survey, this research did not ask if the law should be changed in Australia, but in response to a question which asked if "it would be a good thing" if the situation in The Netherlands were to exist in Australia, 65% responded in the affirmative. This question was similar to one asked in the Kuhse and Singer survey for which the response was "yes" 59%, "no" 37%. However, methodological weaknesses in the questionnaires used in these surveys, both of which asked leading questions of this nature mean that it is difficult to give much credence to these responses.

Both surveys indicated a lack of unanimity in current medical thinking on these ethical issues, although it is unrealistic to expect that there would ever have been complete unanimity. However, the results do indicate that a majority of medical practitioners do not subscribe to traditional medical views and reflect attitudes held by members of the wider community.

(b) Attitudes of Nurses

Kuhse and Singer (1992) have also undertaken a survey of nurses' attitudes and practices towards euthanasia and found that only 25% of nurses replied in the affirmative to the question "was it sometimes right for a nurse to take active steps to bring about the death of a patient who has asked her or him to do so, without having been asked directly by a doctor to do so". Nurses were also asked if the law should be changed to allow doctors to take active steps to bring about a patient's death under some circumstances. Seventy eight percent of respondents were in favour of a change in the law (p. 22).

(c) Community Attitudes

There has been an increasing trend for a shift in the locus of authority in decision making away from the medical practitioner to the patient. This shift has occurred as a result of the growing awareness among medical practitioners of the need to take greater cognisance of patients' wishes concerning medical treatment, especially in the terminal

stages of an illness. This heightened sensitivity comes in response to increasing community demands for a shift away from the hierarchical, authoritarian, paternalistic, externally imposed decision making traditions of the past. Changing community attitudes are themselves partly a response to the problems generated by the greatly increased ability of medical science to control the length of life, but not necessarily quality of life. The result has been that people have demanded the right to greater self determination regarding medical treatment.

A report prepared for the South Australian Parliamentary Select Committee on the Law and Practice Relating to Death and Dying (1992b) did not deal specifically with this issue, but canvassed the degree of satisfaction of bereaved relatives with terminal care. Many relatives felt that information about dying had been given insensitively or inappropriately. Relatives of 25% of patients with severe pain did not feel their pain had been sufficiently controlled. While the majority of those whose relatives died at home were satisfied with the services provided, some experienced difficulties in gaining access to their general practitioner and in obtaining practical help with caring. For those who died in hospitals, there was a perception that there was insufficient information given about the patient's condition and progress, and some doctors were seen as uncaring or insensitive. The findings suggest that the relatives of many patients did not feel they had control of, or adequate access to information about decision making for their relative. This problem was especially acute for those whose relatives died in public hospitals, as only 52% felt sufficiently informed about the patient's condition and progress (p. 25).

Not only have social attitudes to authority altered but increasing proportions of people in the community consider that there needs to be further changes in what are regarded as permissible medical practices. In an opinion poll conducted by the Sydney Morning Herald newspaper in 1982, 69% of people polled believed that if an adult had a terminal or chronic illness and wished to end his life, a doctor should help him die if asked to do so. Only 24% considered the doctor should refuse, and 8% were undecided [15 Nov 1982, p. 2, cited in Kirby (1986) p. 84]. A poll conducted in 1985 in America

similarly found that 68% of respondents believed that "people dying of an incurable disease should be allowed to end their lives before the disease runs its course" [Associated Press/Media General, Poll No 4, Richmond, Va, cited in Wanzer et al. (1989) p. 844].

In a Morgan Gallup Poll of Australian public opinion on attitudes towards voluntary euthanasia for the terminally ill was conducted in May 1992, 73% of respondents believed that a doctor should let a person who was hopelessly ill and in great pain, die. Only 18% felt the doctor should try to keep the patient alive, while 9% were undecided.¹ In the same poll 76% of respondents said a doctor should be permitted to help a patient die if requested by the patient. Eighteen percent said this should not be permitted and 6% were undecided.²

RESOURCE ALLOCATION

Increasingly the absolute cost of delivery of health care to the community is questioned. It is recognised that the economic costs of new medical technology, techniques and procedures are significant, and concern has been expressed about the indiscriminate application of medical treatment where there are doubtful benefits to the individual patient in terms of longevity or quality of life. Further, the benefits of much of the expenditure on sophisticated equipment and procedures have often been confined to a comparatively small number of patients, and these have been directed to the final, days, weeks or months of their lives.

The problems of the absolute costs of health care, and the equitable sharing of benefits to the community is exacerbated in Australia by two interrelated factors. Firstly, the belief that access to health care is a right which should be available to all has resulted in the provision of universal health care. In countries such as America, where medical care is mainly privatised, the issue of resource allocation becomes a matter of

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- 1 Respondents were asked in a question about people who are hopelessly ill and in great pain, "if there's absolutely no chance of a patient recovering, should the doctor let the patient die - or should the doctor try to keep the patient alive as long as possible?"
 - 2 People were asked "if a hopelessly ill patient, in great pain, with absolutely no chance of recovering, asks for a lethal dose, so as not to wake again, should a doctor be allowed to give a lethal dose, or not?"

individual ability to pay or an equity problem, with the people most likely to be rationed in their access to medical care being the poor. In Australia where access is not based on class, if rationalisation of expenditure is to occur, decisions must be based on either the category of patient, illness or disability; a statistical approach; quality of life criteria or a combination of all three. Secondly, although there are two fundamental principles which underpin modern medicine, the preservation of life and the relief of suffering, the former has tended to dominate traditional approaches to medical health care delivery, thus the focus has been on the maximum delivery of services to the individual in order to preserve that life. Medical practitioners therefore feel an obligation to do everything possible for the individual regardless of cost.

While it may or may not be ethically proper to continue all measures to maintain a life no matter what its quality, there is increasing divergence between what medical science can achieve and the resources society is willing to provide for particular cases. Resources are finite and decisions must be made concerning the way they will be apportioned, and who should be rationed. The dilemmas posed by the acknowledgement of this issue as one of resource allocation for the entire society, not simply as a medical or ethical problem to be resolved at an individual case level are now beginning to be discussed more openly.

The problems of costs incurred in intensive care wards have been raised by several writers. While there are no figures available for Australia it has been estimated that intensive care represents 15% of hospital budgets in the USA (Fisher & Raper 1990a). In the area of neonatal intensive care the costs per day are said to be nearly twice the costs in other wards (The South Australian Health Commission 1991). Wells (1989) suggests that the mortality rate for extremely premature babies of less than 25 weeks gestation and weighing less than 1000 gms can be as high as 90% with or without intensive care (p. 197).

It is also acknowledged that the ongoing treatment of the physical problems of premature and low birth-weight infants as well as those born with profound neurological and other physical abnormalities who survive as a result of intensive care, may involve

considerable financial costs to the community (Wells 1989). Similar problems may exist for adults following intensive care, but the balance of benefits may be considerably outweighed by the costs, especially when intensive medical intervention occurs in the later stages of terminal illness.

It has been suggested that funds would be more profitably allocated to health programs which would reach a wide range and number of people rather than simply expending large sums on maintaining elderly people during the last year of their lives (Crispell & Gomez 1987). Fisher & Raper (1990a) suggest that decisions regarding overall allocation of resources between competing medical programs should be made at governmental level. Where decisions are required concerning treatment for individual patients an assessment must be made of the balance of costs versus benefits (Fisher and Raper 1990b). This assessment must be made using objective medical data concerning prognoses, and subjective evaluations of quality of life. Because both are difficult to assess it is proposed that at the beginning of life, the preservation of life must be the highest priority, while at the end of life, alleviation of suffering, or care, must take precedence over preservation of life, or cure.

CHAPTER 5

METHODOLOGY

RESEARCH AIMS

The aim of this research is to examine the attitudes and practices of medical practitioners and nurses in South Australia towards the management of death, dying and euthanasia. In particular the research aims, firstly, to examine whether medical practitioners and nurses are ever asked to hasten the death of patients, and the ways such requests are handled; and secondly, to investigate how medical practitioners and nurses consider such requests could be handled, and whether guidelines should be established to clarify the current legal position.

METHODOLOGY

A limited number of individual interviews were conducted initially, the purpose of which was to (1) familiarise the researchers with some of the medical and nursing issues surrounding the care of persons with severe or terminal medical conditions, (2) supplement the researcher's awareness of the ethical issues involved in the management of death, (3) inform members of key groups of the research, and (4) obtain assistance in the research undertaking. The South Australian Minister of Health and Chairman of The House of Representatives Select Committee on Death and Dying was also informed of the research. A complete list of individuals consulted is contained in Appendix A.

To heighten awareness of the research among potential respondents, notices were placed in, and articles written for a number of newsletters and publications. These included the *South Australian Medical Review*, the official publication of The Australian Medical Association (SA Branch), which is sent to all registered medical practitioners in South Australia irrespective of membership of the AMA; *Hospres*, the quarterly newsletter of The South Australian Association for Hospice Care Inc.; and the newsletters of The Nurses Board of South Australia, The Australian Nursing Federation, and The Royal District Nursing Society of South Australia.

To answer the questions posed at the outset of the research, surveys using mail-back, self-administered questionnaires sent to medical practitioners and nurses, were the principal primary data used.

The questionnaires (see Appendix D) were developed from those used by Kuhse and Singer (1988) and Robertson and Tobin (1989). They were further refined following consultations with and suggestions from the following persons: the President of the Australian Medical Association (SA Branch), members of the Working Party on Euthanasia of that organisation, The Adjunct Director of The Southern Cross Bioethics Institute, the President of the South Australian Voluntary Euthanasia Society, the Bioethicist at Flinders Medical Centre, and two other independent medical practitioners.

Sample sizes were limited to 500 nurses and 500 medical practitioners resident in South Australia.

The list of medical practitioners registered to practice in South Australia, published by The Medical Board of South Australia, was used to obtain the sample of medical practitioners. The register published in March 1990 was used to draw a 10% sample, which, when non-residents of South Australia were excluded (112 persons), comprised 494 persons.

The sample of 500 nurses was obtained from the register of General Nurses who are registered to practice in South Australia, or who have practised in the past five years. This register is maintained by The Nurses Board of South Australia. As The Nurses Board did not give direct access to these data, the sample was randomly drawn by computer, and questionnaires were mailed to potential respondents by the Board.

To maintain confidentiality the questionnaires were not marked numerically by the researcher, nor were respondents required or asked to reveal their names or addresses. Questionnaires were mailed in August 1991, with two reminder/thankyou letters posted to medical practitioners at a later date, and one follow up letter sent to nurses. As it was not possible to know who had responded, follow up letters were sent to all persons in each of the medical practitioner and nurse samples.

Response Rate

A total response rate of 68% was obtained from the sample of medical practitioners, 60% of which (298) were usable returns, while 57.8% of nurses responded to the survey, 55% of which (278) were usable returns (see Table 1).

Table 1: Survey Response Rate

| | Doctors | Nurses |
|------------------|---------|---------|
| Total returns | 68.2 | 57.8 |
| Usable returns | 60.3 | 55.2 |
| Unusable returns | 7.9 | 2.6 |
| | 100.0 | 100.0 |
| | N = 494 | N = 500 |

Data Analysis and Presentation

Data for medical practitioners and nurses are generally presented separately throughout the report, and comments made where necessary on differences in responses between the two groups. Sub-group differences according to age, gender and religious affiliation have been examined for each question, and for some questions differences according to the number of years of medical practice and medical speciality were also examined. These are discussed where differences proved to be of statistical significance.

CHARACTERISTICS OF THE SAMPLE POPULATION

A summary of the characteristics of the sample population is provided in Table 2.

Table 2: Sample Population

| | | Doctors | | Nurses | |
|-------------------------|-------------|------------|------|------------|------|
| | | No | % | No | % |
| Sex | | | | | |
| | Male | 222 | 75.5 | 18 | 6.5 |
| | Female | 72 | 24.5 | 257 | 93.5 |
| | Not stated | 4 | 1.3 | 3 | 1.1 |
| Age | | | | | |
| | 20-29 yrs | 19 | 6.4 | 60 | 21.8 |
| | 30-39 yrs | 95 | 32.2 | 108 | 39.3 |
| | 40-49 yrs | 85 | 28.8 | 69 | 25.1 |
| | 50-59 yrs | 39 | 13.2 | 38 | 13.8 |
| | 60+ yrs | 57 | 19.3 | - | - |
| | Not stated | 3 | 1.0 | 3 | 1.1 |
| Religion | | | | | |
| | C of E | 86 | 29.2 | 65 | 23.7 |
| | Other Prot. | 58 | 19.7 | 101 | 36.9 |
| | Catholic | 50 | 16.9 | 50 | 18.2 |
| | Other | 25 | 8.5 | 12 | 4.4 |
| | None | 76 | 25.8 | 46 | 16.8 |
| | Not stated | 3 | 1.0 | 4 | 1.4 |
| Area of Medicine | | | | | |
| | GP | 131 | 44.0 | - | - |
| | Specialist | 152 | 51.0 | - | - |
| | Not stated | 15 | 5.0 | - | - |
| Total | | 298 | | 278 | |

CHAPTER 6

SURVEY RESULTS

INTRODUCTION

This chapter reviews the results from the survey on the attitudes and practices of medical practitioners and nurses towards the management of death, dying and euthanasia. The findings are divided into four main sections. The first part examines the question of whether medical practitioners and nurses are ever asked to hasten the death of a patient. Part two reviews respondents' attitudes to the issue of hastening or bringing about a patient's death. Part three considers the way requests are currently handled, while part four explores attitudes towards alternative ways for managing the dying process in the future.

REQUESTS TO HASTEN THE DEATH OF PATIENTS RECEIVED BY MEDICAL PRACTITIONERS AND NURSES

All respondents were asked if they ever received requests to hasten the death of a patient either by withdrawing treatment or by taking active steps, and whether these requests came from the patient or the patients' family. No definition of the term 'active steps' was given in the questionnaire but it was considered that the meaning was implicit in the juxtaposition of the term with the phrase 'withdrawal of treatment', and that no confusion should therefore exist between passive and active euthanasia in this context.

Medical Practitioners

Table 3 shows that 47% said they had received a request from the patient to hasten death by withdrawing treatment, and the same proportion had received such a request from the patients' family. Thirty three percent said they had received a request from a patient to hasten death by taking active steps and 22% had received a request from a patients' family.

There were only minor differences in reported requests according to age. The only significant differences were for reported requests from patients for withdrawal of treatment (see Table 4). Sixty eight percent of medical practitioners aged 20-29 years

reported receiving such requests compared with only 30% of those aged 60 years and above.¹

Table 3: Requests to Hasten a Patient's Death by Withdrawal of Treatment or by Taking Active Steps

| | Doctors | | Nurses | | Total Population | |
|--------------------------------|---------|------|--------|------|------------------|------|
| | No | % | No | % | No | % |
| <u>Withdrawal of treatment</u> | | | | | | |
| Request made by patient | 140 | 47.5 | 129 | 47.6 | 269 | 47.5 |
| Request made by family | 138 | 46.8 | 105 | 38.2 | 243 | 42.6 |
| <u>Active Steps</u> | | | | | | |
| Request made by patient | 97 | 32.9 | 78 | 30.0 | 175 | 31.5 |
| Request made by family | 64 | 21.8 | 42 | 16.5 | 106 | 19.3 |
| Total = Doctors | 298 | | | | | |
| = Nurses | 278 | | | | | |

There were some statistically significant differences between the proportions of male and female medical practitioners who reported receiving requests to hasten death from patients by withdrawal of treatment and active steps. Fifty percent of male medical practitioners said they had been asked to hasten death by withdrawal of treatment compared with only 36% of female medical practitioners, while 35% of male medical practitioners reported they had received requests to hasten death by taking active steps compared with only 21% of females.

These differences may be due to the perception that there is greater sympathy towards patient involvement in decision making by young medical practitioners rather than by older doctors. Similarly gender differences may be due to patient perceptions that males possess greater authority and power in this regard than females; or it may simply mean that female doctors in this sample were concentrated in areas of medicine where these issues did not arise.

¹ Patient requested withdrawal of treatment, $\chi^2 = 11.5$, D.F. = 4, $P = < .05$

Table 4: Requests for Withdrawal of Treatment or Active Steps by Age, Sex and Religion

| | | Withdrawal of Treatment | | | | Active Steps | | | |
|-----------------|-------------|-------------------------|------|---------------------|------|----------------------|------|---------------------|------|
| | | Request from Patient | | Request from Family | | Request from Patient | | Request from Family | |
| | | N | % | N | % | N | % | N | % |
| DOCTOR | | | | | | | | | |
| <u>Age</u> | 20-29 yrs | 13 | 68.4 | 11 | 57.9 | 6 | 31.6 | 3 | 15.8 |
| | 30-39 yrs | 46 | 48.4 | 48 | 51.6 | 29 | 31.2 | 19 | 20.4 |
| | 40-49 yrs | 40 | 47.1 | 37 | 44.0 | 29 | 34.1 | 18 | 21.2 |
| | 50-59 yrs | 23 | 59.0 | 21 | 53.8 | 17 | 44.7 | 14 | 36.8 |
| | 60+ yrs | 17 | 30.9 | 19 | 33.9 | 14 | 25.0 | 8 | 14.8 |
| NURSE | | | | | | | | | |
| <u>Age</u> | 20-29 yrs | 39 | 65.0 | 30 | 50.0 | 24 | 40.7 | 14 | 24.1 |
| | 30-39 yrs | 45 | 42.1 | 41 | 38.0 | 28 | 27.5 | 14 | 14.3 |
| | 40-49 yrs | 31 | 47.0 | 23 | 34.3 | 19 | 30.6 | 10 | 15.9 |
| | 50-59 yrs | 12 | 34.3 | 9 | 24.3 | 6 | 17.1 | 3 | 8.8 |
| | 60+ yrs | - | - | - | - | - | - | - | - |
| DOCTOR | | | | | | | | | |
| <u>Sex</u> | Male | 112 | 50.9 | 105 | 47.7 | 79 | 35.7 | 51 | 23.3 |
| | Female | 26 | 36.1 | 30 | 42.9 | 15 | 21.7 | 10 | 14.5 |
| NURSE | | | | | | | | | |
| <u>Sex</u> | Male | 13 | 72.2 | 11 | 61.1 | 12 | 66.7 | 7 | 38.9 |
| | Female | 114 | 45.6 | 92 | 36.2 | 65 | 27.1 | 34 | 14.5 |
| DOCTOR | | | | | | | | | |
| <u>Religion</u> | C of E | 41 | 47.7 | 39 | 45.3 | 29 | 33.7 | 21 | 24.4 |
| | Other Prot. | 22 | 37.9 | 23 | 41.1 | 19 | 33.3 | 7 | 12.3 |
| | Catholic | 23 | 46.9 | 26 | 52.0 | 16 | 32.7 | 11 | 22.9 |
| | Other | 14 | 56.0 | 13 | 54.2 | 6 | 24.0 | 6 | 24.0 |
| | None | 39 | 52.0 | 35 | 46.7 | 25 | 33.8 | 16 | 21.9 |
| NURSE | | | | | | | | | |
| <u>Religion</u> | C of E | 38 | 59.4 | 26 | 40.6 | 20 | 33.3 | 11 | 18.6 |
| | Other Prot | 38 | 39.2 | 38 | 37.6 | 26 | 27.4 | 13 | 14.1 |
| | Catholic | 16 | 33.3 | 11 | 22.9 | 11 | 23.9 | 4 | 8.9 |
| | Other | 5 | 41.7 | 4 | 33.3 | 2 | 16.7 | 1 | 8.3 |
| | None | 29 | 63.0 | 24 | 52.2 | 17 | 38.6 | 11 | 25.0 |

(There are cases missing in each category where the age, sex or religion of the medical practitioners or nurses were not known.)

Nurses

As the data in Table 3 shows, 47% said they had received a request from the patient to hasten death by withdrawing treatment, and 38% had received a similar request from the patients' family. Thirty percent said they had been requested by a

patient to hasten death by taking active steps, while 16% had received a similar request from a patients' family.

Age was a significant factor associated with differences in the reported receipt of requests to hasten death by withdrawal of treatment by patients among nurses (see Table 4).² Greater proportions of nurses aged 20-29 years had received requests to hasten death by withdrawal of treatment than nurses in all other age cohorts, while lower proportions of those aged 50 years and above had received these requests than all other age cohorts. Sixty five percent of nurses aged 20-29 years had received requests to hasten death by withdrawal of treatment compared with only 34% of nurses aged 50-59 years.

Although more male than female nurses reported they had received requests to hasten death both by withdrawal of treatment and active steps both from patients and families,³ (see Table 4), the number of male nurses in the sample was very small (males 18 : females 257). It is not certain if these differences would be valid for the total population.

The similarities in age and gender request rates among both medical practitioners and nurses provide support for the concept that patients may perceive young people as more amenable to patient involvement in decision making than older health care deliverers. Gender differences may be due to patient perception that relativities of power exist between the sexes, or because males convey an aura of authority and ability to fulfil requests.

Differences in Rates of Request to Hasten Death Made to Doctors and Nurses

While there were almost no differences in the proportion of medical practitioners and nurses who said they had received requests to hasten death from patients by withdrawing treatment or taking active steps, fewer nurses than medical practitioners reported they had received such requests from the families of patients. This variance

2 Patient requested withdrawal of treatment $\chi^2 = 11.09$, D.F. = 3, $P = < .05$

3 Patient requested withdrawal, $\chi^2 = 4.7$, D.F. = 1, $P = < .05$,
patient requested active steps, $\chi^2 = 12.5$, D.F. = 1, $P = < .05$,
family requested withdrawal, $\chi^2 = 4.4$, D.F. = 1, $P = < .05$,
family requested active steps, $\chi^2 = 7.3$, D.F., $P = < .05$.

may be due to firstly to the close contact between patients and nurses; secondly, the lack of intimate contact between nurses and the families of patients, and thirdly, the relative authority of the medical practitioner in caring for the patient in the eyes of families.

REASONS FOR REQUESTS TO HASTEN DEATH

Respondents who had been asked to hasten a patient's death either by the patient or the family were asked to rank the reasons for such requests. A checklist of reasons were suggested in the questionnaire and these were listed in the following order,

- 'persistent and irrelievable pain',
- 'terminal illness',
- 'incurable condition',
- 'infirmities of old age',
- 'not wanting to be a burden on others',
- 'afraid of a slow decline while dying' and
- 'any other reason'.

For those who had received requests to hasten death, Table 5 demonstrates the primacy of 'persistent and irrelievable pain' as the most commonly cited reason for appeals from patients and their families. This was followed by 'terminal illness' and 'incurable condition' in that order (see Table 5). However, it is interesting that the frequency rates for ranked reasons followed the order in which the reasons were listed in the questionnaire. It is not known if the results would have been different if the questionnaire order had been different, although subsequent responses to an open-ended question on why respondents considered a request to hasten death could be considered rational or not, (discussed below), would suggest that the relative importance of these factors was sustained when respondents were required to specify reasons without direct prompting. On the other hand, the list itself would have acted as indirect guide for open-ended responses to the later question.

Table 5 also demonstrates that not only were the reasons 'not wanting to be a burden on others' and 'afraid of a slow decline while dying' ranked first least often, but

that respondents were more divided about the relative importance of these factors to both patients and families.

A few additional reasons were raised and included 'long illness', 'fear of the future', 'no desire for intensive treatment' and 'depression', but these were raised by only a minority of respondents.

Table 5: Ranking of Reasons for Requests to Hasten Death

| | Ranking | | | | | | | |
|--------------------------------------|---------|----|----|----|----|----|---|---------------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | Not Ranked |
| <u>Request from Patient</u> | | | | | | | | |
| Persistent & irrelievable pain | 67 | 34 | 8 | 8 | 2 | - | - | 38 |
| Terminal illness | 61 | 44 | 15 | 8 | 2 | - | - | 38 |
| Incurable condition | 20 | 19 | 35 | 13 | 9 | - | - | 31 |
| Infirmities of old age | 19 | 13 | 17 | 13 | 5 | 14 | - | 17 |
| Not wanting to be a burden on others | 9 | 20 | 21 | 22 | 14 | 4 | - | 21 |
| Afraid of slow decline while dying | 6 | 14 | 17 | 10 | 14 | 12 | 1 | 18 |
| <u>Request from Family</u> | | | | | | | | |
| Persistent & irrelievable pain | 75 | 16 | 9 | 3 | 1 | - | - | 26 |
| Terminal illness | 40 | 43 | 11 | 2 | 1 | - | - | 33 |
| Incurable condition | 32 | 16 | 24 | 6 | - | - | - | 23 |
| Infirmities of old age | 11 | 6 | 5 | 10 | 5 | 3 | - | 11 |
| Not wanting to be a burden on others | 2 | 4 | 3 | 1 | 4 | 4 | - | 8 |
| Afraid of slow decline while dying | 5 | 8 | 4 | 5 | 4 | 1 | - | 5 |

(Respondents were asked to rank the reasons for requests to hasten death: the majority ranked a few items only, while others ticked categories but did not rank them.)

ATTITUDES TO HASTENING DEATH

Opinions on Whether a Request to Hasten Death is Rational

There was evidence that an overwhelming majority of respondents (88%) believed that a request to hasten death could be considered rational. Only 10% considered it was not, while 2% felt it could be considered rational under some circumstances. There were no differences between medical practitioners and nurses in response rates to this question.

In an open-ended question, respondents were asked to explain why they thought requests to hasten death could be thought rational or not, and their responses have been grouped into categories which are listed in Table 6. There were four main reasons for judging a request to hasten death as rational and these were:

- (a) the patient suffered intractable pain and suffering, (23% of responses; 38% of cases);
- (b) the patient was near death or death was inevitable, (18% of responses; 30% of cases);
- (c) the patient experienced a quality of life which was extremely poor (17% of responses; 28% of cases);
- (d) this was a matter of individual freedom of choice (17% of responses; 28% of cases).

Table 6: Reasons for Thinking a Request to Hasten Death is Rational or Not - Total Population

| | Number | % Responses | % Cases |
|---|------------|--------------|---------|
| <u>Request is Rational</u> | | | |
| Death is inevitable | 144 | 18.4 | 29.9 |
| Pain and suffering | 182 | 23.3 | 37.8 |
| Quality of life is poor | 136 | 17.4 | 28.3 |
| Costs - social and economic | 10 | 1.3 | 2.1 |
| Matter for individual choice | 133 | 17.0 | 27.7 |
| Patient/family fears the future | 22 | 2.8 | 4.6 |
| Treatment only delays death | 33 | 4.2 | 6.9 |
| The patient/family accepts death | 30 | 3.8 | 6.2 |
| Other reasons | 28 | 3.6 | 5.8 |
| <u>Request is Not Rational</u> | | | |
| Patient is mentally abnormal | 5 | 0.6 | 1.0 |
| A request is morally wrong | 12 | 1.5 | 2.5 |
| Request is due to a crisis which may pass | 4 | 0.5 | 0.8 |
| Give pain relief only | 4 | 0.5 | 0.8 |
| It is a matter of individual responsibility | 3 | 0.4 | 0.6 |
| Relatives may be selfish | 1 | 0.1 | 0.2 |
| Depends on mental stability of patient | 33 | 4.2 | 6.9 |
| Depends if request is for withdrawal of treatment or active steps | 2 | 0.3 | 0.4 |
| | 782 | 100.0 | |
| <hr/> Total = 481 <hr/> | | | |

Differences between Medical Practitioners and Nurses

There were only minor differences between medical practitioners and nurses in the reasons given for believing that a request to hasten death could be considered rational. However it is interesting that greater proportions of medical practitioners than nurses regarded a request to hasten death as rational where the patient was near death or death was considered to be inevitable. Greater proportions of nurses than medical practitioners ascribed rationality to such requests on the basis that they constituted an exercise of individual freedom of choice (see Table 7).

Table 7: Reasons for Thinking a Request to Hasten Death is Rational or Not - Doctors and Nurses

| | Doctors | Nurses |
|---|----------------|----------------|
| <u>Request is Rational</u> | | |
| Death is inevitable | 35.2 | 24.5 |
| Pain and suffering | 39.8 | 35.9 |
| Quality of life is poor | 29.9 | 26.6 |
| Costs - social and economic | 2.5 | 1.7 |
| Matter for individual choice | 16.8 | 38.8 |
| Patient/family fears the future | 3.7 | 5.5 |
| Treatment only delays death | 6.6 | 7.2 |
| Patient/family accepts death | 6.6 | 5.9 |
| Other reasons | 9.0 | 2.5 |
| <u>Request is Not Rational</u> | | |
| Patient is mentally abnormal | 1.2 | 0.8 |
| Request is morally wrong | 2.0 | 3.0 |
| Request is due to a crisis which may pass | 0.4 | 1.3 |
| Give pain relief only | 0.4 | 1.3 |
| It is a matter of individual responsibility | 1.2 | - |
| Relatives may be selfish | 0.4 | - |
| Depends on mental stability of patient | 4.1 | 9.7 |
| Depends if request is for withdrawal of treatment or active steps | 0.8 | - |
| | N = 244 | N = 237 |

Table is based on percentage of respondents

Among the comments made in response to this question pain and suffering proved to be a major issue, but other points included the futility of prolonging life in certain circumstances, the fact that medical treatment may at a certain stage cause a

postponement of death rather than an extension of life, and the belief that patients have the 'the right to die'. It was said -

'in occasional situations prolongation of life may lead to increased pain and suffering without benefit';

'the alternative (prolonged pain) is inhumane';

'a visit to any nursing home would reveal reasons for hastening death simply based on the infirmities of old age';

there can come a time when life is not worth living and there is no prospect of improvement';

'on occasions there is no realistic alternative'

'in the situation of a terminal illness for which no therapy or no helpful additional therapy is available and the quality of life is very poor, it becomes a question of prolonging dying rather than prolonging living';

'no animal (human or otherwise) should be allowed to suffer needlessly. A dignified death when appropriate in cases of chronic pain of severe nature, terminal disease and loss of personality through dementia should be everyone's right';

'any individual should have the right to die. No one should be compelled to live in pain or indignity. Our medical and social resources should not be expended on those who do not wish it';

'one should be able to be in control of one's destiny'.

Some respondents drew a distinction between requests on the basis of the lucidity of the person making the request, as for example,

'... rational people, depending on their philosophical slant, and all circumstances considered, are capable of making decisions about their future. However this is not to say that all people requesting "death" are rational'.

Others made distinctions according to the particular situation in which the request arose, as for example it was said,

'it depends on the circumstances. Not all such requests are necessarily rational, but it is perfectly possible that a request may be'.

There was also a feeling among a few respondents that while the request could be rational, it was not necessarily acceptable to act upon it. Examples of this attitude were the following statements:

'rational, yes, but not acceptable on ethical or moral grounds'; and

'obviously (it) may be rational if the patient is suffering and has no hope of recovery, but what is rational is not necessarily right'.

The most frequently cited reason for not considering a request to hasten death to be rational was the question of the mental stability of the person making the request (4% of responses; 7% of cases).

However, a number of other issues were raised by the few who felt such a request was not rational and the following quotations are examples of varying perspectives :

'in my experience such requests have come at a time of crisis and all relevant factors and consequences have not been considered by the protagonists. Subsequent events and outcomes have reinforced this stance';

'depression/social factors often surround such a request. The onus is on us to attend to these rather than considering hastening death'; and

'it is not an area of "shared responsibility" that a medical practitioner should involve himself or herself in, as it is contradictory to all other aspects of our profession'.

Attitudes to Passive and Active Euthanasia

To further ascertain attitudes towards passive and active euthanasia, respondents were asked if it is ever right to bring about the death of a patient by withdrawing treatment, or by taking active steps. These questions did not define 'right' and respondents were free to interpret the meaning in a legal, moral or ethical sense as they wished.

Is it Right to Bring About a Patient's Death by Withdrawal of Treatment

(a) Total Population

To the question concerning the 'rightness' of withdrawal of treatment to effect the death of a patient, 59% of all respondents said yes it was right, a further 31% said 'yes, but only if requested by the patient', while 10% said it was not (see Table 8).

For the total sample population there were some significant differences in attitudes to whether it was regarded as ever right to bring about the death of a patient by withdrawing treatment on the basis of age, sex and religion (see Table 8). The main variations lay between males and females, and between those who professed no religion and those who subscribed to a faith.

Table 8: Is it Ever Right to Bring About the Death of a Patient by Withdrawing Treatment - Total Population

| | Yes | | Yes, Only on Patient Request | | No | |
|------------------------------|------------|-------------|------------------------------|-------------|-----------|------------|
| | Number | % | Number | % | Number | % |
| <u>Age</u> ¹ | | | | | | |
| 20-29 yrs | 44 | 56.4 | 30 | 38.5 | 4 | 5.1 |
| 30-39 yrs | 122 | 60.1 | 69 | 34.0 | 12 | 5.9 |
| 40-49 yrs | 86 | 55.8 | 46 | 29.9 | 22 | 14.3 |
| 50-59 yrs | 47 | 62.7 | 16 | 21.3 | 12 | 16.0 |
| 60+ yrs | 35 | 61.4 | 17 | 29.8 | 5 | 8.8 |
| <u>Sex</u> ² | | | | | | |
| Male | 158 | 65.8 | 65 | 27.1 | 17 | 7.1 |
| Female | 176 | 54.0 | 112 | 34.4 | 38 | 11.7 |
| <u>Religion</u> ³ | | | | | | |
| C of E | 85 | 57.4 | 51 | 34.5 | 12 | 8.1 |
| Other Prot. | 89 | 56.0 | 56 | 35.2 | 14 | 8.8 |
| Catholic | 51 | 54.1 | 33 | 33.0 | 16 | 16.0 |
| Other | 20 | 54.1 | 12 | 32.4 | 5 | 13.5 |
| None | 88 | 72.1 | 26 | 21.3 | 8 | 6.6 |
| Total | 337 | 58.8 | 179 | 31.2 | 57 | 9.9 |

1 $\chi^2 = 16.0$, DF = 8, P = <.05

2 $\chi^2 = 8.5$, DF = 2, P = <.05

3 $\chi^2 = 16.7$, DF = 8, P = <.05

Total cases = 573

Missing = 3

(b) Medical Practitioners

Sixty five percent of medical practitioners said yes it was right to bring about the death of a patient by withdrawing treatment, a further 27% said 'yes, but only if requested by the patient', while 8% said it was not (see Table 9). There were subgroup differences in response rates among medical practitioners according to age, sex and religion but these were not statistically significant.

(c) Nurses

Fifty two percent of nurses said yes it was right to bring about the death of a patient by withdrawing treatment, a further 36% said 'yes, but only if requested by the patient', while 12% said it was not (see Table 9).

When we examined sub-group differences in response rates among nurses, only variability according to age was statistically significant. The proportion of female nurses who answered no to this question increased with age, from 3% of those aged 20-29 years to 22% of nurses aged 50-59 years.

Table 9: Is it Ever Right to Bring About the Death of a Patient by Withdrawing Treatment - Doctors and Nurses

| | Yes | | Yes, Only on Patient Request | | No | |
|------------------------------|-------------|-------------|------------------------------|-------------|------------|-------------|
| | Dr | Nurse | Dr | Nurse | Dr | Nurse |
| <u>Age</u> ¹ | | | | | | |
| 20-29 yrs | 57.9 | 55.9 | 31.6 | 40.7 | 10.5 | 3.4 |
| 30-39 yrs | 70.5 | 50.9 | 25.3 | 41.7 | 4.2 | 7.4 |
| 40-49 yrs | 58.8 | 52.2 | 30.6 | 29.0 | 10.6 | 18.8 |
| 50-59 yrs | 74.4 | 50.0 | 15.4 | 27.8 | 10.3 | 22.2 |
| 60+ yrs | 61.4 | - | 29.8 | - | 8.8 | - |
| <u>Sex</u> ² | | | | | | |
| Male | 66.7 | 55.6 | 25.7 | 44.4 | 7.7 | - |
| Female | 61.1 | 52.0 | 29.2 | 35.8 | 9.7 | 12.2 |
| <u>Religion</u> ³ | | | | | | |
| C of E | 64.0 | 48.4 | 30.2 | 40.3 | 5.8 | 11.3 |
| Other Prot. | 62.1 | 52.5 | 27.6 | 39.6 | 10.3 | 7.9 |
| Catholic | 58.0 | 44.0 | 30.0 | 36.0 | 12.0 | 20.0 |
| Other | 52.0 | 58.3 | 36.0 | 25.0 | 12.0 | 16.7 |
| None | 77.6 | 63.0 | 17.1 | 28.3 | 5.3 | 8.7 |
| Total | 65.1 | 52.0 | 26.8 | 36.0 | 8.1 | 12.0 |

¹ Doctors $\chi^2 = 7.3$, DF = 8, P = <.05

Nurses $\chi^2 = 15.0$, DF = 6, P = <.05

² Doctors $\chi^2 = 0.7$, DF = 2, P = <.05

Nurses $\chi^2 = 2.5$, DF = 2, P = <.05

³ Doctors $\chi^2 = 10.0$, DF = 8, P = <.05

Nurses $\chi^2 = 8.6$, DF = 8, P = <.05

Total = Doctors 298

Nurses 275

(Data shown in percentages)

(d) Differences in Response Rates Between Medical Practitioners and Nurses

There were statistically significant differences between medical practitioners and nurses in attitudes to whether withdrawal of treatment was regarded as ever right.⁴ A higher proportion of doctors than nurses considered it was right to bring about the death of a patient by withdrawing treatment, whether this was requested by the patient or not. Nurses were more inclined than doctors to regard this as right only on the request of the patient. The association of righteousness with patient self determination and autonomy is similar to the pattern of responses made by nurses to the question of whether requests to hasten death could be considered rational.

While the differences between medical practitioners and nurses were generally sustained when we controlled for sex, age and religion, it was found that Catholic nurses tended to hold more conservative views on this question than Catholic medical practitioners (see Table 9). The table also demonstrates that the differences between medical practitioners and nurses aged 50-59 years were more marked than those for other age cohorts, and that those who professed no religion were more likely to agree that withdrawal of treatment was right unconditionally than members of religious groups.

Is it Ever Right to Bring About a Patient's Death by Taking Active Steps

(a) Total Population

In response to the question whether it is ever right to bring about the death of a patient by taking active steps, only 18% of the total population said yes, a further 29% said 'yes, but only if requested by the patient', while 50% said it was not, and two percent were unsure.

For the total population religion was the only variable for which there was a significant association with attitudes towards this question (see Table 10). While 32% of persons with no religion said it was right whether this was requested or not, only 14% of catholics and 'other protestants', and 16% of Anglicans did so.

⁴ $\chi^2 = 10.2$, D.F. = 2, $P = < .05$

Table 10: Is it Ever Right to Bring About the Death of a Patient by Taking Active Steps - Total Population

| | Yes | | Yes, Only on Patient Request | | No | |
|------------------------------|------------|-------------|------------------------------|-------------|------------|-------------|
| | Number | % | Number | % | Number | % |
| <u>Age</u> ¹ | | | | | | |
| 20-29 yrs | 14 | 18.2 | 29 | 37.7 | 34 | 44.2 |
| 30-39 yrs | 33 | 17.3 | 67 | 35.1 | 91 | 47.6 |
| 40-49 yrs | 30 | 19.9 | 39 | 25.8 | 82 | 54.3 |
| 50-59 yrs | 15 | 20.5 | 15 | 20.5 | 43 | 58.9 |
| 60+ yrs | 11 | 19.6 | 15 | 26.8 | 30 | 53.6 |
| <u>Sex</u> ² | | | | | | |
| Male | 48 | 20.3 | 61 | 25.8 | 127 | 53.8 |
| Female | 55 | 17.7 | 101 | 33.4 | 152 | 48.9 |
| <u>Religion</u> ³ | | | | | | |
| C of E | 24 | 16.6 | 49 | 33.8 | 72 | 49.7 |
| Other Prot. | 21 | 14.1 | 49 | 32.9 | 79 | 53.0 |
| Catholic | 14 | 14.3 | 27 | 27.6 | 57 | 58.2 |
| Other | 4 | 11.1 | 9 | 25.0 | 23 | 63.9 |
| None | 39 | 32.5 | 31 | 25.8 | 50 | 41.7 |
| Total* | 104 | 18.4 | 167 | 29.5 | 283 | 50.0 |

1 $\chi^2 = 9.2$, DF = 8, P = <.05

2 $\chi^2 = 3.7$, DF = 2, P = <.05

3 $\chi^2 = 23.1$, DF = 8, P = <.05

Total = 554

*Not shown in table total = 12 (2.1%) who were unsure.

(There are cases missing in each category where the age, sex or religion of the medical practitioners or nurses were not known.)

(b) Differences in Response Rates Between Medical Practitioners and Nurses

There was considerable congruity in the responses made by medical practitioners and nurses to this question, although the former were more likely to respond negatively than nurses (see Table 11). Higher proportions of nurses considered it was right to bring about the death of a patient by taking active steps when there had been a request from the patient than medical practitioners. This pattern of regarding action as right if it was in accord with patient desires or on patient request is consistent with previously discussed rates of response made by nurses to other questions.

There were interesting differences in attitudes between Catholic medical practitioners and nurses. While only 8% of Catholic medical practitioners said it was right to take active steps, 20% of Catholic nurses felt it was unconditionally right to do so (see Table 11). This is puzzling given the generally more conservative views held by Catholic nurses towards the question of whether it is right to bring about the death of a patient by withdrawing treatment than those of Catholic doctors.

Table 11: Is it Ever Right to Bring About the Death of a Patient by Taking Active Steps - Doctors and Nurses

| | Yes | | Yes, Only on Patient Request | | No | |
|------------------------------|-------------|-------------|------------------------------|-------------|-------------|-------------|
| | Dr | Nurse | Dr | Nurse | Dr | Nurse |
| <u>Age</u> ¹ | | | | | | |
| 20-29 yrs | 11.1 | 20.3 | 16.7 | 44.1 | 72.2 | 35.6 |
| 30-39 yrs | 18.2 | 16.5 | 30.7 | 38.8 | 51.1 | 44.7 |
| 40-49 yrs | 20.0 | 19.7 | 23.5 | 28.8 | 56.5 | 51.5 |
| 50-59 yrs | 15.8 | 25.7 | 23.7 | 17.1 | 60.5 | 57.1 |
| 60+ yrs | 19.6 | - | 26.8 | - | 53.6 | - |
| <u>Sex</u> ² | | | | | | |
| Male | 18.8 | 38.9 | 25.2 | 33.3 | 56.0 | 27.8 |
| Female | 16.7 | 18.0 | 28.8 | 34.7 | 54.5 | 47.3 |
| <u>Religion</u> ³ | | | | | | |
| C of E | 15.3 | 18.3 | 32.9 | 35.0 | 51.8 | 46.7 |
| Other Prot. | 16.4 | 12.8 | 23.6 | 38.3 | 60.0 | 48.9 |
| Catholic | 8.3 | 20.0 | 18.8 | 36.0 | 72.9 | 44.0 |
| Other | 4.2 | 25.0 | 25.0 | 25.0 | 70.8 | 50.0 |
| None | 33.8 | 30.4 | 24.3 | 28.3 | 41.9 | 41.3 |
| Total | 18.4 | 19.1 | 26.0 | 34.6 | 55.5 | 46.2 |

¹ Doctors $\chi^2 = 3.8$, DF = 8, P = <.05

Nurses $\chi^2 = 9.7$, DF = 6, P = <.05

² Doctors $\chi^2 = 0.3$, DF = 2, P = <.05

Nurses $\chi^2 = 5.1$, DF = 2, P = <.05

³ Doctors $\chi^2 = 24.7$, DF = 8, P = <.05

Nurses $\chi^2 = 7.0$, DF = 8, P = <.05

Total = Doctors 298

Nurses 266

(Data shown in percentages)

CURRENT MANAGEMENT OF DEATH AND DYING

Extent of Consultation Following Requests to Hasten Death

(a) Total Population

To understand the initial processes which may take place when medical practitioners and nurses receive requests to hasten a patients death, respondents were asked if they would or did discuss what should be done with any other individuals following the receipt of a request. A list of persons was provided in the questionnaire which included, 'another medical practitioner or medical practitioners', 'nursing staff', 'relatives/friends of patient', 'religious adviser/counsellor', 'bioethics advisor/committee' and 'anyone else'. The majority said they would or did discuss the request with another medical practitioner (81%), nursing staff (79%), or relatives (79%), while lesser proportions were prepared to consult with a religious adviser (40%), bioethics adviser (24%) or anyone else (21%).

(b) Differences in Response Rates Between Medical Practitioners and Nurses

There was some variation between medical practitioners and nurses in their preparedness to consult others on such requests, and with the exception of consultations with relatives, generally nurses were more prepared to consult with others than medical practitioners. Seventy one percent of medical practitioners said they would or did consult with another medical practitioner compared with 92% of nurses. Sixty three percent of medical practitioners said they would or did consult with nursing staff compared with 95% of nurses, and 27% of medical practitioners said they would or did consult with a religious adviser compared with 56% of nurses.

These differences are probably related to the hierarchical nature of authority in health care delivery in which medical practitioners possess pre-eminent status and principal power in decision making, while nurses are more likely to be expected to carry out the decisions of others. It is interesting that while the majority of doctors did or were prepared to consult their peers on this issue, a considerable minority were not prepared to do so. This may be due to a perception that acceptable options are obvious

and unambiguous, or because medical practitioners have been educated to act as autonomous individuals rather than as members of a team.

Treatment Options Offered by Medical Practitioners

Medical practitioners only were asked whether, in discussing the options of medical treatment available to a patient, they had ever suggested withholding or withdrawal of treatment as possible choices. Eighty two percent of medical practitioners said they had suggested withholding treatment, while 72% said they had suggested withdrawal of treatment.

There were some differences between medical practitioners who reported they had suggested withholding medical treatment, with variability according to age and number of years of medical practice of statistical significance (see Table 12). Only 57% of medical practitioners over the age of 60 years reported they had ever suggested withholding treatment, compared with 92% of those aged 30-39 years.⁵ The number of years of medical practice is closely linked with age, and not surprisingly it was also found that while 59% of medical practitioners who had practised medicine for over 30 years had suggested withholding treatment at some time, over 80% of medical practitioners who had practised medicine for 30 years or less had presented this as an option to patients and their families.⁶ (see Table 12).

There were lesser but not significant differences between medical practitioners who suggested withholding treatment as an option according to specialist/general practitioner status and religion, but little variation according to sex (see Table 12).

Among medical practitioners who reported they had at some time suggested withdrawal of medical treatment, there were significant differences according to age, number of years of medical practice and religion (see Table 12). With the exception of medical practitioners aged less than 29 years, there was a steady decline with age in the proportion of medical practitioners who said they had ever suggested withdrawal of treatment. Eighty one percent of those aged 30-39 years had suggested withdrawal of

⁵ $\chi^2 = 25.7$, D.F. = 4, $P = < .05$

⁶ $\chi^2 = 24.8$, D.F. = 5, $P = < .05$

treatment compared with only 57% of medical practitioners over the age of 60 years. Not surprisingly there was evidence of a similar pattern for the number of years of medical practice. Thus, with the exception of medical practitioners who had been in practice for less than five years, there was a tendency for the proportion of medical practitioners who had recommended withdrawal of medical treatment at some time to decline with increasing years of medical practice. Greater proportions medical practitioners who professed 'no religion' said they had suggested withdrawal of medical treatment on occasions compared with members of religious denominations.

Table 12: Have Doctors Ever Suggested Withholding or Withdrawing Treatment when Discussing the Options of Medical Treatment Available to Patients

| | No Treatment - Yes | | Withdrawal of Treatment - Yes | |
|-------------------------------|--------------------|-------------|-------------------------------|-------------|
| | Number | % | Number | % |
| <u>Occupation</u> | | | | |
| GP | 108 | 86.4 | 92 | 74.2 |
| Specialist | 113 | 77.9 | 98 | 69.0 |
| <u>Age</u> | | | | |
| 20-29 yrs | 15 | 83.3 | 12 | 63.2 |
| 30-39 yrs | 87 | 92.6 | 77 | 81.1 |
| 40-49 yrs | 68 | 81.9 | 59 | 72.8 |
| 50-59 yrs | 32 | 82.1 | 24 | 66.7 |
| 60+ yrs | 27 | 57.4 | 27 | 57.4 |
| <u>Sex</u> | | | | |
| Male | 170 | 80.6 | 150 | 71.4 |
| Female | 58 | 84.1 | 49 | 73.1 |
| <u>Religion</u> | | | | |
| C of E | 65 | 82.3 | 61 | 76.3 |
| Other Prot. | 37 | 68.5 | 33 | 61.1 |
| Catholic | 41 | 83.7 | 33 | 66.0 |
| Other | 20 | 83.3 | 16 | 64.0 |
| None | 67 | 89.3 | 57 | 82.6 |
| <u>Years Medical Practice</u> | | | | |
| < 5 yrs | 19 | 82.6 | 13 | 56.5 |
| 6-10 yrs | 44 | 93.6 | 39 | 81.3 |
| 11-15 yrs | 48 | 92.3 | 43 | 82.7 |
| 16-20 yrs | 38 | 80.9 | 33 | 70.2 |
| 21-30 yrs | 52 | 81.3 | 44 | 74.6 |
| > 30 yrs | 29 | 59.2 | 27 | 55.1 |
| Total | 231 | 81.6 | 201 | 71.8 |

(There are cases missing in each category where the occupation, age, sex, religion or number of years of medical practice were not known.)

Extent of Practice of Active Euthanasia

In response to the question 'have you ever taken active steps which have brought about the death of a patient', which was asked of all respondents, 19% said yes (108 individuals), 75% said no (431 individuals), 5% did not wish to answer (29 persons), and 1% were unsure (8 persons). There was very little variation between medical practitioners and nurses in their response rates to this question. Nineteen percent of both groups answered in the affirmative. The only differences lay in the percentage who responded no (medical practitioners 72%: nurses 77%) and those who did not wish to answer (medical practitioners 6%: nurses 3%).

(a) Practice of Active Euthanasia and its Relationship with Requests to take Active Steps

There was a strong association between taking active steps which had brought about a patient's death and the receipt of a request to do so, either from a patient or the patient's family. But a considerable proportion of persons who had taken active steps which had brought about the death of a patient took action without receiving such a request either from a patient or the family of a patient. The data in Table 13 reveal that of the medical practitioners who had taken active steps, 49% had never received a request from a patient, and 54% had never received a request from the family of a patient. The corresponding figures for nurses were 48% and 63% respectively.

The differences between medical practitioners and nurses may be related to the issue of the locus of authority in health care because many nurses reported that they took active steps on the orders of the medical practitioner in charge of patient treatment.

(b) Relationship Between Practice of Active Euthanasia and Attitudes to Euthanasia

Not surprisingly there was also a strong association between action i.e. whether a respondent had taken active steps and belief that taking active steps was ever right. Table 14 shows that of all medical practitioners who had taken active steps 50% considered active steps to be right, and 32% felt it was right when requested by the patient. Clearly, this group interpreted 'right' in the ethical rather than legal sense. It is

interesting that 18% of medical practitioners who had taken active steps did not think it was ever right to do so. The corresponding figures for nurses were 42%, 44% and 13% respectively.

Table 13: Ever Taken Active Steps which have Brought About the Death of a Patient by Whether there Had Been a Request for this Action

| | | | Ever Taken | Active Steps |
|-------------------------|------------------------------|-----|------------|--------------|
| | | | Yes | No |
| <hr/> | | | | |
| <u>Doctors</u> | | | | |
| A | Patient Request ¹ | Yes | 50.9 | 26.3 |
| | | No | 49.1 | 73.7 |
| B | Family Request ² | Yes | 45.5 | 15.6 |
| | | No | 54.5 | 84.4 |
| <u>Nurses</u> | | | | |
| C | Patient Request ³ | Yes | 52.0 | 23.1 |
| | | No | 48.0 | 76.9 |
| D | Family Request ⁴ | Yes | 36.7 | 10.7 |
| | | No | 63.3 | 89.3 |
| <u>Total Population</u> | | | | |
| E | Patient Request ⁵ | Yes | 51.4 | 24.8 |
| | | No | 48.6 | 75.2 |
| F | Family Request ⁶ | Yes | 41.3 | 13.3 |
| | | No | 58.7 | 86.7 |

1 $\chi^2 = 12.3$, DF = 1, P = <.05

2 $\chi^2 = 22.7$, DF = 1, P = <.05

3 $\chi^2 = 16.2$, DF = 1, P = <.05

4 $\chi^2 = 19.8$, DF = 1, P = <.05

5 $\chi^2 = 28.2$, DF = 1, P = <.05

6 $\chi^2 = 42.4$, DF = 1, P = <.05

Total A = 268

B = 266

C = 249

D = 245

E = 517

F = 511

(Data shown in percentages)

The table also demonstrates that while there was also a strong association between action and attitudes among those who had never taken active steps which had brought about the death of a patient, a small minority of those who had not taken such action felt that active euthanasia was right either unconditionally or under certain circumstances. Ten percent of medical practitioners and 13% of nurses who had never taken active steps said active euthanasia was right, and a further 21% of medical practitioners and 31% of nurses said active euthanasia was right if requested by the patient.

Table 14: Ever Taken Active Steps which have Brought About the Death of a Patient by Whether Active Steps are ever Considered to be Right

| Ever Taken Active Steps | Are Active Steps Ever Right | | | |
|----------------------------------|-----------------------------|------------------------------|------|--------|
| | Yes | Yes, Only on Patient Request | No | Unsure |
| A <u>Doctors</u> | | | | |
| Yes ¹ | 50.0 | 32.1 | 17.9 | - |
| No | 9.9 | 21.2 | 67.5 | 1.4 |
| B <u>Nurses</u> | | | | |
| Yes ² | 42.3 | 44.2 | 13.5 | - |
| No | 12.8 | 31.8 | 52.1 | 3.3 |
| C <u>Total Population</u> | | | | |
| Yes ³ | 46.3 | 38.0 | 15.7 | - |
| No | 11.3 | 26.5 | 59.8 | 2.4 |

¹ $\chi^2 = 61.0$, DF = 3, P = < .05

² $\chi^2 = 37.1$, DF = 3, P = < .05

³ $\chi^2 = 96.2$, DF = 3, P = < .05

Total A = 268

B = 263

C = 531

(Data shown in percentages)

Table 14 also confirms the differences between medical practitioners and nurses on this issue. Medical practitioners' views on whether it was ever right to take active steps were more polarised than those of nurses, while nurses demonstrated greater propensity than medical practitioners to regard active steps as right if a request had been made by a patient.

(c) Practice of Active Euthanasia and its Relationship with Age, Sex, and Religious Affiliation

(i) Medical Practitioners

While there were differences between medical practitioners who had practised active euthanasia according to sex and religious affiliation, these were not found to be statistically significant. Twenty two percent of male medical practitioners said they had taken active steps compared with only 5.6% of female medical practitioners (see Table 15). Not surprisingly the main differences lay between Catholic medical practitioners, only 4% of whom had taken active steps, and all other groups.

(ii) Nurses

While there were differences between nurses who had taken active steps which had brought about the death of a patient on the basis of sex and religious affiliation, these differences were not statistically significant (see Table 15). Thirty three percent of male nurses said they had taken active steps compared with 18% of females, but male nurses comprised only a small proportion of the sample (18 persons) and this variability may therefore be due to self selection among respondents who chose to return the questionnaire or sampling error.

Among nurses variation according to religious affiliation was less marked than for medical practitioners, although 32.6% of those with no religion had taken active steps compared with only 14% of Catholics and 12% of Anglicans.

Table 15: Ever Taken Active Steps which have Brought About the Death of a Patient by Age, Sex and Religion

| | Doctors | | | Nurses | | | Total Population | | |
|-------------------|-------------|-------------|------------|-------------|-------------|------------|-------------------|-------------|------------|
| | Yes | No | Not Known | Yes | No | Not Known | Yes | No | Not Known |
| A Age | | | | | | | | | |
| 20-29 yrs | 15.8 | 73.7 | 10.5 | 26.7 | 68.3 | 5.0 | 24.1 | 69.6 | 6.3 |
| 30-39 yrs | 13.7 | 77.9 | 8.5 | 17.6 | 76.9 | 5.5 | 15.8 | 77.3 | 6.9 |
| 40-49 yrs | 18.8 | 70.6 | 10.6 | 17.4 | 81.2 | 1.4 | 18.2 | 75.3 | 6.4 |
| 50-59 yrs | 30.8 | 59.0 | 10.6 | 13.2 | 86.8 | - | 22.1 | 72.7 | 5.2 |
| 60+ yrs | 17.5 | 77.2 | 5.3 | - | - | - | 17.5 | 77.2 | 5.3 |
| B Sex | | | | | | | | | |
| Male | 22.5 | 68.9 | 8.6 | 33.3 | 61.1 | 5.6 | 23.3 ¹ | 68.3 | 8.4 |
| Female | 5.6 | 84.7 | 9.7 | 17.9 | 78.6 | 3.4 | 15.2 | 79.9 | 4.9 |
| C Religion | | | | | | | | | |
| C of E | 20.9 | 65.1 | 14.0 | 12.3 | 84.6 | 3.1 | 17.2 | 73.5 | 9.2 |
| Other Prot. | 20.7 | 74.1 | 5.1 | 19.8 | 75.2 | 5.0 | 20.1 | 74.8 | 5.0 |
| Catholic | 4.0 | 88.0 | 8.0 | 14.0 | 84.0 | 2.0 | 9.0 | 86.0 | 5.0 |
| Other | 16.0 | 84.0 | - | 16.7 | 83.3 | - | 16.2 | 83.8 | - |
| None | 23.7 | 68.4 | 7.9 | 32.6 | 63.0 | 4.4 | 27.0 | 66.4 | 6.6 |
| Total | 18.8 | 72.5 | 8.7 | 18.7 | 74.8 | 4.0 | 18.8 | 74.8 | 6.4 |

(chi square tests shown only where significant)

¹ $\chi^2 = 10.2, DF = 3, P = <.05$

Total A Doctors = 295, Nurses = 275, Total Population = 570

B Doctors = 294, Nurses = 275, Total Population = 569

C Doctors = 295, Nurses = 274, Total Population = 569

(Data shown in percentages)

Did Those who had Undertaken Active Steps Still Feel they had Done the Right Thing

To further examine the relation between action and attitudes, persons who had taken active steps were also asked if on reflection they still felt they had done the right thing. There were 56 medical practitioners and 52 nurses who had undertaken active euthanasia at some time. Eighty five percent of medical practitioners and 90% of nurses felt they had done the right thing, 13% of medical practitioners and 5% of nurses considered they had not, while 1% of medical practitioners and 2% of nurses were unsure.

An open-ended question requested respondents to explain their answer, and those who elaborated on this issue tended to focus on humanitarian concerns as well as the futility of continuing treatment in certain situations. The reasons which were given most frequently for believing that the right thing had been done when active steps were taken to hasten the death of a patient, were :

- (1) this action had relieved pain, suffering and distress experienced by the patient
 medical practitioners (24% of responses : 42% of cases)
 nurses (20% of responses : 34% of cases)
- (2) the patient was near death
 medical practitioners (18% of responses : 31% of cases)
 nurses (12% of responses : 20% of cases)
- (3) the situation was hopeless
 medical practitioners (18% of responses : 31% of cases)
 nurses (8% of responses : 14% of cases)
- (4) the patient had no prospect of a meaningful or independent existence
 medical practitioners (8% of responses : 15% of cases)
 nurses (7% of responses : 12% of cases)
- (5) acted on orders
 medical practitioners (2% of responses : 3% cases)
 nurses (18% of responses : 30% cases).

With the exception of the last named 'acted on orders', there are similarities between these justifications for active euthanasia, and the rationale of respondents who regarded a request to hasten death as rational, as well as reported motives for requests to hasten death made by patients and their families.

The following comments given by medical practitioners are typical of responses to this question:

'both patients were in coma, following large CVA's. They were both already dying from broncho-pneumonia. This was a prolonged process, distressing to the family and possibly to the patient. I elected to administer large doses of morphine';

'both individuals were elderly and suffered an acute surgical condition for which they were not (on the grounds of medical condition and dementia) candidates for surgery. Their deaths were painful and would have been prolonged without euthanasia or the use of adequate doses of morphine. The treatment (i.e. that of pain) could not medically be questioned, however probably hastened death';

'the patient's death was inevitable. I played a part in making the death less frightening, more dignified, and in so doing hastened the time of death';

'neonate with no prospect of useful life and no "independent" existence. "Therapeutic" death (was) more appropriate than gradual dehydration';

'because there was no doubt in my mind that to do otherwise would have been cruelty for no just purpose';

'the patient was struggling, suffering and with no hope of long term survival';

'seldom do patients with terminal malignancy, terminal Alzheimers or many incurable diseases die with dignity or comfort unless there is intervention by a doctor. What is wrong with hastening their course?';

'I was in general practice for two years only. During that time I gave two elderly patients a large dose of morphine. One had inoperable cancer of the mouth, the other had irreversible heart failure and was grossly oedematous. I asked no one's opinion. I just did what I thought was right, and would do it again if the need arose. I am so firm in my belief that I would be prepared to defend my actions in court';

'in the course of dealing with a patient with terminal illness I have always discussed early, when the patient is fully capable, the outlook and option of the terminal few days. I have always been prepared to use narcotics to a dose regime adequate to make the patient comfortable, with addiction or respiratory depression, minor considerations. If the dose required has caused respiratory depression, then this has been unavoidable. Twice, both with patients with terminal malignancy and total bowel obstruction, hence intractable faecal vomiting and pain, I have increased the narcotic dosages above levels providing comfort, and I believed hastened death by hours or a few days. I don't know how I would react to a non-terminal, but progressive disorder like motor neurone disease/muscular dystrophy etc., though probably only to the extent of withdrawing treatment at their request.'

Only a minority of those who had taken active steps which had brought about the death of a patient did not feel they had done the right thing, and one said it had led to 'many years of guilt feeling', while another described it as 'a foolish act, being young and faced with a patient of my own age and in great pain'. One medical practitioner said,

'I believe that changes can occur, even though (the) possibility may be extremely small, and that the patient may feel differently on a later occasion. I therefore think it preferable that a natural course of dying should occur and that appropriate management e.g. pain relief (and all that entails) only should occur. It was too stressful for me personally. ... I knew (the) patient's relative would have tried his own method (suffocation) whereas I knew my way would be painfree and less distressing. Both patient and relative had signed declarations stating what they wanted and the degree of their intent'.

Nurses made similar comments to those made by medical practitioners but a number stated that they acted on the orders given by medical practitioners (15 individuals), or on a decision made by a medical team (4 persons). While some nurses agreed with the decision, others felt less positive about their actions. Thus it was said,

'the decision was only made with all the necessary personnel involved, and it was a team decision, not an individual one';

'in the 1970s nurses were not consulted - merely "instruments" of treatment;

'as a student I was instructed to give a large dose of narcotic to a critically but terminally ill patient who died twenty minutes later. I did not agree with this at the time, as I was given no option, but in retrospect feel it was the kindest for the patient';

'in most circumstances I feel I did the right thing and my conscience is not troubled by actions undertaken. In one circumstance I am uncomfortable with actions I was ordered to undertake and feel now I should have protested more loudly or refused to be involved'.

Effect of Current Law on Action

People who had not taken active steps which had brought about the death of a patient, were asked if they had rejected the request because it would have been illegal. Thirty eight percent of medical practitioners (91 individuals) and 34% of nurses (91 individuals) said the question of legality was not a factor in their decision making. Illegality was the reason the request was rejected by only 16% of medical practitioners (40 persons) and 21% of nurses (58 persons). For 45% of medical practitioners and 44% of nurses this question was not applicable as they had received no request to hasten death by taking active steps.

These findings indicate that higher proportions of respondents used internalised ethical and moral values to guide their decision making than the proportion who depended on externally imposed legal sanctions to circumscribe their actions. These and previous findings suggest, firstly, that alteration or clarification of the law would not necessarily change the practices of individual medical practitioners and nurses, and secondly, that questions of legality are currently not the principal considerations used by health care delivers when making decisions to terminate or withhold treatment or to take active steps.

FUTURE MANAGEMENT OF DEATH AND DYING

Utility of Current Legislation

To ascertain the level of awareness of current legislation in South Australia pertinent to the management of death and dying, (The Natural Death Act, 1983, which was discussed in Chapter 3), all respondents were asked firstly, whether they were aware of this legislation, and secondly, how many times in the last five years they had been presented with declarations made under this act. Levels of awareness of the Natural Death Act were quite high with 72% of medical practitioners and 68% of nurses aware of the legislation. However, 76% of both medical practitioners and nurses had never been presented with declarations made under the act (see Table 16). This indicates that, for whatever reason, levels of awareness of the act amongst the general population are quite low; that medical practitioners and nurses have not brought this legislation to the notice of their patients; and that the Act has therefore proved to be ineffective in dealing with the issue of medical treatment of terminally ill patients in South Australia whose deaths are imminent.

Table 16: Number of Times Doctors and Nurses Have Been Presented with Living Wills Made in Accordance with the Natural Death Act, 1983

| Times | Doctors | | Nurses | | Total Population | |
|------------|------------|--------------|------------|--------------|------------------|--------------|
| | No | % | No | % | No | % |
| Never | 225 | 76.3 | 213 | 76.9 | 438 | 76.6 |
| Once | 19 | 6.4 | 23 | 8.3 | 42 | 7.3 |
| 2-5 times | 40 | 13.6 | 27 | 9.7 | 67 | 11.7 |
| 6-10 times | 4 | 1.4 | 6 | 2.2 | 10 | 1.7 |
| > 10 times | 7 | 2.4 | 8 | 2.9 | 15 | 2.6 |
| | 295 | 100.0 | 277 | 100.0 | 576 | 100.0 |

Attitudes to Possible Guidelines for Withdrawal or Withholding of Treatment

Evidence from the review of literature had indicated that the current legal position of medical practitioners who withdraw or withhold medical treatment is ambiguous. All respondents were therefore asked if they thought 'guidelines should be

established so that the legal position of medical practitioners regarding withholding and withdrawal of treatment could be clarified'.

(a) Medical Practitioners

Sixty eight percent of medical practitioners responded in the affirmative, 18% said no, and 13% were unsure, (see Table 17). The only significant differences between medical practitioners on this issue were between males and females. Twenty one percent of males were opposed to the idea of guidelines compared with only 8% of females, and 23% of females were undecided compared with 10% of males.

Table 17: Should Guidelines be Established so that the Legal Position of Doctors Regarding Withholding and Withdrawal of Treatment could be Clarified

| | Doctors | | | Nurses | | | Total Population | | |
|--------------------------|-------------------|-------------|-------------|-------------|------------|-------------|-------------------|-------------|-------------|
| | Yes | No | Unsure | Yes | No | Unsure | Yes | No | Unsure |
| A <u>Age</u> | | | | | | | | | |
| 20-29 yrs | 78.9 | - | 21.1 | 91.7 | - | 8.3 | 88.6 ² | - | 11.4 |
| 30-39 yrs | 69.5 | 12.6 | 17.9 | 84.8 | 1.0 | 14.3 | 77.5 | 6.5 | 16.0 |
| 40-49 yrs | 68.2 | 21.2 | 10.6 | 72.1 | 8.8 | 19.1 | 69.9 | 15.7 | 14.4 |
| 50-59 yrs | 61.5 | 25.6 | 12.8 | 80.0 | 8.6 | 11.4 | 70.3 | 17.6 | 12.2 |
| 60+ yrs | 67.9 | 25.0 | 7.1 | - | - | - | 67.9 | 25.0 | 7.1 |
| B <u>Sex</u> | | | | | | | | | |
| Male | 68.3 ¹ | 21.7 | 10.0 | 94.4 | - | 5.6 | 70.3 ³ | 20.1 | 9.6 |
| Female | 68.1 | 8.3 | 23.6 | 81.6 | 4.0 | 14.4 | 78.6 | 5.0 | 16.5 |
| C <u>Religion</u> | | | | | | | | | |
| C of E | 65.9 | 22.4 | 11.8 | 85.7 | 3.2 | 11.1 | 74.3 | 14.2 | 11.5 |
| Other Prot. | 69.0 | 13.8 | 17.2 | 81.4 | 3.1 | 15.5 | 76.8 | 7.1 | 16.1 |
| Catholic | 64.0 | 22.0 | 14.0 | 78.0 | 4.0 | 18.0 | 71.0 | 13.0 | 16.0 |
| Other | 84.0 | 12.0 | 4.0 | 83.3 | - | 16.7 | 83.8 | 8.1 | 8.1 |
| None | 67.1 | 18.4 | 14.5 | 84.4 | 6.7 | 8.9 | 73.6 | 14.0 | 12.4 |
| Total | 68.4 | 18.5 | 13.1 | 81.9 | 4.1 | 14.0 | 74.3 | 11.6 | 13.6 |

(chi square tests shown only where significant)

1 $\chi^2 = 12.8$, DF = 2, P = <.05

2 $\chi^2 = 33.5$, DF = 8, P = <.05

3 $\chi^2 = 33.4$, DF = 2, P = <.05

Total A Doctors = 294, Nurses = 268, Total Population = 562

B Doctors = 293, Nurses = 268, Total Population = 561

C Doctors = 294, Nurses = 267, Total Population = 561

(Data shown in percentages)

(b) Nurses

Eighty two percent of nurses agreed that there should be guidelines established so that the legal position of medical practitioners regarding withholding and withdrawal of treatment could be clarified (see Table 17). Only 4% opposed this concept, while 14% were undecided. There were no statistically significant differences between nurses according to age or religion, and although there were differences in attitudes between male and female nurses it was not possible to test these for significance as there were too few male respondents for reliable testing. Table 17 shows however that 94% of male nurses were in favour of guidelines compared with 81% of females.

(c) Differences in Response Rates Between Medical Practitioners and Nurses

Differences between medical practitioners and nurses on this issue are interesting and significant, for while 68% of medical practitioners answered in the affirmative, 82% of nurses did so.⁷ Eighteen percent of medical practitioners said guidelines were not necessary compared with only 4% of nurses. Currently nurses exercise little authority in the medical treatment of patients and tend to be the conduits for the decisions of medical practitioners, but coevally spend more time with patients than medical practitioners. Thus, close physical and emotional involvement in the care of patients occurs without the concomitant authority to effect substantive change in patient treatment. If guidelines were established to clarify the legal position of medical practitioners in relation to withdrawal or withholding of treatment, this change could be perceived by nurses as a means of either gaining a share of authority in decision making, or ensuring that power was no longer concentrated in the hands of one individual or with one discipline. This would be in line with current trends in society away from authoritarian decision making. So too, for nurses guidelines probably constitute a means of preventing current abuses over which they have no control, be they perceived as continuing treatment long after this is deemed necessary, or withholding treatment which they consider could or should be continued.

⁷ $\chi^2 = 29.0$, D.F. = 2, $P < .05$

Before considering the suggestions of respondents for the nature of possible guidelines for the withdrawal and withholding of medical treatment, it is interesting to consider why the minority were not in favour of the introduction of guidelines. Firstly, it was suggested that such guidelines were unnecessary. Among comments to this effect were the following:

the *'present guidelines are adequate'*, the

'Natural Death Act is sufficient',

'the legal position is clear', and there is

'no official obligation to undertake treatment that is unlikely to be effective or to continue such treatment'.

Secondly, it was suggested that the presence of guidelines might make it more difficult to undertake medical treatment in such situations. Among comments made were the following:

'the involvement of the law in clinical decision making only complicates difficult cases';

'difficult decisions are few and making guidelines to fit these cases would make bad law';

'guidelines could not cover all factors, therefore decisions should be in the hands of Doctor, patient and relatives'.

Thirdly, concerns were also expressed about establishing rules, either because this would/might encourage the press for further changes in practices i.e. the slippery slope argument, or because their rigidity may lead to less than ideal treatment for the patient. It was said,

'if you have guidelines the scope is too broad. There will always be a deserving case, by someone's standards, who falls outside the rules. If the rules aren't changed to accommodate them it was a waste of time introducing the rules in the first place. If they are changed, then you have just moved the boundary closer to the next grey area';

'guidelines might make it more difficult to withdraw/withhold treatment as time (is) involved in obtaining permission to act';

it is better to state what is not permitted, rather than what is permissible'.

Suggested Guidelines for Withdrawal and Withholding of Treatment

In an open-ended question, respondents who felt that guidelines should be established were asked for suggestions on what these guidelines could be. A wide ranging selection of possible parameters for guidelines were proposed, and Table 18 lists those which were raised most frequently.

(a) Total Population

Twenty percent of respondents said it should be possible to withdraw or withhold treatment on the request of the patient and/or their family, while 17% felt this should only be considered on the request of the patient. Many respondents wished to ensure that decision making in such situations was not the sole prerogative of a single medical practitioner, and 16% said the decision should be made by two or more medical practitioners. Respondents also attempted to define the type of situations or medical conditions of patients who could be considered for withdrawal or withholding of treatment. Twenty one percent of respondents considered this should be permissible when the patient was terminally ill, 11% when the patient suffered intractable pain and suffering, and a further 11% said the patients' quality of life should be considered when making such decisions. A number of respondents felt consideration should be given to the type of treatment which should or should not be permitted to be withheld or withdrawn, and 9% felt this could or should occur in situations where medical treatment was valueless. Thirteen percent of respondents thought patients and their families should be fully informed of the medical situation, the prognosis, and treatment options. Full documentation of all decisions was considered necessary by 13% of respondents.

(b) Differences in Response Rates Between Medical Practitioners and Nurses

There were some differences between medical practitioners and nurses on the relative importance of proposed guidelines, the most noticeable of which was that more nurses suggested withdrawal or withholding of medical treatment should occur on the request of the patient or the patient and/or the family than medical practitioners (see Table 18). Thirty one percent of nurses felt this should occur on the request of the patient and/or family compared with only 11% of medical practitioners, while 20% of

nurses felt withdrawal/withholding of treatment should occur on the request of the patient alone compared with 15% of medical practitioners.

Not surprisingly nurses were more concerned than medical practitioners to see decision making move from being the sole responsibility of the single treating medical practitioner and for other health or caring professionals to be included in the process.⁸ More nurses than medical practitioners were in favour of decision making being in the hands of a medical panel (9% : 5%), or a multidisciplinary panel (8% : 6%). Similarly more medical practitioners than nurses felt decisions should be the province of two or more medical practitioners only (17% : 14%) or the treating medical practitioner, patient and family only (7% : 3%). Nurses were also more concerned than medical practitioners that all decisions in such situations should be documented (18% : 8%).

The findings concerning the desire of nurses to provide for the involvement of persons other than medical practitioners in medical decision making, and for these decisions to be placed in the public arena, and the converse interest of medical practitioners in retaining control of decision making or maintaining it within the doctor/patient relationship are all consistent with earlier findings in this survey.

Attitudes Towards Legalisation of Active Euthanasia

Attitudes towards legalisation of active euthanasia were canvassed in the question, 'do you think it should be legally permissible for medical practitioners to take active steps to bring about a patient's death under some circumstances?'.⁸

(a) Total Population

For the total population, 298 individuals (52%) responded yes, 176 (31%) said no, and 97 (17%) were unsure.

⁸ Persons such as other medical practitioners, nurses, social workers, lawyers and ministers of religion.

Table 18: Suggested Guidelines for Withdrawal/Withholding of Treatment

| | Doctors | | | Nurses | | | Total Population | | |
|--|---------|--------|---------|--------|--------|---------|------------------|--------|---------|
| | Number | % Resp | % Cases | Number | % Resp | % Cases | Number | % Resp | % Cases |
| <u>Guidelines</u> | | | | | | | | | |
| Only on patient request | 25 | 6.5 | 15.2 | 28 | 8.3 | 20.1 | 53 | 7.3 | 17.5 |
| On patient and/or family request | 19 | 4.9 | 11.6 | 43 | 12.7 | 30.9 | 62 | 8.6 | 20.5 |
| Decision to be made by 2 or more doctors | 28 | 7.2 | 17.1 | 20 | 5.9 | 14.4 | 48 | 6.6 | 15.8 |
| Decision to be made by doctor, patient & family | 12 | 3.1 | 7.3 | 4 | 1.2 | 2.9 | 16 | 2.2 | 5.3 |
| Decision to be made by medical panel | 9 | 2.3 | 5.5 | 13 | 3.8 | 9.4 | 22 | 3.0 | 7.3 |
| Decision to be made by multi-disciplinary panel | 10 | 2.6 | 6.1 | 12 | 3.6 | 8.6 | 22 | 3.0 | 7.3 |
| Document all decisions | 14 | 3.6 | 8.5 | 25 | 7.4 | 18.0 | 39 | 5.4 | 12.9 |
| Ensure there is legal indemnity for doctor | 14 | 3.6 | 8.5 | 10 | 3.0 | 7.2 | 24 | 3.3 | 7.9 |
| Psychiatric assessment of patient | 11 | 2.8 | 6.7 | 7 | 2.1 | 5.0 | 18 | 2.5 | 5.9 |
| Patient & family to be fully informed | 19 | 4.9 | 11.6 | 21 | 6.2 | 15.1 | 40 | 5.5 | 13.2 |
| When patient is terminally ill | 36 | 9.3 | 22.0 | 28 | 8.3 | 20.1 | 64 | 8.5 | 21.1 |
| When patient has incurable disease | 14 | 3.6 | 8.5 | 16 | 4.7 | 11.5 | 30 | 4.1 | 9.9 |
| When patient has intractable pain and suffering | 23 | 5.9 | 14.0 | 12 | 3.6 | 8.6 | 35 | 4.8 | 11.6 |
| When patient is brain dead | 6 | 1.6 | 3.7 | 12 | 3.6 | 8.6 | 18 | 2.5 | 5.9 |
| Consider quality of life of patient | 14 | 3.6 | 8.5 | 19 | 5.6 | 13.7 | 33 | 4.6 | 10.9 |
| Exceptional cases to be defined | 9 | 2.3 | 5.5 | 4 | 1.2 | 2.9 | 13 | 1.8 | 4.3 |
| In situations where medical treatment is valueless | 14 | 3.6 | 8.5 | 15 | 4.4 | 10.8 | 29 | 4.0 | 9.6 |
| State the treatment to be withheld | 7 | 1.8 | 4.3 | 5 | 1.5 | 3.6 | 12 | 1.7 | 4.0 |
| Withdraw active treatment only | 3 | 0.8 | 1.8 | 7 | 2.1 | 5.0 | 10 | 1.4 | 3.3 |
| | N=387 | | | N=338 | | | N=725 | | |
| | N=164 | | | N=139 | | | N=303 | | |

(Table includes main guidelines only) (Resp = Responses; Cases = Respondents)

Not surprisingly, there was a strong association between positive attitudes to the legalisation of active euthanasia and whether active steps were ever considered to be right.⁹ Eighty eight percent of persons who considered active steps to be right unconditionally, and 79% who felt they were right on the request of the patient, said active steps should be legally permissible. There was less certainty about the desirability of legalisation of active euthanasia amongst those who felt active steps were not right. Although a small majority (57%) of those who felt active steps were not right were opposed to legalisation of active euthanasia, 22% were in favour of its legalisation, and 20% were undecided.

Despite the strong tendency for those who had taken active steps which had brought about the death of a patient to also hold that active steps should be legally permissible, (77% were in favour of legalisation), it was interesting that 12% were against legalisation, and 10% were unsure.¹⁰

Attitudes to the question of whether active steps should be legally permissible or not did not vary in any way with whether a request had been received from a patient to hasten death by active steps. There were however some differences, which were not statistically significant, between rates of response depending on whether a request had been received from the family of a patient. Slightly more persons who had received such requests were in favour of legalisation of active euthanasia than those who had not received requests (23% : 16%).

(b) Differences in Response Rates Between Medical Practitioners and Nurses

There were marked and significant differences between medical practitioners and nurses in responses to this issue (see Table 19). Only 45% of medical practitioners were in favour of legalisation of active euthanasia, compared with 60% of nurses, while 39% of medical practitioners were opposed to legalisation compared with only 22% of nurses.¹¹ Nurses in all subgroups displayed much higher affirmative response rates than

9 $\chi^2 = 220.5$, D.F. = 4, $P = < .05$

10 $\chi^2 = 36.5$, D.F. = 2, $P = < .05$

11 $\chi^2 = 19.2$, D.F. = 2, $P = < .05$

medical practitioners, but this differential was particularly evident in the response rates of nurses in the age cohort 20-29 years compared with those of medical practitioners in the same age group, and in the rates of response among Catholic nurses compared with Catholic medical practitioners (see Table 19).

Table 19: Should it be Legally Permissible for Doctors to Take Active Steps to Bring About a Patient's Death under Some Circumstances

| | Doctors | | | Nurses | | | Total Population | | |
|-------------------|-------------------|-------------|-------------|-------------------|-------------|-------------|-------------------|-------------|-------------|
| | Yes | No | Unsure | Yes | No | Unsure | Yes | No | Unsure |
| A Age | | | | | | | | | |
| 20-29 yrs | 31.6 | 36.8 | 31.6 | 69.5 ¹ | 15.3 | 15.3 | 60.3 ² | 20.5 | 19.2 |
| 30-39 yrs | 46.2 | 33.3 | 20.4 | 63.0 | 14.8 | 22.2 | 55.2 | 23.4 | 21.4 |
| 40-49 yrs | 43.5 | 40.0 | 16.5 | 51.5 | 36.8 | 11.8 | 47.1 | 38.6 | 14.4 |
| 50-59 yrs | 41.0 | 41.0 | 17.9 | 54.1 | 27.0 | 18.9 | 47.4 | 34.2 | 18.4 |
| 60+ yrs | 50.9 | 45.6 | 3.5 | - | - | - | 50.9 | 45.6 | 3.5 |
| B Sex | | | | | | | | | |
| Male | 44.8 | 39.8 | 15.4 | 66.7 | 11.1 | 22.2 | 46.4 | 37.7 | 15.9 |
| Female | 43.7 | 36.6 | 19.7 | 59.8 | 22.8 | 17.3 | 56.3 | 25.8 | 17.8 |
| C Religion | | | | | | | | | |
| C of E | 51.2 ³ | 33.7 | 15.1 | 67.2 | 17.2 | 15.6 | 58.0 ⁴ | 26.7 | 15.3 |
| Other Prot. | 46.6 | 43.1 | 10.3 | 54.5 | 24.2 | 21.2 | 51.6 | 31.2 | 17.2 |
| Catholic | 20.4 | 61.2 | 18.4 | 52.0 | 30.0 | 18.0 | 36.4 | 45.5 | 18.2 |
| Other | 52.0 | 32.0 | 16.0 | 58.3 | 41.7 | - | 54.1 | 35.1 | 10.8 |
| None | 49.3 | 30.7 | 20.0 | 71.7 | 10.9 | 17.4 | 57.9 | 23.1 | 19.0 |
| Total | 44.9 | 38.9 | 16.2 | 60.0 | 22.2 | 17.8 | 52.2 | 30.8 | 17.0 |

(chi square test shown only where significant)

1 $\chi^2 = 15.8$, DF = 6, P = <.05

2 $\chi^2 = 25.3$, DF = 8, P = <.05

3 $\chi^2 = 18.7$, DF = 8, P = <.05

4 $\chi^2 = 18.1$, DF = 8, P = <.05

Total A Doctors = 293, Nurses = 272, Total Population = 565

B Doctors = 292, Nurses = 272, Total Population = 564

C Doctors = 293, Nurses = 271, Total Population = 564

(Data shown in percentages)

Several factors may account for this variation. The question asked whether it should be permissible for medical practitioners to take active steps to bring about the

death of a patient under certain circumstances, not whether it should be permissible for nurses or others to do so. As the medical profession would be responsible for undertaking active euthanasia if it were to become legal, it could be expected that there would be greater opposition to its legalisation from doctors who would be expected to undertake active euthanasia, than from nurses who would be observers not perpetrators. Apart from more general ethical and moral considerations, medical practitioners also felt this should not constitute their role, as it would harm the doctor/patient relationship and would be contrary to medical ethics. The phrasing of the question enabled nurses to respond without taking personal or professional responsibility for undertaking active euthanasia in future. As the onus lay with members of the medical profession, this distance meant the ultimate moral responsibility for hastening death would lie elsewhere.

It has been said earlier that nurses spend considerable time with patients and have the responsibility for patient care but not for treatment, whilst medical practitioners spend less time with patients, but possess the major role in making medical treatment decisions. This dual dichotomy means that medical practitioners can maintain a distance from their patients and may be less aware than nurses of the impact of their treatment decisions on patient lives. Doctors may therefore respond to the issues of management of death, dying and euthanasia more objectively and dispassionately than nurses. But, at the same time medical practitioners may minimise or ignore the result of too rigorous pursuit of their role of saving life versus their role of relieving suffering. Prolonged and close proximity to patients means that nurses may be more involved with the patient as a person rather than as a case or an organ, but with ultimate responsibility for the patient's life absent. This means that their response to the issue of active euthanasia may be made more at an emotional and individual level rather than on an intellectual or abstract plane, and may be made without full consideration of the social implications of proposed changes in the law.

Circumstances in which it was Thought Appropriate for Active Steps to be Taken

Respondents who had answered in the affirmative to the question 'do you think it should be legally permissible for doctors to take active steps to bring about a patient's death under some circumstances', were asked in an open-ended question to indicate the circumstances.

(a) Total Population

Fifty two percent of all respondents thought that active euthanasia should be possible in the case of terminal illness, and 44% thought this should be possible where the patient suffered intractable pain and suffering. Thirty one percent thought it should be possible on the request of the patient. Smaller numbers of respondents considered active steps should be possible in situations where there was an incurable illness (26%) or where the patient experienced a poor quality of life (24%) (see Table 20).

(b) Differences in Response Rates Between Medical Practitioners and Nurses

There was considerable congruity between medical practitioners and nurses in the proposed circumstances under which active steps could be legally permissible. The main differences were that more doctors than nurses considered this action should be possible where the patient suffered an incurable illness (32% : 21%), while more nurses considered this should be possible on the request of the patient than medical practitioners (34% : 28%) (see Table 20).

ISSUES RAISED BY RESPONDENTS

Respondents were invited to make general comments on the issues surrounding the management of death, dying and euthanasia and 39% of medical practitioners and 55% of nurses did so. (A complete list of all comments is included in Appendix D.) Attitudes ranged from those who maintained a strict interpretation of the sanctity of life position and were completely opposed to euthanasia, to those who argued in favour of its legalisation from the quality of life perspective, using the requirement for kindness and compassion as well as the need for moral autonomy and self determination as their rationale.

Table 20: Suggested Circumstances under which it should be Legally Possible for Doctors to Take Active Steps to Bring About a Patients Death

| | Doctors | | | Nurses | | | Total Population | | |
|-------------------------------|---------|--------|---------|--------|--------|---------|------------------|--------|---------|
| | Number | % Resp | % Cases | Number | % Resp | % Cases | Number | % Resp | % Cases |
| <u>Circumstances</u> | | | | | | | | | |
| Terminal illness | 61 | 21.5 | 51.3 | 78 | 24.3 | 53.8 | 139 | 23.0 | 52.7 |
| Incurable illness | 38 | 13.4 | 31.9 | 31 | 9.7 | 21.4 | 69 | 11.4 | 26.1 |
| Intractable pain & suffering | 57 | 20.1 | 47.9 | 59 | 18.4 | 40.7 | 116 | 19.2 | 43.9 |
| Physical handicap | 10 | 3.5 | 8.4 | 5 | 1.6 | 3.4 | 15 | 2.5 | 5.7 |
| Mental disability | 19 | 6.7 | 16.0 | 22 | 6.9 | 15.2 | 41 | 6.8 | 15.5 |
| Poor quality of life | 24 | 8.5 | 20.2 | 40 | 12.5 | 27.6 | 64 | 10.6 | 24.2 |
| Patient request | 34 | 12.0 | 28.6 | 49 | 15.3 | 33.8 | 83 | 13.7 | 31.4 |
| Family request | - | - | - | 2 | 0.6 | 1.4 | 2 | 0.3 | 0.8 |
| Patient & family request | 21 | 7.4 | 17.6 | 26 | 8.1 | 17.9 | 47 | 7.8 | 17.8 |
| Decision of 1 doctor | 2 | 0.7 | 1.7 | 2 | 0.6 | 1.4 | 4 | 0.7 | 1.5 |
| Decision of 2 or more doctors | 10 | 3.5 | 8.4 | 2 | 0.6 | 1.4 | 12 | 2.0 | 4.5 |
| Committee decision | 5 | 1.8 | 4.2 | - | - | - | 5 | 0.8 | 1.9 |
| Decision of health team | 3 | 1.1 | 2.5 | 5 | 1.6 | 3.4 | 8 | 1.3 | 3.0 |
| | | N=284 | N=119 | | N=321 | N=145 | | N=605 | N=264 |

(Table includes main circumstances only) (Resp = Responses; Cases = Respondents)

Between these extremes a number of other important issues were mentioned. The difficulty of identifying the nature of acceptable treatment from the legal point of view, and the problems this poses for those wishing to frame legislation were raised by one doctor who said,

the difference between active and passive measures may at times be difficult e.g. a baby with severe asphyxia and no higher cerebral function. - Is not sucking out respiratory secretions active or passive? - Is not feeding active or passive? On the other hand, if the baby, though severely affected - even terminally ill, was going to suffer much pain which could be relieved by a simple surgical procedure - would it be right to withhold this treatment (which may or may not prolong life) even if the parents requested withdrawal of active therapy? These are the sort of cases that are dealt with every day. Can legislation cope with all possibilities?

This difficulty, and the complexity of the issues involved, constituted grounds for many doctors to believe that decisions about medical treatment for the dying should continue to be a matter for doctors and patients alone, and should not be a matter for guidelines or legislation. These were believed to be undesirable. Thus it was said by medical practitioners,

It should be managed at the local level. The majority of such decisions are privately handled and this remains, in my view the best way. I don't believe an all encompassing law is necessary at all.

The issues should not become formalised into laws of the land or even into guidelines issued by some government agency or other third party. They should remain the subject of discussion between concerned patients and their medical caregivers whom they individually come to trust and to rely on for humane care, discretion, and respect for their intelligence and dignity.

The matters under consideration are in my experience best handled where a close professional relationship exists between the dying patient and his/her family and a practitioner. The long established ethics of the profession cope with this problem very adequately in these circumstances without the intrusion of legislation/guidelines.

There was opposition to this viewpoint from other medical practitioners, one of whom said,

(the) current situation where doctors are able and commonly do address the issue of withholding care or active treatment and may make unilateral decisions or decisions in consultation with affected individuals/families without definite legal or professional guidelines is unsatisfactory.

Other medical practitioners expressed the opinion that guidelines and laws were unnecessary because good medical care meant they were redundant.

The issues surrounding terminal care, palliative care are infinitely variable and in my view attempts to codify these complexities would not produce great benefit. The difficult decisions are few and far between and 'hard cases make bad law'. In general I have found that conscientious care of patient and relatives has not been accompanied by agonising decisions about withholding treatment - the decisions almost make themselves by consensus at the time. I do not think it is mans' (doctors or patients or relatives) place to determine the time of death. I am often asked to comment in patient notes whether resuscitation should be attempted in the event of so called cardio-respiratory arrest (previously called death) in the elderly/infirm - usually 75+ with malignancy, advanced metabolic disorder or widespread vascular/cerebrovascular disease. This is because nursing staff are currently expected to set in train resuscitation for everyone unless specifically instructed not to. In the majority of cases commonsense tells us that it would be fruitless to attempt resuscitation (or would merely seem to prolong the patients suffering to resuscitate them). That is usually the tenor of the comment I make. In rare cases an elderly person survives a crisis and the DNR comment is withdrawn.

However, it was also suggested that one of the reasons for public pressure for the legalisation of euthanasia was that medical treatment of the terminally ill was defective in certain respects. Pain relief was said to be inadequate.

(there is) inadequate pain relief available generally. Patients (are) therefore frightened of suffering. If patients could be confident that they wouldn't suffer, (they) would not need to ask for or take drastic measures.

Similarly it was also suggested that good palliative care, and pain relief in particular, obviated the need for active euthanasia. Thus it was said,

quality of life remains a key issue and where we have access to adequate pain relief and support services euthanasia becomes redundant.

I feel if patients' symptoms are controlled then (there) should be no reason for euthanasia.

I think the current care in hospice situations is so good that it would be unnecessary to actively speed up the dying even if it was legally right to do so.

Concern was also expressed that in the current situation where there were no guidelines or where the legal situation was unclear, doctors and nurses felt obliged to undertake all measures to keep patients alive. A doctor said,

things are bad when hospital rules and nursing staff pressure doctors to attempt to resuscitate "dead" patients brought in by ambulance or who die suddenly in wards who have other medical problems when they would be better left. The major concern here is litigation from family and concern where the profession stands in law. Could I be held responsible for a patients death if I do nothing (doctor and nurse).

It was felt that many doctors pursue active treatment long after it was obviously inappropriate. Fear of litigation was a factor, but so too were medical attitudes to

patients and treatment. Among comments made by nurses to this effect were the following:

I personally feel doctors are afraid to let patients die. One reason is the legal implications brought on by the family of the person, another reason I believe is the fact that many doctors believe a person dying under their care is a failure to their profession.

(the) Doctors' Hippocratic oath should be reviewed. Preserving life at all costs is not always humane, or in patients' best interests.

I feel we as nurses do not treat the dying patient as well as we could. Unfortunately in the larger Cpv hospitals particularly, death is considered a failure to the system. But in some instances a peaceful, painfree death should be considered as a good outcome.

It is the fear re legal implications that prevent us doing our job of quality care to a patient at a time when they need it most - even if this care is accepting the patient's time to let go and ensure a high quality of death. We as nurses and other health professionals are constantly encouraged to keep the patient going - no matter what ... I think it's cruel. There do have to be strict guidelines but it has to be addressed soon ... and not ignored.

A number of respondents expressed concern that legalisation of active euthanasia could lead to abuses. Medical practitioners said the following:

Active euthanasia is open to abuse. It creates a general climate that will lead the old and infirm and terminally ill to believe they should do the "brave thing" and request euthanasia as they have become a nuisance and a burden etc. and are better off dead. Relatives apply subtle pressure on the old to go into nursing homes - why not pressure them to ask for euthanasia.

I consider there is a big difference between euthanasia and withholding treatment in a consenting terminally ill patient. Euthanasia has the potential for abuse and overuse and could eventually (if accepted by society) be forced unwillingly on the aged, infirmed and deformed members of our community.

Other instances of potential abuse were also given. A nurse said,
great care must be taken when making laws regarding euthanasia. Governments could use euthanasia as a means of cost cutting in the community.

Cost factors were also raised by those who were in favour of legalising euthanasia. Medical practitioners said,

there is a whole area concerning the cost of artificially prolonging life by medically/technologically heroic means e.g. massive anti viral doses with severe viral encephalitic cases, AIDS, respirators and ICU for neonates or brain damaged adults or severe quadraplegics, which somehow needs to be weighted against the chances of a successful outcome of the heroic treatment, plus ongoing costs of managing severely disabled persons VERSUS social/epidemiological means of investing in community health costs. I feel

bioethics committees need to look at this whole area, as well as that of individual euthanasia.

Community/politicians/legislature must decide how much money should or can be spent in continuing to treat conditions where death is imminent or quality of life is negligible, e.g. severe head injuries, ICU patients, high spinal cord. C2/3 injuries, terminal cancer, liver failure, kidney failure.

CHAPTER 7

CONCLUSION

Advances in medical knowledge and expertise have resulted in changes in the causes and timing of death in most western countries. People are now living longer and chronic, degenerative diseases which cause a gradual deterioration in health over long periods have replaced communicable diseases as the major causes of death. So too the survival rate amongst premature babies with low birth weights or those with congenital defects has improved.

These advances have been made possible by a combination of a number of factors including increasing wealth, technology, medical ethics which foster the drive to sustain life and relieve suffering, belief in individualism, and legal frameworks based on the notion of the sanctity of life. Medical and social ethics as well as legal sanctions therefore all incline the medical profession towards vigorous attempts to prolong the lives of their patients and cure at all costs.

The very success of medicine in treating illness means that death is postponed until old age, but people may live long periods with chronic, painful, debilitating conditions which are not terminal, or not immediately fatal. So too, while the positive benefits of advances in medical treatments have led to increased life expectancy and greater longevity, many treatments, especially those of an invasive nature or those used to treat the severely or chronically ill, also involve some element of risk, pain, and the possibility of greater or lesser permanent damage or temporary side effects. Increasingly too, considerable medical resources are expended in prolonging life in situations where survival is transitory or accompanied by severely impaired quality of life.

Paradoxically, therefore, the continuation of this successful and active pursuit of curing illness and preserving life may cause problems for patients suffering from terminal or grave, chronic illness. It can also cause dilemmas for medical practitioners and members of other health professions where the harm caused to patients by treatment appears to outweigh the benefits. In the future it may also pose difficulties in

financing health care delivery in societies where equitable access to health care is regarded as a fundamental right irrespective of means.

The research addressed the first two of these issues, and probed whether medical practitioners and nurses were ever asked to hasten the death of their patients and the reasons such requests were made. In doing so an attempt was made to reveal if patients or their families ever wanted to halt the prolongation of life and whether this was prompted by a perception that the disadvantages of medical treatment outweighed the beneficial effects. The study revealed that it was common for medical practitioners and nurses to receive such requests from their patients. Almost half of those surveyed had received requests to hasten death by withdrawing treatment from patients, and almost half medical practitioners had received such requests from the families of patients. A considerable minority of nurses surveyed had received requests from the families of patients. Lesser proportions of both medical practitioners and nurses had also received requests to hasten the death of patients by taking active steps. It was found that the most common reasons for requests to hasten death were persistent and irrelievable pain, terminal illness and incurable conditions.

The study also revealed that an overwhelming majority of medical practitioners and nurses believed such requests could be considered rational. The main reasons for this ascription were situations where patients suffered pain, were near death or experienced an extremely poor quality of life. The evidence therefore suggests that there is a widely held perception among medical practitioners and nurses that medical treatment pursued to the stage at which it is no longer deemed beneficial by the patient, their families, or by the medical personnel charged with patient care, is unreasonable.

In the past the struggle to maintain life and the decisions that involved were inevitably faced by the medical practitioner alone or with colleagues. The patient could do little but place himself/herself in their expert hands. Recently there has been a shift in the balance of issues confronting medical practitioners away from simply attempting to keep patients alive, towards finding answers to the question of when to allow patients to die. Greater control over life and death processes has inevitably meant that it is also

now seen as appropriate that patients should become increasingly involved in the medical decisions which affect their lives. The survey data on the proportions of patients and their families who request that death be hastened either by withdrawing treatment or taking active steps indicates the extent to which patients and their families wish to participate in medical treatment decision making during the terminal stages of illness. More importantly, it suggests that a considerable proportion of patients and their families believe this can no longer be left to medical practitioners alone. Finally, the data also provides some evidence on the extent of the public perception that some members of the medical profession may persevere too long or may be over zealous in their pursuit of all treatment options.

Medical practitioners must now increasingly face the problem of evaluating or helping the patient to evaluate when the costs to the patient of continued treatment in terms of pain, discomfort or disability, outweigh the advantage of extended lifespan. The overwhelming majority of medical practitioners surveyed reported that they had suggested to patients that no treatment be undertaken, while a considerable majority had suggested to their patients that treatment be discontinued. That this is a recent phenomenon is indicated by the fact that much higher proportions of young medical practitioners had suggested withholding and withdrawal of medical treatment than those over the age of 60 years or those who had been in practice for more than 30 years. The findings also suggest however that many doctors regard hierarchical, authoritarian decision making as the norm, and do not engage in consultation with patients regarding withholding or discontinuation of treatment. It is of course possible that medical practitioners do withhold and withdraw medical treatment but do not discuss this with their patients. Further, the data indicate that a small proportion of medical practitioners appear never to withhold or withdraw medical treatment. This suggests that some doctors continue to undertake treatment regardless of prognosis or treatment efficacy. Finally, the survey also revealed that few medical practitioners consult with peers or other health professionals when patients request their deaths be hastened.

The survey also revealed divergent opinions held by medical practitioners and nurses concerning the desirable locus of authority in medical decision making. Considerable proportions of nurses felt that decision making should not simply be the prerogative of the medical profession, but should be a shared undertaking between doctors, patients, families and other staff. Medical practitioners, on the other hand were more likely to feel that decision making should be left to the doctor alone, or should be shared with the patient and/or family only.

There is growing tension between the dual roles of sustaining life and relieving suffering, and this conflict has resulted in an expanding debate on what constitutes right, correct or proper medical care for the terminally ill. The study confirmed a lack of unanimity concerning the moral, ethical and legal status of decisions to withhold or withdraw medical treatment, where the effect of these actions would be to hasten the death of a patient. While a small majority of medical practitioners believed this to be right, a minority thought this to be right only when requested by a patient, and a small percentage felt it was not right under any circumstances. Lower proportions of nurses, albeit still a majority, considered this action to be right, while a large minority considered this to be right only when requested by a patient. For this group too, a small proportion felt this was not right under any circumstances.

Not only do questions exist in the minds of medical practitioners and nurses concerning when it is proper medically, ethically, morally and legally to withhold, initiate and withdraw medical treatment, but increasingly, if and/or when is it proper in a medical, ethical or moral sense to actively terminate the lives of their patients. While the survey revealed that a small majority of medical practitioners did not consider this to be right, a sizeable minority considered this to be right if it was requested by a patient and a minority felt it to be right unconditionally. For nurses only a minority did not consider this to be right. Nurses were more likely than doctors to regard the taking of active steps to hasten the death of patients as right if this was requested by the patient. This evidence suggests that there is no unanimity on attitudes toward what currently

constitute reasonable medical standards, and further that what many regard as reasonable or proper medical practice is in conflict with the law.

The research found that there was some preparedness by medical practitioners and nurses to overlook the law and take active steps to hasten the death of their patients. Eighteen percent of both groups had undertaken active euthanasia, a proportion which was lower than the 29% found by Kuhse and Singer (1988) in their study of doctors in Victoria.¹ While many had undertaken active euthanasia in response to requests from patients, the families of patients or medical practitioners in charge of the patient, approximately 50% acted on their own volition, with no request having been made. The majority of those who had practised active euthanasia were confident they had done the right thing in the circumstances. This evidence suggests that a minority within the medical and nursing professions perceive the law as too rigid to allow for the problems posed by individual situations, and that legality, morality and ethical behaviour are not necessarily regarded as synonymous. The data also indicate that there is some inconsistency between medical practice and the law. However, the disjunction itself, and individual justifications for it given by those involved, do not by themselves constitute sufficient reasons for making official changes to current codes of practice relating to active euthanasia. Attitudes to the efficacy of current legislation, and guidelines to clarify the position regarding withholding or withdrawal of medical treatment, as well as the question of the legalisation of active euthanasia, are more relevant indicators of the perceived need for legal change.

The survey revealed that South Australian legislation which permits living wills to be made by terminally ill adults, has not proved an effective mechanism for giving patients control of medical treatment decisions at the end stages of life. Few medical practitioners or nurses surveyed had ever been presented with declarations made under the Natural Death Act. Minimal numbers of patients had availed themselves of this

1 This differential may be partly explained by the methodology used in the two studies. In this research all doctors were asked whether they had taken active steps which had brought about the death of a patient. Kuhse and Singer (1988) asked only those doctors who treated terminally or incurably ill patients, whether they had 'ever taken active steps to bring about the death of a patient who asked you to do so?'

opportunity, either because they were unaware of their ability to do so, or because the living will is perceived as having meagre value due to the limited circumstances under which it is operational. Neither has the legislation addressed other and equally important questions faced by the medical profession and their patients. These include treatment decisions for the non-competent or never competent, and those who are not terminally ill as defined by the Act.

The survey revealed majority support amongst both medical practitioners and nurses for guidelines to be established to clarify the legal position of medical practitioners regarding withholding and withdrawal of medical treatment. Doctors were less interested than nurses in clarifying the legal ambiguities of decisions made in this area, and this is possibly because the current situation allows considerable personal flexibility and autonomy, with little fear of prosecution for those who wish to withdraw or withhold treatment. The variability in support for guidelines may stem from the desire on the part of a minority of medical practitioners to retain individual or medical discipline control over decision making. Nursing support for guidelines may derive from their frustration at what they regard as current abuses of that power, be they perceived as unnecessary prolongation of treatment or withholding and withdrawal of treatment, as well as their exclusion from decision making processes.

There was a minority view that such guidelines would make treatment decisions more difficult, as it would be impossible to cover all situations, and the procedures involved might delay or hamper decision making. The problem with not delineating guidelines is that patients will be at the mercy of the ethical and moral codes of individual doctors, and there are demonstrated wide-ranging differences between medical practitioners in their attitudes to treatment, non-treatment or withholding of treatment. Inequities could result where patients are unaware of the bias of their treating physician.

Medical practitioners were divided on the question of the legalisation of active euthanasia, with considerable and almost equal minorities opposed to, or in favour of changes in the law. Nursing views were far more polarised, and a clear, although small

majority of nurses were in favour of the legalisation of active euthanasia under some circumstances. The proportion who were undecided was similar for both medical practitioners and nurses. Response rates to such an important issue are inevitably coloured by the wording of the question, and the phrasing may have influenced the higher affirmative response rate among nurses. As stated earlier, the question asked if it should be legally permissible for doctors to take active steps to bring about a patient's death under some circumstances. As the responsibility for hastening death, or killing, would lie with medical practitioners not nurses, the latter were not required to assume direct moral responsibility for such actions and therefore might have been more ready than doctors to condone such a change. Conservatism among medical practitioners may be also due to the relative detachment of medical practitioners from their patients, as opposed to the close personal involvement of nursing staff. Distance may promote objectivity and the ability to question the future social implications of possible changes in the law. For nurses empathy with the physical and emotional traumas of individual patients may have influenced attitudes, and caused them to focus on the need to reduce personal suffering and for kindness, as well as concern for self determination and 'the right to die', rather seeing active euthanasia as an abuse of these very principles and concerns.

The question concerning attitudes to the legalisation of active euthanasia used the words 'under some circumstances' and this too may have influenced greater proportions of all respondents to answer in the affirmative. Among those who favoured the legalisation of active euthanasia there was considerable consensus that terminal illness and intractable pain and suffering constituted circumstances in which active euthanasia could or should be legal. However there were minority opinions that poor quality of life, mental disability and physical handicap should also be valid circumstances for active euthanasia. The diversity of opinion on these issues invites caution to ensure that in framing guidelines or legislation, current abuses which result from enthusiastic and aggressive pursuit of the aim of preserving life do not become transmuted into abuses due to lack of adequate protection of life.

APPENDIX A

List of persons consulted for research project:-

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Ms Rosemary Seager
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Mr Tony Brown
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APPENDIX B

THE NATURAL DEATH ACT, 1983

An Act to provide for, and give legal effect to, directions against artificial prolongation of the dying process.

1. This Act may be cited as the "Natural Death Act, 1983"
2. This Act shall come into operation on a day fixed by proclamation.
3. In this Act -

"extraordinary measures" means medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation:

"recovery", in relation to a terminal illness, includes a remission of symptoms or effects of the illness:

"terminal illness" means any illness, injury or degeneration of mental or physical faculties -

- (a) such that death would, if extraordinary measures were not undertaken, be imminent;

and

- (b) from which there is no reasonable prospect of a temporary or permanent recovery, even if extraordinary measures were undertaken.

4. (1) A person of sound mind, and of or above the age of eighteen years, who desires not to be subject to extraordinary measures in the event of his suffering from a terminal illness, may make a direction in the prescribed form.
- (2) The direction must be witnessed by two witnesses.
- (3) Where a person who is suffering from a terminal illness has made a direction under this section and the medical practitioner responsible for his treatment has notice of that direction, it shall be the duty of that medical practitioner to act in accordance with the direction unless there is reasonable ground to believe -

- (a) that the patient has revoked, or intended to revoke, the direction;
or
 - (b) that the patient was not, at the time of giving the direction, capable of understanding the nature and consequences of the direction.
- (4) This section does not derogate from any duty of a medical practitioner to inform a patient who is conscious and capable of exercising a rational judgement of all forms of treatment that may be available in his particular case so that the patient may make an informed judgement as to whether a particular form of treatment should, or should not, be undertaken.
- (5) The Governor may, by regulation, prescribe a form for the purposes of subsection (1).
- 5.
 - (1) This Act does not affect the right of any person to refuse medical or surgical treatment.
 - (2) This Act (other than section 6) does not affect the legal consequences (if any) of -
 - (a) taking, or refraining from taking, therapeutic measures (not being extraordinary measures) in the case of a patient who is suffering from a terminal illness (whether or not he has made a direction under this Act);
or
 - (b) taking, or refraining from taking, extraordinary measures in the case of a patient who has not made a direction under this Act.
 - (3) A medical practitioner incurs no liability for a decision made by him in good faith and without negligence as to whether -
 - (a) a patient is, or is not, suffering from a terminal illness;
 - (b) a patient revoked, or intended to revoke, a direction under this Act;

- (c) a patient was, or was not, at the time of giving a direction under this Act, capable of understanding the nature and consequences of the direction.
- 6.
 - (1) For the purposes of the law of the State, the non-application of extraordinary measures to, or the withdrawal of extraordinary measures from, a person suffering from a terminal illness does not constitute a cause of death.
 - (2) This section does not relieve the medical practitioner from the consequences of a negligent decision as to whether or not a patient is suffering from a terminal illness.
- 7.
 - (1) Nothing in this Act prevents the artificial maintenance of the circulation or respiration of a dead person -
 - (a) for the purpose of maintaining bodily organs in a condition suitable for transplantation;
 - or
 - (b) where the dead person was a pregnant woman - for the purpose of preserving the life of the foetus.
 - (2) Nothing in this Act authorizes an act that causes or accelerates death as distinct from an act that permits the dying process to take its natural course.

APPENDIX CDEBATE SURROUNDING THE SOUTH AUSTRALIAN NATURAL DEATH ACT, 1983(a) Submissions to the Select Committee of the Legislative Council on The Natural Death Bill, 1980

The Select Committee received submissions from a number of organisations and individuals including Christian denominations, professional medical associations, the Australian Law Reform Commission, the South Australian Health Commission and the Council for Civil Liberties.

(1) Medical aspects

Several submissions questioned the need for the legislation. In their evidence, the medical associations suggested that in cases of terminal illness only conservative, passive medical measures were indicated and it was not usual or good practice to transfer patients suffering chronic illness to intensive care units during the terminal stage of their illness. Artificial life support measures are usually only undertaken in situations of acute injury or when prognosis was uncertain. Further, it was stated in a verbal submission that medical practitioners already do not generally treat cases of intercurrent disease, such as pneumonia, in infirm and terminally ill patients. Judgements concerning whether treatment should be therapeutic or palliative were usually made by the medical practitioner on the basis of the physical and mental state of the patient. It was stated that while in the USA medical practitioners felt the need to use all possible means for all patients, this was not current practice in South Australia.

Although it was generally stated in the submissions from medical bodies that the legislation was unnecessary, it was also conceded that many people were unaware of usual medical practice in these situations and harboured fears that they may be subjected to aggressive, meddlesome medical treatments which would unnecessarily prolong the terminal stage of illness. That these fears were not groundless was conceded in a written submission from a medical association which stated that there had

been episodes in which the optimum support of the patient and relatives had not occurred and inappropriate treatment given.

Other fears concerning the motivation of medical practitioners were also raised. The representatives of a medical organisation stated in their verbal submission that the community believes that the medical profession is interested only in keeping life going to the last second at all costs, a belief which was corroborated in a submission from a non-medical individual who suggested that decisions should be taken out of the hands of doctors because of their pecuniary interest in prolonging life.

Other submissions from representatives of Christian denominations, as well as the Health Commission also considered the legislation unnecessary in that it neither added to, or enabled anything to be done which was not already being done by doctors.

While the submissions from medical organisations felt that the legislation was unnecessary because of the way medicine was practised in South Australia, it was conceded that it would have benefits in reducing patient fear and uncertainty, although it was felt this could also be achieved by greater publicity and community education. It was also suggested that the legislation may restore faith in the medical profession and provide a means by which patients wishes may be made known more clearly. In addition it was believed that the legislation may help resolve some of the dilemmas faced by medical practitioners, and protect them against litigation should they not undertake certain types of therapy or withdraw life supports.

(2) Moral, ethical and religious considerations

The submissions from Christian denominations drew distinctions between euthanasia or "mercy killing" and withdrawal of artificial life support systems, the latter of which was regarded as quite proper. All groups endorsed the overall intentions of the Bill, but some fears were expressed that the legislation may either unwittingly prepare the way for euthanasia, or constitute the first step on the way to its introduction.

Two submissions considered that the legislation should be extended to encompass the withdrawal of "ordinary" or therapeutic treatment of severely ill people. One suggested that patients should be able to appoint a committee to decide their

future should they enter a "vegetable state", but one which was not terminal illness as defined by the Bill.

(3) Legal Points

Several submissions made comments which related to the timing of a declaration. It was stated that the legislation aimed to provide for informed consent, the aim of which was to ensure that the patient made an informed choice on the basis of all the alternatives. However, the very nature of living wills precludes the ability to make informed choices because the person anticipates a prospective situation. Decisions would therefore be made without full knowledge of the event or the consequences of choices made.

Similarly, concern was expressed that declarations made well in advance of a terminal illness could not necessarily be interpreted as the current desires in relation to treatment, especially when the time interval was considerable.

Several submissions suggested that one of the results of the legislation could be that pressures would be placed on patients to make declarations.

A question was raised concerning the interpretation placed on the absence of a declaration. Would this be seen as a conscious decision not to make a declaration, inertia or evidence of lack of knowledge of the law? In the absence of a declaration concern was expressed that patients may be treated with greater zeal.

Questions were also raised as to what constitutes grounds to believe that a person has revoked a declaration, and what constitutes an intention to revoke.

(b) Parliamentary Debate

There were divergent views on the need for, and advisability of this legislation among parliamentarians, and these views reflected the varying attitudes of sections of the community. It was said during the second reading in 1983, that despite attempts to ensure that the legislation was clear, unambiguous and simply a clarification of existing common law rights, there was some misunderstanding within the community about the scope of the Bill, especially the strict and limited definitions of "extraordinary measures" and "terminal illness". Further, the Bill was open to misinterpretation. There were

some in the community who regarded the legislation as a euthanasia Bill, and while some opposed it on these grounds, others were in favour of euthanasia and therefore supported it. However it was suggested during the 1980 debate that the legislation was an anti-euthanasia measure, as it removed the conditions by which people could be kept alive on life support systems against their wishes. Thus the emotive appeal of euthanasia was eliminated. It was reported that some in the community felt the legislation was too restricted and failed to address the issue of refusal of therapeutic treatment for treatable conditions. It was also suggested that the declarations or living wills to be made under this Act would be less effective than a statement concerning remedial treatment made outside the scope of this legislation.

A number of points were raised by members who opposed the legislation during the debates on the 1980 and 1983 Bills. Firstly, it was felt that the legislation was unnecessary on a number of grounds. It was said that medical specialists closely involved with death and dying in intensive care units in South Australia saw no reason for the legislation. The Act would not benefit anyone because current practices operated quite satisfactorily. Further, the legislation simply enshrined a common law right which already existed and therefore would not enhance any existing rights. However it was acknowledged by those who opposed the Bill on this ground that many people were not aware of their rights under common law. In addition, it was said the legislation was only necessary where there was no definition of death and no code of practice for the definition of death, and this situation no longer applied in South Australia in 1983. Secondly, the legislation would not prevent any present malpractice, and in fact opportunities existed with the Act for the collusion of witnesses and medical practitioners to terminate treatment in order to obtain organs for transplant. It was suggested that witnesses should be persons well known to the patient. Thirdly, the wording of the legislation was ambiguous and open to inconsistent interpretation in practice. Two clauses were considered to be problematic. Clause 4 (3) (a) which permits medical practitioners to undertake treatment where "there is reasonable ground to believe that the patient has revoked, or intended to revoke, the direction", could

cause difficulties in determining the criteria for believing that the patient wished to revoke a declaration. It was felt that this clause opened the way for disputes. Clause 7 (2) which states that "nothing in the Act authorises an act that causes or accelerates death as distinct from an act that permits the dying process to take its natural course" contains inherent ambiguities. Fourthly, some members foresaw difficulties surrounding the existence of declarations. The legislation was criticised as it contained no time frame during which declarations would be considered valid. Neither was any provision made for where declarations are to be kept.

A number The arguments of members who supported the legislation were according to the following lines. Firstly, it was said there was considerable support for such legislation amongst the general community. The rise in the percentage of persons responding in the affirmative to Gallup Poll questions which asked should doctors let patients die if there was no chance of recovery was cited as supporting evidence.¹ Secondly, it was said that many people in the community believe the medical profession keep dying people on life support machines unnecessarily. This attitude is pervasive despite the fact that this is not current practice by medical practitioners in this state. Thirdly, it is widely believed by the general public that medical practitioners do not consider the total person and their wider needs when making treatment decisions. It is feared that death is prolonged rather than life preserved. It was hoped that the legislation would reduce both these fears and concerns. Fourthly, the legislation is a statement of individual rights which will enable people to have some control over their own bodies and to refuse treatment which artificially prolongs the dying process. While people may make declarations about their wishes concerning medical treatment under common law, such declarations have no legal status. This legislation was intended to confer legal status on these declarations.

1 Gallup Poll question - "If there is no chance of a patient recovering should the doctor let the patient die or should he try to keep him alive as long as possible."

let the patient die - response 1962 (54%), 1979 (60%).

keep the patient alive as long as possible - response 1962 (32%), 1979 (23%).

(reported in Hansard 20 April 1983, P896, The Hon. Anne Levy)

APPENDIX D

Question: 'Do you have any further comments you would like to make concerning the issues surrounding the management of death, dying and euthanasia.'

DOCTORS

Doctors have been managing this problem for hundreds (thousands) of years. The public trusts us with their life, perhaps they should trust us with their death.

It should be managed at the local level. The majority of such decisions are privately handled and this remains, in my view the best way. I don't believe an all encompassing law is necessary at all.

People should be advised to make living wills. Extraordinary life support measures (including parenteral nutrition) should not be instituted on a prolonged basis in persistent vegetative states unless a patient has made an advanced directive to indicate that this is his/her wish.

I have serious reservations about the ability of lawyers and politicians to produce a rational and compassionate system or legislation to cope with patient needs.

Community/politicians/legislature must decide how much money should or can be spent in continuing to treat conditions where death is imminent or quality of life is negligible, e.g. severe head injuries, ICU patients, high spinal cord. C2/3 injuries, terminal cancer, liver failure, kidney failure.

I don't think that active intervention should be taken by one person. I agree with the legislation as stated in Qu 19 (Natural Death Act 1983) but if active steps e.g. lethal injection is proposed then at least two professionals as well as the patient need to be involved.

I believe the profession's responsibility is to be compassionate and support patients with pain relief and hope. Euthanasia to me is the resort of the despairing and should not be supported by the profession.

Difficult area - many views enthusiastically stated by opposing groups. Withdrawal of treatment needs to be the subject of legislation, where patient unable to be part of the decision.

Yes. On the one occasion when I would have ended a patients suffering at her request I was prevented from doing so by a sister who threatened to report me to the Medical Board.

There is a surplus of old people and it is a burden on society to have them - on the other hand most seem to be content with their life. They have the right to refuse treatment, but do not have the right to be actively killed by some other person. Pain and suffering is usually controlled by modern methods.

The difference between active and passive measures may at times be difficult e.g. a baby with severe asphyxia and no higher cerebral function. - Is not sucking out respiratory secretions active or passive? - Is not feeding active or passive? On the other hand, if the baby, though severely affected - even terminally ill, was going to suffer much pain which could be relieved by a simple surgical procedure - would it be right to withhold this treatment (which may or may not prolong life) even if the parents requested withdrawal

of active therapy? These are the sort of cases that are dealt with every day. Can legislation cope with all possibilities?

Death is a natural event. People should be allowed to die as naturally as possible and when death is inevitable not be subject to the indignity of a "cardiac arrest".

Inadequate pain relief available generally. Patients therefore frightened of suffering. If patients could be confident that they wouldn't suffer, would not need to ask for or take drastic measures.

Voluntary euthanasia in the light of severe suffering on the part of the patient and/or his family is humane and in fact justifiable. Once the pros and cons are weighted and the patient has made an informed consent, then an active humane method should be used so that suffering should not be prolonged. If at all possible, this final step of ending life should be taken by the patient himself/herself to minimise the psychological repercussions on the doctor.

Many patients are afraid of suffering severe pain while dying, or afraid of becoming "vegetables" being kept alive in nursing homes. If there were rigid controls but patients knew that they could get a peaceful way to die then this would ease much anxiety, as well as making some deaths much more peaceful and acceptable to both patients and relatives. Apart from this, many demented people are kept alive but as mental vegetables in nursing homes and preventing care for those people who are alert but need extra care, and forcing great hardship on many elderly frail people. This will only get worse. The most important aspect would be a choice. If the patient or relatives (if the patient was incapable) refused euthanasia, then the patient should be kept alive.

I feel euthanasia should become a possibility, within certain legal guidelines.

There is a whole area concerning the cost of artificially prolonging life by medically/technologically heroic means e.g. massive ant viral doses with severe viral encephalitic cases, AIDS, respirators and ICU for neonates or brain damaged adults or severe quadraplegics, which somehow needs to be weighted against the chances of a successful outcome of the heroic treatment, plus ongoing costs of managing severely disabled persons VERSUS social/epidemiological means of investing in community health costs. I feel bioethics committees need to look at this whole area, as well as that of individual euthanasia.

The main point has always to be the patient's interest. His wishes must be respected as long as he/she is able to make a rational decision. The doctors interest (religious objections) must come last.

I think an anonymous general public survey would be helpful for pro case for euthanasia but it would be important to ascertain their level of awareness of the real situation with the terminal. Most people who I have spoken to who are against euthanasia have never seen anyone die showing that their decision is based on the weightless concept of "preserve life at all costs".

Patients should be free to choose when to die and when they want to prolong their life when they have a terminal illness.

Quality of life remains a key issue and where we have access to adequate pain relief and support services euthanasia becomes redundant. In contrast, once accepted legally, the boundaries defining its practice are quickly eroded and a situation such as that in Holland arises - involuntary euthanasia becomes incalculably rampant.

Medical staff need to be much more willing to discuss death and dying with patients and relatives than they have been traditionally in the past. Continuing support is needed for

research into pain relief, provision of home supports for families and hospice care when appropriate.

I do not think the inclusion of the euthanasia question along with death and dying is constructive. This clouds the whole issue of promoting "appropriate" care for patients with "terminal illnesses".

There should always be distinctions between active and passive euthanasia, together with further education of professionals involved re palliative care, especially with regard to analgesia.

I believe my job is to support and care for the patient with terminal illness and their family.

I will be happy when some of the compassion expressed to other living beings in distress can be transferred to the issues in human suffering (because of sickness). I am happiest if the patient has made the decision with a clear mind and has had an opportunity to be counselled to be entirely happy with their choice.

The issues should not become formalised into laws of the land or even into guidelines issued by some government agency or other third party. They should remain the subject of discussion between concerned patients and their medical caregivers whom they individually come to trust and to rely on for humane care, discretion, and respect for their intelligence and dignity.

There is still great confusion even amongst nursing staff and lay public regarding the meaning of the word euthanasia. I don't believe that withdrawal of extraordinary means constitutes euthanasia. Active killing or assisted suicide does.

Seeking legality would create further problems of a medico-legal nature. Keep the legal vultures out.

It will be a tragic day when the Hippocratic oath is scrapped by a decree. I am of the opinion that high professional ethics set by Hippocrates should be rigorously defended as otherwise we may reduplicate the state of affairs introduced by Adolf Hitler where handicapped and chronically sick would be destroyed as defective and unproductive and turned into dust and become food for worms.

Unnecessary treatment is too frequently often given to patients who clearly are unsalvageable and who undergo extra suffering as a consequence.

Patient and relatives should be protected by two independent opinions and advice.

I am totally opposed to euthanasia. Doctors need better training to cope with and assist with the dying process. I agree with the provision of The Natural Death Act that if death is inevitable and imminent extraordinary or burdensome treatment can be withdrawn provided the patient agrees or his guardian consents and it seems truly in his best interests.

Yes it makes a lot of sense to avoid futile treatment in people whose lives are burdens to themselves and others.

How many people are quadraplegics in unremitting agony? The rest are not suffering (coma, dementia - the observer suffers) or can kill themselves. The public view of doctors is precarious enough without being seen as bringers of death. Do not expect people/doctors/lawyers to be magnanimous and benevolent just because you and I are. One generation ago being a Jew or a Gypsy was grounds for euthanasia. In another generation will dementia (by whose standard) or pain (even now proper uses of

analgesia is not understood by most doctors that I encounter) be the grounds to legally kill?

I consider there is a big difference between euthanasia and withholding treatment in a consenting terminally ill patient. Euthanasia has the potential for abuse and overuse and could eventually (if accepted by society) be forced unwillingly on the aged, infirmed and deformed members of our community.

Offer morphia for terminal case: include comfortable ear phones and play best of the classic composers - pleasure enhanced by narcotic.

This is a big issue and public debating could be encouraged.

So called medical ethicists do not have a greater claim to knowing what is right than the common man on the street. Their so-called expert views are ultimately based on their philosophical and religious beliefs.

As an intern it was easier to expedite death. You see a lot more unnecessary suffering as a junior doctor and as your own lot can be miserable you feel fewer qualms about helping release a patient from their torment if a peaceful death is near at hand.

We are not God, but if it is obvious God's decision is made and the patient is in undue distress, alleviation of suffering seems reasonable.

Detailed information should be made available to all doctors. (Knew nothing of Natural Death Act).

What is extraordinary and poorly understood by those who do not work in hospitals (where death is common) is how miniscule the above issues are. Decisions about dying are made every day.

Problems include deeply ingrained aim of the medical and nursing profession to preserve life; the differing attitudes of responsible individuals (whether medical, nursing or relatives) to euthanasia - or even to failure to take the most extreme steps to prolong life (or dying).

The doctor must have the right to decline participation.

Persons who wish to terminate their life may by their own hand. Assistance could not be expected from the family doctor.

I firmly believe a rational approach to death and dying and euthanasia can be taken that would alleviate considerable suffering but would nonetheless guard against 'murder'. I would have no qualms about helping a patient die under circumstances acceptable to the general public.

A lot of my senior patients have discussed their wish that they do not wish life prolonged in any terminal illness they may suffer. Only two have given me a written document which I hold with their case notes. Neither of these has needed to be acted upon yet.

The Natural Death Act should be accompanied by an enduring power of attorney to enable it to be activated in unconscious or disphasic patients.

We are all fallible, even patients! They not infrequently say they want to die when feeling very ill but when ? (healing) occurs are very pleased to hold onto life! I believe as doctors we should always give people the chance to exercise this change of heart as death is so final.

It won't stop at clarification of doctors legal position, it will mean rules and regulations dictating our mode of care at the end.

Decisions about death, dying and euthanasia tend to be made by people in the academic milieu when they are in no danger of dying and unable to envisage how they would feel in the face of what conventional wisdom suggests is an abhorrent state of illness or dependency. They use rights and autonomy reasoning to inflict their views on those who are at risk but unable to voice their feelings. The issues of life and death then become trivialities, as in the Netherlands.

I feel very comfortable with withholding treatment in cases from which recovery (is) very unlikely or impossible but would find active measures to bring about death would present a much more difficult situation for me at this point in time.

It is my opinion that the Natural Death Act should have no place in the decision as to whether to treat someone in ICU. The public and probably many doctors are unaware of the implications of intensive support for an acute illness. Only a specialist in the field can judge. This is the most difficult area in ICU and is handled differently by each individual doctor and some legal guidelines are long overdue.

The issues surrounding terminal care, palliative care are infinitely variable and in my view attempts to codify these complexities would not produce great benefit. The difficult decisions are few and far between and 'hard cases make bad law'. In general I have found that conscientious care of patient and relatives has not been accompanied by agonising decisions about withholding treatment - the decisions almost make themselves by consensus at the time. I do not think it is mans (doctors or patients or relatives) place to determine the time of death. I am often asked to comment in patient notes whether resuscitation should be attempted in the event of so called cardio-respiratory arrest (previously called death) in the elderly/infirm - usually 75+ with malignancy, advanced metabolic disorder or widespread vascular/cerebrovascular disease. This is because nursing staff are currently expected to set in train resuscitation for everyone unless specifically instructed not to. In the majority of cases commonsense tells us that it would be fruitless to attempt resuscitation (or would merely seem to prolong the patients suffering to resuscitate them). That is usually the tenor of the comment I make. In rare cases an elderly person survives a crisis and the DNR comment is withdrawn.

It should be an inalienable right to die in some conditions but guidelines must be set to exclude any transient depressive states.

Life is a sexually transmitted terminal disease. There is no need to throw a single bucket of water on the fire which is burning someone at the stake - it will only prolong the agony - but we all die eventually so where do you put the line? It is an individual and societal decision.

Many of the situations you mention arise quietly and quickly in regular clinical practice. I would like to think that patients in the future may have the privilege and opportunity to die without fuss and without unnecessary distress, perpetuated by health professionals more concerned with the principles than with humanity.

This (declaration under The Natural Death Act) has been presented when patient no where near death - how appropriate? Is making someone to die a statement of anxiety in the same way of our concern about the time of birth? A lot of family conflict can be resolved prior to elderly people's dying. A great opportunity for family to say I love you.

I would agree to (a) withdraw treatment (b) not institute heroic treatment in consultation and agreement with patient/family if it was not aimed at the quality of life but only at prolonging life in a hopeless situation. If the patient/relatives asked (for) treatment I would treat. I would never actively take a life.

It is difficult for a human to accept the responsibility for someone else's death. Why should doctors be the ones to accept responsibility. Why not the patient's spouse or other person chosen by the patient to end his/her life.

Although it seems rational to terminate the life of a terminal suffering patient it seems wrong, could easily be abused, and may be a very heavy burden for caregiver. It is much easier to withhold intervention which is not likely to succeed, and to give drugs in sufficient doses to relieve suffering.

In favour of euthanasia.

I have given "not to be resuscitated" orders and have given medication to control terminal pain and distress which incidentally would have shortened life.

I feel strongly that euthanasia (by positive measures) should be a legal option available to patients where this is governed and monitored by strict and correct guidelines.

I believe this to be an extremely delicate issue with a lot of potential for abuse. Nothing less than a referendum should empower the state to pass such a law. (euthanasia)

Current situation where doctors are able and commonly do address the issue of withholding care or active treatment and may make unilateral decisions or decisions in consultation with affected individuals/families without definite legal or professional guidelines is unsatisfactory.

As doctors I think we have much to offer the dying and their families etc. We are especially privileged to be asked to be part of such a time in their lives. We must do all in our power to make it comfortable short of deliberately killing anyone.

I think the current care in hospice situations is so good that it would be unnecessary to actively speed up the dying even if it was legally right to do so. I feel it is not right to actively hasten death. I realise that by giving pain relief that is adequate a life may be shortened but to give a single lethal injection is out of the question and would be open to abuse, destroy trust and put the doctor under pressure.

More public discussion should be encouraged to allow society to set the guidelines - not the medical profession.

A request starts with the subjects (the patients) - approach their request without prejudice or fixed ideas - all decision making must issue from the patient - the end must be totally dignified.

Things are bad when hospital rules and nursing staff pressure doctors to attempt to resuscitate "dead" patients brought in by ambulance or who die suddenly in wards who have other medical problems when they would be better left. The major concern here is litigation from family and concern where the profession stands in law. Could I be held responsible for a patients death if I do nothing (doctor and nurse).

Needs to be much wider community awareness of the issues so that decisions regarding treatment can be made in a considered setting.

The guidelines need to be absolutely clear.

While society believes in the sacredness of human life and its intrinsic right to the care and preservation of it then it is only right that we should help everyone who is ill to live with dignity and when we can do no more to let them die with dignity. I am quite sure your results will be a broad spectrum of views and positions. It is clear to me after a

quarter of a century of practice of medicine that sick people appreciate and want our help. They are grateful for all we do to keep them alive and as well as possible. If we once change the mind set of health workers from "help people back to health" to "help some people to die" we will irrevocably change the value placed on human life and just as, in the process of abortion we have totally devalued the worth and status of millions of babies worldwide who are destined to be disposed of neatly before the 3rd trimester, and are not grieved or loved by the majority. We will find it hard to prevent some people who really would like to live, from taking decisions for the sake of others (? as if when) subtle psychological pressures placed upon them.

Patient have right to determine medical treatment.

I think it is most important that those for whom this is a personal issue be given most credence! It's all very well for so-called "experts" - philosophers, bioethicists etc to expound their views. That's important too, but the real experts are those in the situation of need. There was a disturbing - but not unexpected - report of a meeting of "experts" with a "token disabled person" present in a recent medical journal (Drs Weekly) which described the patronising manner in which the intelligent, aware, "disabled" person was treated.

One should not strive unnecessarily (and hopelessly) to keep alive.

It is a very difficult situation at present. I would like to think it was legal to withdraw/withhold treatment in terminally ill cases with patient and/or next of kin permission.

I think that in many cases the process of dying is prolonged by medical treatment rather than increasing the quality of life by good medical management. The law should be changed to fit the practice of medicine as it is with modern medical technology able to keep dead individuals "alive" on respirators etc. The definition of death needs to be assessed carefully.

Drs in practice need more information. Public debate is essential and public acceptance is imperative.

Withdrawal of treatment or no extraordinary measures to be taken if requested by terminally ill patient is OK. Doctors should not be involved in the administration of drugs etc. to actively kill patients. If terminally ill patients want this it should be their responsibility or that of their families or loved ones to administer lethal doses of medication.

The matters under consideration are in my experience best handled where a close professional relationship exists between the dying patient and his/her family and a practitioner. The long established ethics of the profession cope with this problem very adequately in these circumstances without the intrusion of legislation/guidelines.

As an obstetrician the dilemma I am faced with is involuntary active euthanasia (termination of pregnancy) or involuntary passive euthanasia (turning off life support of prem infant) If these are acceptable surely a rational decision of an adult is as well.

With children the guidelines are more easily drawn than with adults. I am convinced however that with adults a clear declaration of intent or will by the patient should be honoured and that in the past, for whatever reasons, keeping patients alive against their expressed wishes has done more harm than allowing nature to take its course without extraordinary treatment or interference. Thirty years ago my mother (aet 78) had an extensive CVA. During the ensuing week I supervised her being nursed at home without IVT or any form of maintenance therapy. Careful nursing to keep the bed clean and dry and pressure areas monitored and supported only. She did not recover

consciousness, deteriorating visibly over the last 24 hours and died quietly 1 week after the initial CVA. This in consultation and with approval of my father her one surviving sister, and the local GP as well as and in line with her own oft expressed earlier wish. With IVT and parenteral nutrition she would almost certainly recovered consciousness at some point - and found the resultant dense hemiplegia and communication difficulties intolerable. I would love to be able to ensure a similar exit for myself when the time comes.

I suspect far too much is made of this issue which should consist of choices made under uncontroversial circumstances and, if possible, just the concern of the patient and his/her doctor.

Individual specialists must be discouraged from addressing only "their organ". Panels need to review all available data and adjudicate as to intensity of treatment versus simply conservative humanitarian assistance with approaching death.

No one doctor should be expected to make the decision concerning such issues.

Hopefully they (issues surrounding the management of death, dying and euthanasia) can remain more in the medical sphere than in the legal sphere.

I think the matter of Question 19 (The Natural Death Act) should be taken as a civil right - rather than something for which an action must be taken by the patient to validate.

I think there should be more guidelines to legally protect doctors and give patients the right to request active steps to be taken to alleviate suffering which may result in an earlier death than if these measures had been withheld.

As before keep legal people out of arena as this may legitimise killing of people. It would be wise for doctors involved in this to have an avenue for discussion with a bioethics group for verbal guidelines.

Humankind (man) behaves absurdly in endeavouring to keep alive a suffering/invalid/demented individual at great length and cost yet develops weapons to mass destruct healthy young people in war! Almost every healthy person I have spoken to on the subject has expressed fear of dying slowly or of cancer or of going into a nursing home demented, but would prefer to die quickly and cleanly with dignity instead.

The need for hospice facilities is enormous. We need to train people and provide facilities for the dying patient.

I do not believe in euthanasia but I do believe that in patients with a terminal illness and in whom the prognosis is hopeless, should be kept very comfortable at the end. I know this hastens the process of dying and I am in favour of that.

Yes. I cannot understand the reluctance of doctors to do what they must know is right just because they fear litigation. We all do it for our animals as an act of kindness, why on earth can we not do the same for our patients. I am appalled by the thousands of vegetables who are kept alive in nursing homes being treated with antibiotics when they develop pneumonia. It used to be called the old mans friend in my student days. I think we are obsessed with saving life at all costs.

Active euthanasia is open to abuse. It creates a general climate that will lead the old and inform and terminally ill to believe they should do the "brave thing" and request euthanasia as they have become a nuisance and a burden etc. and are better off dead.

Relatives apply subtle pressure on the old to go into nursing homes - why not pressure them to ask for euthanasia.

I think that it is acceptable and perhaps possible without incredible bureaucracy in "certain" hospitals. If it was not to be performed in hospital or at smaller hospitals then peer/community review akin to the guardianship board may be possible.

Dealing with the dying is a privilege and rewarding experience that to be able to assist a person and his/her family to an emotionally satisfying conclusion, be it death if this is inevitable, as an important function of a family practitioner. We do handle death in general much better than hospital doctors or specialists. Euthanasia is an option which has to be treated with respect neither encouraged nor dismissed arbitrarily.

The onus of causing death should not be placed on the doctor, if alternatives exist. The patient on request, may be given appropriate medication to terminate their life if and when they desire, e.g. "if you take all of those pain killers at once it will kill you". This factual suggestion is not often followed up!

Whenever "legality and laws" enter a situation it becomes a complicating factor. If the medical "team" is caring compassionately for a person in consultation with the family and friends there should not need to be involvement with the law. In the case of criminal homicide the law is involved.

Death is a taboo subject in our community. Unless society as a whole is willing to discuss and initiate action regarding these issues, then doctors will always find themselves in a legal nightmare.

This issue is very difficult because of the religious influences; doctor's poor awareness of the intricacies of death, and acceptance of their own life/death; medical model training - does not look at quality, looks at treatment modalities etc.

Whole hospice care management in this state needs reappraisal as it stands in its present form is not satisfactory. One thing lacking is a positive approach for the patient.

Total participation of all concerned with the dying is very important. The patient should have the dignity and right to decide when suffering and pain (is) destroying his/her life.

Leave it to the evolution of common law. Exclude opinions of theoreticians who have never had to make clinical decisions.

It is obviously an area of great difficulty, but it cries out for clarification. I believe that given the appropriate protocol and safeguards that such management and the concept of euthanasia itself can benefit patients of terminal illness in certain situations.

I fear that trying to legalise euthanasia will provide great difficulties to the legal and medical professions in weighing up the rights of the individual and protection of doctors for their actions.

Active steps are grossly undesirable but very different from withdrawal of treatment for pain relief.

Needs control so as not to get out of hand, but as a principal I agree with it.

I agree with the position adopted by SAVES.

The diversity of living relatives in their opinion of patient health and status. The danger medically and legally of involving any other person in forming any opinion.

Euthanasia should be confined only to patients state and condition, NOT for relatives request.

Death is ultimately inevitable and there are times when it is more important to help prepare people for eternity than to prolong life on this earth at all costs.

NURSES

It seems to me everyone rushes around to save a life and then handed to the families or relatives or hospitals to care for, causing more pain and suffering and they become the forgotten people of the human race with no quality of life for them or the carers. (sic)

I firmly believe the patient should have the choice to die. Doctors are so taken up with prolonging life but sometimes they are only prolonging the suffering. And yes, I have been asked by my own mother, and other members of my family as well as patients I have nursed.

I personally feel doctors are afraid to let patients die. One reason is the legal implications brought on by the family of the person, another reason I believe is the fact that many doctors believe a person dying under their care is a failure to their profession.

Euthanasia should not be legal.

I believe all measures to preserve the quality of life should be implemented. Longevity is not the point here, it is more a question of quality.

I sincerely hope that euthanasia is never introduced in this country. Doctors remain reluctant to discuss the matter of resuscitation with their patients and nursing staff. I don't think they will find euthanasia any easier to discuss. Who is to make the decision of who is to live and who dies, and when?

I do not believe in euthanasia. However I believe as much narcotic should be given as needed for pain relief.

I believe that a patient should be comfortable i.e. provided adequate pain relief to maintain comfort and that hydration is always maintained. If death is obviously imminent then other invasive procedures should not be attempted.

I have answered generally supporting the notion of euthanasia. However, the circumstances of such action are very complex and we must at all times be aware of the real probability of misuse of such legislation.

Very difficult area, but surely if patients are to be considered as clients for whom a health service is supplied then they must have a say in termination of this service. There needs to be clear legal and ethical standards set that cater for clients needs as well as protecting the health profession in dealing with this sensitive area.

Overall euthanasia for dying is kinder than seeing a patient in pain, but all his family affairs should hopefully be fixed up first, before any euthanasia takes place, e.g. wills etc. if the patient is able to do this. If the patient is found to be suffering from depression and his condition e.g. quadriplegic will not lead to dying sooner, then euthanasia should not be done until further investigations and treatment of depression are first sorted out, then allow the patient time to think.

I am a fundamentalist Christian and do not believe man has the right to play God, who has the keys to life and death. Because we don't understand everything about death, doesn't put us in a position to facilitate premature death.

God gives life and God takes life.

Death is inevitable. Pain can be controlled. Quality of life is as important as quantity. Dying can be comfortable.

I think that the people who are so wrapped up in the ethics and morals of euthanasia should try hard to picture themselves in some sort of these scenarios - how would they feel? Would they have the strength to go on? Some people do - others don't but we should all have the right to choose whether to go on or to die? I know what I'd choose.

I have worked as a senior nurse for some 20 years and my views on euthanasia have never changed. Through the years many situations have arisen in regard to this and it has only enforced my views. I have seen the order 'Not for Resuscitation' abused on many occasions i.e. young people left because their case, although not terminal or incurable was just too difficult - same was not discussed with the patient or relatives. I could go on but I feel you get the point I am making.

I have many times given terminal patients IM and IV morphine and pethadine but I do not see this as active steps to death as these were also given to relieve pain. Even though these patients have died soon after it has made their death less painful and more comfortable (I hope).

Doctors and nurses (think) that sometimes nothing more can be done for a patient and therefore have to justify the continued suffering against the potential benefits (if any). There is more to life than just living or 'existing'. Nurses are placed in difficult situations e.g. a terminal patient may be commenced on a morphine infusion to control pain, with orders stating give enough to keep the patient comfortable. Isn't this just slow euthanasia over a couple of days, rather than just one single injection, when we all know that it is the drug that will kill them in the end.

I feel that passive euthanasia is already practised in the aged care industry. However having had a relative die at a public hospital after extraordinary measures were taken when there was no possibility of his survival, I feel they need to look at who they try to resuscitate. Similarly St Johns also have tried to resuscitate a 92 year old with terminal cancer. I would like to see dignity in death.

I believe that every person if lucid and rational (above the age of 18) has the right to ask for treatment to be stopped when terminally ill.

Each person is an individual so therefore each case is separate.

I am unsure as to how much these questions relate to the situation of a relative deciding to withhold treatment. No matter how close they are to the patient I feel it is too ambiguous an area to allow them the decision making not to mention the guilt that must accompany a decision either way. I know that if one of my immediate family were to be in a situation where life was merely being "prolonged" by extraordinary measures, I would feel obligated to try to put an end to it, but whether I could really justify it and make that final decision I do not know.

I feel that more should be done to ensure the feelings and decisions of terminally ill patients are taken into account and wishes of hastening death in these patients documented and respected.

I believe everyone has the right to die with dignity and have the right to do this with the appropriate means available, I believe in euthanasia.

I know that my parents do not want to be kept artificially alive, yet because they have never given me such a declaration I cannot under present law do anything to help them. Nobody expects to be kept artificially alive. It is always somebody else. Verbal knowledge of very close relatives/friends should be sufficient.

As in Question 18 [guidelines on withdrawal/withholding] I am unsure of how to clarify such issues both legally or morally but I do feel that a patients request for euthanasia should be seriously considered. Many facets of one's life are not always understood by others and if counselling/talking to both patient and relatives (I think its important that family be involved but the patient to be capable of this decision and its implications understood (establishing the sanity of the person making the request and his/her understanding of such a request would have to be the responsibility of more than one medical practitioner).

As a nurse I feel it is my duty to provide care to my client and help them to attain realistic health goals. Where it is inevitable that death is imminent and pain and suffering may be experienced I would support euthanasia providing the client agrees. If the situation arises that the patient is not able to make that decision then consultation should occur between all members of the health team and the relatives.

I feel if a patient of sound mind dying of a painful terminal illness should be able to make the decision to terminate their life. In a brain death situation the family or spouse would have to make a decision after being given the facts straight of this irreversible condition.

During my training I witnessed many cases of withdrawal of treatment although I was not actively involved in the decision making, e.g. mostly comatosed patients.

Any doctor who, because of religious beliefs, etc., should not be placed in a position of having to make a decision.

I feel strongly about people who have to suffer extreme pain. Its wrong and up to the individual person to say when enough is enough!! Even children are capable of saying that they do not want to suffer any more.

I feel we as nurses do not treat the dying patient as well as we could. Unfortunately in the larger Cpv hospitals particularly, death is considered a failure to the system. But in some instances a peaceful, painfree death should be considered as a good outcome.

Life is too short anyway.

God is sovereign.

A carefully, strict legally controlled euthanasia program is warranted in this country. I think the cost of keeping alive the terminally ill and elderly and dying is a great expense that could be better spent investigating children's diseases, SIDS, cancer, leukemia, AIDS, etc.

Support networks need more assistance/structure for staff dealing with dying patients, i.e. hospital based, community nurses also.

Make sure the person is comfortable not in any kind of distress. When time comes the death will occur. No one has to re[b/c amond*] regarding that. It will take by itself.
(sic)

[*unable to decipher this word]

I agree with current 'hospice' type care for dying patients, as treatment has been withdrawn leaving only pain management in progress. I feel euthanasia at a patients

request is similar to suicide. I don't think I could 'aid' a client to die, except for stopping treatment, as I would see it as murder.

I would like the law in Sth Aust to remain as it is regarding death and dying. I can see no cause for change.

It would make very interesting reading and will become more appropriate as our population of 'elderly' increases.

It is my definite belief that patients who wish to die should be made as comfortable as possible given the best nursing care, and if terminally ill the extraordinary means be taken to prolong life, but also no action be taken to hasten death as our life is not our own but in God's hands.

Pain control is of major importance for the dying.

Each case is individual and should be treated as such. Some people can never accept that they are terminally ill, while other have seen friends or relatives die in such a way that they feel is unnecessary for them or their family. It is important, especially for children, to see death as peaceful and dignified. It is also important for the patient to say 'goodbye' to friends and family. The patient and their family will accept death a little easier if he or she has had time to put business in order, which is not often possible due to treatments, hospitalization or mental deterioration.

I do not believe in active euthanasia.

In principle, I agree with the alleviation of suffering. However I am concerned that euthanasia would be open to abuse if legalised and feel that no human being has the right to decide.

People have been cured and have lived a full life when they have been given no hope. So it is not up to 'us' to decide. If it is left to the relatives to decide, are we going to end up with another medical problem "psychiatric" I'm not sure about the patient deciding.

This is a complex issue which requires wide bio-ethical debate.

I think always the quality of life and the wishes of the dying person must always be considered first before the wishes/needs of relatives, carers, doctors, etc.

I personally disagree with active steps - euthanasia. Switching a ventilator off when someone is brain dead - its the disease or injury that causes the brain death that causes the eventual death but giving someone a lethal dose of medication - its that act of giving the drug that causes death, therefore the giver of the dose is the perpetrator of death equal to murder or suicide.

Fortunately I am not involved in this area but management of death should be done with thought and dignity - prolonging the obvious outcome by continuing treatment - which is painful not only to the recipient, but also those near and dear to them, seems cruel. I feel like grabbing all the tubes and monitors from the poor patient and chucking them! We should not act as God either, but certainly I don't believe in prolonging life with treatment for the sake of it, or just because we "seem" to be doing all we can.

The issues are clouded because management or terminally ill elderly are often lumped in with active termination of lives of deformed infants and every other issue in between. The fears that relaxing laws in any area will lead to "open season" for extreme cases, is preventing rational debate.

I am not happy about life to be ended except the giving of analgesics to relieve pain and maintain "quality of life".

I think you need to consider Christian/ethical views. Legislating men to make decisions about actively ending life is so dangerous however desirable. Where do you draw the line? How/who draws the line for legal termination of pregnancy? Morally conception is the potential for life unless God deems otherwise.

Each case should be considered individually. Management of death and dying to be discussed by patient, relatives, medical, nursing and other health care workers as appropriate. Extraordinary measures to prolong life for the terminally ill or those with incurable conditions should not be taken, but these patients should be made as comfortable as possible without active deliberate euthanasia taking place.

Euthanasia is a very delicate issue and should continue to be discussed, evaluated, etc., as it concerns the whole community.

I would personally hate to choose the time of death for a terminally ill members of my family as I do not think at a moment of stress I could make a rational decision. However if it was myself I would like the ability to end my life if my condition was such that it was only a matter of time and I would like the right to die with dignity.

Euthanasia - do not agree with unless severe circumstances exist, e.g. severely handicapped, premie infant - low birth weight, poor prognosis.

All medical professionals should be encouraged to explore their views/beliefs on death and dying - their own death and that of patients (particularly during their training/education).

I feel if a patient is unaware of his/her surroundings, fully dependent and prognosis is poor we should discuss with the family future plans, able to make a choice regarding euthanasia. It is really a matter of being objective and sympathetic to the patients needs, dignity and status. Focus being on the patient not our own personal ethics.

There is too much medical interference in the dying process. Often active treatment is pursued, when a comfortable painfree death should be supported. If euthanasia was legalised it would be open to abuse.

That I have not been asked for assistance to quicken death is due (1) because of the social taboos to converse about it (I believe); (2) because I do not work in an area where the matter is an issue. Patients I have looked after have been classified "not for resuscitation" and died subsequently. Also respiratory failure following morphine admin has occurred. We allow great cruelty to those who live in great pain, want to die and we do not assist them to die.

I think that the Natural Death Act is not adequately known to the general public and should be.

I feel helpless when you see some patients suffering, but sometimes the suffering brings about changes for the families, etc. God works in mysterious ways and I have prayed for people really suffering especially terminal cancer patients, to be released from the suffering. In God's time when he choses is the right time for each of us. I could never live with myself if I'd taken someone's life. Even if though at the time it would be ok because of the pain, etc.

Even though I have no contact with patients making use of the Natural Death Act I believe a lot of suffering can be avoided in many of these cases.

I have on many occasions (as a nurse) been angry and distressed at the management of people in this situation, particularly by the medical profession. There have been many occasions where (I consider) inappropriate procedures have been carried out on patients when it is obvious that they would be ineffective and often cause undue stress on the patient and/or for their relatives and friends.

Do not believe changes should be made. Where do we stop???

I do not believe it is right to even contemplate euthanasia. I believe all life is very precious. I also believe patients with terminal illness have the right to refuse active treatment. It is not necessary for any patient to suffer. Palliative care these days is excellent. Loving and supportive care for patients and their families is essential.

Everyone of us has the right to die with dignity. Relatives should always be involved in these issues. Spiritual aspects, whatever the religion is, should also be considered.

I find the main issues associated with death and dying is the inability of everyone except the patient to cope with their own mortality. That is what causes the main problems. Also some doctors suffer from God Syndrome and can't cope with what they perceive as failure.

I think it should be the patient's decision, of how he wants his illness handled in these cases. He should have guidance and counselling but the ultimate decision should be his (especially if death is imminent). If he's not of sound mind, then immediate family should have the right along with perhaps two other bodies ... then perhaps two out of three is enough to go ahead (other bodies ... perhaps medical and religious).

My opinion about euthanasia - I don't think it should be legalized as it is in Holland - who is acting God on who lives and dies? Terminal patients should be allowed to die at home, in comfort, privacy and pain free with community support for the family and relatives.

I do not believe in euthanasia but I believe in giving adequate pain relief for pain even though that can sometimes result in hastening death.

If a client wants to die let them take their own life without assistance. I believe society has been educated to promote life and expect it hence difficulty of many patients and families inability to accept the final death and grief process. People no longer die quietly at home but seek extended life at hospital and often traumatic times prior to death. Education and attitudes need to be changed. The right to live or die ultimately belongs to the client if in a fit state to make this decision.

I think it needs to be looked at as quantity against quality and pain and suffering and prolonging the inevitable. We can try and make people comfortable when near death; and if by some miracle we could remove the mental person from the physical body, and ask what do you want us to do. The mental aspect would look at themselves, look at loved ones hurting as well, feeling your pain and anguish and almost wishing for your death to end your suffering. I'm sure the mental aspect would very quickly say "end it". We must offer some dignity to our dying residents.

This is a very delicate subject, and as I have nursed for 17 years I have seen many terminal patients and often feel that if it was me in their position I would prefer to die if there was no quality of life.

I would like to see a pain management protocol instigated for people with chronic pain/terminal illness available in general wards. Pain most distressing factor for patient/relatives.

Very personal and complex issue - not only covering the elderly (terminal) mainly these have been what I have been in contact with - but a lot of younger and babies would also have to come under the management of death, dying and euthanasia.

This area is a legal and moral minefield. Withholding treatment is one thing, active actions (e.g. euthanasia) quite another. If euthanasia were legalised I would like to see extremely strict guidelines. The release form signed by at least three medical personnel and three relatives if the patient was unable to communicate in any way and these six people present to witness his/her wishes if the patient was able to communicate. It may seem a lot of witnesses, but there are many unscrupulous people about who could use legal euthanasia for their own selfish gains and/or simply because it was "convenient". This whole business of euthanasia is quite frightening. On the surface it looks simple enough, but human beings are not simple. They are complex with many motivations driving them. For every "good" law or act, there is often a "bad" use of it. Lawyers could have a field day. The population is ageing, hospital and medical funds and resources are being stretched to the limit. Quite a temptation to "bump off" legally the considered "useless" in whatever category in society.

A difficult topic! socially the government lack of funding for low birth weight babies and lack of treatment for cancer patients results in hastening patients death - the doctors should not be accountable legally overall. Morally - I don't think a patient's request to 'hasten death' should give anyone 'the right' to carry out the procedure.

I find it difficult to nurse patients where there is a poor prognosis and he/she is just being kept alive by artificial means. I think it is important that once a point of maximum intervention has been reached and still the prognosis is poor that "nature" should be able to decide the outcome. I do not like to see patients and their loved ones suffer unfairly.

Death is one of the last great taboos and it is good that work is being done in this area. The work of Elizabeth Kubler-Ross and others has helped to raise awareness about death and coming to terms with its many facets. I believe death is a transition from one level of consciousness to another and in the eternal nature of the soul. I believe there needs to be special attention paid to the spiritual needs of the dying, and while this is increasing, there needs to be more.

I feel that care of the person's body and spirit needs special care. That individual's wishes should be respected and pain relief not seen as secondary to survival in the terminally ill. Allow patient to go home sooner when time is limited.

Doctors, pathologists, chemists, etc. - medical people in general seem to often 'sponge' off poor old helpless innocents. Lingering painful deaths are so unnecessary - we wouldn't expect animals to go through some of the things we allow humans to endure. As the numbers of old people increase in the community proportionately the cost of medical care as we have now will be prohibitive. How can we make people more productive longer. How to 'police' or where do you 'draw the line' re active euthanasia?

I feel that the individual's right should be respected at all times and that if a request has been made that this should be followed through with.

I had a very elderly relative die in a nursing home recently. I felt the management of her death was not appropriate. Due to her frequent complaints of pain I believe the last week of her life could have been made more comfortable by administration of IV opiates. The request had to come from the family to have this initiated. She died comfortably approx 18 hours later.

People are still terrified of the prospect of death. Families who are faced with their relative having some terminal illness or irreparable head injuries should consider how that person would feel "living", continuing to "live" like that. Often we become selfish

because we want to "hang on to them". We've not learnt how to handle death. We should accept death and accept euthanasia as a more humane way of treatment and not try to play gods.

I am inclined to think that patients are not given the option to refuse treatment. Patients aren't fully informed of their prognosis, and allowed to make decisions about their treatment. I believe quality is better than quantity.

I do believe its right to switch off life supports where people are brain dead - but to give the families the option of donating organs, prior to this happening.

To certain degrees it happens all the time; not running to a cardiac arrest because you know the patient is 92 and 'ready to die'. MOs deciding to stop antibiotic treatment on an unconscious stroke patient with pneumonia; but it always feels uncomfortable because you know that legally you're in the wrong, but normally you feel you've done the right thing.

All people have the right to life and death.

Something soon must be decided on that will cover all the legal, moral, ethical hurdles - that hinder the path of the patient and family through the dying process, especially in those many situations where mankind and 'doctor' can no longer produce answers and cures.

I do not believe in euthanasia but certainly feel a patient should be allowed to die with dignity and not merely have the act of dying prolonged.

It is the fear re legal implications that prevent us doing our job of quality care to a patient at a time when they need it most - even if this care is accepting the patient's time to let go and ensure a high quality of death. We as nurses and other health professionals are constantly encouraged to keep the patient going - no matter what ... I think it's cruel. There do have to be strict guidelines but it has to be addressed soon ... and not ignored.

It's God's decision when you leave this world and man should not hasten it. However there are times when a patient should be permitted to die in dignity.

Very personal, many legal aspects involved.

I know that it is a debatable subject. However, I believe that euthanasia has its place in society. I see it as a waste and very cruel to refuse someone their last wish to die when in so much pain.

I would like to see it introduced. I think more should be done in gerontics to not actively treat residents.

People are very vulnerable when terminally ill and it should not be taken lightly (sic), we are not God and should not necessarily have final say in the death of patient. "Situational ethics" should not govern our choices. Morally I could not agree to participating in euthanasia, just as with abortion.

In my own case I have been upset at times by extraordinary measures to keep 70-80 year olds and terminally ill people alive, e.g. resuscitation and being put on the respirator.

Nursing staff are not given enough training to deal with the issues concerning death, dying or euthanasia.

Medical, nursing and paramedical staff should be trained to accept that a patient may die despite the treatment. Some staff feel they have to try all avenues to 'save' the patient and feel a failure if the patient dies.

I am unsure of what legal actions are or should be, but I feel very strongly that under circumstances such as a terminal illness people afflicted have the right to say what they want or don't want, after all it is their life and quality means a lot.

Everyone should have the right to quality of life and a dignified death. We are a long way from that. My peers and fellow health professionals, too many times make decisions that are not only thoughtless and God-like but may be illegal according to the Act of the 1983. Legislation must not only be extremely carefully thought out but health care workers must be aware of such legislation and its consequences and some of us must stop playing God - we have not the right.

Many doctors appear to be unprepared to talk to patients/relatives about their diagnosis if it happens to be terminal.

No one should be allowed to request any actual drug treatment to kill them but have the right to refuse treatment which will keep them alive.

Most of my patients probably want to be left alone to die. They hate living the way they do but usually struggle on because they fear the finality of death. Their relatives however are almost always the opposite, and want everything possible done to help their loved one.

Although it may seem merciful and humanistic, even very enlightened, to modify existing law to permit assisted suicide and voluntary euthanasia, it is potentially VOLATILE. No law would guard sufficiently against exploitation, corruption and the further eroding of basic values which are intrinsic to civilised society. We need to rather care well for the dying, protect the weakest in our society and eliminate human distress rather than eliminate the human in distress.

Comfort care, adequate pain relief and let nature take its course.

Fortunately I work in an area that does not encounter this ultimate issue, as these individuals leave the workforce before this stage [in occupational health]. Personally I feel strongly that I have the choice of life while still alive and far better that it is a caring, painless relief of death than a self inflicted bullet, drug overdose, cliff jump.

Since working as a nurse in an acute care hospital it has become apparent that many patients and relatives have expressed the need that euthanasia becomes legal.

Great care must be taken when making laws regarding euthanasia. Governments could use euthanasia as a means of cost cutting in the community. The Natural Death Act should be enough. This enables the doctor to abide by the wishes of the patient, when the patient can make a rational decision.

No extraordinary means used in terminally ill patients.

Euthanasia - problem with when - 'who commits the act' - decision needs to be made before the patient has lost facilities (sic), if possible, in cases of terminal illness.

I remain confused as to the difference between withholding and withdrawing treatment and actively bringing about the death of a person. The former seems more acceptable, although I don't see ending someone's endless suffering as wrong. Can professionals make active decisions without in the long term being affected by them.

In my experience in intensive care areas these decisions are made too slowly. This causes distress to the family and also to nursing staff to the point they cannot look after the patient. Recently, withdrawal of treatment forms were signed, the family had made funeral arrangements and were down from the country to say goodbye. When a change of medical staff occurred and further treatment was instigated, many nursing staff refused to be involved in this as the family were extremely confused and the patient had been on so much Adrenalin, her hands and feet were necrosed. However, nursing staff are NOT consulted about the decision to withdraw treatment.

There are so many variables to be considered that it's difficult to make generalized comments. I suppose I feel that any person (regardless of circumstances) has the right to end their life if they are considered to be mentally fit, but some responsibility has to be placed in them if they are physically capable, i.e. pressing a button to commence a lethal painless infusion. Legal papers have to be signed and situation assessed by several knowledgeable people to obtain a consensus. If euthanasia was introduced the procedure to obtain permission (or legalize the act) would have costs made as minimal as possible or subsidized by the govt, therefore the involvement of the legal profession would have to be minimal. In any case I feel if lawyers were involved it would turn the situation into a circus [for] legal profit and prolonging the time to make a decision thereby [leading to the] patient and family suffering stress.

I feel if patients symptoms are controlled then should be no reason for euthanasia. Time left to patient and family could be valuable and of great benefit to everyone. God gives and God takes away.

Yes, people are becoming more aware and involved in death and are often prepared and have their own thoughts. I feel it is out of respect to help fulfill (sic) the individual's choice - it's their right.

I do not believe in euthanasia as a way out for disposing of our elderly and disabled people. I feel that we as caregivers to these people, we should always treat them with due care and respect. In the case of the terminally ill it is our vocation to nurse them with care and allow them to die with as much dignity and love as possible. Many of these people have been of great inspiration to me - and my fellow colleagues. I have seen happy deaths even though pain has been a part of it.

The process of dying is the end stage of living and there should be a greater awareness about the dying process and grief. Dying should be with dignity and a person should have a choice of a 'living will'. The management of death should be given more prominence in nursing education.

If a patient wants to refuse food as they die, let them. If people are facing death their spiritual needs must not be overlooked and played down. Most of the discussion on euthanasia centres on the physical aspect of death, the physical suffering and pain. questions of spiritual needs and emotional needs should also be considered. Dying people require the opportunity for people who take spiritual needs seriously to be a sounding board for them, to hear their fears.

Happens all the time anyway. Need to formalize the process. Hope someone would do it for me.

My main concern is for the comfort of the dying patient. When it becomes obvious that a terminal disease of irreversible brain damage condition will not respond to medical treatment - then I feel strongly that a person should be allowed to die peacefully, comfortably and still keep a high degree of dignity.

I believe that the right and dignity of the patient must come before the legal aspects of our society. The patient must not abnegate the freedom of choice in any situation - to

lose control is to deny life. I value life - and death - having seen both war and peace I believe that we should above all value the choice of life (male, was in Vietnam, pro euthanasia).

Working in the geriatric field and being a specialised nurse with a loving caring approach which promotes quality of life I am constantly in turmoil about how far we go in maintaining life. Our aged who are frail and virtually no more than bedfast 2 hourly turns. But they can spend 3 years in this vegetative state with good care - at what cost? Would they choose it if they could? Is it what we would want for ourselves? Who chooses? Thank you for asking me to participate. It is a fairly passionate issue for me since I am involved in providing a service promoting quality of life. In many cases we are no longer doing this but prolonging life because we are legally bound to continue to provide the basics that will maintain life - food and nourishment to those who could not do so without nursing intervention. We would not keep hundreds of our pets alive under the same circumstances as we would not want them to suffer that end, so why Humans?

Doctors' Hippocratic oath should be reviewed. Preserving life at all costs is not always humane, or in patients best interests.

Patients with terminal illness should not be for resuscitation - this should be discussed with the patient. We should be able to put people out of their suffering. Every patient that comes into hospital should be asked if they want to be resuscitated. Doctors and nurses should have ethical components in their courses.

I believe clients have the right to withhold extraordinary treatment if they express that desire.

It (euthanasia) is avoided by most people. Hence the almost never used Natural Death Act by hospital staff. Most hospitals operate on the basis of the medical model which is about care at all costs and not about death with dignity. Many nurses are uncomfortable about providing active treatment to terminal/dying persons, i.e. giving IVs, antibiotics, ventilators, etc. The person needs to be comfortable and pain free, not 'attacked' by medical staff wishing to try new treatment protocols.

Legalize euthanasia.

I feel there should be more of an effort made to look after the patients emotional and spiritual needs not just their physical needs as is often the case. There are too many elderly people especially dying lonely.

More laws = less freedom = confined parameters. If quietness and discretion and common sense is used there would be no need for firmer guidelines. I can understand that a nurse in intensive care or paediatrics would have a different attitude [in palliative care]. Where financial cost would be a factor offset against poor and long term quality of life plus inability to contribute to society and greater expense to the taxpayer and psychological factors with both patient and family (their friends soon forget them) after 6 months and everyone battling alone and then relatives die!

I feel that the living will was a step forward but it is necessary to educate people - particularly medical officers from earliest stage. For example during their training.

All circumstances are not covered by the living will, especially in the areas of newborn babies, children, adopted/fostered children, dementia. One area not covered in this questionnaire is that nurses can have pressure applied from health professionals to "do something". One question could have been "Have you ever been asked to take active measures to hasten a patient's death/" The added a list of "by whoms".

Euthanasia in the proper context (and everyone's view is different) is reasonable and it has already appeared to be "accepted" in the field of oncology. Psychological counselling needs to be provided for health professionals faces with such situations and should not be expected to comply if their beliefs are not similar or the same.

I have many comments, too many for this space. It is a very personal thing for all involved, and each person needs to come to terms with their own thoughts.

Don't make the rules standard and easily enforceable (sic).

This is a very difficult subjective topic. What may be correct in one situation can be very inappropriate in another. But - there should be guidelines set out.

In such cases many considerations have to be made. It is however, ultimately the patient's right and as advocacy to these rights we should be aware and able to fulfil these rights on behalf of the patient. Importantly the quality of life should be considered not the quantity.

People should be given a choice of terminating their own life or refusing treatment but should not expect other people to participate in terminating their life by taking measures (medical) to maintain life.

Many patients/relatives are resigned to a situation in which they all recognize a dignified death (death which is inevitable in any case) is much less demoralising as watching relatives watching a loved one fade away in pain. Many people do not fear death, they fear the pain preceding it.

I'm glad there is 'public' debate, however I do not have the confidence that the 'legal' system will alone be able to provide a resolution. The issue challenges the health care/ill health care services fundamental assumptions and will be agony.

I think it is ethical for doctors to refuse to treat terminal illness only from the point of view of extending life as long as possible. It is not ethical to refuse to provide relief from pain and suffering even if that relief is such that it hastens death.

I believe it is important to consider individual cases and ensure that all information re clients case is available to enable informed decision making - also counselling as a standard procedure for staff and relatives/carers involved in situation. I believe some cases are irretrievable and should be allowed to die with dignity.

The request for no active measures to be taken to preserve life under the Natural Death Act is sometimes disregarded by medical practitioners - I find this entirely unacceptable in terms of removing the freedom of choice. The practice of euthanasia would depend very greatly on each specific case, making legislation governing it extremely difficult to formulate.

The responsibility is a personal thing and no amount of legislation will solve the problem. It could even complicate things. Few people would like to be responsible for making drastic decisions. Spiritual guidance is the answer (I think).

People have the right to life and expect the best medical treatment possible when they are ill. People also should have the right to "live with dignity" and if this is not possible chose (sic) to die without needless pain, suffering and humiliation that prolonged living will cause.

A neglected area of nursing, but also a most important one. Definitely needs 'legal' input and definite guidelines. I feel a person who is going to die or who is in pain, mentally or physically without cure should be allowed to die.

If I were the patient I would take advantage of the Natural Death Act. Medical intensive care units (my area of experience) have too often mismanaged extending life of patients with little hope, through being not adequately informed of prognosis (i.e. the patient and family). I feel physicians are trained to cure at the expense of quality of life and preventative medicine.

Suicide should be legally available - subject to precautions which would provide for counselling and for medical supervision or assistance where required.

I realise euthanasia is a very contentious issue, and one which has bothered me throughout my nursing career, I believe, in essence, that **QUALITY** of life is far more important than life itself and that ultimately, the patient should have freedom of choice.

I would like to see maximum support given to families who wish to manage a dying relative at home. I received such support to nurse my father-in-law until his death as it was his greatest wish to die at home, but it was only a lot of nursing experience that made that possible for me.

Everyone needs to take a good hard look at the whole issue of euthanasia, and realise in one way or another that it is being practised in all major hospitals (in one form; the withdrawing of treatment). Euthanasia is an ethical concern and we cannot go around play (sic) ostrich (sticking our heads in the sand) and pretending it does not exist and that it won't effect us.

Several questions I didn't answer because I personally do not think I could assist anyone to do. However I can say that because I have never had to face that problem, if I did I might respond differently. I feel each case needs to be dealt with individually and cannot be generalised and categorised.

We cannot have any concrete rules on this, each case must be assessed as per individual rights, family, cultural, ethical and moral issues considered.

APPENDIX E
QUESTIONNAIRE FOR DOCTORS

When answering questions please mark your response with a circle around the appropriate number.

- 1 Are you
- (a) in general practice 1 _____
- (b) a specialist 2 _____
- please list your speciality _____
- 2 In the course of your medical practice has a patient ever asked you to hasten his or her death by :
- (a) withdrawing treatment Yes _____ No _____
- (b) taking active steps Yes _____ No _____
- 3 In the course of your medical practice have you ever been asked to hasten a patient's death by a member of the patient's family by :
- (a) withdrawing treatment Yes _____ No _____
- (b) taking active steps Yes _____ No _____

If no, go to Question 5

- 4 Why were you asked to hasten death ?
- (If you mark more than one item please rank responses in order of importance on a scale of 1 - 7, with 1 being the most important or frequent reason).

| | <u>Request made by</u> | |
|--|------------------------|---------------|
| | <u>Patient</u> | <u>Family</u> |
| (a) persistent and irrelievable pain | _____ | _____ |
| (b) terminal illness | _____ | _____ |
| (c) incurable condition | _____ | _____ |
| (d) infirmities of old age | _____ | _____ |
| (e) not wanting to be a burden on others | _____ | _____ |
| (f) afraid of a slow decline while dying | _____ | _____ |
| (g) any other reason (please specify) | _____ | _____ |
| | _____ | _____ |
| | _____ | _____ |

5 If you were asked to hasten a patient's death, would/did you discuss what should be done with :

- | | | | | |
|----------------------------------|-----|-------|----|-------|
| (a) another doctor or doctors | Yes | _____ | No | _____ |
| (b) nursing staff | Yes | _____ | No | _____ |
| (c) relatives/friends of patient | Yes | _____ | No | _____ |
| (d) religious advisor/counsellor | Yes | _____ | No | _____ |
| (e) bioethics advisor/committee | Yes | _____ | No | _____ |
| (f) anyone else | Yes | _____ | No | _____ |

6 Do you think that a request to hasten death can be considered rational ?
Yes _____ No _____

7 Why do you think so ?

8 In discussing the options of medical treatment available to a patient, have you ever suggested the following as possible choices ?

- | | | | | |
|-----------------------------|-----|-------|----|-------|
| (a) no treatment, | Yes | _____ | No | _____ |
| (b) withdrawal of treatment | Yes | _____ | No | _____ |

9 Do you think it is ever right to bring about the death of a patient by withdrawing treatment ?

- | | |
|-------|---|
| _____ | Yes |
| _____ | Yes, but only if requested by the patient |
| _____ | No |

10 Do you think it is ever right to bring about the death of a patient by taking active steps ?

- | | |
|-------|---|
| _____ | Yes |
| _____ | Yes, but only if requested by the patient |
| _____ | No |

11 Have you ever taken active steps which have brought about the death of a patient ?

- | | |
|---------------------------|-------|
| (a) Once | _____ |
| (b) More than once | _____ |
| (c) Many times | _____ |
| (d) No | _____ |
| (e) Do not wish to answer | _____ |

If No go to Question 14

12 Do you still feel that you did the right thing ?

Yes _____ No _____

13 Please explain your response to Question 12.

- 14 Did you reject the request because such an action would have been illegal ?

Yes _____ No _____

- 15 Do you think it should be legally permissible for doctors to take active steps to bring about a patient's death under some circumstances ?

Yes _____
No _____
Unsure _____

- 16 Why do you think so ?

In your response, if appropriate, please indicate under what circumstances.

- 17 Do you think guidelines should be established so that the legal position of doctors regarding withholding and withdrawal of treatment could be clarified ?

Yes _____
No _____
Unsure _____

If yes

- 18 Please give your suggestions for what these guidelines could be.

19 Since the passing of the Natural Death Act in South Australia in 1983, it has been possible for patients over the age of 18 years, to make an advance declaration (commonly referred to as a living will) that extraordinary means need not be taken if they are terminally ill and death is imminent.

Are you aware of this legislation ? Yes _____ No _____

If Yes

- 20 In the course of your medical practice, how many times in the last five years have you been presented with declarations made under this act ?

Never _____
One time _____
2 - 5 times _____
6 - 10 times _____
More than 10 times _____

- 21 Do you have any further comments you would like to make concerning the issues surrounding the management of death, dying and euthanasia ?

Background Information

- 22 What is your age ?

(a) under 30 years _____
(b) 30 - 39 years _____
(c) 40 - 49 years _____
(d) 50 - 59 years _____
(e) 60 years and over _____

23 What is your sex ?

Male _____
Female _____

24 What is your religion ?

(a) Church of England _____
(b) Other Protestant _____
(c) Catholic _____
(d) Jewish _____
(e) Muslim _____
(f) Buddhist _____
(g) Hindu _____
(h) Other (please specify) _____
(i) No religion _____

25 How many years have you been practising medicine ?

Thank you for your cooperation in this survey.

QUESTIONNAIRE FOR NURSES

When answering questions please mark your response with a tick on the line provided.

- 1 Are you currently employed in the field of nursing ?
 Yes _____ No _____
- 2 In which area of nursing do/did you practice ?

- 3 Where did you undertake your nursing training ?
 (a) hospital _____
 (b) college of advanced education _____
 (c) university _____
 (d) other _____
- 4 In the course of your nursing practice has a patient ever asked you to hasten his or her death by :
 (a) withdrawing treatment Yes _____ No _____
 (b) taking active steps Yes _____ No _____
- 5 In the course of your nursing practice have you ever been asked to hasten a patient's death by a member of the patient's family by :
 (a) withdrawing treatment Yes _____ No _____
 (b) taking active steps Yes _____ No _____

If no, go to Question 7

- 6 Why were you asked to hasten death ?

(If you mark more than one item please rank responses in order of importance on a scale of 1 - 7, with 1 being the most important or frequent reason).

| | <u>Request made by</u> | |
|--|------------------------|---------------|
| | <u>Patient</u> | <u>Family</u> |
| (a) persistent and irrelievable pain | _____ | _____ |
| (b) terminal illness | _____ | _____ |
| (c) incurable condition | _____ | _____ |
| (d) infirmities of old age | _____ | _____ |
| (e) not wanting to be a burden on others | _____ | _____ |
| (f) afraid of a slow decline while dying | _____ | _____ |
| (g) any other reason (please specify) | _____ | _____ |
| | _____ | _____ |
| | _____ | _____ |

7 If you were asked to hasten a patient's death, would/did you discuss what should be done with :

- (a) a doctor or doctors Yes _____ No _____
- (b) other nursing staff Yes _____ No _____
- (c) relatives/friends of patient Yes _____ No _____
- (d) religious advisor/counsellor Yes _____ No _____
- (e) bioethics advisor/committee Yes _____ No _____
- (f) anyone else Yes _____ No _____

8 Do you think that a request to hasten death can be considered rational ?
Yes _____ No _____

9 Why do you think so ?

10 Do you think it is ever right to bring about the death of a patient by withdrawing treatment ?

- _____ Yes
 _____ Yes, but only if requested by the patient
 _____ No

11 Do you think it is ever right to bring about the death of a patient by taking active steps ?

- _____ Yes
 _____ Yes, but only if requested by the patient
 _____ No

12 Have you ever taken active steps which have brought about the death of a patient ?

- (a) Once _____
 (b) More than once _____
 (c) Many times _____
 (d) No _____
 (e) Do not wish to answer _____

If No go to Question 15

13 Do you still feel that you did the right thing ?

Yes _____ No _____

14 Please explain your response to Question 13.

15 Did you reject the request because such an action would have been illegal ?

Yes _____ No _____

- 16 Do you think it should be legally permissible for doctors to take active steps to bring about a patient's death under some circumstances ?

Yes _____
 No _____
 Unsure _____

- 17 Why do you think so ?

In your response, if appropriate, please indicate under what circumstances.

- 18 Do you think guidelines should be established so that legal position of doctors regarding withholding and withdrawal of treatment could be clarified ?

Yes _____
 No _____
 Unsure _____

If yes

- 19 Please give your suggestions for what these guidelines could be.

20 Since the passing of the Natural Death Act in South Australia in 1983, it has been possible for patients over the age of 18 years, to make an advance declaration (commonly referred to as a living will) that extraordinary means need not be taken if they are terminally ill and death is imminent.

Are you aware of this legislation ? Yes _____ No _____

If Yes

- 21 In the course of your nursing practice, how many times in the last five years have you been presented with declarations made under this act?

Never _____
 One time _____
 2 - 5 times _____
 6 - 10 times _____
 More than 10 times _____

- 22 Do you have any further comments you would like to make concerning the issues surrounding the management of death, dying and euthanasia ?

Background Information

- 23 What is your age ?

(a) under 20 years _____
 (b) 20 - 29 years _____
 (c) 30 - 39 years _____
 (d) 40 - 49 years _____
 (e) 50 years and over _____

- 24 What is your sex ?

Male _____
 Female _____

25 What is your religion ?

- (a) Church of England _____
- (b) Other Protestant _____
- (c) Catholic _____
- (d) Jewish _____
- (e) Muslim _____
- (f) Buddhist _____
- (g) Hindu _____
- (h) Other (please specify) _____
- (i) No religion _____

Thank you for your cooperation in this survey.

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