

PSYCHOLOGICAL PERSPECTIVES ON EUTHANASIA AND THE TERMINALLY ILL

**An APS Discussion Paper
prepared by a Working Group of the
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Summary

- 1 This paper addresses euthanasia and related rights to the terminally ill, to assist policy makers, psychologists and other professionals in considering these matters and contributing to the debate and policy formulation.
- 2 Definition: The term “euthanasia” refers to the intentional termination of a person’s life, usually but not always at that person’s request, and usually in the context of terminal illness and/or incurable suffering. However, there are at least eight different versions involving active versus passive and voluntary versus involuntary euthanasia.
- 3 The intentional termination of the life of a patient at his/her competent request - voluntary active euthanasia - is the main focus of this paper.
- 4 Arguments in favour of euthanasia revolve around matters of the patient’s autonomy, quality of life (and death), avoiding unnecessary and inevitable suffering, preserving a patient’s dignity in the dying process, the use of sophisticated medical technology to prolong life for its own sake, the need for legal safeguards for current practice, regulating procedures to provide quality assurance for current practice, and responding to changing public and professional attitudes about euthanasia.

Arguments against euthanasia rotate around respect for human life, the possibility of coercing a person to request euthanasia, the possibility that the person requesting it is not fully competent or informed about his/her prognosis, conflicts of interest in other parties involved, misuse e.g., “ethnic cleansing”, difficulties in ensuring proper and effective procedures are used, the possibility of diagnostic errors or related medical incompetence, reduced motivation to resource best practice treatments, spiritual beliefs in the sanctity of life and/or divine punishment in afterlife, and the danger of embarking upon a ‘slippery slope’ once euthanasia is accepted as a viable option.

- 5 Research: Research in the area focuses on the attitudes of medical and nursing carers towards euthanasia and, to a lesser extent, on community attitudes; inconsistent definition of variables and methodology makes definitive conclusion difficult. Australian research suggests that a majority of medical practitioners believe that in principle they should be allowed to take active steps to end a patient’s life; a higher percentage of nurses appear to support this principle and a smaller majority would be prepared to assist; a minority of palliative care nurses appear prepared to assist.

The broader Australian community strongly supports voluntary active euthanasia as a legal option, with support having risen from around 50% to around 80% over the past 40 years. Research has emphasised the need for cultural factors, including language, to be integrated into considerations of euthanasia. Research suggests

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Research into the effects of a patient's mental state, and in particular clinical depression and cognitive impairment, on decision making and attitudes towards euthanasia has generated inconsistent results; more work needs to be done.

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- 6 The situation in Australia. The Northern Territory Rights of the Terminally Ill Act enables a medical practitioner to assist to end a patient's life where the patient requests it, has had a terminal illness diagnosed and confirmed by two medical practitioners, is experiencing pain, suffering and/or distress to an extent unacceptable to him/her, and has been assessed by a psychiatrist to be of "sound mind" and not suffering clinical depression. Several other possible complicating psychological conditions are not mentioned. There is no requirement to address the psychological needs of close relatives of the patient or attending staff. The possibility of using a clinical psychologist and a second medical practitioner where there is no available psychiatrist is not mentioned. The Northern Territory Rights of the Terminally Ill Act (1995) was over-ruled by the Euthanasia Laws Bill (1996).

Current practices in the rest of Australia are not well known; poorly defined terms and procedures are a barrier to elucidation. Medical Treatment Acts in some States allow for people to be allowed to die through the cessation, withdrawal or lack of implementation of "heroic" procedures; these should not be confused with active euthanasia, although they overlap with the concept of passive euthanasia.

- 7 Issues in decision making around the liberalising of laws relevant to euthanasia include:

- the patient's competence to request euthanasia, assessed on more than one occasion;
- the competence of the subsequent decision making by all concerned;
- the wide range of physical and psychological clinical factors in the patient's condition that could bear on a request;
- the physical and mental state of the carer(s);
- the adequacy of total care provided to the patient with special reference to palliative care but including physical, medical, psychiatric and psychological care;
- quality assurance around the response to a request, e.g., that it can be reversed during a mandatory "cooling off" period and that adequate standards of care are maintained during that period

- best practice in terms of psychosocial support, requiring that the patient fully understands his/her alternatives and the main ramifications of his/her decision;
- the psychological needs of significant others and carers;
- the need to avoid carers' personal views adversely affecting the objectivity of the patient's assessment process.

8 Roles for psychologists could include:

- Assessment of the patient;
- treatment/counselling of the patient as appropriate;
- an advocacy role for the patient and/or relatives and/or carers;
- ensuring that euthanasia never occurs for want of adequate psychological services;
- debriefing those involved following euthanasia;
- educating decision makers, clinical staff, patients and the public in the psychological aspects of euthanasia and what psychologists can offer in the area;
- facilitating others' professional development in the area;
- conducting research in the area and disseminating knowledge;
- including euthanasia in psychologists' education at all appropriate levels.

9 Conclusions: Psychologists have the knowledge and skills to allow them to become involved in these issues in a variety of ways; they can enter the debate on euthanasia, be involved in policy development and in practice for the care of the terminally ill, and in the process of support and decision making, and assessment of competence. Good policy making will also require attention to these issues.

1 Introduction

The mission statement of the Australian Psychological Society (APS) includes "the promotion of community well-being". Psychological research and practice dealing with appraisal, assessment and change of cognitive and emotional states, attitudes, beliefs, fears, separation and loss contribute directly to this objective. While much psychological work deals with the on-going lives of clients, some concerns the end of life: support for people exposed to violent death (e.g., from accident, war or crime), support for terminally ill people, and support for bereaved survivors.

In 1995 the Northern Territory Parliament passed a Rights of the Terminally Ill Act, which was due to be implemented in July 1996. Despite the fact that that Act did not use the word "euthanasia" at all, it has become known as the "Euthanasia Act", and a great deal of public debate has ensued over the last 13 years. In 1996 the Northern Territory Rights of the Terminally Ill Act (1995) was over-ruled by the Euthanasia Laws Bill (1996). In 2008, a Senate Inquiry was conducted into the Rights of the Terminally Ill (Euthanasia Laws Repeal) Bill 2008.

Given this context, it is appropriate that the APS should offer a thoughtful contribution to the debate. This paper attempts to set out some of the psychological issues related to euthanasia in the hope of encouraging well-informed discussion, both within the profession and more widely. The paper does not take a position on the debate, either in favour of or against the practice of euthanasia or changes in legislation relating to it. Nor does it attempt to cover all the legal issues involved. Rather it suggests a variety of ways in which psychologists can be usefully involved in the debate and in terminal care issues. The paper also tries to illustrate some of the complexities associated with the deliberate bringing about of death.

2 Defining Euthanasia

Dictionary definitions of euthanasia describe it as an easy or painless mode of death, and as the act of putting painlessly to death, especially in cases of incurable suffering. Most descriptions of euthanasia imply that the person concerned has asked for death, but this is not universally the case. Bringing about death (shortening life) can occur in several different ways. Table 1 is included to illustrate basic differences in modes of euthanasia; it should aid discussion, but the distinctions it makes are not definitive. For instance they do not include:

Physician Assisted Suicide: The physician assists in the patient's death by providing information and/or drugs which the patient will then use to bring about his or her own death.

Non-Voluntary Euthanasia: A patient has made no specific request for death due to incompetence but an agent has requested death on his or her behalf and the principal professional carer administers the means of death or withholds or withdraws life-supporting drugs or mechanisms.

Good Medical Or Palliative Care: A terminally ill person who is suffering extreme distress may have that distress relieved by drugs or procedures which are known to shorten life.

Table 1: Some Important Distinctions Regarding Euthanasia

	Voluntary	Involuntary
Active	A asks for death B administers the means of death, and A's death ensues	A (or C) makes no request for death or may express a wish to live B administers the means of death, and A's death ensues
Passive	A asks for death B withholds or withdraws life-supporting drugs or mechanisms and A's death ensues	A (or C) makes no request for death or may express a wish to live B withholds or withdraws life-supporting drugs or mechanisms and A's death ensues

(Derived from "50 Something", April/May 1995)

- A represents the suffering person whose death is to be the outcome
- B represents the principal professional carer or adviser (doctor, nurse or other patient)
- C represents A's agent (eg. next of kin, next friend, guardian or executor)

Issues concerning grossly impaired, disabled or terminally ill infants and young people need separate consideration, and are beyond the scope of this paper. Establishing the age at which a young person may be judged competent to ask for death needs both psychological and legal consideration; this is a complex issue, particularly because of individual differences in competence within any age group.

This paper focuses on voluntary active and passive euthanasia, for persons competent to decide their future; that is, on the intentional termination of the life of a patient at his or her request. Jochemsen (1994), in evaluating the situation in The Netherlands, defined euthanasia as "the *intentional termination* of the life of a patient at his/her request by a physician" (p 212, Jochemsen's italics). In his view, euthanasia is defined by "*the factual intentional shortening of life, either by commission or by omission*" (p 213, his italics). That is, euthanasia is defined not only by the intention to shorten life but also by the certain shortening of life as a side effect of treatment. This account deletes the distinction between active and passive euthanasia, since the decision-making and the intention are the same in both cases. Jochemsen argued that, by contrast, where a physician initiated *both* treatment to alleviate unendurable suffering *and* life-sustaining treatment, this would not constitute euthanasia.

In terms of prevalence of both the request for and the practice of euthanasia, it has been reported that only 2% of deaths in the Netherlands each year result from euthanasia (Hellema, 1991). In a British study (Cartwright & Seale, 1990), only 3.6% of 2192 patients who had died had expressed a wish for euthanasia. Twenty five percent of these patients, however, had expressed some desire for an earlier death.

3 Arguments For and Against Euthanasia

As the biological and medical sciences become more adept at prolonging life, we have been brought to consider the extent of a person's right, and ability, to choose, to accept, and to reject treatment for some treatable condition. Cases may become complicated by the mental state of the patient (e.g., depression, intellectual disability), by the effect of certain physical conditions on cognition, (e.g., kidney damage), by religious and cultural beliefs, by balancing the rights and welfare of an individual against those of the population, and by the practical costs and requirements of providing treatment and care.

Psychologists, by virtue of their knowledge and skills in dealing with mental states, cognitive abilities, beliefs, and individual characteristics, have a useful perspective to offer the debate on the rights of a terminally ill person to request assistance from a medically qualified person to voluntarily terminate his or her life.

In the following section, we set out arguments, without endorsement, which are often advanced in favour of, and opposing, making euthanasia more accessible than it is now.

Arguments in Favour of Euthanasia

3.1 Ethical/Moral

3.1.1 To respect sufferers' autonomy

This argument rests on the ideal of being able at all times to exercise as much control over one's own life as is possible. This ideal is stated, for example, in Principle 6 of the Australian Council of the Ageing's "Rights of the Elderly": "The right of individuals to consultation and participation in decisions affecting all aspects of their lives". The issue of self-control is the crux of such notions as "the right to die", and "the right to die with dignity", which assume that suffering persons have the absolute right to choose whether to live or to die, that the moral agent is the suffering person. If and when a sufferer decides that life should end, legal euthanasia would provide the means for ending it, safely, without placing another person or group of persons in legal jeopardy.

3.1.2 To allow individuals to value "quality of life" over "sanctity of life"

Here it is argued that people have the right to decide whether quality of life or sanctity of life is most important to them. When a person is suffering severe pain or is severely restricted by illness, or when life depends, for example, on drugs which cloud consciousness and reduce control, those who value quality of life more highly may seek an end to life. Euthanasia would allow them to do so, without placing other people in legal jeopardy.

3.1.3 To end suffering

One argument in favour of making euthanasia a legal option for someone who is terminally or incurably ill or incapacitated, is suffering intolerably, and has expressed a wish to die, rests on the belief that suffering should be relieved or ended, that suffering harms the sufferers by robbing them of peace or pleasure, and demeans them.

Another aspect, sometimes raised, concerns the suffering of carers: caring for or watching someone suffer, without any chance of relief or recovery, can become difficult to tolerate for the carers and watchers, both emotionally and physically, so that the carers' only prospect of relief resides in the death of the patient.

3.1.3 To reduce reliance on life support systems and/or advanced medical knowledge

The cost of health care has increased greatly and shows every sign of continuing to increase. The perceived impropriety of making use of high technology and expensive medical procedures in cases where the only positive outcome is the temporary lengthening of life, without improvement in quality of life or prospect of recovery, is often seen as an argument for euthanasia. While it is ethically distasteful to ask for establishment of priorities for access to advanced medical technology, the issues of need and good outcome may make it imperative. If such priorities are at least implicit in, say, medical policy and hospital practice, then those priorities would, in fact, imply covert practice of euthanasia. Some form of legalisation would allow a more honest acknowledgment that euthanasia is an option.

3.1.4 To reduce risk of premature suicides

Some terminally ill patients who wish to end their suffering without incriminating loved ones take their own lives in secret, sometimes violently. Knowing that they will be physically unable to do so at a later stage, some patients end their lives early on into their disease. Seven percent of doctors questioned in a Medix-UK survey reported that at least one of their terminally ill patients had committed or attempted suicide (Medix, 2004).

3.2 Legal

3.2.1 To reduce the legal jeopardy of those who implement euthanasia

Euthanasia occurs now. Legally, a person who kills another or connives at the death of another, breaks the law and may be charged with a serious criminal offence (murder or manslaughter), and may be convicted and punished. That the killing resulted from requests from the sufferer, and that it was done from motives of empathy and compassion, will not necessarily alter the legal situation. If euthanasia were recognised as an option, and provided that accompanying regulations were observed, then a person who assists a person to die would be protected from prosecution, or at least have a defence.

3.2.2 To allow regulation of procedures regarding euthanasia

It is widely recognised that euthanasia does occur covertly. Overt recognition would allow regulations to be developed governing modes of request and consent, counselling for sufferers and families, decisions about modes of death, and so on.

3.3 Public Opinion

3.3.1 Changes in professional and public attitudes to euthanasia

Surveys and polls over the past decade show that both professionals and the public are more ready to consider euthanasia as an alternative to sustaining a life of suffering (see Section 5). If it is believed that legislation should be responsive to public opinion, this would constitute an argument in favour of legislative change.

Arguments Against Euthanasia Being Available

3.4 Ethical/moral

3.4.1 Absolute respect for human life

Certain sets of beliefs will remain totally inconsistent with a belief in the propriety of euthanasia, regardless of particular situations. Persons holding these beliefs and opinions deserve to have them recognised. In most societies there are strict bans against taking human life except under prescribed circumstances such as war or sometimes capital punishment. Survival of the species demands that life be protected.

3.4.2 Possibility of coercion, loss of autonomy

Public recognition that euthanasia is available might lead to assaults on individual autonomy. People may be subjected to pressure to ask for their own death by being made to feel more guilty for the burden they impose on family and carers. Euthanasia may be offered as an option even when the patient had not previously raised it. Further, medical professionals (doctors, nurses) may be pressed into taking life against their own judgements.

3.4.3 Poor decision-making by the sufferer

A person's expression of a desire to end his or her life may be influenced by a state of depression, uncontrolled pain or dysphoria, conditions which may be relieved by proper treatment. If given such treatment, it is argued that the person may no longer desire to die. A person's capacity to make an informed and competent decision may be difficult to ascertain.

3.4.4 Conflicts of interest

This applies only if others are empowered to make decisions on behalf of the individual. When carers are obliged to take a very large measure of responsibility for ill or incapacitated persons, it may be easy to assume total responsibility, even to the point of deciding when or whether the helpless person should die. When some advantage may accrue to the carer on the death of the helpless person (for example, independence, money, property), then there may be more motivation to make independent arbitrary decisions, without taking account of the helpless person's wishes. That is, the interests of the carer may conflict with those of the sick person.

3.4.5 Misuse, such as genocide or "ethnic cleansing"

The Nazi holocaust and more recent events in the Balkans and in Africa show that power can be misused to get rid of specified individuals or groups. Dreams of establishing a "master" or superior human breed have periodically surfaced and continue to do so, for

example, as knowledge about genetic engineering increases. The corollary, of removing those who are perceived to be inferior or unproductive, or those who consume but do not produce, is feared to be a possibility. While this argument applies to groups, it can equally be applied to individuals.

The four issues above (4.4.2 - 4.4.5) may be possible problems even where there are no penalties for euthanasia. They might be reduced with appropriate legislative safeguards.

3.5 Legal

3.5.1 Difficulty of enforcement and monitoring

It may be very difficult to discover, after a person's death, whether that death had occurred from "natural causes" or as a result of correctly (or incorrectly) carried out procedures of euthanasia. On the basis of a survey of medical practices in the Netherlands prior to 1993, Jochemsen (1994) found that 65-75% of physicians reported that, following euthanasia, they attributed the death to natural causes. It is clear that accurate establishment of the causes of death is difficult, although provision for inquests and autopsies may provide some safeguards. This concern exists now; it is not dependent on public or legal recognition of euthanasia.

3.6 Technical

3.6.1 Failure to bring about an easy death

An accepted method of euthanasia may fail to kill the person within a reasonable time and may cause more suffering. The same procedures may produce different results in different people.

3.6.2 Diagnostic errors and medical advances

Diagnosis is not a perfect skill, art, nor science, and mistakes can occur in prediction about the outcome of any given medical or health condition. As knowledge expands, new drugs and new procedures and technologies are introduced, and a condition which may have been terminal at one time (or in one country) may respond to treatment at another time, or in another place. To accept euthanasia may therefore deprive people of the possibility of continuation of life.

3.6.3 Reduction of efforts in diagnosis, treatment, and care

Availability of euthanasia may reduce efforts to provide, or to improve, diagnosis, treatment and care. If suffering persons are able to choose to die, and do so, their removal may reduce the motivation of financial sources to fund research, provision of caring facilities, training of carers, and maintenance of support systems. Economic considerations may motivate authorities to support euthanasia.

3.6.4 Adequacy of modern medical and palliative care

Some argue that advances in medical treatment, pain control and palliative care have been such that it is no longer necessary for a terminally ill person to have to confront unbearable pain and suffering. This then removes one motivation for euthanasia.

3.7 Spiritual

3.7.1 Belief in the sanctity of life

Certain belief systems hold not only that life is sacred, but also that human beings sin by taking life. Some people believe that sin is punishable by a divine power, and that the taking of life will bring down punishment upon the perpetrator. These beliefs are incompatible with the acceptance of euthanasia.

For some with these beliefs, it is acceptable to hasten death through "the principle of double effect", whereby treatment aimed at easing suffering has the secondary effect of causing death. Some also believe it is acceptable to allow the withdrawal of, or non-implementation of, life-sustaining treatment under certain circumstances, i.e., passive euthanasia is acceptable to some who reject active euthanasia.

3.7.2 Belief in divine punishment

Some people who believe in a life after death also believe that a happy afterlife depends upon virtue in this life. If virtue incorporates a ban on killing people, then at least some of these believers would consider that either conniving at one's own death, or helping someone else to die, would jeopardise their chances of a happy afterlife. Therefore such believers would oppose euthanasia.

3.8 The "Slippery Slope" Argument

Several of the preceding arguments imply what has become known as the 'slippery slope' or 'precedent' argument. Mann (1995) argued that once traditional prohibitions and taboos are broken, society may be drawn down an unanticipated path towards acceptance of practices which, at the time of the initial breach, would be considered unacceptable. Similarly Helme (1993), in discussing the possibility of euthanasia becoming legal in some way, stated: "if the law was to be changed, the balance of opinion would alter so that what would be intended as an extension of the rights of some, and possibly only a small minority, might result in the transference of an obligation to others. Once a legal precedent has been established, social endorsement of euthanasia might place undue pressure on patients to class themselves as a burden to others, and to submit to it rather than defend their individual interests" (p.459). He suggested that some patients may make a request for euthanasia "in bad faith" in order to manipulate, threaten or exploit over-conscientious carers. Helme balanced these arguments by pointing out that other patients may enter their final illnesses reassured by the knowledge that euthanasia was available to them, even though they may never request it.

4 Relevant Research on Euthanasia

4.1 Introduction

Issues relating to the practice and legalisation of euthanasia are debated at length in academic literature and the public domain, but empirical research studies, particularly in Australia, are few, and limited in scope. The debate centres around a range of issues, which include ethical considerations, the influence of religious beliefs, patient rights and autonomy in decision making, quality of life, patient competence and economic factors.

Emotive language is common in the debate. Arguments often split into pro-life, pro-choice and pro-mercy, each corresponding to one of the duties to protect life, to defend liberty and to prevent cruelty, while at the same time dismissing opposing positions. Most empirical research, however, focuses on attitudes of physicians and nurses towards euthanasia, and to a lesser extent, general community attitudes. Results from this research are consistent in reporting that physicians are a social group most unlikely to support access to legal euthanasia, though many practise it covertly. Nurses are almost as likely as the public to support legalisation and the vast majority of Australians now support legalisation.

4.2 Attitudes towards Euthanasia

A large number of studies have investigated physicians' and nurses' attitudes towards euthanasia, "euthanasia" being variously defined as passive euthanasia, active euthanasia or physician assisted suicide. A study on the current state of opinion and practice among doctors in Victoria, Australia, regarding end-of-life decisions and the legalisation of voluntary euthanasia, found that 53% of doctors in Victoria support the legalisation of voluntary euthanasia. Of doctors who have experienced requests from patients to hasten death, 35% have administered drugs with the intention of hastening death (Neil, Cody, Thompson & Kuhse, 2007).

Other Australian studies of physicians' and nurses' attitudes towards euthanasia have been conducted by Kuhse and Singer (1988, 1991). In the earlier study, 2000 Victorian medical practitioners were surveyed, with a response rate of 46%. Sixty per cent said that doctors should be allowed to take active steps to end a patient's life although only 40% said they would practise euthanasia if it were legal. When the same questionnaire was used with 2000 nurses, with a response rate of 49%, 75% were in favour of laws to allow doctors to end a patient's life under some circumstances and 65% would be prepared to assist with active euthanasia. This study was replicated with medical practitioners (Baum & O'Malley, 1990) and palliative care and oncology nurses (Aranda & O'Connor, 1995) with similar results, although only 40% of the latter respondents were prepared to assist with active euthanasia if legalised. A South Australian study of nurses' attitudes (Stevens & Hassan, 1994) revealed 60% of respondents favoured legalisation of voluntary euthanasia under certain circumstances. Additional qualitative data in the study by Aranda and O'Connor (1995), however, suggested that the context in which requests to die were made was an important factor but could not be adequately explored in the forced choice format of the survey questionnaire.

An U.S. study (Cohen, Fihn, Boyko & Jonsen, 1994), investigated attitudes toward assisted suicide and euthanasia among physicians in Washington State by presenting subjects with statements about aspects of euthanasia and its legalisation. Results showed 48% agreed that euthanasia was never ethically justified, 54% indicated that euthanasia should be legal in some situations and 33% stated they would be willing to perform euthanasia. Two studies of nurses' attitudes (Richardson, 1994; Shuman, Fournet, Zelhart, & Roland, 1992) investigated the relationship between various demographic factors and attitudes toward euthanasia. Shuman et al. (1992) found strong religious belief to be a predictor of opposition to euthanasia and Richardson's (1994) study indicated religious belief to be a significant variable in the formation of attitudes to voluntary active euthanasia. An Australian study by Munn (1994) surveying medical practitioners' attitudes towards euthanasia found religious values were a consistent barrier to the practice of euthanasia.

Helme (1993) reported that polls carried out as part of larger surveys, putting the same questions to comparable population samples over a long period of time, demonstrated a definite shift in public attitudes in several countries, with support rising on average from 50% in the 1960s to 80% by the mid-2000s. The 1996 British Social Attitudes Survey found that 82% of the public believe people suffering from painful, incurable diseases should have the right to ask their doctors for help to die (Donnison & Bryson, 1996). Every opinion poll since then has produced similar results including in Australia where between 1993 and 2002, Australians supported access to voluntary euthanasia of the terminally ill, but had reservations when death was not imminent. The age of patients was relatively unimportant in these considerations. Non-voluntary euthanasia of babies and adults received widespread approval only when particular situations could be defined as 'letting die' rather than 'killing' (Sikora & Lewins 2002). A 2007 Newspann reported that 80% of Australians believe that terminally ill people should have a right to choose a medically assisted death.

Whilst there are studies of terminally ill patients' interests in euthanasia and medically assisted death, there is not much data on the attitudes and desires of terminally ill patients regarding these issues. Emanuel et al., (2000), of 988 terminally ill patients, found that a total of 60.2% supported euthanasia or physician-assisted suicide (PAS) in a hypothetical situation, but only 10.6% reported seriously considering euthanasia or PAS for themselves. Patients were more likely to consider euthanasia or PAS if they had depressive symptoms, substantial caregiving needs, or pain. At the follow-up interview, half of the terminally ill patients who had considered euthanasia or PAS for themselves changed their minds, while an almost equal number began considering these interventions. However other research suggests that patients' responses can vary according to how the questions are framed. People have their own definitions of euthanasia (Parkinson et al., 2004). The same problem is found in research on medical practitioners, where there can be substantial disagreement among doctors concerning the definition of euthanasia (Neil et al., 2007).

4.3 Cultural Considerations

Cultural differences in attitudes towards dying patients have been observed among both health care professionals and the broader community. Davis and Slater (1989) compared US and Australian nurses' responses to situations involving dying patients and reported disagreement between the two groups of professionals about preferred and usual practices when a patient is dying. Attitudes of both the recipients of care and carers may differ across cultures, with broad implications.

A qualitative study conducted in Australia investigated Greek, Italian and Chinese speaking immigrants' attitudes toward euthanasia as well as attitudes of an Anglo-Saxon group (Kanitsakie, 1994). The participants were cancer sufferers and this research was part of a larger study examining opinions of medical care received since the participants' diagnosis of a terminal illness. Responses revealed a general lack of information amongst the non-English speaking groups about issues of euthanasia and ignorance of the public debate. Views of Greek and Italian respondents were predominantly negative on religious or moral grounds, whilst Chinese participants had difficulty comprehending the concept of euthanasia. Anglo-Saxon participants, on the other hand, were fully aware of the public discussions and the majority in this study supported the practice under certain circumstances. These interviews indicated that non-English speaking people do not appear to have been included in the public debate, a serious issue given that people

from non-English speaking backgrounds (NESB) constitute approximately 25% of the Australian population. The age and scarcity of this type of study, and the total absence of studies with Indigenous populations, are particularly concerning given the argument that vulnerable groups might be seen as more dispensable (see Section 4.4.5), and given that the original legislation was introduced in the Northern Territory, where the Indigenous proportion of the population is the highest in the country. Despite the popular contention that Indigenous people oppose the practice of euthanasia and would be less likely to enter hospital if it were legalized, there has been no research at all on this question.

4.4 Effects of Depression on Decision Making

The notion of competence to make rational decisions is a prominent issue in the euthanasia debate, particularly in cases where medical conditions involve cognitive impairment or depression. The wish to die among palliative care patients has been associated with treatable comorbidity, such as major depression (Brown, Henteleff, Barakat, & Rowe, 1986). Hooper, Vaughan and Jenke (1995) studied depressed elderly patients' preferences for active and passive euthanasia, before and after depressive episodes. When in remission, patients showed a statistically significant increase in preferences for life sustaining treatments, and a trend toward a decreased desire for voluntary active euthanasia. A similar study in the U.S. by Lee and Ganzini (1994), which examined the effect of recovery from depression on preferences for life sustaining therapy in older patients, showed that pre and post intervention preferences did not change significantly regardless of whether subjects had recovered from depression or remained depressed. However, depressed subjects' preferences were more unstable than those of control subjects. The fluctuations in depressed people's preferences suggest that careful assessment for depression is important in the case of euthanasia.

4.5 Correlates of Attitudes

Ho and Penney (1992) studied 168 adults in Darwin, finding general support for active and passive euthanasia, although most were more accepting of passive euthanasia. The most consistent predictor of attitudes towards both euthanasia and abortion was level of conservatism, whereas religiosity was a significant predictor of attitudes to abortion only.

An unpublished study by Hansen (1995) found high agreement with euthanasia for a vignette presenting the "best case" (i.e., the person was old, in pain, suffering from a terminal illness, mentally competent and made a clear request to die), but less agreement with less clear-cut cases, and no agreement for involuntary euthanasia. Hansen interpreted results as suggesting that there is a "slope" in people's attitudes (from strong support to strong disapproval, depending on the particular situation), but it is not a "slippery slope" since these attitudes are based on clear criteria such as the quality of life and rational decision making capacity of the suffering person. The need for research to monitor attitudes, and changes in attitudes, in Australia was emphasised.

These studies do not address the question of possible differences between attitudes that people might express in response to hypothetical questions and attitudes to euthanasia where there is personal involvement. Expressed attitudes may not be the same as personal choices, especially if the person expressing them has never been confronted with making a decision of this sort. Once again, the need for further research is evident.

5 Current Situation

Euthanasia is not legal in Australia at present, though physician-assisted suicide was briefly permitted in the Northern Territory. The Northern Territory Rights of the Terminally Ill Act (1995) was over-ruled by the Euthanasia Laws Bill (1996). Below we describe some of the problems and issues which can arise from legislation, particularly in relation to psychological concerns.

5.1 Northern Territory Rights of the Terminally Ill Act 1995

5.1.1 Background

The NT Rights of the Terminally Ill Act (1995) began: "To confirm the right of a terminally ill person to request assistance from a medically qualified person to voluntarily terminate his or her life in a humane manner; to allow for such assistance to be given in certain circumstances without legal impediment to the person rendering the assistance; to provide procedural protection against the possibility of abuse of the rights recognised by this Act; and for related purposes." The term "euthanasia" was not mentioned. The Act was confined to the terminally ill person making a request on his or her own behalf.

The Act defined "terminal illness" as an illness which "in reasonable medical judgement will, in the normal course, without the application of extraordinary measures or of treatment unacceptable to the patient, result in death of the patient". A medical practitioner might assist to end a patient's life if all of 15 conditions spelled out in the Act were met. A patient who was eligible to request assistance to terminate his or her life was "in the course of a terminal illness, [and] experiencing pain, suffering and/or distress to an extent unacceptable to the patient". A clause prohibited any person from giving or promising any reward (beyond "reasonable payment") to assist, or threat to disadvantage for refusing to assist, with a penalty of \$10,000.

Under the Act's procedures, the diagnosis and prognosis given by the patient's medical practitioner had to be confirmed by two other medical practitioners, one of whom must be a psychiatrist. The psychiatrist had to state that the patient was of "sound mind" and did not have treatable clinical depression.

In order to increase understanding of the Act, and to achieve some equity of access to the provisions of the Act, an education program was to be implemented. The availability of adequate palliative care services was also required by the Act.

5.1.2 Some Psychological Issues in relation to the Rights of the Terminally Ill Act

In excluding psychological disorders which may be influencing a patient's decision, the emphasis in the rights to the terminally ill Act is upon clinical depression. There are, however, several alternative clinical possibilities such as 'related toxic or other organic brain syndrome', anxiety disorders, delirium and adjustment disorders which should also be considered.

Under the Act, the patient's medical practitioner must inform the patient of the treatment options available, including palliative care, counselling and psychiatric support. Psychologists could have a role here in informing medical practitioners of the counselling and psychotherapeutic services that are available and may be appropriate.

The medical practitioner must be satisfied that the patient has given fully informed consent, and has considered all the possible implications of his/her decision for his/her family. This eliminates the applicability of the Act to those patients who are unable to communicate fully. However there would be few patients with whom some sort of communication could not be established.

Neither the Rights of the Terminally Ill Act nor its regulations make provision for the need to address the psychological needs of close relatives of the patient through counselling. A clinical or counselling psychologist, as a party not involved in the actual process of the administration of euthanasia, could reasonably be involved in such counselling.

Given the spread of the population of the NT over rural and remote areas, access to a psychiatrist would be very difficult for some patients. The option of replacing the psychiatrist by another medical practitioner without psychiatric training plus a psychologist to undertake the psychological assessment, would be worthy of consideration in any new legislation.

5.2 Current Practices

Some States have 'right to die' laws either operative or proposed (e.g., the ACT Medical Treatment Act 1994, the Victorian Medical Treatment Act 1988). For example Section 5 of the Victorian Act specifies that, under certain conditions, a patient (or their agent) may sign a refusal of treatment certificate which their doctor may honour (Dunn, 1996). Patients can also request that no 'heroic measures' be taken to prolong their life. Thus voluntary 'passive' euthanasia is, in some places and under some circumstances, legally permissible. However, proponents of medically assisted suicide argue that passive euthanasia is not 'a kinder option', and that allowing people to die slowly of thirst and starvation is very cruel, and also distressing for the watching relatives.

In terms of actual practice it is difficult to ascertain what the current situation is. Individual doctors and nurses sometimes publicly acknowledge that they have been involved in voluntary active euthanasia. However, there appear to be no reliable recently published data on the prevalence or circumstances of such practices. The earlier work by Kuhse and Singer (1988; 1992) is still likely to be the most reliable.

6 Issues in Decision-Making

Following a liberalising of laws relevant to euthanasia, serious issues concerning the process of decision-making would arise. Some principal concerns would be to ensure that an appropriate level of patient autonomy in the process was maintained, and that the imposition of a dehumanised bureaucratic process was avoided, while still ensuring that safeguards were in place. Some suggestions about what might be required are offered below.

6.1 Ensuring the Decision is Competent

Any patient with a serious medical illness or potentially terminal condition is entitled to the same thorough psychological and/or psychiatric assessment and treatment as a person without physical morbidity. Voluntary euthanasia may be the outcome preferred by some terminally ill patients, but its consideration as a treatment option requires the careful

examination of all possible medical, palliative, psychiatric and psychological factors which may be contributing to the request. Thus a patient's request for euthanasia is a necessary but not sufficient justification for acquiescence. In order to determine whether a person is competent to make such a decision, a careful and thorough clinical assessment is required by a psychologist or psychiatrist, administered on more than one occasion with a reasonable time interval between assessments, while taking account of situations of great pain and suffering.

In order to protect the interests of the individual and the community, and to eliminate the chance of an error of judgement, assessment should include detailed history taking and listening to the patient's experience of life and of illness, and his/her fears and expectations. It would also involve careful mental status testing, including assessment of cognitive state, mood, form and content of thought, and a precise examination of the stated and implied reasons for the request. The possibility of changes in mind in response to psychological or palliative care interventions and/or as the disease progresses should always be acknowledged. Indeed the current care regime should be carefully reviewed by an independent expert in order to ensure that the best possible medical care has been made available to the patient.

6.2 Other Factors which may Influence a Person's Request for Euthanasia

6.2.1 Patient Factors

Koetsier (1995) claimed that pain is not the only reason for terminally ill people to wish to hasten their deaths. Symptoms which may make the patient's life unbearable and may not respond to palliative care, such as persistent nausea, vomiting, double incontinence, fatigue, discomfort and paralysis, may also influence a request for assisted death.

Helme (1993) asserted that a wish to die is often the result of mental illness. Psychiatric disorder such as depression, anxiety disorder, delirium or adjustment disorder can affect decision making (Kelly, 1995). However, it can also be argued that depression can stem from a person's powerlessness in the situation, and might be alleviated by a sense of choice. Given the inconsistent results across studies, there is a clear need for further investigation.

Patient feelings of burden or guilt in response to professional, family or community discomfort, and fear of dependency or of loss of control over the process of death (Dillner, 1994; Helme, 1993) may also influence decisions.

6.2.2 Carer Factors

Unrecognised and untreated psychiatric morbidity in carers, family members or health providers may also influence a seriously ill person's thinking. Carer and professional fatigue, anxiety, depression or despair may also impact on the patient.

Boundaries between the terminally ill patient and carers are not always clear. Emotions are often projected and it is sometimes difficult to ascertain who is feeling the most pain and who needs to endure it or be relieved of it (Weddington, 1981). Helme (1993) claimed that patients may be used as objects for defensive, narcissistic or even perverse purposes by relatives or staff. Compulsive caregiving may exacerbate or prolong suffering. When appeals for 'mercy' are made on behalf of patients, it may actually be an

indication that it is the relatives or staff who are suffering the most pain. Adequate recognition of carers as workers, who need holidays, meal breaks and remuneration, might go some way towards alleviating some of the practical challenges of their role, if not the personal distress and powerlessness associated with watching a loved one suffer. Caring is a highly gendered activity, whether paid (e.g., nurses) or unpaid (e.g., family members), and yet there has been very little attention to issues of gender and power in the literature on end of life issues and euthanasia (Wolf, 1996; Parks, 2000).

The response to a patient's request for assistance to die may signify to the patient the value that others place on his/her continued existence. A carer's or professional's willingness to acquiesce may confirm or amplify a patient's feelings of worthlessness or hopelessness, whereas hesitancy and an approach indicating cautious, sympathetic understanding may actually challenge feelings of despair. However a study in the Netherlands interviewing relatives of those who had died by euthanasia reported that 92% of those close relatives viewed the intervention as favourable in ending and preventing suffering (Georges et al., 2007).

6.2.3 Other Factors

A request for euthanasia may follow a failure of one or more parts of the health system to provide adequate care. Inadequate medical, palliative or psychiatric care or support may significantly influence a request for premature death (Komesaroff, Lickiss, Parker & Ashby, 1995).

Health providers operating under severe economic constraints may not have an emotional investment in maintaining the lives of the sick, frail and dying. They may not consider the relevance of ethical and human rights issues and may even see some benefits in early termination of life. The patient may be picking up on covert economic rationalist messages (Miles, 1994).

6.3 A decision-making process to ensure patient autonomy

If, after due consideration of the factors noted above, a patient still desired assistance with ending their life, a process would need to ensue which fulfilled several criteria to ensure:

- that the person requesting euthanasia was in control of the process;
- that the person making the request was given multiple opportunities to withdraw that request, by incorporating 'cooling off periods';
- that withdrawing the request would not result in prejudice, discrimination or recrimination;
- continuance of adequate palliative care and concern for quality of life issues;
- adequate professional psychosocial support, as requested by the person expressing the wish to die; and
- adequate professional psychosocial support for carers and family members of the person expressing the wish to die.

Counselling for the patient may be required throughout the process, and support may be needed for those affected by the decision. Detailed documentation of consent may be required so as to safeguard against any deterioration of mental state (including loss of consciousness). Detailed exploration would be needed of the method of death, of those to represent the person throughout the process if required, with a timeframe for review of the process. One proposed way to ensure that these criteria are met is the formulation of a

Living Will or Bill of Rights that formally acknowledges the request and provides guidelines for the ensuing process (see "Choosing to Die", AIDS Council of NSW, 1994). Such a document would have the advantage of being a structural key to the counselling process formalising the ownership of the euthanasia process by the client.

The roles of the professional providing psychosocial support in such a process would include ensuring that the person who initiates the request does so with:

- (i) clear understanding of the alternatives to euthanasia, including palliative care and continuing psychosocial support and counselling;
- (ii) understanding of the process, the medico-legal issues, and with exploration of the impact of the process on relationships;
- (iii) exploration of broader issues (change in relationships, distribution of property and wealth, how to die, when to die etc.); and
- (iv) counselling and psychosocial support available to significant others/carers/family

It is not intended that this section, in spelling out some of the characteristics required in any humane process of implementing euthanasia, is necessarily implying support for the introduction of such a process.

6.4 Procedure where Patient is not Competent

This discussion paper focuses primarily on situations where, with appropriate safeguards and precautions, it is possible to become reasonably confident that a competent decision is being made. However, situations exist where a patient is clearly not competent (e.g., unable to communicate, in a coma) but hastening death is considered by some to be in their best interest. Besides the inability of the person involved to exercise autonomous decision making, all of the concerns outlined above also apply.

In recent years several cases have been reported of patients in what is described as a "persistent vegetative state", who are wakeful following coma but appear to have no cognitive function. In some such cases, action has been taken to terminate life. Murphy (1995) argued that very thorough and continued psychological and neuropsychological assessment of such cases is needed, over and above clinical observation. She pointed out that unpredicted recovery sometimes occurs, and that, from case evidence, some patients can show awareness and response after training. Psychological assessment and management skills are needed in caring for these patients.

7 The Roles of Psychologists

7.1 Attitudes and feelings

Health professionals, including psychologists, need to consider their own views on euthanasia, and to examine the influences on their own position. Training, rational argument, personal beliefs, values, and experiences, attitudes to and fear of death and suffering, and personal locus of control are all likely to contribute to an individual's perspective on euthanasia. Since psychologists are (or should be) highly cognisant of situational determinants, cognitive dissonance, and ethical requirements to respect individual decision making, it seems highly desirable that they should try to articulate their personal attitudes towards euthanasia. To do so should help to guard against an unacknowledged value system standing in the way of appropriate assessment of mental

states, or preventing or biasing adequate discussion with a terminally ill client, relatives, or other professional carers.

An individual psychologist's views and wishes about their own future medical care deserve examination, along with recognition that these views and attitudes may change with changes in their own life circumstances, and such changes may have implications for their professional orientation and practice. Examining their own views and preferences may also help psychologists to recognise the conditions influencing the views and preferences of their clients and their family and carers.

7.2 Potential Contributions

Below is a range of ways in which psychologists can provide services to patients and their family and carers, as well as become more generally involved in the public debate about euthanasia:

7.2.1 Psychologists working in palliative care and with terminally ill patients

- Psychological assessment to determine the existence or otherwise of psychological/psychiatric morbidity.
- A therapeutic role in treatment of psychological disturbances including depression, and in promoting the patient's psychological well-being.
- A therapeutic role by assisting the terminally ill person to come to know and understand why he/she has requested voluntary euthanasia; to explore the meaning of the person's life and present experience of suffering; and to help him/her move closer to a position of control over his/her life.
- An advocacy role to ensure that the patient receives highest quality palliative care.
- Participation with the patient in a skilled, multidisciplinary team approach to the issue - e.g., psychologist, general practitioner, medical specialist and patient's representative.
- Counselling and support for those caring for someone with a terminal illness.
- A debriefing role for professionals and family members involved in active euthanasia.

7.2.2 Psychologists in General

- Involvement in terminal care issues and the euthanasia debate.
- Involvement in formulating and shaping policy. Education of key players about the skills that psychologists can offer.
- An advocacy role for the unheard voices in the debate e.g. people who are mentally and physically disabled, aged, non-English speaking or inarticulate.
- Running workshops and seminars for medical, nursing and allied health staff.

- Organisation of public meetings in local areas, inviting speakers who will present different views.
- Becoming involved in euthanasia research.

7.3 Professional Education and Training

A further question for the profession is the specialised training needed in order for psychologists to become involved most effectively in this area. Consideration should be given to the inclusion of life span development, with elements on ageing, death and bereavement, in the core undergraduate psychology courses. The issue of euthanasia could be incorporated here. Expansion of these elements, with evaluation and counselling skills for healthy and ill aged persons, as well as other groups, could be built into postgraduate professional courses such as clinical psychology and clinical neuropsychology, counselling, community, and health psychology. A postgraduate degree in gerontological psychology could also embrace such elements. Provision of elements in these areas should also be a feature of continuing education for professionally qualified psychologists.

8 Conclusions

The ethical, psychological, medical and legal issues involved in euthanasia and terminal care are both complex and challenging. The psychologist, with other professionals, must decide if the request for assisted death is a rational and autonomous one, unaffected by treatable psychological disturbances such as depression.

There exists an inherent tension between respecting individual autonomy and relieving people from unbearable suffering while still protecting the principle of valuing human life. Any liberalising of laws in relation to euthanasia needs to achieve a satisfactory mechanism which balances this tension, achieves respect for individual rights (of patients, carers and professional health workers), and prevents abuse, without becoming too unwieldy, bureaucratic and time consuming to be practical.

The research cited suggests that overt requests for euthanasia are made by a small number of chronically or terminally ill patients. It is possible that there are more patients who sense that medical professionals are uncomfortable talking about death, and do not pursue a request after they drop hints that are ignored. Perhaps the debate more than anything highlights the need for all sections of the community to give more considered thought and effort into managing a humane, dignified, respectful passage to death for the aged and terminally ill.

The complexity of the psychological issues which need consideration becomes clear from the preceding analysis. Whether or not voluntary active euthanasia is legalised, it is clear that the need for high quality care remains. In fact, perhaps one beneficial consequence of the current debate is the increased recognition of the rights of the terminally ill to the highest quality of care, including palliative care, and including also concern for their psychological as well as physical welfare. Adequate psychological services need to be available to those terminally ill patients who are depressed or suffering other psychological disorders concomitant with, or as a consequence of, their terminal illness. Services also need to be available to respond to carers' psychological needs.

Another need which is apparent from our review of the research literature is for much more Australian research on community and professional attitudes to euthanasia, including research on those from NESB and indigenous cultures. The evidence suggests that people from these groups have neither been involved in the debate nor have their opinions been sought. If legislation were to change, it would be important to ensure that those from minority groups had equitable access to information and options. Considering the centrality that the “slippery slope” argument plays in the debate, i.e., the fear that legislation will encourage growing acceptance of weaker criteria for the practice of euthanasia, it is crucial that research investigates evidence for the occurrence or non-occurrence of such a slide in attitudes.

The decision-making process raises many difficult psychological issues. It is clearly apparent that every case where a patient requests assistance to die should be assessed individually. Many elements of what might be required for an acceptable process have been identified here.

Finally, it is clear that there are several places where psychologists can and should enter in the debate on euthanasia, in policy development and in practice for the care of the terminally ill, and in the process of support and decision-making should requests for assistance to die be made.

We urge policy makers to consider these issues seriously, and to bring them to the attention of other professionals and policy makers. Psychologists should strive to establish and keep up to date their knowledge in this area, e.g. through continuing professional education, so as to be prepared to enter into social action and professional service in this field if called upon.

9 Resources and References

Resources

To explore further the issue of euthanasia and care for the terminally ill, the following organisations are useful resources for providing information and speakers.

- (i) The Voluntary Euthanasia Societies in most States. (On the Internet through: <http://www.vicnet.net.au/vse/vl.htm>)
- (ii) The AIDS Councils in each State. See especially AIDS Council of NSW (ACON) proposed Voluntary Euthanasia Bill, and booklet entitled "Choosing to Die" (2nd ed.).
- (iii) The Law Associations
- (iv) The Australian Association for Hospice and Palliative Care Inc., and State groups. See especially Victorian Association for Hospice and Palliative Care Statement on Voluntary Active Euthanasia
- (v) Local Hospice and Palliative Carers

- (vi) The Royal Australasian College of Physicians. See especially "Ethics: Voluntary Euthanasia: Issues involved in the case for and against". Bridge Printery, Sydney, 1993
- (vii) Local District Divisions of General Practice Inc.
- (viii) Catholic, Anglican and Uniting Churches, Society of Friends
- (ix) The Right to Die Society
- (x) The Australian Council on the Ageing in each State. See especially NSW branch's Policy on the Needs of the Dying, Social Policy Committee, 1991.
- (xi) Dying with Dignity Society
- (xiii) Carers Australia (and peak bodies in each state)

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