Regulating Medical End-of-life decisions

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Introduction

The theme for this conference is ‘The Limits of the Law’. In the conference call for papers, some questions that were raised including questions of whether it is appropriate or possible to regulate in the area of health law, and whether ‘lacks can be flexible but still effective?’

Medical end-of-life decisions have been the subject of varying degrees of regulation ranging from ‘Natural Death’ type legislation that is intended to give effect to people’s wishes as they approach the end of life, to the more comprehensive Consent to Medical Treatment and Palliative Care Act 1995 (SA) and our only experiment with euthanasia in the Rights of the Terminally Ill Act 1995 (NT). All of these attempts to regulate medical end-of-life decisions have had their limitations, both in the types of decisions that they regulate, and the degree of intrusion into the doctor/patient relationship.

Assumptions

In this paper I want to suggest a model for the regulation of medical end-of-life decisions. This model rests on a number of assumptions that I cannot defend here, but have done elsewhere. The assumptions are:

1. Decisions are currently made, in a medical context that have the effect of shortening a patient’s life. That is patient’s are not treated, or treated in a way, that means they die sooner than they otherwise might.

2. At least some of these decisions, such as a decision to withdraw ‘futile’ treatment, to respect a patient’s decision to refuse life sustaining treatment or to administer treatment that may in fact hasten death when trying to alleviate pain or suffering, are, in appropriate circumstances, both lawful and ethical.

3. Controversially, I assume that in some circumstances there is no significant causal difference between those decisions and active euthanasia. Where the sure result of withdrawing nutrition or ventilation is the death of the patient, then any causal distinction between them fails. Some examples here will make my point:

Assume that a person in a relatively stable condition seeks euthanasia as a release from their suffering. It is clear that the decision to administer a fatal injection is the cause of her death. On the other hand, a decision to suspend some treatment that means that she may die sometime earlier than she would with the treatment is a cause in her ultimate death but it would be inappropriate to call it ‘the’ cause of death. Rather the treatment decision merely sets the scene that allows the death to occur at that earlier time. In this case there is a significant causal difference between euthanasia and the decision to withhold treatment.

Consider next a person who is bleeding to death but refuses a blood transfusion due to his religious objections, even though he could be saved with the transfusion. Here the decisions to refuse and withhold the treatment are significant causes in his death and there is less causal difference between the decision not to treat and active euthanasia. In this case it is known, with a great degree of certainty, that without the treatment, the patient will die. On the assumption that he could be saved if the transfusion was given, failure to give it is a significant causal factor in his death.

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2 It is possible to argue here that the doctor’s decision is not the cause of death because the patient has the right to refuse treatment and that a doctor cannot treat a person without their consent in circumstances where they are able to give or refuse consent. Accordingly, the doctor appears to be in the same position as a layperson; they may want to save the patient, but they cannot. To say that the doctor cannot save the patient in this situation is however, not true. The doctor could administer the blood transfusion but chooses not to. That decision, to respect the patient’s wishes, is still a causal factor in the patient’s death. What happens however is that the practitioner puts the moral principle of respect for patient autonomy (or perhaps fear of legal action) above the principle of the sanctity of human life. He or she may agree that all human life is inherently valuable but he or she allows the patient to die because in some circumstances, patient autonomy overrides the sanctity of human life.
Finally, consider a patient who is not terminally ill, but a decision is made not to provide nutrition and hydration or treat complications of her condition. In these circumstances there is no causal difference between that decision and active euthanasia; the decision to withhold nutrition and hydration from a patient in a persistent vegetative state causes her death as surely as administering a fatal injection.

4. The need for safeguards, that is the need to be sure that persons making medical end-of-life decisions are acting in good faith, with the best available information and with respect for the patient’s informed choices apply with equal force whether the decision is to administer euthanasia or to act in some other way that shortens the patient’s life. A patient who wishes to live, or a patient who is incorrectly diagnosed, suffers the same harm whether they are allowed to die by having life sustaining treatment withdrawn or whether they are given a fatal injection.

Objectives

Those assumptions, if true, have implications for law reform in the area of medical end-of-life decisions. Again, without fully defending the position, I suggest that the law in this area should be reformed to meet the following objectives:

1. Ensure that like cases of medical end-of-life decisions are treated alike;

2. Ensure adequate safeguards against abuse and error; and

3. Be as minimally intrusive as possible.

Detailed Regulation

One way to meet my stated objectives may be to subject all medical end-of-life decisions to the type of regulation that was contained in the Rights of the Terminally Ill Act 1995 (NT). That Act inter alia, required that a person be seen by at least three doctors to confirm the diagnosis, prognosis and that the patient was not suffering from a clinically treatable depression.

Whilst it may be possible to develop an ‘all encompassing’ legislative scheme, to regulate and safeguard all medical end-of-
life decisions, it would appear that such a scheme would be overly burdensome, necessarily bureaucratic, intrusive, and unworkable. Given that medical end-of-life decisions are made today without such a system in place, and without public outcry over the decisions then it would seem that such a scheme is not desired by the community. There is no precedent for such a scheme and judicial decisions\(^3\) and reports world wide have not recommended the implementation of such a scheme, so it also appears that such a scheme is not required.

**Expand the status quo**

Another way to meet the stated objectives would be to expand the status quo to include euthanasia in the list of accepted medical end-of-life decision, to be administered effectively in private. The *Consent to Medical Treatment and Palliative Care Act 1995* (SA) is an Act that codifies the rights of patients and medical practitioners to administer treatment that is in the best interests of the patient, even if it may shorten their life. The key section in this regard is s 17(1). That section says:

A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of a patient under the medical practitioner’s supervision, incurs no civil or criminal liability, by administering medical treatment with the intention of relieving pain or distress—

(a) with the consent of the patient or the patient’s representative; and

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\(^{3}\) See *Airedale NHS Trust v Bland* [1993] AC 789 (where it was recommended that decisions to withdraw treatment should be brought before a court for review, this was considered a interim requirement only); *Auckland Area Health Tribunal v Attorney General* [1993] 1 NZLR 235; See also House of Lords, *Report of the Select Committee on Medical Ethics*, London, 1994 and the Senate of Canada, *Report on the Legal, Social and Ethical Issues Relating to Euthanasia and Assisted Suicide*, Ottawa, 1995, (http://www.parl.gc.ca/english/senate/com-e/euth-e/rep-e/lad-tc-e.htm). Both Committees recommended some safeguards be in place for all medical end-of-life decisions but neither recommended a stringent regulatory system such as the hypothetical regulatory scheme developed here. In Australia, although legislation governing medical end-of-life decisions has been enacted in the Northern Territory, the A.C.T, Victoria and South Australia, in no case has a scheme such as the one adopted in the *Rights of the Terminally Ill Act 1995* (NT) been applied to other medical end-of-life decisions.
(b) in good faith and without negligence; and
(c) in accordance with proper professional standards in palliative care, even though an incidental effect of the treatment is to hasten the death of the patient.

In would be possible to extend this approach to euthanasia by amending s 17(1) as follows:

A medical practitioner responsible for the treatment or care of a patient in the terminal phase of a terminal illness, or a person participating in the treatment or care of a patient under the medical practitioner’s supervision, incurs no civil or criminal liability, by administering medical treatment with the intention of relieving pain or distress—*in the best interests of the patient*—

- (a) with the consent of the patient or the patient’s representative; and
- (b) in good faith and without negligence; and
- (c) in accordance with proper professional standards in palliative care, even though an incidental effect of the treatment is to hasten the death of the patient.

This amended provision would make it lawful to deliberately hasten the death of a patient by removing the requirement that the doctor only act with an intention to relieve pain or distress and that the hastening of death is only ‘incidental’. The relevant motivation must be what is in the patient’s best interest. This amended section would have a stronger patient, rather than practitioner, focus.

This legislative provision would not however provide any safeguards, other than the high ethical standards of the medical profession. That raises the questions of what sorts of safeguards are necessary.

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**House of Lords Select Committee on Medical Ethics in 1994.**

This was a question that was considered by the House of Lords Select Committee on Medical Ethics in 1994. The Committee recommended that medical end-of-decisions could be left in the hands of medical practitioners, acting largely without
independent review or safeguards. The Committee felt that they
could rely upon the medical profession who:

By virtue of their vocation, training and
professional integrity ... may be expected to act
with rectitude and compassion.\footnote{4}

Although medical practitioners are entitled to provide treatment
that was considered to be in the best interests of the patient,
there can be conflict as to what constitutes the best interest or
uncertainty over whether proposed treatment (or withdrawal of
treatment) is legal. For these cases the Committee
recommended:

... a new judicial forum ... be established with
power to authorise the commencement,
withholding or withdrawal of treatment where
this is in the patient’s best interests. … We do
not envisage that application to the forum would
be a routine event … But in the event of
dispute ... recourse to an authoritative forum
would be of advantage. We also support the
proposal ... that certain “special category”
procedures should always require the authority
of the forum.\footnote{5}

This type of model already exists in the area of Guardianship
law. In New South Wales the Guardianship Tribunal\footnote{6}
has the power to supervise the treatment administered to people who are
unable to give consent. The Tribunal has broad powers of
consent and can appoint guardians who have the power to
consent to treatment. Some treatments must be consented to by
the Tribunal.

Assuming that a provision such as the one based on s 17(1) of
the \emph{Consent to Medical Treatment and Palliative Care Act 1995}
(SA) discussed above, were incorporated into law, a body such
as the Guardianship Tribunal could be used to ensure that there
were adequate safeguards to protect person whose lives may be
shortened by medical end-of-life decisions.

\footnote{4}{House of Lords op cit n 3, p 56.}
\footnote{5}{Ibid p 50}
\footnote{6}{Created by the \textit{Guardianship Act 1987 (NSW)}.}
Safeguards based on Guardianship Law

The *Guardianship Act 1987* (NSW) identifies three types of treatment, ‘minor treatment’, ‘major treatment’ and ‘special treatment’. The ‘person responsible’ for the patient, or the Guardianship Tribunal may give consent for minor medical treatment. Major and special medical treatment may be given without consent in an emergency, but in other cases the consent of the Guardianship Tribunal is required.

If the definition of ‘special medical treatment’ were amended to include “any treatment that is intended, or is reasonably likely, to hasten the death of the patient” and “the withdrawal of any treatment where the withdrawal of that treatment is intended, or is reasonably likely, to hasten the death of the patient” then it would not be lawful to administer to, or withhold that treatment from, an incompetent patient without the consent of the Guardianship Tribunal. This would allow the Tribunal to review the decision to ensure that the diagnosis is correct and that the treating practitioners and family members are acting solely in the best interests of the patient.

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7 These terms are defined (in s 33) as follows:

“major treatment” means treatment (other than special treatment) that is declared by the regulations to be major treatment for the purposes of this Part;

“minor treatment” means treatment that is neither special treatment nor major treatment;

“special treatment” means:

(a) any treatment that is intended, or is reasonably likely, to have the effect of rendering permanently infertile the person on whom it is carried out; or

(b) any new treatment that has not yet gained the support of a substantial number of medical practitioners or dentists specialising in the area of practice concerned; or

(c) any other kind of treatment declared by the regulations to be special treatment for the purposes of this Part.

8 ‘Person responsible is defined (in s 3A) to mean the persons guardian (appointed under the *Guardianship Act*); if there is no guardian, then their spouse (provided that they have a close, continuing relationship); if no spouse then the person who has care of the patient; if no person has the care of the patient then a close friend or relative, or, if the person is in the care of the Director-General of the Department of Youth and Community Services, then the Director-General of that Department.

9 Ibid s 36.

10 Treatment is considered emergency treatment if it is required to save the patient's life; or (b) prevent serious damage to the patient's health; or (c) except in the case of special treatment to prevent the patient from suffering or continuing to suffer significant pain or distress. (*Guardianship Act 1987* (NSW) s 37(1)).
The Guardianship Tribunal’s jurisdiction is however, limited to cases where the patient is not competent to give consent for medical treatment.\textsuperscript{11} This limitation would deny the process of review in cases where it was alleged that the patient was competent but was being subject to undue pressure to consent to, or refuse consent to, treatment that may shorten or prolong their life respectively. The Guardianship Tribunal, as currently constituted, would not have jurisdiction to determine whether fraud or other illegal or improper activity was involved in obtaining a patients consent for, or refusal of, treatment.

In order to meet the objective of ensuring safeguards for all medical end-of-life decisions, it would be necessary to amend the \textit{Guardianship Act 1987 (NSW)} to provide that the Tribunal has jurisdiction whenever it is intended to administer medical treatment, or withdraw medical treatment, and it is intended or reasonably likely that the action proposed will hasten the death of the patient. In that case, any person that has an interest in the affairs of the patient, including the patient themselves, their medical practitioner, their spouse and children and any other person who can establish an interest should have standing to make an application to the Guardianship Tribunal to review the decision to administer or withhold the treatment in question.

If the Tribunal found that the patient the subject of the application was not in fact competent then the Tribunal would be in a position to give consent, or refuse consent, to any proposed action on behalf of the patient.\textsuperscript{12} If the patient was competent, then the power of the Tribunal should be limited to ensuring that the patient’s decision was voluntary, that there was no undue influence being brought to bear, that all treatment alternatives had been considered, and that the recommendation that treatment be commenced or withdrawn was made bona fides in the interests of the patient. If it was determined that the decision was voluntary, informed and bona fide, the Tribunal would have no power to override the decision even if they disagreed with the decision in the circumstances (so that, for example the Tribunal could not override a Jehovah’s Witness refusal of blood transfusions simply because they felt it was inappropriate or irrational). If it was determined that the decision was not voluntary, informed or made in good faith then the Tribunal could either override the decision or, alternatively,

\textsuperscript{11} Within the meaning of s 33 of the \textit{Guardianship Act 1987}. This section says that a person is incompetent if they are incapable of understanding the general nature and effect of the proposed treatment; or they are incapable of indicating whether or not they consent, or do not consent, to the treatment being carried out.

\textsuperscript{12} \textit{Guardianship Act 1987 (NSW)}, Part 5.
ensure that the circumstances are altered (eg by ensuring that information is giving, or undue pressure removed, or that second or third medical opinions are obtained) to allow the patient to make a voluntary and informed decision.

This scheme would allow both currently accepted medical end-of-life decisions and euthanasia to be practised under the same regulatory scheme. If the patient were incompetent the Guardianship Tribunal (or a Guardian appointed under the Act with the authority to consent)\(^\text{13}\) would need to consent, or refuse consent, to medical end-of-life decisions. The Tribunal would have the power to review decisions by competent persons where there was any suggestion that the decision was not truly voluntary, informed and made in good faith. For competent patients, where no issue arose as to voluntariness and good faith, then the medical end-of-life decision would be a matter for them and their medical practitioners without the need for review by the Tribunal.

This scheme would regulate morally equivalent medical end-of-life decisions in the same way, but would also draw a distinction between morally dissimilar medical end-of-life decisions. For example, assume a patient attends his doctor with severe migraines and argues that the pain is unbearable and he wishes to have euthanasia. Although the patient wants that treatment, he cannot force the doctor to administer it. The doctor, as an autonomous professional, thinks that euthanasia is not appropriate and only agrees to prescribe strong pain relieving medication. If the patient chooses to refuse the treatment, there would not be any grounds to have that decision the subject of any review, as it would not be a decision that is intended or likely to hasten their death. On the other hand, if the practitioner agreed to perform euthanasia, then that decision could be reviewed on the application of any person with an interest in the affairs of the patient.\(^\text{14}\) In this case the decision to refuse treatment is treated differently, which reflects that in the

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\(^{13}\) Ibid s 36(2).

Euthanasia in these circumstances would not be legal in any event. It would be both negligent and contrary to the standards of the medical profession to administer euthanasia for sever headaches until all other treatment options had been considered and appropriate information provided. Just as it would be inappropriate to withdraw nutrition and hydration on the basis of severe headaches, so too, euthanasia would be inappropriate as, on the facts given, it could not be said to be “in the patient’s best interests”. The situation may be different is the condition was chronic, non-responsive to any other treatment and debilitating.
circumstances that decision is significantly different from euthanasia.

On the other hand, if the patient is in a persistent vegetative state, the decision by a medical practitioner to withdraw nutrition and hydration would be subject to the same level of review as a decision to perform euthanasia, reflecting that in these circumstances the conduct is morally equivalent and that the patient is entitled to protection from an improper decision that will cause their death, however that action is described.

**Conclusion**

Although the details of this scheme have been skimmed over, it is argued that it is possible to regulate in the area of medical end-of-life decisions in a way that meets the objectives stated at the start of this paper, and have the advantage of being both flexible and effective. I have developed a scheme based on the *Guardianship Act 1987* (NSW) and influenced by the *Consent to Medical Treatment and Palliative Care Act 1995* (SA) that meets the objectives stated at the start of this paper, namely

1. Ensures that like cases of medical end-of-life decisions are treated alike;

2. Ensures adequate safeguards against abuse and error (by providing a system of review prior to any action that may hasten death in order to ensure issues of voluntariness, certainty of diagnosis and improper motive can be explored if need be); and

3. Is as minimally intrusive as possible (thereby allowing medical practitioners and their patient’s to make personal end-of-life decisions in the context of the doctor/patient relationship and with necessary consultation with family, friends and other health care professionals.)