

End-of-life decisions and the law: a new law for South Africa?

There are a number of deficiencies in the draft legislation regarding end-of-life decisions.



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SOUTH AFRICAN LAW COMMISSION'S PROPOSED LAW

A survey done in 1992 shows that many South African doctors have withheld or withdrawn life-support from patients. For example, most doctors surveyed stated that they would honour an advance directive, such as a living will, that directs withdrawal of life-support when a patient is critically ill. Many responded that they have willingly and actively participated in terminating the life of a patient, e.g. by issuing a Do Not Resuscitate (DNR) order or withholding or withdrawing life-sustaining therapy.¹

Although these practices are consistent with widely accepted legal and ethical principles,² South African law does not expressly permit doctors to withdraw life-sustaining treatment. Arguably, any act that hastens an incompetent patient's death, even though consistent with the patient's earlier expressed preference, is a violation of criminal law. No law or court decision permits a doctor to honour a living will or medical power of attorney made when a now incompetent patient was competent. The only South African court to consider the issue refused to recognise the legal validity of a living will (Box 1). A large gap exists between the law and ethically accepted actions routinely performed by South African doctors.

BOX 1

The patient was in a persistent vegetative state and had expressly declared in a living will that he did not want to be kept alive if he fell into this condition. Although it refused to accept the living will as legally binding, the court permitted the patient's widow to instruct the doctors to withdraw life support on the basis this would be in the patient's best interests. *Clarke v. Hurste No and Others* 1992 (4) SA 630 (D).

In a groundbreaking effort to close this gap, the South African Law Commission (SALC) initiated a research project in 1992 and, after extensive public hearings, proposed a new law.³ In response to wide public support, the draft law would authorise doctors to honour an advance directive (AD) — a living will or medical power of attorney prepared by a patient, now incompetent, at a time when the individual was competent. The proposed law also defines other circumstances in which doctors may withdraw life-support, and establishes a process by which doctors must make these decisions. Finally, the SALC proposes several options that, if enacted into law, would legitimise voluntary active euthanasia performed by a doctor at the request of a competent patient (Box 2). Since 1998 the proposed law has been in the hands of the Minister of Health, who has the authority to forward the draft law, or a revised version of it, to Parliament for possible enactment.⁴

BOX 2

This article does not assess the legal, ethical and social problems that could arise if either of these highly controversial options authorising active euthanasia were to become law. For a comment that favours adoption of the proposed option, see Benatar D.

Euthanasia and assisted suicide: the right to life and its corollary. *Specialist Med* 2000; 22(6): 354-358.

The SALC has taken an important step by its proposal to recognise patients' living wills and medical powers of attorney as legally valid, and to set criteria by which doctors and families decide when and under what circumstances to withhold or withdraw life-sustaining treatment. Although the proposed law has positive features (for example, it adopts a definition of death that includes 'whole brain' death) and provides a process for decision making, it contains ambiguities and gaps that will create practical, legal and ethical problems for doctors, patients and families. Despite these differences the draft law should be advanced to Parliament, where it can be publicly debated. When that happens, the medical community must become involved to ensure that the new law takes notice of the practical clinical realities of end-of-life decision making.

THE PROPOSED LAW IN A NUTSHELL

Four parts of the draft law deal with actions that would hasten death. Two regulate end-of-life decisions made by *competent* patients, while the second pair govern decisions made on behalf of *incompetent* patients.

Competent patients: withdrawal and euthanasia

First, competent patients 18 years or older may refuse life-sustaining medical treatment for any illness, whether terminal or otherwise.

Second, and more controversially, the proposed law provides several options that would legitimise voluntary active euthanasia. Under both options a competent patient becomes eligible for euthanasia if two doctors agree that he or she has either:

- a 'terminal' illness (as defined below) or
- an illness that has no reasonable prospect of being cured and causes severe physical or mental suffering 'not reasonable to be endured' *and*
- ending the patient's life is the 'only way for the patient to be released from his or her suffering'.

The first option that would permit active euthanasia allows the patient and a doctor to decide to end the patient's life without informing the patient's family. The second option requires a patient to submit a request, together with the doctor's findings, to a committee of five, one of whom must be from the patient's family.

Incompetent patients: with or without advance directive

Third, an individual may, when competent, make an AD by signing either:

- a living will that directs withholding or withdrawal of any medical treatment when a patient has a 'terminal illness', or
- a power of attorney to appoint a surrogate to make medical decisions if the patient becomes incompetent and 'terminally ill'.

The draft law provides that an AD may be honoured only if doctors decide the patient cannot make or

communicate decisions and has a 'terminal illness' defined as either:

- persistent vegetative state (PVS), or
- any condition that:
 - will inevitably cause 'untimely death', *and*
 - causes the patient 'extreme suffering'.

Only after deciding to withhold or withdraw treatment from an incompetent patient must doctors inform family members of their findings. Doctors are not required to consult with the family about their decision or to take the family's views into consideration before implementing the decision (cf. the next section). This omission is striking. Since ADs are often vague, family members should be allowed to provide evidence as to what the patient really intended and would want. Finally, the draft law does not grant courts jurisdiction to consider a family's claim that a doctor has wrongly interpreted the patient's living will.

Fourth, if the incompetent patient did not sign an AD that directs this, a doctor may still grant 'written authorisation' to terminate life-sustaining treatment. The doctor need only determine that the patient is incompetent and suffers from a 'terminal' illness as defined above. However, if the family objects, the doctor cannot implement his/her decision unless he/she first obtains a court order.

Whether or not the patient has an AD, the treating doctor must obtain confirmation of the patient's condition from a non-treating doctor, with expert knowledge, who has examined the patient.

PROBLEMS WITH DRAFT LAW

The proposed law would achieve some important purposes. However, as currently drafted, it is

flawed in several significant ways:

- The draft law rigidly limits circumstances in which a living will may be honoured by doctors.
- It allows doctors to make an initial decision to end a patient's life without consulting the patient's family.
- It overlooks legitimate reasons for withdrawing treatment, e.g. futility of treatment and limited medical resources.

Unless these defects are corrected, the proposed law will fail to accomplish some of the most important goals pursued by the SALC and those who support reform of the law.

Advance directives and patient preferences may be ignored

Consistent with South Africa's Constitution and generally accepted ethical principles, the draft law allows competent patients to refuse treatment for any illness. However, the preferences of incompetent persons, expressed when they were competent, are not granted the same validity. Although competent persons may sign ADs directing doctors to withdraw treatment, the proposed law provides no guarantee that doctors must honour their clearly expressed desires once the patient becomes incompetent. On the contrary, doctors may withdraw treatment only from a patient who is in a PVS — the rare case — or who faces an 'untimely death' and exhibits 'extreme suffering'.

Vague terms such as 'untimely' death and 'extreme suffering' have no accepted, quantifiable meaning in medicine, particularly in the context of incompetent patients with chronic, life-threatening diseases. Nor is it clear why interpretation of a 'terminal illness' should not, as is presently done, be determined by clinical judgement of treating doctors.

Patients with serious chronic diseases are encouraged to make a liv-

ing will or grant a power of attorney. In these documents and privately to their families, individuals often request that they not be sustained by aggressive medical interventions if they become incurably ill and lose their cognitive abilities and/or basic physical functions. It would be the unusual AD that would meet the conditions of the proposed law for withdrawing life-sustaining treatment, i.e. that the patient is in a PVS or afflicted with 'extreme suffering'. Commentators and courts have generally abandoned any notion that a patient must exhibit suffering to qualify for withdrawal of life-support.²

An unfortunate result of the draft law's narrow approach is that it shifts the focus from the patient's preference for ending treatment — the necessary beginning point for any ethically acceptable decision to honour an AD — to a process in which doctors initially serve as the main moral agents and decision makers. The proposed law does not require doctors to attempt to understand the patient's wishes, as reflected in an AD and through consultation with the family; instead, it requires doctors to try to fit the patient's condition into the draft law's rigid, unrealistic definition of 'terminal' illness. This could lead to a continuation of the current unfortunate situation in which the law diverges from universally accepted, ethically justifiable medical practice based on respect for a patient's autonomy and dignity.

The draft law's restricted, medically inappropriate definition threatens to undermine one major goal of the SALC: to authorise competent patients to direct their doctors to withhold or withdraw unwanted medical interventions once the individual has become incompetent.

Families are marginalised

The proposed law's failure to incorporate families into the decision-making process flows from its erroneous view of the nature of a decision to withhold or withdraw aggressive treatment. The draft law apparently envisions such decisions as pure medical decisions that usually should be made — at least initially — by doctors alone. Given this myopic view of the nature of life-ending decisions, it is enough that families are notified only after experts have made their findings as to the medical 'facts'.

A decision to withdraw medical treatment in order to allow an incompetent patient to die is as much a moral decision as a medical determination. Doctors have no special expertise in making moral decisions for others or in interpreting a patient's intent as expressed in an often vague AD. To convert doctors into moral agents to decide when to end a patient's life in circumstances of ambiguity is to 'medicalise' these decisions. Whenever possible, decisions should be made jointly by families, who are best acquainted with the patient's values and preferences for medical treatment, and doctors who can provide accurate medical information. In any event, a doctor who decides whether to continue or withdraw an incompetent patient's life-sustaining treatment must not act in conscious ignorance of the family's wishes.

If the draft law is applied literally, a family could claim no legal role in a decision by a doctor to withdraw, or refuse to withdraw, life-support from a patient who has signed an AD. Similarly, under one proposed option to legitimise euthanasia (when no committee is involved), doctors would have no obligation to inform a patient's family of their agreement to end the patient's life by administering a lethal agent.

MAIN TOPIC

These decisions encompass value judgements with profound implications not only for the patient and the medical profession, but also for the family and broader society. Yet the decision to administer a lethal agent could have been made, and the patient could already be dead, before the family learns of this. Involvement by supportive family could prove a critical safeguard to a patient's hasty or misconceived decision or to an agreement by doctors who lack information about the broader context of the patient's circumstances.⁵ A law that ignores the moral interests and duties of patients and families — and that relies only on doctors to make what the draft law mistakenly perceives to be solely 'medical' rather than moral decisions — is bound to meet with strong resistance.

The proposed law's marginalisation of the family is inconsistent with widely held views, especially among traditional South African cultures, about the importance of the family's role in important decisions made by a family member.^{6,7} There are, however, exceptional situations in which doctors may justifiably withdraw life-sustaining interventions without obtaining consent from either the patient or family. Curiously, in these situations discussed below, the draft law allows the family to override the doctor's decision to withdraw life-support. As we will see, to permit a family unilaterally to impose its preference for continued aggressive treatment in these exceptional circumstances raises a different set of problems.

Medical resource allocation and futility ignored

The draft law overlooks two compelling factors that must be considered when deciding whether and under what circumstances to withhold or withdraw life-support.

First, health resources are limited, and not all patients can be provided the best, most expensive treatments. Hospitals may adopt fair and reasonable policies to select which chronically ill patients are entitled to scarce, life-sustaining medical interventions that cannot be provided to all who can benefit (Box 3).

BOX 3

The Constitutional Court approved a hospital policy, forced by shortages of funding, equipment and personnel, to limit dialysis for chronically ill patients only to those eligible for a kidney transplant. All who failed medical criteria for a transplant were denied life-saving dialysis.

Soobramoney v. Minister of Health, KwaZulu-Natal 1998 (1) SA 765 (CC)

The proposed law makes no provision for withdrawing life-sustaining treatment in order to comply with validly adopted resource allocation policies that seek to distribute medical resources in a fair, efficient and non-discriminatory fashion. It allows doctors only to determine whether the patient has a 'terminal' illness, as narrowly defined by the draft law. If a patient has no AD — and this is the usual case — doctors may not withdraw even from a patient who is in a PVS or endures extreme suffering, if the family objects. An ICU doctor who proposes to withdraw life-support under a hospital or government resource allocation policy might be faced with an objection from a family. A cautious hospital would be forced to bring a lawsuit in order to determine whether it could withdraw treatment, over the family's objection, from a patient who is no longer entitled to it

under a resource allocation policy. The resulting delay could significantly undermine implementation of fair and rational resource allocation policies of the kind approved by the *Soobramoney* court (the referenced article provides an example of such a policy)⁸. It remains to be seen whether a court would interpret the SALC law to permit withdrawal of life-support for purposes of implementing a rationing policy, or whether families will be allowed to reverse the effect of such policies by objecting to withdrawal, regardless of such considerations.

The proposed law also ignores possible application of the familiar concept of futility. Under the futility doctrine, doctors are not obligated to continue to treat patients for whom treatment is futile, and will merely extend biological life without providing a cure or return to meaningful existence.⁹ Both the *Clarke* case (Box 1) and the UCT statement² recognise that treatment that merely continues biological existence, without providing a minimal quality of life that includes meaningful communication, is futile and need not be continued. As drafted, the law takes no account of this rationale for ending treatment. Doctors are only permitted to withdraw if they find that the patient has a 'terminal' illness in the narrow sense defined by the law. A patient's family could rely on the draft law to demand treatment for a patient who failed to make an AD, even though all treating doctors deem further treatment to be futile.

A court could interpret the law so that it does not provide the exclusive criteria for withdrawing life-support, and allow introduction of concepts such as 'futility' that are well-recognised in medical ethics. But it would be imprudent to assume this. The better approach is

to solve the problem before it occurs and to revise the draft law so that it recognises other well-accepted rationales for withdrawing and withholding aggressive medical treatment.

CONCLUSION

The SALC recently opened a separate investigation that could provide an alternative legal vehicle to legitimise advance directives. The new project focuses on the current welter of laws that guide decisions made by adults with diminished capacity. Its goal is to produce coherent, uniform standards for decision-making on behalf of persons who are medically and legally incompetent to make important judgements about their lives. Unfortunately, the SALC has announced that it will exclude medical decisions made on behalf of incompetent patients from its investigation — including decisions made at the end of life — because this topic was addressed in its proposed end-of-life law still pending before the Minister of Health.¹⁰

Since no action has been taken on that proposal, the SALC should now take the opportunity to incorporate an improved version of widely supported features of the draft end-of-life law into a proposed law on diminished capacity. This should include clauses that would authorise living wills and medical powers of attorney. Euthanasia options could be left behind to suffer whatever fate the Minister of Health has in mind for them. Without the politically sensitive baggage of these options, other portions of the end-of-life law that attracted wide public support would gain a new lease on life and a chance of enactment by Parliament.

The SALC expects to publish a discussion paper early in 2003, and the public will be given a chance to respond. The medical community should support a proposal to incorporate portions of the end-of-life law that would authorise ADs, and other uncontroversial clauses, into newly drafted diminished capacity legislation. This may be the best

opportunity to bring some light into the dark corners in which end-of-life decisions are now made.

SALC project documents and contact information for SALC staff can be found at <http://wwwserver.law.wits.ac.za/salc/salc.html>.

References available on request.

IN A NUTSHELL

A gap exists between ethical end-of-life decisions and the law.

Terminating life-support could violate the law.

The South African Law Commission has submitted proposals to reform the law.

It is proposed that living wills and powers of attorney be legitimised.

The draft law prescribes the process for ending life.

Problems with the draft law:

- incompetent patients' wishes might be overridden
- families could be marginalised
- ethical reasons for ending life support could be ignored.

Reform can be accomplished through another vehicle.

SINGLE SUTURE

Treating alcoholism: no magic bullet

The FDA-approved naltrexone for treatment of alcohol dependence is based on proven efficacy in randomised trials.

Nevertheless, questions remain about the importance of clinical setting, patient characteristics, and concomitant therapies in determining naltrexone's effectiveness. Researchers from the US Department of Veterans Affairs studied naltrexone (given daily for 3 or 12 months) in a large, multicentre, placebo-controlled trial that included 627 veterans with alcohol dependence. All subjects received counselling based on the tenets of Alcoholics Anonymous, initially weekly and then monthly (*N Engl J Med* 2001; **345**:1734-1739 and 1770-1771). At 13 weeks, there was no significant difference in return to heavy drinking. At 1 year, there were no significant differences in percentage of drinking days or number of drinks per drinking day. In the 2 naltrexone groups, medication adherence (percentage of days that the medication bottle was opened) was 72% at 13 weeks and 43-44% at 1 year. Medication adherence, attendance at counselling, and AA participation were associated with improved outcomes, regardless of treatment assignment.

Richard Saitz, MD, MPH writing in *Journal Watch* 4 January 2002, says that editorialists point out that, in this study, naltrexone was ineffective in a population that comprised mainly men who had long-standing alcoholism and relatively little social support and who received minimal counselling; these patient characteristics contrast with those in prior studies that demonstrated naltrexone's efficacy. Can naltrexone cure alcoholism? Clearly, the answer is 'no, not alone', and we shouldn't expect that any one drug could cure a complex, chronic medical illness. Nonetheless, the current results do not negate previous findings of modest efficacy when the drug is used with appropriate counselling in less severely affected patients.