



PERSONAL VIEW

LEGALISING ASSISTANCE WITH DYING IN SOUTH AFRICA

Willem A Landman

South Africa is in the process of deciding whether to legalise (medical) assistance with dying in the forms of physician-assisted suicide (PAS) and voluntary active euthanasia (VAE). A Discussion Paper¹ by the South African Law Commission (SALC), published in 1997, encouraged the South African public to make submissions about specific sections of the Paper's accompanying Draft Bill. This Draft Bill is an omnibus legislative proposal about all aspects of end-of-life medical decision making, including palliative care, advance directives, withholding and withdrawal of life-sustaining treatment, PAS and VAE.

In August 1999 the SALC published a final report,² incorporating a modified Draft Bill, and submitted it to the Minister of Justice. Section 5 of the Draft Bill proposes three options for public debate and discussion regarding PAS and VAE (jointly referred to as 'active voluntary euthanasia'). Option 1 is 'the confirmation of the present legal position', with PAS and VAE remaining unlawful. Option 2, 'decision making by the medical practitioner', proposes legislation enabling a physician – upon satisfying certain conditions and meeting safeguards aimed at preventing abuse – to assist a patient with PAS or VAE. Finally, Option 3, 'decision making by a panel or committee', proposes that 'euthanasia' (PAS and VAE) be regulated through legislation permitting a multidisciplinary ethics committee to consider requests for euthanasia on the basis of strict guidelines.

Internationally, legalising PAS or VAE would be extremely controversial. Still, I believe that South Africa should legalise both PAS and VAE,³ but that such a momentous step should be preceded by informed public debate. Both PAS and VAE are morally justifiable in carefully circumscribed circumstances.^{4,5} However, even if one believes a practice to be morally undesirable, in a democracy it may nevertheless be right to

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legalise and regulate that practice, given that not all citizens of good will share the same beliefs. With a view of contributing to the debate initiated by the SALC, I recommend the following nine questions for public debate, and comment briefly on each one.

1. Should neither PAS nor VAE be legalised? Legalising these practices is justified in terms of fundamental moral values such as well-being (mercy) and autonomy, and the principles that underlie these values.⁷ Moreover, given that the withholding and withdrawal of life support is generally accepted, legalising PAS and VAE would serve the ends of justice by being both formally consistent and substantively fair.

Legalising assistance with dying is likely to decriminalise practices that should not be regarded as crimes, thus shielding institutions, physicians and other health care professionals from criminal and civil liability. In addition there are constitutional reasons peculiar to South Africa for legalising PAS and VAE. Firstly, the South African Constitution's Bill of Rights⁸ includes potentially conflicting rights. For example, the right to life has to be weighed against the right to freedom and security of the person (more specifically, the right not to be deprived of freedom arbitrarily or without just cause), and the right of control over one's body. Also, rights can be waived. Secondly, a recent ruling by the Constitutional Court in the case of *Soobramoney v. Minister of Health (KwaZulu-Natal)*⁹ means that the State, in certain circumstances, may be inconsistent if it denies a request for PAS or VAE. If the State can legitimately withhold scarce resources necessary for life (for example, kidney dialysis, as in this case), how can it justifiably deny a 'condemned' man's request for assistance with dying so that he may die sooner, and perhaps with less suffering?

Ultimately, the goals of medicine are at issue. Given our inevitable destiny, dying is a part of life. Medicine, therefore, cannot simply be about restitution (curing, healing, or extending life) and palliative care; it must also be about facilitating an easy or gentle death when appropriate, and that may require, among other options, PAS or VAE.

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2. Should only PAS, and not VAE, be legalised? In the USA the moral and legal debate is predominantly about PAS, not VAE;¹⁰ in Oregon only PAS has been legalised,¹¹ as was the case with the short-lived law in Australian's Northern Territory.¹² Contrary to conventional wisdom, the claim that there is a general moral difference between PAS and VAE such that any act of PAS would be morally preferable to any act of VAE, is weak¹³ and should not influence the legalisation debate. The bare fact that a physician is not the final cause of death (as occurs in PAS but not VAE) does not rule out the possibility that his action may have causally contributed to the death or that he did not intend it, and it does not absolve him of moral responsibility. Furthermore, bad consequences (such as death when a patient still wants to live), should they occur, would not follow only from PAS or only from VAE. Moreover, obligations to be merciful or to respect autonomy may, under the circumstances, call for either PAS or VAE. Consequently, it would be inconsistent to make a general moral distinction between PAS and VAE in order to justify the legalisation PAS but not VAE. Grounding legislation in this distinction may lead to the arbitrary abandonment of patients who are unable to commit suicide, such as those with quadriplegia, or those who may prefer more active assistance with dying. In addition, legalising only PAS may constitute the kind of unfair discrimination against the physically disabled prohibited by the Bill of Rights.⁸

3. Should PAS and VAE be limited to the terminally ill? Apart from the difficulty of determining when someone is terminally ill,³ there are also medical conditions that cause extreme suffering but that are not terminal. It is significant that in a submission to the SALC, the University of Cape Town (UCT) Bioethics Centre, whose members include prominent academic physicians, argues that since end-of-life options as envisaged by the Draft Bill are grounded in autonomy, it would be arbitrary to permit these options only to those whose deaths are relatively imminent and to deny them to those suffering from chronic and degenerative conditions including multiple sclerosis, amyotrophic lateral sclerosis, motor neuron disease and quadriplegia.¹⁴ Consequently, the UCT Bioethics Centre proposes that legislation should also make provision for 'intractable and unbearable illness', that is, disorders that cannot be cured or successfully palliated and that cause such severe suffering that death is preferable to continued life.¹⁴ Significantly, both Options 2 and 3 of the final SALC report and the Draft Bill incorporate this suggestion.²

I agree with this extension, but it raises an important question of interpretation: does 'intractable and unbearable illness' include mental or dementing disorders that do not render a patient mentally incompetent?³ If suffering is understood as an emotional response to more than minimal pain or distress, then it can be either physical or mental (or both). To extend the meaning of 'illness' in the context of legalising assistance with dying to include patients who may

be neither terminal nor in (physical) pain would be extremely controversial, and raises questions about the moral commitments underlying the legislation debate. Still, wouldn't mercy, respect for autonomy and justice (consistency and fairness) call for such an extension when life for the patient irreversibly ceases to be worth living?

4. Should patients be legally empowered to request VAE in an advance directive? If advance directives (living wills and durable powers of attorney) are legalised following, for example, state legislation in the USA,^{15,16} then it would be inconsistent not to make provision for a VAE request in such directives. An advance directive enables a competent person to prescribe or influence decisions about his medical care if he is no longer competent to make those decisions. Consequently, if a competent individual may opt for VAE, then there is no ground for excluding this option from advance directives.

5. Should minors be empowered legally to request PAS or VAE? The Draft Bill excludes minors (persons under 18 years of age) from the provisions regulating PAS and VAE. With older children and adolescents chronological age becomes less accurate as an indicator of mental competence. Some mature minors may indeed be mentally competent to choose PAS or VAE on account of, for example, prolonged experience of repeated hospitalisation, treatment for illness, or suffering. South African abortion law¹⁷ requires consent for abortion only from the pregnant woman, whatever her age, thus entrusting serious medical decisions to minors. Some commentators argue persuasively that minors suffering from, for example, end-stage renal disease¹⁸ or terminal cancer,¹⁹ and who have the cognitive and emotional capacity, should have the right to refuse life-sustaining treatment. Why should it be any different with regard to active assistance with dying?

Minors are, however, under the legal decision-making authority of their parents since it is presumed that parents will do what is in the best interests of their children. As such, some balance needs to be achieved between parental authority and minors' autonomy. Since mentally competent minors are a special case, parents should respect their capacity for self-determination and their considered choices in pursuit of their own well-being and best interests, even if it means that their lives are shortened. Legislation may require additional procedural safeguards to make provision for the unique position of mature and competent minors.

Significantly, whereas Option 2 of the final SALC report and the Draft Bill² is confined to patients over the age of 18 years, the ethics committee approach (Option 3) does not contain this limitation.

6. Should persons other than physicians be legally empowered to assist with dying? The Draft Bill states that only physicians ('medical practitioners') should be legally empowered to assist with suicide and to perform VAE. An alternative approach would be to insist that while the



responsibility for making clinical determinations (diagnoses, prognoses, outlining clinical options) and prescribing drugs should remain solely with physicians, the tasks of actual administration of assistance with dying (handing over pills, increasing the morphine dose, giving a lethal injection) could also be assigned to other health care professionals and concerned laypersons (family, friends), provided they are knowledgeable about the methods of administration. The UCT Bioethics Centre¹⁴ argues that limiting assistance with dying to physicians only would constitute unnecessary interference with liberty. They maintain that it would be redundant in view of other procedural safeguards, and problematic because dying is a lonely event that should be mitigated by the comfort drawn from close personal relationships. The SALC did not include this suggestion in its final report.²

7. Can procedural safeguards prevent a slide down a slippery slope towards unlawful assistance with dying? Some critics may believe that even if legalising assistance with dying is morally justifiable in terms of basic moral principles (see question 1 above), the dangers inherent in legalisation are simply too great. The argument that legalising PAS and VAE may lead down a slippery slope towards non-voluntary or involuntary euthanasia, or to abuse and exploitation of the poor and vulnerable, needs to be taken very seriously. Procedural safeguards, such as those proposed by the SALC, are designed precisely to foreclose such undesirable consequences.

Available evidence, almost exclusively from the Netherlands,²⁰⁻²² is complex and open to a variety of interpretations. The Dutch and South African situations are different, which makes direct comparisons difficult. The Netherlands has long-standing universal health care, well-developed social support programmes, and physician-patient relationships that are more stable than in most countries. Although PAS and VAE are technically illegal in that country, cases are not prosecuted provided certain criteria are met. However, procedures for their enforcement are less formalised than the safeguards proposed by the SALC. So even if there have been cases of abuse in the Netherlands, it does not follow that procedural safeguards in South African legislation would fail to provide adequate protection for poor and vulnerable patients. Interestingly, early data on the state of Oregon's first full calendar year of legalised PAS (1998) show no evidence of abuse, suggesting that procedural safeguards are probably achieving their goal.²³

More generally, the status quo (PAS and VAE being unlawful) is not free from inhumane suffering and abuse, and any statistics on legalised assistance with dying have to be assessed against the background of such facts. Furthermore, if legalising a practice would be morally acceptable only if absolute compliance were guaranteed, then we would have to ban practices such as driving cars or implementing basic rights, for

example the right to self-defence. Surely it is wrong to curtail the legitimate liberties of individuals because others may and do abuse them? All human endeavour, including the status quo, has the potential for abuse, and demanding (near) absolute guarantees diverts attention from substantive deliberation about what is the right thing to do and how to do it.

Some critics may argue that legalising assistance with dying will undermine palliative care. This does not necessarily follow, since PAS and VAE, like the withholding or withdrawal of life support, should be voluntary, complementary options to palliative care.

8. Are there slippery-slope objections to legalising assistance with dying that are unique to South Africa?

Despite these general remarks about the possible slippery slope, some critics may argue that South Africa, in particular, is not the place to experiment with such potentially dangerous legislation. Firstly, South Africa is a multicultural society, which makes misunderstanding in personal communication a very real possibility. Additional safeguards involving qualified interpreters and professional oversight²⁴ would be needed to address this problem. In the SALC's final report Option 2 calls for an interpreter where necessary.²

Secondly, many South Africans have educational deficits that may limit their ability to understand fully the meaning and implications of a legal right to assistance with dying. Still, PAS and VAE would be consistent with rights guaranteed in the Constitution, and would not be imposed on anyone provided that procedural safeguards are respected.

Thirdly, since South Africans have hugely different access to scarce health care resources, some critics may argue that the risk of abuse with regard to legalised PAS and VAE will be greater than in wealthier and more egalitarian societies. With effective procedural safeguards in place, however, why should PAS and VAE be singled out if withholding and withdrawal of life support likewise save scarce resources required to keep patients alive? Moreover, it may be preferable for a patient to know that there is an escape route when health care insurance

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cover is exhausted, rather than having to suffer because of a combination of scarce resources and legal prohibition.⁹ This would not compromise the freedom of a request for PAS or VAE any more than it would other treatment or non-treatment decisions made in an environment of scarce resources. However, none of this detracts from the need and obligation to address inequities or inequalities in the transformation process to a just health care system.

Finally, some critics may believe that South Africa, with its past of white-on-black racial discrimination, should be the last place in the world to legalise PAS and VAE. Several countervailing considerations are to the point. For example, there is no empirical evidence to suggest that current end-of-life decisions in South Africa are any different from those in the UK.²⁵ New legislation allows for more effective control of the health professions through the exercise of expanded, including disciplinary, powers of newly established professional boards.²⁴ During the 1990s admission of black students to medical schools has increased significantly.²⁶ Generally speaking, physicians are held in high esteem in South Africa and are usually trusted to have the interests of their patients, black and white, at heart. Ultimately, the South African parliament will decide on the issue of legislation, and the vast majority of its members are black.

9. If PAS and VAE were legalised, should decision-making authority be located in patients and their attending physicians, or in an ethics committee? The SALC's final report and Draft Bill² present two legalising options worthy of public debate and discussion. Option 2 (leaving decisions to patients and their attending physicians under strict guidelines) is unclear about the issues of a conscience clause for physicians, or the position of patients with mental and dementing illness.

Option 3 (the ethics committee approach) may, in the political process, turn out to be a viable compromise proposal between Option 1 (PAS and VAE remain unlawful) and Option 2. However, it introduces new difficulties. Firstly, who would constitute an ethics committee and how would it function? Who would elect or appoint the committee? Could someone who is in principle opposed to PAS/VAE serve on such a committee? How would decisions be taken, for example by majority vote or consensus? Secondly, shouldn't provision be made for appeal against the decision of an ethics committee? Thirdly, and most significantly, Option 3 raises issues of distributive justice. Since a committee approach is premised on the availability of additional resources, it could lead to discrimination against patients in areas with poor access to health care facilities. Ethics committees where membership must include, *inter alia* two physicians, a lawyer, and a member of a multidisciplinary team, are likely to be limited to tertiary and therefore urban centres, while rural areas may not have an 'ethics capacity'.

Option 2 is preferable to Option 3, since an ethics committee would be an unjustifiably cumbersome and paternalistic

institution that would take control away from the patient and physician and give it to a group of outsiders. Attending physicians can exert the same caution and circumspection as a committee, and together with patients, they would be able to focus on the tragic choices at hand while avoiding general debates about the morality of an already legalised practice, which may be the fate of an ethics committee approach.

In conclusion, although the subject of PAS and VAE is being debated internationally with increasing frequency, attempts to legislate assistance with dying evoke emotive responses, even from learned participants. Thus, well-known bioethicist Arthur Caplan refers to the Northern Territory's legislative effort as a 'whimper' from an 'obscure' part of the world, and likens it to 'euthanasia' practised by the Nazis.²⁷ In contrast, the internal South African debate, as well as the debate with international critics, should be civilised, focusing on substantive arguments. PAS and VAE can be defended strongly on moral grounds, as can legalising these practices. In South Africa there may be unique constitutional reasons for doing so.⁹

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