‘Aid-in-dying’ and the taking of human life

Courtney S Campbell  Oregon State University, USA

Author’s abstract

In several US states, the legalisation of euthanasia has become a question for voters to decide in public referenda. This democratic approach in politics is consistent with notions of personal autonomy in medicine, but the right of choice does not mean all choices are morally equal. A presumption against the taking of human life is embedded in the formative moral traditions of society; human life does not have absolute value, but we do and should impose a strict burden of justification for exceptions to the presumption, as exemplified by the moral criteria invoked to justify self-defence, capital punishment, or just war. These criteria can illuminate whether another exception should be carved out for doctor-assisted suicide or active euthanasia. It does not seem, in the United States at any rate, that all possible alternatives to affirm the control and dignity of the dying patient and to relieve pain and suffering, short of taking life, have been exhausted. Moreover, the procedural safeguards built into many proposals for legalised euthanasia would likely be undone by the sorry state of the US health care system, with its lack of universal access to care, chronic cost-containment ills, a litigious climate, and socioeconomic barriers to care. There remains, however, common ground in the quest for humane care of the dying.

No longer is the debate over the legalisation of doctor-assisted suicide and active euthanasia limited to the pages of ethics journals or the forums of scholarly conferences. The social policy debate over these issues crossed a significant threshold in the United States in November of 1991 when citizens of Washington State participated in an unprecedented public referendum on whether to amend their 1979 Natural Death Act to permit ‘aid-in-dying’, a ‘medical service provided in person by a physician, that will end the life of a conscious and mentally competent qualified patient in a dignified, painless and humane manner …’ (1). While the referendum failed by a 53 per cent – 47 per cent margin, proponents pointed to the over 700,000 votes cast in favour of the referendum as evidence of mounting public support for legal change, and have begun the process of bringing similar proposals before the voters of California in 1992 and Oregon in 1994.

Should doctor-assisted suicide or performance of active euthanasia on voluntary request be legally permitted? I want to examine the ethical and policy dimensions of this new threshold by drawing upon the moral criteria invoked in those situations in which society already allows for justified exceptions to the traditional rule prohibiting the taking of human life. We will then be positioned to ask whether a new exception to this rule should be carved out for the practices embedded in the concept of ‘aid-in-dying’. We need first to attend to some cultural and social factors that help explain why the religious, moral, professional, and policy debate over doctor-assisted suicide and voluntary euthanasia has emerged with such vigour in recent years.

The social nexus

We need first to recall that the practice and the term ‘euthanasia’ have a value-laden history. As several medical historians have indicated, for example, the prohibition of euthanasia in the Hippocratic Oath, ‘I will neither give a deadly drug to anybody if asked for it, nor will I make a suggestion to this effect’, presumes a background of acceptance and practice of administering ‘deadly drugs’ in the earliest western cultures of Greece and Rome (2). Moreover, the etymological root of euthanasia conveys a meaning of an ‘easy, painless, happy’ death, and it is with this meaning that the term first entered the English language in 1646 (3). It is this classically-informed meaning that contemporary proponents want to retrieve in their use of the language of ‘aid-in-dying’. A different terminology is required, however, because ‘euthanasia’ has acquired strong negative moral connotations over the last century owing to assumptions that such a ‘good death’ can be brought about only through violating religious, professional, and social prohibitions against killing. Embedded in these two diverse associations – the ‘classical’ and the ‘Nazi’ sense of euthanasia – is the cultural conundrum responsible for the emergence of ‘aid-in-dying’ as a question on the contemporary social policy agenda: we often seem to have foreclosed easy and painless deaths

Key words

Assisted suicide; euthanasia; respect for life.
short of resorting to some lethal action. Why is this the case?

This century has witnessed some very dramatic shifts in central cultural attitudes and practices regarding dying and death. A first shift concerns the gradual institutionalisation of dying and death. Even up to the early part of this century, most death occurred at home in the presence of one’s family members. Yet, as the historian, Philippe Aries, has suggested, a ‘displacement’ of death has occurred in our era from these earlier traditions (4), to the extent that 80 per cent – 85 per cent of the 2.2 million annual deaths in the US now occur in institutions, such as hospitals or nursing homes. Such settings are often experienced as impersonal and alienating to the dying person, for the caregiving role of the family may be taken over by those who know little more about the patient than a medical history, or through the use of technologies as the mediators of more specialised care.

A second important shift concerns the causes of death. Medicine has been enormously successful in eradicating the infectious and communicable ‘killer diseases’ responsible for the deaths of so many people in an earlier era – pneumonia, influenza, smallpox, tuberculosis, polio – which kept life-expectancy in developed nations at the beginning of this century at 47 years of age. One consequence of successful vaccines and antibiotics, of course, is an increase in current life-expectancy to over 75 years of age. Yet, while we now live longer, we also have more sickness and morbidity and the vast majority of people die from chronic and degenerative diseases that are debilitating over an extensive period of time. A perusal of the leading causes of death in the US in 1988 shows death from cardiovascular diseases at the top of the list (970,822 or 45 per cent), followed by cancer (485,468 or 22 per cent), cerebrovascular diseases (150,696 or 7 per cent), and (after accidents) chronic pulmonary and lung diseases (82,900 or 4 per cent) (5). That is, 76 per cent of the deaths were caused by chronic illnesses, and if such ailments as arterial diseases, diabetes, Alzheimer’s, and AIDS are added, the ratio of death by chronic conditions climbs to 84 per cent. In many of these cases, the diseases are diagnosed more than two years in advance of death. The points I wish to emphasise here are that the dying process is now, for most people, protracted and prolonged and that we know in advance this will be the case.

Moreover, we might make recourse to the many available technologies to stretch the dying process out even longer. The public images of what it means to die in a society obsessed with a technological conquest of death are familiar and deeply disturbing: the media portrays persons, sometimes elderly, sometimes younger, as oblivious to their surroundings, including the presence of family; pained facial expressions and distorted hand gestures; and omnipresent in the background, the machines, tubes, and technological monitoring that sustain bodily life. It is little wonder that such public images of modern dying have given rise to a very pronounced ‘populist’ reaction by patients and their families against the technological control of dying and death. Those voices have come to the fore in Washington State and elsewhere as a vociferous protest against a dying experienced as a demeaning, less-than-desired existence of a prolonged duration. We perhaps can find great meaning in Shakespeare’s words in King Lear: ‘Vex not his ghost/ Let him pass/He hates him that would upon the rack of this tough world/Stretch him out longer’ (6).

As a consequence of these cultural changes in the settings, the causes, and the technological management of dying and death, an important shift in attitude towards the relation of dying and death has transpired. The existential fear that most concerns us is now perhaps not so much the event of death, but rather the process of dying. Death is seen as liberation or freedom from the protracted agonies of dying. Moreover, we view the dying person as having lost control of his or her own dying – to strangers, to institutions, and to technologies.

Paradoxically, this experience of loss of control by patients has occurred precisely during the era that medicine, ethics, and the law have converged to place tremendous stress on respect for patient autonomy and self-determination. This ideology of patient control of end-of-life decisions has, of course, been the motivation for much of the political and legislative activity in the area of ‘advance directives’, ‘living wills’, and ‘durable power of attorney for health care’ statutes, which culminated in the United States in the passage of the Patient Self-Determination Act of 1990. This Act requires, as of December 1, 1991, all health-care facilities that receive federal funds to provide information about advance directives to patients on admission into the facility (7). This discrepancy between the ideology of personal control and the experience of loss of control can, in the view of some, be rectified only by recognising, a ‘fundamental right’ possessed by terminally ill patients to ensure control, the right to assistance in dying, in suicide, or to euthanasia.

To explain some of the cultural catalysts for public debate and referenda on ‘aid-in-dying’ does not, to be sure, suggest how either the ethical or the legal debate ought to be resolved. It does illuminate, however, several features to which any such discussion needs to be sensitive: a caring, supportive context for dying (such as is provided by hospices); a need of terminally ill patients to be free from protracted pain and suffering; and, an assertion of freedom and control over how, and when, and where one is to die. The question I now wish to engage is whether it is possible to express adequate sensitivity to these considerations, and affirm the dignity of the dying while relieving their pain and suffering, short of resorting to taking their lives. Can we, in other words, eliminate the conditions that cause prolonged suffering in dying without in the course of the process eliminating the person who suffers as well?
The presumption against taking human life

I have structured the preceding question in such a way as to reflect what I take to be the dominant perspective towards the taking of human life, whether by oneself or others, as conveyed in the religious, philosophical, professional, and legal traditions from which society gains its moral bearings. There is within all of these traditions both an affirmative responsibility for the protection, preservation, and promotion of human life, and a strong presumption against the taking of human life. In what ways might doctor-assisted suicide or voluntary euthanasia reflect or diverge from ethos? Let me propose a way of understanding this core presumption.

Within these formative traditions, human life, while valued, sanctified, and dignified, is seldom ever given the status of a moral absolute, that is, a value that admits of no exceptions. Instead, liberal political cultures have, in varying degrees, recognised three principal scenarios as valid exceptions to the prohibition of taking human life, namely, self-defence, capital punishment and just war. Implicit in each of these scenarios is what could be called a ‘defence paradigm’, in that there must first exist some attack or credible threat to individual persons, a community, or the society as a whole for the taking of human life to be warranted. Thus, in self-defence, an individual may legitimately thwart violent assaults on his or her person with proportionate force; in capital punishment, a community seeks to defend itself against internal threats to its stability and proper functioning, and in war, a society or state seeks to defend itself and its interests against actual or implied threats imposed by a foreign foe.

In any of these situations, however, a substantial burden of justification, of giving valid reasons for actions, before diverse audiences is required of the person or institutions that take life. Crossing the line to take life, whether the context be self-defence, punishment for heinous crimes, military aggression, or medical practice in the care of the terminally ill, unavoidably invokes the following kinds of questions:

(1) What or who is the source of authorisation for the taking of life?
(2) What is the purpose, cause, or objective for which life is taken?
(3) Have all alternatives to obtain this purpose, short of taking life, been exhausted?
(4) What outcomes can reasonably be anticipated to ensue from the taking of life?
(5) Will there be a favourable proportion between the anticipated benefits of taking life and the certain harms of such an action?
(6) What safeguards will ensure that the taking of life is limited to those for whom it is intended?

Since all parties engaged in the debate over doctor-assisted suicide and voluntary, active euthanasia affirm the premise of the relative value of human life and the general presumption against taking human life, these questions embedded in the cultural ethos and explicated in its moral traditions can be used as a moral framework to assess proposals for legitimating such practices.

Authorisation

Who can justly authorise the taking of life in a medical context? The patient’s voluntary and informed request is of course a necessary condition of moral validity, based on rights to autonomy and self-determination; if any of these three elements are omitted, that is, if the request is not the patient’s, or is involuntary, or is uninformed, then the problem under consideration is an instance of involuntary euthanasia, for which there are few advocates in the public forum.

The Washington ballot referendum was not inattentive to such points; indeed, it was designed with safeguards to ensure that such procedural elements would be present in a patient choice for ‘aid-in-dying’. One may nevertheless dispute whether the procedural protections were in fact met by the proposal: unlike the de facto requirements in the Netherlands, for example, it did not stipulate that the patient’s request must be persistent and continual, nor did it require that the participating doctor be in an ongoing relationship with the patient, both of which requirements would seem crucial to assessing the moral authenticity of the patient’s request for assisted suicide or active euthanasia.

At the same time, moral attention must necessarily focus on the substance of the request and I would question whether patient self-determination is or should be the exclusive moral consideration in assessment of doctor-assisted suicide or active euthanasia. There are first of all issues regarding the scope of the right to self-determination: in the same way that Mill felt the principle of freedom did not permit alienating freedom through voluntary slavery (9), we can ask whether the right to self-determination encompasses the capacity to extinguish the determining self. Moreover, the general right of self-determination regarding the choice of the manner and time of one’s death is a right of non-interference against others, particularly the state; for that same reason, however, it cannot obligate any particular individual, let alone the entire medical profession, to assist a given patient in carrying out his or her desires. Doctors too have rights in health care, including rights not to become merely tools or instruments for someone else’s benefit. If the exercise of such a right depends on the discretion of others, or if the responsibility to meet such a request is, to use Mill’s language, an ‘imperfect duty’, then it is simply mistaken to call a request for assistance in suicide or for euthanasia a fundamental right. It is important to note, however, that though the American Medical Association has expressed strong objections to the full implications of ‘aid-in-dying’, surveys of doctors in many locales in the United States,
the United Kingdom, and Australia reveal that there is not a monolithic professional position on this question.

A final concern is that even though self-determination is a necessary condition for such a request to be morally valid, it should not be deemed sufficient. We need instead to distinguish between having a right and right conduct. Rather than assuming that the right of choice implies that all choices are morally equal, this distinction requires us to consider the other criteria of justification for taking human life.

**Cause or purpose**

In practices of caring for the dying, what moral purposes or ends might give support to the taking of human life? It is possible to differentiate morally permissible and impermissible reasons. For example, the restoration and affirmation of human dignity in dying is a valid and important objective in any programme of care for the terminally ill and certainly extends to efforts to give the person a sense of control over his or her own dying by promoting their decision-making capacity. Secondly, caregivers are rightly concerned with the pain and suffering of the terminally ill and how they can best express the virtues of care and compassion, that is, to suffer with another.

At the same time, proposals for doctor-assisted suicide or active euthanasia that appeal to efficiency or cost-effectiveness seem callous and morally indefensible. In a recent commentary in the *American Medical News*, doctor John Wrable, after relating that in the preceding six months three terminal cancer patients had asked him to terminate their lives, asserted: 'Active euthanasia is a realistic alternative to the extraordinary measures being used today to keep patients alive, and it's cost effective ... because it reduces the terminally ill patient's hospital stay and stops the use of expensive machines and drugs'. Wrable then calculated that 'strictly controlled' active euthanasia in ICU's would save $16,500/patient, and millions of dollars overall. 'With active euthanasia the cost of medical care of the terminally ill would drop precipitously' (10).

Still others have expressed strong objections to the 'social costs' of prolonging the life of a terminally ill patient relative to money and resources consumed that might be spent instead on education, housing for the homeless, or better general health care. On such accounts, the paramount reason for euthanasia is neither patient dignity nor relief of patient suffering, but saving money; not the patient's interests but those of society. That way of thinking exacts a moral price society and the healing professions cannot afford. Yet, given the chronic cost-containment crisis in American health care, it may not be surprising if overt economic defences of active euthanasia become commonplace in the United States.

**Last resort**

If we acknowledge that restoring patient control and alleviating patient pain and suffering are morally valid objectives in caring for terminally ill patients, we still need to ask whether all alternatives to obtain these objectives, short of taking life, have been exhausted. With respect to patient control, one legal alternative that needs to be a priority in patient and public education are relevant statutes for advance directives. For all the attention given to such legal mechanisms in the past fifteen years, only some 10 per cent – 15 per cent of eligible persons have signed advance directives in the United States. While the new Patient Self-Determination Act may assist this task, much more work is required to facilitate informed decision-making by patients and their families and to indicate that legal mechanisms are available that give them control over end-of-life decisions, as an alternate to being trapped by the terror of technology.

What of measures to alleviate the pain and suffering of patients? It is important to acknowledge that all sides in the debate over legalised euthanasia seem to agree that more effective pain therapy in the terminal stage would substantially lessen patient requests for assistance in dying or euthanasia. Yet, ongoing collaboration with caregivers, including discussions with doctors who perform active euthanasia in the Netherlands, have convinced me that the US at any rate has not fully depleted biomedical research alternatives for pain control. A consequence of the obsession with the technological conquest of death is the failure to make pain relief the primary goal in care of the dying, and a lessened priority to developing such methods in medical research.

In addition, stronger social support needs to be given to alternative settings or approaches, such as hospices, which assign a high priority to the relief of pain and suffering. Yet the hospice movement in the United States actually began to decline in the late 1980s. As well, the US ought to rethink its societal prohibition of heroin as a method of pain relief in light of the experience of Great Britain, which has used heroin for terminally ill cancer patients for several years without uncontrollable problems (11). Thus, current practices all seem to conspire to tell patients that dying means abandonment and that assisted suicide or euthanasia is the only resort that provides deliverance. My contention, by contrast, is that these various failures indicate there is not yet sufficient evidence that in caring for the dying, the US has reached the point at which doctor-assisted suicide or active euthanasia are the only resorts caregivers have to affirm patient dignity and control and alleviate patient pain and suffering.

**Outcomes**

If assisted suicide or euthanasia were a legal option for terminally ill patients, what results or consequences might reasonably be expected to ensue? For many opponents, the burden of the case against legalising such practices finally rests on the 'slippery slope' objection, namely, that even if isolated acts of doctor-assisted suicide or voluntary active euthanasia might be
Proportionality
The question of whether a practice of doctor-assisted suicide or voluntary euthanasia will produce a favourable balance between the benefits and harms of taking life needs to be addressed not simply to the merits of a particular legislative proposal, but also to whether such a proposal provides a more favourable balance than other alternative approaches. In this respect, proponents of legal change have overlooked how much flexibility already is built into our current legal structure. Such actions in general might currently be treated under homicide statutes, but as illustrated recently by the controversy in the state of Michigan over the participation of doctor Jack Kevorkian in the suicides of three non-terminal patients, there is considerable flexibility and discretion involved at every stage in the legal process, from prosecuting a case, to convicting a person (the 'temporary insanity' defence has been successfully used in some cases to excuse persons from responsibility for their actions), to sentencing, in which the motive of 'mercy' might be grounds for a reduced sentence or even clemency. Although Dr Kevorkian has been charged with violations of the law, he has neither been convicted nor sentenced (though after the latest episode in October 1991, his medical licence was suspended by the Michigan Board of Medicine. However, this decision is currently on appeal).

One might well contend that if the law is being flouted, either overtly or covertly, then there is little value in retaining the law. However, the issue here is one of a quite different magnitude than breaking a speed limit on the motorway. Taking human life, in any context, is a morally and existentially serious matter, and we want would-be mercy killers to understand in advance the gravity of their actions. Rather than espousing a fairly substantial change in the laws governing medical practice, society is better served, I maintain, by having a general, blanket prohibition of 'aid-in-dying'. This approach will symbolically affirm the social value of respect for human life and also serve as a form of deterrent. We can at the same time acknowledge the necessity for flexibility and discretion in individual cases that is already embedded in the law.

Limitations
Can the taking of life be limited to those persons for whom it is intended? In short, what assurances are there that individual acts of informed and voluntarily requested assistance in suicide or active euthanasia by terminally ill patients will not eventuate in a general practice of non-consensual taking of life of the permanently comatose, persons with dementia, the seriously but not terminally ill, or of other classes of vulnerable and voiceless persons?

These concerns, on some accounts, can perhaps be met with very stringent procedural criteria and careful monitoring to preclude abuses; indeed, the public debate in the United States often portrays the de facto toleration of euthanasia in the Netherlands as an example of how public and fairly specific guidelines can facilitate a regulated practice of euthanasia. Recent empirical studies have, to be sure, raised some critical
questions about both the scope and the voluntariness of euthanasia in the Netherlands, with van der Maas et al observing that in 0.8 per cent of all deaths the strict criteria for euthanasia were not fulfilled (12).

Yet, even if the Netherlands presented an ideal ethical system, it seems mistaken to assume that such a system could be transposed to a culture such as the United States without substantial difficulties. The US does not have a system of universal coverage for health care, which as intimated earlier, will inevitably bring issues of cost-effectiveness into prominence in a decision about euthanasia. There is already an embedded litigiousness to medical practice in the US and the additional monitoring required to ensure that criteria for euthanasia were implemented would require more intrusions of the state and the law into medicine – to ensure voluntariness, a patient’s terminal condition, sufficient documentation, etc – than most medical professionals are typically willing to accommodate. The US is a vastly more heterogeneous society than the Netherlands and this expresses itself in economic, gender and racial disparities and discrimination. Finally, doctors and patients in the US typically do not have the close relationship of intimates that is characteristic of such relationships in the Netherlands. Thus, given the current underlying structural inadequacies of the US health care system, the idea that the Dutch system of disincentives, controls and safeguards would work in the US seems extremely dubious.

These structural failings also require us to ask whether the constructed safeguards and controls would adequately address a more subtle way in which ‘voluntary’ requests for assistance in dying may mask a more fundamental ‘involuntariness’. A kind of moral psychology can develop, as already reflected in the comments of some policymakers about a ‘duty to die’, in which what is discretionary can, through the force of common practice and habituation, become expected and almost obligatory. Given the inherently social dimension to our lives, it is important to ensure that requests for assistance in suicide or for active euthanasia are genuine expressions of individual self-determination, lest social expectations and pressures (for example, financial costs) diminish voluntariness.

Common ground

For the reasons I have articulated, I don’t think that recent proposals to legalise doctor-assisted suicide or voluntary, active euthanasia satisfactorily meet the burden of justification imposed by the six questions above. One could respond that such questions are simply generated by the wrong paradigm, that the language of ‘aid-in-dying’ signals one vital moral difference between assisted suicide or voluntary euthanasia and the kinds of situations – self-defence, capital punishment, just war – conventionally seen as justifiable exceptions to the rule prohibiting the taking of human life, namely, that in the medical context a person is voluntarily consenting to his or her own death. Whatever the appropriate moral paradigm for ‘aid-in-dying’, however, it needs to be acknowledged squarely that the contemplated actions do symbolise a departure from the traditional norms governing medicine, ethics, and law and therefore need assessment independently of refusals of life-sustaining medical treatment. Moreover, the questions I have identified are so central to our discourse about the taking of human life that it’s rather difficult to imagine a discussion of the issue without having at least implicit recourse to them.

It is important in conclusion, to emphasise the ground common to different perspectives in this debate. There is a great deal of consensus about the rights of competent patients both to choose and to decline medical treatment and about the need to protect incompetent patients. There is common ground on the importance of restoring control over dying to the patient and of alleviating patient pain and suffering, and that society needs to provide the resources such that caregivers can do a better job in both areas. There is general agreement that there are social, legal, and practical alternatives – advance directives, hospices, pain control – to assisted suicide and euthanasia that can obtain these objectives, so that even in ideal circumstances, the taking of life in medical practice must always be morally optional, not obligatory. There is a shared view that questions of social productivity or cost-effectiveness, which might well ground a notion of obligatory suicide or euthanasia, are not morally valid features for this particular debate. If our public discussion of euthanasia is not to be a dialogue of the deaf, we need to build on this common ground.

Courtney S Campbell, PhD, is Assistant Professor of Religious Studies in the Department of Religious Studies, Oregon State University, Corvallis, Oregon, USA.

References
(8) The questions articulated here are derived from the
criteria of the 'just-war' tradition, but my normative point is that similar questions and criteria emerge in any context where we contemplate making an exception or overriding a moral obligation or moral presumption, such as the rule prohibiting the taking of human life.


Guest editorial: The ethics of ignorance

(Continued from page 118)

sheer number and range of interventions, and the difficulty of conducting experiments. Indeed, chaos theory suggests that the complexity of health care may make it intrinsically unpredictable (10): we may never be able to know what we would like to know.

What can be done about our ignorance?

Our first priority must be to understand the extent of our ignorance and share it with the public, patients and policymakers. To some extent this is happening but mostly the urge to confess to limitations is driven by the fear of being sued. Litigation against doctors does seem to be a nemesis for what Ivan Illich called their hubris (11).

Charting our ignorance should also allow us to set research priorities: we should concentrate on researching what we most need to know. The setting of research priorities cannot, however, be driven entirely by the need to know because many things that we would like to know may at the moment be essentially unknowable – for example, an effective treatment for dementia would be wonderful but is unlikely to be forthcoming when our knowledge of brain function is so primitive. A more honest admission of ignorance might mean an increase in funding for research and technology assessment, and even if new money cannot be found it might make sense to shift resources from the provision of unproved services to research.

Those who fund research and publish its results may need to set higher standards, and everybody involved in health care and research should insist on evidence for statements and should focus on outcomes. There is already an increase in consensus statements and practice guidelines, but these need to be examined critically. Finally, there needs to be more analytical training in medicine: doctors need to be better at assessing the quality of the evidence on which they base their practices.

Richard Smith is editor of the British Medical Journal.

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