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The ethics of palliative care and euthanasia: exploring common values

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The ethical underpinnings of palliative care and those of voluntary euthanasia and assisted suicide (VE/AS) are often viewed as opposites. In this article, we review the values held in common by the euthanasia legalization movement and palliative care providers. Outlining this common ground serves to define, with greater clarity, the issues on which differences do exist, and ways in which some open questions, which are as yet unresolved, could be approached. Open discussion between VE/AS legalization advocates and palliative care providers is important to address these open questions seriously, and to enrich the care of terminally ill patients by giving members of both groups access to each other's experience. *Palliative Medicine* 2006; **20:** 107–112

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Introduction

Promoting palliative care and advocating the legalization of voluntary euthanasia and assisted suicide (VE/AS) are generally viewed as opposite causes for several reasons. Firstly, they can be viewed as alternatives in individual cases. Palliative management of suffering is trusted to substantially decrease the number of persistent requests for both euthanasia and physician-assisted suicide.[1–3] Secondly, they can be viewed as alternative responses to the problem of suffering at the end of life in general.[4–7] The WHO definition of palliative care specifies that palliative care 'intends neither to hasten or postpone death'.[8] Preventing VE/AS is one of the goals of palliative care.[9] Finally, these differences sometimes reflect the view that these two positions are fundamentally incompatible.[10,11] VE/AS legalization advocates and palliative care providers typically have an adversarial relationship to one another regarding the question of assisted death.[9,12,13]

This opposition between palliative care providers and VE/AS advocates is strong and persistent, and thus seems to rest on fundamental differences between the values fostered on either side. We will argue that this is not the case. These two positions do represent traditionally opposed currents of thought, but, at their root, reflect concern for many common values. Because of the rival traditions, it is unsurprising that discussion between these two groups has been difficult.[14] In this paper, we will identify the values held in common by both the palliative care and the VE/AS legalization movement. We will examine what elements of these common values seem to be understood in ways sufficiently different to account for the apparently irreducible opposition on the question of assisted death, and explore how some open questions, which are as yet unresolved, might be amenable to resolution.

Common values

The first value held in common is a focus on the importance of reducing human suffering.[8,9,15–22] The second value is the aversion for the technical medicalization of the end of life, and the concern that end-of-life care should not reduce human beings to the biological and neglect the dying human as a person.[8,18] The third value is a focus on the importance of control by the patient at the end of life.[10,15,16,18] Finally, both palliative care and the VE/AS legalization movements recognize that death is not always the worst thing that can happen. Something other than death itself is viewed as the 'worst evil' which should be averted. This includes the view that there is such a thing as a 'good death' and that it usually differs from dying in a highly technological environment (Table 1).[9,17]

These concerns seem to outline a common ground, but they leave scope for considerable variance in their application. We will go over each concern and examine the extent of agreement.

Reducing human suffering

Both traditions attach paramount importance to the alleviation of suffering at the end of life.[17,19–22] Both also recognize that there is more to suffering than physical pain. Palliative care teams include a multidisciplinary approach, targeting patients' 'total suffering' or 'total pain',[23] including such dimensions as physical,

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Table 1 Values held in common

(1) A focus on the importance of reducing human suffering, with a rejection of suffering as a positive redeeming value
(2) A concern that end-of-life care should not reduce human beings to the biological and result in neglect of the human patient as a complete person
(3) A focus on the importance of control by the patient at the end of life
(4) A recognition that something other than death itself is the 'worst evil' that should be averted, and a view that a 'good death' is possible

emotional, social and spiritual suffering. Suffering described as physical, psychological, and existential, has also been put forward by patients requesting euthanasia or assisted suicide, and recognized by VE/AS legalization movements. In one US study, physicians reported more willingness to perform assisted suicide when requests were based on existential suffering.[24] Acting on such a position is, however, controversial. In one Dutch case, a man received euthanasia on the grounds that he was 'tired of life'. The physician was found guilty on appeal, but the court, recognizing that he had acted out of great concern for his patient, imposed no punishment.[25] Although public support exists for VE/AS in the case of existential suffering,[26,27] the public's support for VE/AS is stronger in cases of intractable physical, as opposed to mental, suffering.[26] The difference between the two traditions is not in the stance towards suffering or in its definition. It is about whether any kind, or all kinds, of intractable suffering can indeed justify VE/AS.

Another point of agreement is the fact that much suffering can be alleviated, and that palliative care can decrease the number of persistent requests for VE/AS through the successful treatment of suffering. How much it can do so, however, is a point of disagreement even within the palliative care movement. Some defend the view that well conducted and universally available palliative care would eliminate virtually all persistent requests for assisted death.[13] Others hold that palliative care cannot address all types of suffering with the same high success rate,[9,28,29] or that some palliative interventions can cause discomfort which could be viewed by some patients as worse than the suffering it alleviated, making the evaluation of success highly personal.[17,30] Importantly, psychological, social, or existential suffering, such as depression, loss of community, autonomy, or meaning, seem to lie at the root of euthanasia requests more often than physical suffering.[31,32] That these situations are less amenable to palliative intervention than physical pain is clear to many palliative care providers.

Further disagreement focuses on the importance of those situations in which palliative care fails to alleviate suffering sufficiently to eliminate the request for VE/AS. Is the plight of those patients for whom palliative care fails to reach its goals important enough to justify the legalization of assisted death? Opponents argue that they are too few to merit such an intervention. Proponents argue that although they are few, the gravity of their plight suffices to justify further intervention. An argument used on both sides is that the legal status of VE/AS is a matter of political principle that warrants explicit legislation whatever the number of patients involved.

The effect of legalizing euthanasia on persons who do not request it is another point of disagreement. One view holds that such legislation would lead to an erosion of their trust in health care providers,[33] increase their discomfort and thus increase their suffering. They also fear that acceptance of euthanasia or assisted suicide would erode compassion towards the terminally ill.[29,34] The opposing view is that trust can be maintained, and indeed may be increased, by clarity regarding the parameters of legal VE/AS and strict and explicit respect of patient choices at the end of life. In addition, legalizing euthanasia or assisted suicide may lead to benefit from the knowledge that it is a personal option. Whether the legalisation of euthanasia erodes or promotes trust in caregivers is a question regarding which empirical data are lacking. One study exploring potential negative impact suggests that, in the public's view, it may be minimal.[35]

Finally, when a patient judges that their own quality of life is irretrievably bad, can they ever be said to be correct? McMahan,[36] and other authors, make a distinction between a life 'worth not living', where this assessment can be correct when made by the person themselves, and the phrase 'not worth living', which can include a claim that the assessment is 'objective' and independent of the view of the person living that life. It is important to note that neither palliative care providers nor euthanasia legalization advocates support this second type of assessment. It is on assessments of the first kind that they differ: on whether a person's own view that their life is 'worth not living' can ever be correct, VE/AS legalization advocates are committed to thinking that they can sometimes be right. This does not commit them to thinking that the person's life is ever 'not worth living', a very different concept that would imply that, if the person thought their life was worth living, they would be wrong. Palliative care providers, on the other hand, are less clear but sometimes seem to claim that patients who think that their life is irretrievably bad and 'worth not living' are always wrong. A patient may accurately judge their current quality of life to be unacceptable, but adequate care would always increase their quality of life to the point where they would reconsider. In addition, there is also fear that accepting such thoughts as legitimate, rather than simply understandable, could comfort an ideology that considers some lives as being

'not worth living', even if the person living this life sees value in it.

Not reducing patients to the biological

Both movements were founded with a concern that highly technological care at the end of life risked reducing terminally ill patients to their biological dimension, and that this could lead health care providers to lose sight of the whole person in their care. Here, the difference lies in the focus on what, exactly, is lost when human beings are seen merely as biological organisms. VE/AS legalization advocates focus on the importance of avoiding loss of control over one's life, up to and including the choice of seeking assisted death. Palliative care providers emphasize compassion, and the will to care for the whole human being. The importance of caring for the whole individual rather than for an organ is underlined, as is the importance of interactions between psychological and physical suffering. Indeed, they sometimes seem to suspect VE/AS legalization of 'coldness' – of focussing too narrowly on free choice, and showing insufficient empathy for the suffering of the terminally ill, and insufficient interest in the individual making this choice. This is denied by VE/AS legalization advocates, who reply that compassion lies at the root of their concern, and that assisting death requires an important emotional involvement.

Control by the patient at the end of life

The importance of being able to choose the circumstances of one's own death is central to both the palliative care movement and the VE/AS legalization movements. Disagreements focus on three points. The first is whether or not the scope of autonomy can include the right to choose assisted death.[1,9] Advocates of the legalization of VE/AS are committed to thinking that autonomy includes this right.[17,18] An alternative view, held by at least some palliative care providers, is that autonomy cannot include the right to choose assisted death, since death puts an end to autonomy itself.[1,9] Opposition to the idea that individuals should be free to choose assisted death in certain circumstances has strong historical roots in palliative care. This movement was initially based on religious values,[37] but seems to be undergoing a 'secular turn'.[9] A degree of tension seems to be appearing in palliative care regarding the concept that choosing death should not be in human hands.[9,38] Some palliative care providers have expressed support for euthanasia.[6,39,40] This could be a consequence of this evolution within the field. Currently, some palliative care providers, working in settings where assisted death is legal, extend respect for the patient's choice to supporting them up to assisted death, though some may refuse to administer lethal drugs or provide a lethal prescription themselves.[29] Despite opposition to the legalization of VE/AS, abandoning a patient does not seem to them to be an acceptable alternative.

The second point of contention is degree of decision-making capacity of terminal patients who request VE/AS. Many palliative care providers question that patients who request euthanasia really mean it, are sufficiently informed, and capable of weighing the options. It has been pointed out that confusion and depression are frequent symptoms in terminal disease,[29,41] that the wish to die may reflect a reaction to a crisis rather than an enduring choice, and that it has been shown to fluctuate.[42] Undue influence of economic circumstances, such as requests to die in order to avoid being a financial burden on loved ones, is also feared. VE/AS legalization advocates maintain that many patients are capable of making a valid choice. These positions are not incompatible, as each could be correct some of the time. It may indeed be difficult to tell in a given case whether the decision to choose death is sincere, informed, competent and voluntary. The importance of exploring a patient's decision-making capacity could thus be defended by both groups. In addition, both groups can agree that safeguards should be in place to ensure minimization of coercion or manipulation of decision-making.

Finally, there is disagreement on the likely effect of euthanasia legislation on freedom of choice. Palliative care providers fear that legalizing euthanasia will lead to undue pressure on the terminally ill to request it.[10,34] They also fear that it could lead to health care providers killing patients who have not requested it.[13,34,43] Euthanasia legalization advocates hold that appropriate rules of application would prevent both undue inducement of the terminally ill, and risks of a slippery slope. Data from the Netherlands,[27,44] have been interpreted in support of both positions.

View on the worst evil

The possibility of a 'good death' is an aim shared by both traditions. This is expressed as the promotion of a good death, and as help in valuing the time that is left in the case of palliative care,[9,45] and as the possibility of voluntarily opting out of a 'life worth not living' in the case of VE/AS legalization advocates.[36] These groups differ in their vision of the good death, however. The first group values acceptance of the spontaneous dying process, and an acceptance of the 'natural' life span,[29,46] while the second accepts the possibility for the patient to take steps to die sooner than would spontaneously have occurred, either by being given or by taking lethal medication. The view of chosen assisted death as a 'good death' is opposed by palliative care providers. In addition to concerns, such as acceptance of the 'natural' life span and the belief in the sanctity of life that may underlie it, some have expressed fear that

assisted death may come to be seen as commonplace, and cease to be viewed with appropriate gravity.

For both, the worst evil is a poor quality of life. For palliative care providers, however, the worst evil is a poor quality of life that is an obstacle to valuing the time that is left. For VE/AS legalization advocates it is the obligation of living on when quality of life is poor. A more subtle element of this difference is the value placed by palliative care on the spontaneous dying process, and on the 'natural' life span, a concept that seems to be implied by the WHO definition of palliative care.[8]

Open questions

In exploring the common values held by palliative care providers and VE/AS legalization advocates, we also found disagreement of various kinds. These open questions range between unsettled empirical matters, and possibly irreducible differences. These are recapitulated in Table 2, and categorized as empirical, normative, and strategic questions. There are overlaps between these categories. For example, the empirical questions regarding the population that would benefit or be placed at risk by the legalization of euthanasia have an impact on the normative question of the importance of the affected population. This point usually focuses on the small number of terminally ill who request euthanasia despite good palliation, but arguments on both sides appeal to larger circles. All terminally ill patients could be affected if the fear that legalizing euthanasia could unduly influence them turns out to be true. All people who may one day be in the position of thinking about euthanasia for themselves could be affected if knowing that they have this option makes their lives better. The normative question arises whatever the case may be, but it is difficult to imagine that the answer would not be shaped, in part, by answers to the related empirical questions.

While open empirical questions are amenable to research, or to case by case evaluation, the normative questions on which palliative care providers and euthanasia legalization advocates disagree may never find generally accepted answers. Both movements have ideological content and neither position reflects a general consensus in western societies. Among the normative questions we have raised, it seems that all could be defended as calling for an appropriate decision-making process centred on self-determined individual answers, were it not for the fact that self-determination itself is controversial in the specific case of chosen death. The question of whether self-determination can *ever* include the right to choose assisted death thus seems to be central

Table 2 Open questions

Empirical	Are patients who ask for VE/AS:	– really asking for VE/AS? – sufficiently informed about the alternatives? – capable of valid decision-making? – uncoerced?
	Does the legalization of VE/AS lead to:	– undue pressure to request VE/AS? – killing of patients in circumstances not intended by the legalization of VE/AS? – loss of trust in the health care system? – benefit from the knowledge that VE/AS is a personal option?
	What is the efficacy of palliative care:	– in the best circumstances? – in currently prevailing circumstances?
	Do VE/AS legalization advocates express sufficient compassion and pain for the suffering of individual patients?	
Normative	Does self-determination *ever* include:	– the right to choose assisted death? – the right to kill on demand by the patient?
	How weighty are the risks and benefits incurred by all persons who could benefit or be placed at risk from the possibility of legal VE/AS?	
	Is sufficient value present in every life to justify a prohibition of killing, even if the person whose life it is thinks not, and sincerely wishes to be killed?	
	Death	Is a good death one that expresses acceptance or choice? Which kinds of good death should people be allowed to pursue? Is death harmful in all circumstances?
	The 'natural life span'	Is there such a thing? Does respecting it trump personal choice and the harmfulness of suffering?
Strategic	Does the legalization of VE/AS:	– hinder the development of palliative care services? – decrease the motivation to provide good palliative care?

to the normative disagreements between palliative care providers and VE/AS legalization advocates. Other central themes are what degree of risk to other persons would justify limiting autonomous choices for assisted death, and whether a single exception would diminish the strength of the rule against killing in other cases.[16]

The least examined kind of question is the strategic kind. The two movements have traditionally viewed each other as adversaries. It is as though each feared that efforts expended in one direction would necessarily harm the other.[16,33] Several authors have argued that this may be mistaken.[47–49] In addition, considering these views as incompatible can translate into a fear that the mental space given to one view would necessarily be lost for the other. In such a context, it can be expected that palliative care providers who feel tolerant towards VE/AS could experience this as dangerous to their identity. Indeed, some reactions to the 2003 EACP position paper did express this uneasiness.[50] VE/AS legalization advocates, on the other hand, may find it difficult not to agree with requestors implicitly and to take sufficient care that other avenues have indeed been sufficiently tried. Clearing this misunderstanding is therefore important.[51]

A shared reflection?

There have been openings to a dialogue on the part of palliative care institutions. The 2003 position statement of the European Association of Palliative Care ethics task force call for 'the EAPC and its members to engage in direct and open dialogue with those within medicine and healthcare who promote euthanasia and physician-assisted suicide.'[16] Although it avoids the suggestion that palliative care providers could come to question their opposition to euthanasia, and endorses a 'them and us' situation, it does represent a step in the direction of shared reflection.

Such a shared reflection is important for four reasons. First, it is dangerous for VE/AS legalization advocates and palliative care providers to ignore each other's experience of end of life issues. Doing so would lead to oversimplification of the other's position,[52] and loss of a valuable exchange of experience. Second, failure to engage in a debate with the opposite side can lead to avoidance of the difficult questions posed by one's own position. Thus, it will fail to be enriched by appropriate questioning. Exploration of their common ground can lead both sides to more fully realize the extent of their own values. This, however, requires them to acknowledge their common ground. Third, the questions that remain open are important. Addressing them seriously can require considering the possibility of agreement with the other side. Finally, euthanasia legalization advocates and palliative care providers share an interest in fostering educated public discussion of end of life issues. In an environment where public discussions of end of life cases have tended to the spectacular rather than to public thoughtfulness, they may turn out to be necessary, if paradoxical, allies in keeping the important nuances of quality terminal care on the public agenda.

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