The Euthanasia Debate

Palliative care on the 'slippery slope' towards euthanasia?

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Introduction

The response to our position paper¹ on palliative care and euthanasia – 55 commentaries, from 32 countries, in the March 2003 issue of *Palliative Medicine* – has been remarkable in its breadth and variety. Moreover, a most welcome 'side effect', as it were, is that many commentators also take the opportunity to provide important information about the development and recent state of palliative care services in their home country as well as giving an overview of the euthanasia debate, or lack of such, in their own context.

The reactions are as diverse as there are authors, one could say. Some think we have made a contribution at the conceptual level that will greatly help the debate worldwide as well as in their own country. Others see a contribution that is relevant to clinical practice (the paper 'will help our day-to-day practice', Malas, p. 150). Whilst a further group think our definitions simply mess things up. To illustrate, van der Wal values our contribution concerning concepts and clarity, saying that I am glad that the Task Force suggests, with regard to euthanasia, that the adjectives 'voluntary', 'active' and 'passive' should no longer be used ... The argumentation is valid. In the spoken and written word this will avoid many unnecessary misunderstandings' (p. 110). On the other hand, Billings is of the opinion that we have 'confused some important definitions and distinctions' (p. 105). While Hänninen states: 'I do not think that the Task Force's report brings anything new to the discussion' (p. 166). In other words, to him, we neither make things clearer nor more muddy! Interestingly, support comes both from those who favour the legalisation of euthanasia and from those who oppose that - as does attack and rejection of our stance.

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The EAPC Ethics Task Force's reply to critics

Since we cannot possibly do justice to all commentators by giving detailed feedback to each and every one, we have instead chosen to focus on eight particular issues, of which all or most are touched on by very many authors in one way or other since they all play a significant role in important portions of our paper (I–VIII).

I. An ethics task force with no ethical basis?

Several authors point to the fact that on some topics, we are quite brief and so they miss a more comprehensive treatment of these topics. Furthermore, particular topics that some would expect to see addressed in a paper like this are missing completely. To illustrate, Stiefel (p. 106) finds it remarkable that a document from an *ethics* task force avoids discussing the ethical basis of its own viewpoints and recommendations.

We did originally produce a much longer document that considers many topics in great detail. However, at our second meeting we realised that were we to go on being that thorough on all the important issues, further down the road there would be a book rather than an article – or at least a very long article indeed. We decided then to take the opposite direction, as it were: to aim instead for a very short paper that would also be more likely to be read by a wide audience.

And as far as ethics is concerned, we could be said to make use of what the philosopher John Rawls (1921–2002) coined 'the method of avoidance'. This method implies that one focuses on a moral goal presumably shared be all (or almost all) and avoids discussing particular, and occasionally fundamentally different and even conflicting, individual 'comprehensive moral doctrines' that would all, in some way or other, underpin that goal. Thus, we presupposed a kind of Rawlsian 'overlapping consensus' on the central goal, or goals, of palliative care. Also, there is good reason for this, since people working within palliative care who share its goals may have quite different ethical viewpoints. For example,

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II. The EAPC Ethics Task Force's position on euthanasia

Does the position paper, as some claim, represent a departure from, and weakening of, the official stance of the EAPC, as stated in the organisation's 1994 paper?³ Are we, as it were, 'soft on euthanasia'? This is of course a most crucial question.

If we start off by looking at the responses from commentators from within the palliative care movement who all oppose euthanasia, it is remarkable how they differ over this issue. Annette Welshman writes: 'As Vice President of the EAPC I warmly welcome and support the position paper of the Ethics Task Force.' (p. 122). Likewise, Dame Cicely Saunders, 'founder of the hospice movement'4 and a well-known critic of euthanasia since 1959,5 says of it: 'This careful presentation from the international Task Force gives a balanced and informed basis for discussion and I believe is true to the considered approach of the Palliative Care Movement as a whole', she also notes that, 'Where the provision of euthanasia or physician-assisted suicide is possible, the Task Force points out that these should not be the responsibility of palliative care.' (p. 102). This is exactly what we say in point 5 under 'Key issues'. So it is surprising, therefore, that a reader like Edenbrandt can claim, 'The view presented by the Task Force is an alarming departure from the clear stance against euthanasia taken by the authors of 1994. The Task Force's view is not opposed to euthanasia and physician-assisted suicide.' What is more, he also believes that if the EAPC were to adopt our paper as its official stance, that 'could force the medical associations out of the EAPC.' (p. 107) Furthermore, Hendin calls our position 'an unwise retreat' from the 1994 paper's 'unequivocal opposition to legalizing euthanasia.' (p. 178). In stark contrast to this, Currow thinks that our paper 'presents unequivocal conclusions' (p. 158).

Perhaps the contradictory reactions are mainly due to the fact that we offer some understanding towards those who defend euthanasia, and that this *in itself* is for some sufficient ground for saying that we have somehow fallen back from the EAPC's opposition to euthanasia. As far as our methodological tolerance here is concerned, we think Pereira's description aptly captures our approach: The euthanasia debate can be divisive. Opponents and proponents alike often make compelling and passionate arguments against or in support of euthanasia or physician-assisted suicide. The EAPC Task Force's views, rather than falling into the quagmire of 'right' versus

'wrong', are pragmatic, clear and appropriate.' (p. 167) So too Adler values the ways in which the paper 'presents arguments without subjective and emotional overtones.' (p. 170). Here one could add the view of Ganzini and Back, who find our 'updated version ... less shrill, more nuanced and flexible, and imbued with a substantial degree of humility' (p. 113).

But is it true that our position on euthanasia is watered down, as some put it, as compared with the 1994 paper? It seems that even the editors of *Palliative Medicine* think so, since they write that 'many regret the softening of stance against euthanasia' (p. 93). We would claim that this is incorrect. The argument is as follows.

First, we do (as pointed out above) say clearly in point 5 that euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care. Some do, however, take this to mean that we condone both practices, where legal, outside of the palliative care setting; that we think it acceptable to leave the job to others. But this interpretation is not very appropriate. On the contrary, in point 7 we list a total of six potential dangers of legalisation. We do not list any possible positive effects of legalisation (if there are such) - a fact some commentators say demonstrates a clear bias against legalisation. For example, Pogge, who himself favours the legalisation of euthanasia alongside the provision of optimal palliative care, clearly sees no. 7 as evidence that 'the Ethics Task Force opposes legalization (paragraph 7)' (p. 119).

Secondly, point 10 speaks of powerful alternatives to calls for legalisation. In other words, we mention what we think are elements that would work to bar a development towards legalisation.

Thirdly, we define nonvoluntary and involuntary medicalised killing as not euthansia but murder – something the 1994 paper does not. This is pretty strong language, and seldom employed in the literature, and can hardly be seen as reflecting a lax attitude. Indeed, the risk that physicians, eager to stamp out what they see as intolerable and degrading suffering, may be inclined to cross boundaries and murder patients is one of the dangers we think resides within the legalisation of euthanasia; cf., point 7 (v). In summary, then, our position on euthanasia should be quite clear.

III. The EAPC's current position on euthanasia

Even though the EAPC itself is also clear on the issue – as stated in its 1994 paper – not all of its collective members are. Netwerk Palliatieve zorg voor Terminale patienten Nederland (NPTN) does not take a stand and is thereby neutral and lets individual members decide for themselves. Societé Suisse de Médecine et de Soins Palliatifs (SSMSP) states that euthanasia and physician-assisted suicide 'should not be offered unless every patient in need has access to quality controlled palliative

care. '7,8 By implication, provided such access is available, the SSMSP actually condones euthanasia if that is a patient's preferred choice over good palliative care.

Furthermore, it has been shown that not all doctors and nurses working within palliative care oppose euthanasia.9

To the extent that the EAPC can live with these differences, it does practice some of the openness and tolerance called for in our paper.

IV. The definition of euthanasia

The most severe criticism of our definition of euthanasia comes from Randall, who thinks there are certain highly problematic assumptions inherent in the definition that 'require defence, if it can be provided.' (p. 116).

Now any proposed definition of any term faces the following, universal dilemma: it is either too wide or too narrow. The first problem means that even phenomena one would want to exclude fall within the scope of the definition. Thus, the definition carries with it counterintuitive, logical consequences. A too narrow definition, on the other hand, simply excludes too much and is therefore inappropriate. Striking the balance is, however, generally no easy task. A classic illustration of this 'toowide-or-too-narrow' dilemma is found in the dialogues of Plato (429–347 BC) in which Socrates (470–399 BC) attacks every definition put forward by the parties to the dialogue; like the various definitions of 'justice'. A quite amusing story is when Socrates asks an army general if he knows what courage is: to which the military man responds that of course he does. Yet, when Socrates is finished with him, the general is totally confused as to the meaning of the term courage (and walks away, feeling very dizzy!).

Some think our definition of euthanasia is too wide – e.g., Mori, who believes euthanasia is justified in the terminally ill only, and therefore that the definition should be limited accordingly (p. 117). Randall, however, claims it is too narrow, since, she observes, it 'assumes that the act of killing must be performed by a doctor. But why not a skilled technician, a nurse, a soldier on the battlefield, even an unemployed philosopher?' (p. 116).

First, in limiting the definition to physicians, we have 'gone Dutch', so to speak, since according to both Dutch medical practice and law only physicians may perform euthanasia; Ch. IV, Section 20.10 Now the idea that philosophers might perform euthanasia - i.e., those amongst them who see no ethical difference between killing and letting die – has been suggested before. 11 (But obviously certain medical skills are needed because the procedures may themselves fail. 12) Randall goes on to write: 'Indeed, some of the arguments against legalizing euthanasia are based on the premise that doctors in particular should not kill people.' That is of course true, but in only pointing out this, Randall bypasses the very important fact that in the Netherlands, it is exactly the other way round: most doctors and the Royal Dutch Medical Association (KNMG) insist that euthanasia should be performed by physicians only. (And Dutch nurses who have injected patients with lethal drugs have been given sentences.) Among the reasons given for this view, is the need for a trusting, preferably longstanding doctor-patient relationship before euthanasia is performed and that in this there are built in many safeguards having to do with proper medical judgement and advice. And contra the view Randall refers to, Dutch anaesthesiologist and well-known euthanasia advocate, Pieter Admiraal, holds: 'I regard [euthanasia] as sometimes morally right, as not only compatible with the properly understood duties and responsibilities of a doctor, but as an act sometimes required by them. To fail to practice voluntary euthanasia under some circumstances is to fail the patient.'13 In addition, an argument goes, one can easily imagine how fearful a patient would be, and how degrading it would be to many, to be referred to an outsider for euthanasia.

In euthanasia and assisted suicide, writes Billings, 'other methods may be used' than drugs. That is theoretically possible, but these - such as the 'plastic bag method' by which a person suffocates himself - are not methods a physician would use as a (trained) physician and are therefore not included in our doctorcentred definition. Even some eccentric physicians who have furnished patients with suicide machines (Kevorkian, Nitschke) used drugs that took the patient's life. 14

V. Research on euthanasia

We would like to emphasise that in reiterating the above standard arguments, we are certainly not saying that euthanasia is part of a doctor's duty. Our reasons for adopting the Dutch perspective lie elsewhere, and are twofold and empirical not ethical: first, the Netherlands is the only country in the world that has a quite long history of euthanasia practice (some 30 years). This makes it appropriate for the debate on euthanasia to, primarily, take place with a view to this history. Parties to the debate - academics, politicians, healthcare workers or members of the public – are therefore well advised to take as their point of departure the Dutch doctor-centred understanding of what euthanasia is, regardless of whether they agree or not with this understanding from an ethical point of view.

Secondly, a substantial portion of the relevant research on euthanasia and the lessons learned stem from the Netherlands. For reasons of international comparability. researchers in the field should, therefore, be careful to formulate questions about euthanasia - to be posed to physicians and nurses as well as to ordinary people – that are in accordance with the Dutch interpretation and not open to misunderstanding. 15,16

And last but not least, patients must be presented with a clear picture of what 'to euthanize' means when being interviewed about the topic. ¹⁷ Much is to be gained from clarity here, since today, in an international research perspective, we know next to nothing about attitudes towards euthanasia in the terminally ill. ¹⁸ It is telling that this kind of patient-centred research has yet to be carried out in the Netherlands.

VI. About medical murder and the killing of persons

Randall believes that in popular usage 'euthanasia' is mercy killing and claims that since we have not mentioned this motivation we assume the motivation is irrelevant to the definition. We do not, but the reason for not including *this particular* motivation is that it would limit the definition's scope in an unwanted way. It would fail to capture the fact that over the years in the Netherlands, respect for self-determination has become the ever more prominent motivation in doctors, as witnessed, for example, in leading court cases – not least in the Chabot case regarding physician-assisted suicide for mental suffering. ¹⁹

Randall further says that, 'By defining the killing of incompetent patients as 'murder', the Task Force has assumed that such killing is necessarily wrongful. But when such killing is an act of mercy some people may regard it as justifiable.' This was indeed the justification for the killing of minors (including 'hopeless idiots') that took place at the German so-called 'euthanasia clinics' – which were in reality nothing less than murder clinics, however compassionately the medical murders may have been carried out. To quote Illhardt: 'NS [National Socialism] committed 'murder' not 'euthanasia' – this document of the EAPC [Ethics Task Force] highlights the fundamental difference' (p. 130).

A fundamental problem with Randall's criticism, though, is that she only mentions incompetent patients, thereby leaving out what we stress, namely that there is such a thing as the medicalised killing of competent individuals as well. In the Netherlands there were 145 such cases in 1990, and one of the reasons given by doctors for their actions was that discussing the issue of euthanasia with the patient 'would have done more harm than good'. 20 In other words, asking some patients whether they might consider euthanasia was judged by these doctors to be worse than murdering them. We do not think that such actions by physicians are justifiable. And as van der Wal noted 10 years ago, if one accepts anything other than euthanasia – by which he means, as we do, voluntary medicalised killing - in principle it will never be possible to draw a clear dividing line between what he calls 'unrequested and unwanted termination of life.'21 The Netherlands has also seen court cases in which physicians have been convicted for murdering patients.²²

Another problem, according to Randall, is that we do not mention the relevant clinical condition and therefore our definition of euthanasia would include 'the killing of people who are not ill but simply weary of life', and that, 'According to the Task Force, the person killed is not necessarily the doctor's patient, but simply 'a person' (who may not be the doctor's patient and therefore not in a relationship of trust with the doctor). The definition assumes that a doctor killing any person at that person's request is euthanasia!' Notwithstanding Randall's curious view that in the modern world the doctor-patient relationship is unproblematically one of 'trust', it is true that our definition would cover a situation in which a doctor kills a person who is tired of living due to, say, old age, physical deterioration, loneliness and dependency. Such a person is not a patient in the sense implied by Randall; hence, our use of the word 'person' rather than 'patient'. Nearly a third of all Dutch doctors hold physician-assisted suicide to be legitimate in very old people who are tired of living.²³ Congruent with this view, when the new Dutch law was debated and enacted in Parliament, the (now former) Health Minister stated that suicide pills should be distributed among the elderly.²⁴ Technically speaking, a person tired of life who sees a doctor to obtain suicide pills, or to get euthanasia, thereby becomes that particular doctor's patient. Consequently, there is a doctor-patient relationship of some kind. Recently, there was also the case of Mr Brongersma, who was tired of life and was assisted in his suicide by his GP Dr Sutorius.²⁵

VII. On futility and potentially life-sustaining treatment

Several authors make remarks about the concept of futility, since the notion of futile treatment is part of our understanding of what euthanasia is not. Billings claims that this concept 'has largely been abandoned as a useful construct.' (p. 104). We would disagree.²⁶ Although occasionally very problematic, the concept is still meaningful. There is a general misconception that a demarcation problem in a concept is by itself something that works to drain that concept of meaning. But this does not follow. Already Aristotle (384-322 BC), a very strong believer in an absolute dividing line between the species of the natural world, acknowledged that there are nevertheless transitional life forms that are hard to categorise (the flying fish being one obvious example). We often make use of concepts the exact meaning of which can be dubious when the concept is scrutinised. Yet the concept can, in general, and in most instances, be sufficiently meaningful. Think only of the concept of 'quality of life' - deeply problematic conceptually, and yet central to the whole philosophy of palliative care.²⁷ As for the concept of futility, there are situations in which medical treatment is undoubtedly futile; to be sure, initiating treatment in such a situation may even amount to overtreatment,

which could also harm the patient. Refraining from overtreatment in a patient is both medically and ethically justified.

Billings goes on: 'More importantly, we recognize the right of patients to refuse any treatment, regardless of whether it can be construed as futile. Withholding or withdrawing a potentially life-sustaining treatment at the wish of the patient is carefully distinguished from euthanasia or assisted suicide.' Now such withholding and withdrawing is implied when we refer to, but reject as a contradiction in terms, the much used notion of 'passive euthanasia'. Apart from that, it is not as clear as Billings would have it that these may not sometimes be forms of euthanasia – although not in our definition. As Rachels has effectively shown, one can kill people through inaction (omission). 28 What matters is intention. The basic question being: what if a physician intends a patient's death through withholding or withdrawing a potentially life-sustaining treatment?²⁹ On this question, see also the commentary by Altisent (p. 132). At the same time, Maltoni observes that our definition does not take into account whether a 'deliberate interruption of life support may be a form of euthanasia.' (p. 139). Yet in identifying the administration of drugs as one of the defining characteristics of euthanasia, we do rule this out; but we do not thereby deny that it may sometimes be viewed as killing.

In their final commentary, in which they sum up the discussion on our paper, Campbell and Huxtable write that, 'the act/omission (or active/passive) distinction is by no means as straightforward as the Task Force implies' (pp. 180-81). The above explanations should suffice to show that we imply no such thing. The point is that the taking of life through omission, which excludes the injection of drugs, would fall outside the scope of euthanasia as here defined.

VIII. The concept of autonomy

Autonomy is something that is not explained by us in the paper. Yet it plays a crucial role when we state that, 'Respect for autonomy is an important goal of palliative care, which seeks to strengthen and restore autonomy and not to destroy it.' Randall, in quoting us on this, concludes that, 'This position clearly suggests complying with patients' request for euthanasia.' (p. 116). But hers is a straw man's argument since she stops short of quoting the words 'and not to destroy it'. If she had done so, her conclusion would not follow. Let us take a brief look at why not.

Etymologically, autonomy is a word that originates from the Greek, auto = self and nomos = law; self-legislation. Few will deny that among modern thinkers, Immanuel Kant (1724-1804) deserves to be called 'autonomy's father'. Now literally speaking, euthanasia and physician-assisted suicide will damage autonomy in the most fundamental sense by eradicating the very possibility of future autonomous acting as such, and this is what we mean when we refer to the destruction of autonomy. In his remarks on suicide, Kant held the idea that autonomy may entail its own destruction to be selfcontradictory and thus against reason - thereby being immoral as well.³⁰

Billings is provoked by our remarks about the destruction of autonomy, which he finds 'biased and inflammatory' (p. 104). Be that as it may, nevertheless our position here has firm roots in the Western liberal tradition that has been, and still is, of utmost importance to the theory and practice of human rights - not least to the notion of an inalienable right to life.³¹

Acknowledgements and final remarks

We thank all those who took the time to respond to our paper. The commentaries are forceful and thought provoking, and written within very tight time and space limits. Also, the editors of Palliative Medicine have done a tremendous job, within a short time indeed, in facilitating this very timely discussion. We now look forward with interest to the response of the Board of the EAPC.

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