The EAPC Ethics Task Force on Palliative Care and Euthanasia

Lars Johan Materstvedt reports on the work of the EAPC Ethics Task Force on Palliative Care and Euthanasia and recent developments within Europe

In the first issue of the *European Journal of Palliative Care* (*EJPC*) in 1994, the European Association for Palliative Care (EAPC) published a paper stating its position on euthanasia.[1] In February 2001, the EAPC Board asked an expert group to form an Ethics Task Force to review the subject and advise the organisation accordingly. In the March 2003 issues of *Palliative Medicine* and the *EJPC,* the task force published a new paper on the subject.[2,3] In the same issue of *Palliative Medicine*, there are no fewer than 55 commentaries from 32 countries across the world, covering many varied and diverging views – both from within and from outside the palliative care community. That in itself serves to testify just how complex the topic is. The task force's reply to critics appeared in the July 2003 issue of *Palliative Medicine*.[4] Although the EAPC Board did not want to originally endorse the paper, since June 2003 the paper has been the Association's official position on the question of euthanasia and physician-assisted suicide (PAS).

Recent developments

The European perspective includes quite different laws on euthanasia and PAS, and most states uphold a ban[5] – despite the fact that in 2002, euthanasia and PAS were legalised in the Netherlands[6] and euthanasia was legalised in Belgium.[7] In 2003, the Council of Europe issued a controversial report on euthanasia in the light of Article 2 (which concerns 'right to life') of the European Convention on Human Rights.[8] In the UK, a House of Lords Select Committee recently reviewed the evidence[9] that has been submitted following a private bill on assisted dying for the terminally ill that would legalise both euthanasia and PAS, providing certain criteria were met.[10] In November 2005, an amended Bill was introduced to allow PAS only.[11] It is worth noting that in June 2005 the British Medical Association dropped its long-standing opposition to euthanasia and PAS, and adopted a neutral position.[12] There is mounting pressure towards legalisation in other European countries too. The EAPC position paper is therefore timely.

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The highly controversial nature of this subject often sparks debate due to the many different clinical, ethical, juridical, religious and cultural views

In addition to the English version, there is also a French, Italian, Hungarian, German, Greek and Finnish translation of the paper. We are hopeful that others will follow and direct anyone wishing to get involved to www.eapcnet.org/projects/ethics.asp, where the guidelines for translation can be found, as well as all the translations available for free.

Key points

- Since June 2003, the EAPC Ethics Task Force paper has been the Association's official position on the question of euthanasia and physician-assisted suicide (PAS).
- The European perspective includes quite different laws on euthanasia and PAS, and most states uphold a ban.
- Even though euthanasia is one concept, there are many conflicting definitions of euthanasia.

Box 1. Task force members

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A 'mission impossible'?

How do you go about formulating a position paper on euthanasia and palliative care? In light of the highly controversial nature of the subject – which also occasionally sparks strong emotion – and the many different clinical, ethical, juridical, religious and cultural views, it seems like a 'mission impossible'.

Our group consisted of eight individuals: six physicians, one sociologist and one philosopher (see Box 1). This mix of people proved very useful. Obviously, clinicians, who are also researchers within palliative care, need to sit on such a committee. But equally, the issue cannot be seen solely from the viewpoint of clinicians and must also be seen from the point of view of society. As the issue also raises many fundamental ethical questions, the philosopher's 'tool box' of various ethical theories and concepts is needed to help analyse and structure the debate. The eight members of the group represented the UK, Norway, Germany, Spain, Switzerland and Sweden. This cultural diversity was also helpful in writing the paper, as it meant there was increased sensitivity towards the significant regional, national and cultural differences in the approach to, and organisation of, palliative care within Europe. These differences are also reflected in professional practice.[13]

The basic problem our group had to address was how to interpret 'euthanasia'

The first issue to be addressed was what the Board expected from the group. Clearly, they wanted a fresh look at the issue, as important developments had taken place since the publication of the 1994 paper. But what if, hypothetically, we were to produce a statement defending euthanasia? We conjectured, with good reason, that they would reject such a document. In any case, there was consensus within our group that we wanted to take a stand against legalisation. But the question remained: how strong should that standpoint be? Here there were diverging views. Some wanted quite a strong message to come across in this respect, whereas others aimed for a more lenient position. Nevertheless, we managed to agree on a 'diplomatic' version, avoiding strong language or playing on emotion. Many of the commentators, who are tired of the fruitless battle over euthanasia, approved of this approach. Others saw it as a sign of weakness and a move towards the euthanasia 'camp'. It seems fair to conclude that some Board members were somewhat sceptical of our liberal stance.

The basic problem our group had to address was how to interpret 'euthanasia'. Euthanasia stems from the Greek 'eu' = good, and 'thanatos' = death. Thus it means a good death. Accordingly, a patient dying peacefully from natural causes would be a case of euthanasia – meaning euthanasia is widespread throughout the world. In fact, it might mean most people's deaths are instances of euthanasia. But surely this is not what a position paper on euthanasia would be about. So what would it be about?

One concept, many definitions

The first point to note here is that even though euthanasia is one concept, there are many conflicting definitions of euthanasia.[14] Thus there is much debate over the definition. Owing to the different backgrounds of the task force members, it might have been expected that the definition of euthanasia would pose the most difficult obstacle of all and that the 'worst case scenario' would be that the group would be unable to agree, causing the work to come to a complete standstill before it had started. However, we managed to agree on a definition that is in line with the Dutch understanding of euthanasia – the hallmark of which is that only physicians carry out euthanasia; that euthanasia

is both voluntary and active by definition; and that it is performed by lethal injection. However, this does not mean that we agree with the Dutch practice of euthanasia. Yet we express great tolerance towards those who do, and indeed encourage an open and direct dialogue between proponents and opponents alike. Hence we make a clear distinction between what we think euthanasia should be conceived of from an empirical point of view and from an ethical point of view. Following the philosopher David Hume, it is one thing to say what something 'is' and quite another to say what this something also 'ought' to be; that is, we are referring here to the fundamental, analytical divide between facts and norms.

The Dutch interpretation of euthanasia is narrow, since non-voluntary (when patients are incompetent) and involuntary (when patients are competent and made no request to die) medicalised killing fall outside its scope. Furthermore, killing by omission, for example, intentionally causing the death of patients, without their request, by withdrawing medical treatment that is *not* futile but would have prolonged life, will not count as euthanasia. Some take this narrow definition to be ethically questionable since they argue that it conceals the fact that much more medicalised killing occurs in the Netherlands than is revealed by official euthanasia statistics.[15] All of this is debatable, but to define and discuss euthanasia, a line must be drawn somewhere. It is worth noting that our way of drawing lines and defining concepts is acclaimed both by the late Dame Cicely Saunders[16] and the leading Dutch euthanasia researcher Professor Gerrit van der Wal.[17]

Terminal sedation

The issue of terminal or palliative sedation in the imminently dying did prove to be difficult. There was much disagreement over the clinical and ethical aspects of this treatment strategy. At this point, our different cultural backgrounds certainly played a role. The discussion was long and exhausting. But it is important not to be discouraged when one faces such 'intellectual fatigue'. We were determined to find a solution. It is worth remembering that if the discussion is difficult, if a solution is found, it is likely to be well thought out. We are particularly pleased to note that Cicely Saunders remarked, 'The paragraph concerning "terminal" or "palliative" sedation is clear and many will be grateful for this as a reference in future debate'.[16]

Advice to prospective task forces

Finally, there are a few technical issues that are important to any task force. First, there is the question of the length of the paper. The complexities of almost any subject a task force is likely to deal with would suggest a long and comprehensive document. Indeed, there is the temptation to be very long. This should be resisted; otherwise, very few will read the document. Instead, a more detailed account can be provided, for example in a reply to critics – as we did; our response is much longer than the original paper.[3,4]

Second, although most correspondence between task force members will be by email, it is recommended that meetings take place. We had three meetings. At these, we used a laptop computer and projected text on to a screen, allowing us to formulate the paper together, word by word, sentence by sentence. The more complex and the more delicate the topic, the more important such a procedure will be.

The issue of terminal or palliative sedation in the imminently dying did prove to be difficult

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