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From the Netherlands

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Indeed, the paper is brief, carefully constructed and presented in clear and simple language. The revision, compared with 1994, has led to a much-improved position, in particular by leaving out the unequivocal stance against (the legalization of) euthanasia. It will give more room for fruitful debate and collaboration in research on end-of-life care, transversing national borders. However, I would still like to make a few remarks.

Although the Task Force is not responsible for the new WHO definition of palliative care (paragraph 3.1), I should like to comment on it, because this is of core importance in the position paper. It is very confusing to say that ‘palliative care intends neither to hasten or postpone death’, and also that ‘palliative care is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy’. Palliative care is either one or the other. This part of the definition devalues the concept of palliative care. I would agree with the first statement, but not with the second. Why, in the situation of the second statement, do we not simply use the (classic) term ‘symptomatic treatment’ (which, sometimes for decades, can or must be used in situations of ‘life-threatening illnesses’, such as multiple sclerosis, diabetes mellitus, dementia and also some types of cancer)? So we could reserve the term ‘palliative care’ for situations in which the patient is incurably ill and the treatment is no longer aimed at prolonging life.

I am glad that the Task Force suggests, with regard to euthanasia, that the adjectives ‘voluntary’, ‘active’ and ‘passive’ should no longer be used (paragraph 3.2). The argumentation is valid. In the spoken and written word this will avoid many unnecessary misunderstandings, which have been apparent in the Netherlands, where for the past two decades the same concepts have been used both for and against euthanasia.

I agree, to a certain extent, with the statements in paragraph four, for instance with paragraphs 4.1, 4.3 and 4.9 entirely, and parts of most of the other statements. However, I also have some criticisms. I will mention only a few points here.

The sentence in paragraph 4.2 that ‘Most of these studies (on euthanasia) however, suffer from significant methodological weaknesses, raising doubts about the evidence base’ is not supported by any cited evidence, is an unnecessary generalization and sounds rather gratuitous. I agree that well-conducted studies ‘may inform the wider debate’ and that ‘a more co-ordinated approach’ is desirable. For instance, in the Netherlands (and to a lesser extent in Belgium) robust empirical studies have been carried out in the past decade, and these have resulted in many publications, which have also been included in leading biomedical journals. The formulation of certain ‘potential’ risks in paragraph 4.7 clearly does not reflect the evidence from such studies and would perhaps have been omitted or couched differently. At least in the Netherlands there is, for example, no evidence whatsoever of pressure on vulnerable persons (i) (e.g., the number of cases of euthanasia among the elderly is relatively low) or of underdevelopment or devaluation of palliative care (ii) (yes, there is underdevelopment, but probably no more than in other countries, and the process of legalization has led to a revaluation of palliative care) or of an increase in the incidence of nonvoluntary and involuntary medicalized killing (iii) (this has not been found in consecutive measurements with a five-year interval). In the discussion of ‘slippery-slope’ it is crucial not to neglect empirical data, if available.

In paragraph 4.6, important comments are made about (the difference between) terminal sedation and euthanasia. Indeed, the intention is different and that is crucial. However, it must be realised that the outcome of terminal sedation is also death, be it not intended but foreseeable, unless artificial hydration and nutrition is administered (which in most cases is not indicated at the end-of-life). Moreover, the physician is also responsible for any foreseeable side effects. This is why, in the case of terminal sedation the (informed) wish or request of the patient is of major importance. Unfortunately, this has not been dealt with in the position paper.

Paragraph 10 is excellent, except for the last sentence, which is not very helpful for those of us who work in the Netherlands or Belgium, or who are not opposed to the legalization of euthanasia. An alternative ending, which would perhaps gain broader support, could be ‘whatever the attitude to (the legalization of) euthanasia, it should never be carried out if optimal palliative care is not provided’.

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