

A question of ethics

“The recent gathering of palliative care professionals at the EAPC congress in The Hague provided an excellent venue for cross-fertilisation of ideas. Arguably, an area in the field of palliative care that needs this type of exchange is that of ethics. The congress certainly did not lack opportunities to address ethical issues. Two of the nine plenary lectures were devoted to ethics. Cultural dependency of the ethics of palliative care and legalisation of euthanasia and physician-assisted suicide (PAS) were the topics covered.

As our hosts were keen to point out, the Netherlands should no longer be regarded as a country devoid of palliative care resources. Their long tradition of open debate of emotive issues, coupled with their well-known legislative policy regarding euthanasia and PAS, were considered by the organising committee an added bonus to the congress discussions.

While most of us will immediately recognise topics such as euthanasia and PAS as within the boundaries of ethics in end-of-life care, there is a significant risk that these ‘big’ ethical questions might completely overshadow ‘smaller’, but still relevant, clinical ethical dilemmas. As you know, the *European Journal of Palliative Care* has a long history of publishing very interesting articles on ethics and psychosocial issues. One recent issue carried two papers on euthanasia,^{1,2} one of them by the EAPC Ethics Task Force. In this issue, André Vagnair and Roland Forster focus on a ‘small’ dilemma frequently overlooked. Their paper is provocatively titled, ‘A room for dying in: patient’s need or nurse’s fantasy?’ The study tries to understand the impact on quality of life of moving terminally ill patients around the rooms of an institution. The authors have been able to show that there is a wish in the nurses to offer patients progressively smaller rooms as death approaches. Interestingly, there was no policy in place in the institution at the time of the study, and there is no evidence that patient or family were consulted in the process.

Our Swiss colleagues have honestly and eloquently uncovered a new, relevant ethical

dilemma. I agree with the authors that we should be actively encouraging care given on the basis of thought that is more formalised and conscious than intuitive. I am sure that we must be overlooking other actions that have an effect on the quality of care we provide.

But the process of writing decision-making protocols for ethical considerations in palliative care is daunting and implies several steps. First we have to describe honestly our clinical practice as it stands today (it is easy to remember here the cry for ‘more facts’ at the beginning of the discussions on palliative/terminal sedation). Second, our practice should be analysed under the criteria of bioethics and described with an appropriate ‘ethics’ language. Third, we have to establish local clinical protocols that might guarantee excellence of care. Finally, discussions at a regional, national and international level (depending on the relevance of the topic) should be attempted in order to achieve consensus. By doing so we are building up the new *lex artis* – the ‘laws of art’ – that characterise our field of expertise. Some of us believe this to be an ethical imperative. There are also other gains to be considered when interacting with the judiciary or legislative powers. Unfortunately, no one is going to do this painstaking process for us. The ongoing debate on palliative/terminal sedation is a good example of this problem. At this point, consensus has been achieved at national levels in Europe with strong position papers endorsed by relevant bodies, but the time is perhaps not yet ripe for an international consensus.

In spite of these difficulties, let me invite all those of you who are interested to the ethics workshop at the next EAPC Research Forum, scheduled to be held in Stresa, Italy in June 2004. I am sure that together we will be able to start the approach to our ‘relevant’ ethical questions.

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References

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2. Núñez Olarte JM. Research on attitudes towards euthanasia in terminally ill patients. *EJPC* 2003; **10**(2): 68–71.

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