How should I know? Researching attitudes and practices around hastening death

The discussion on potential relationships between euthanasia, hastening death and palliative care has been going on since the invention and implementation of modern palliative care 40 years ago. The older position that palliative care is the antidote to the wish for hastened death has been refuted by proponents of the legalization of euthanasia in the Netherlands and Belgium, who have held against it that these countries have put considerable resources in the development of palliative care. Indeed, these countries have succeeded in ranking high in international comparisons of palliative care.1 In spite of the ongoing development of palliative care the frequency of requests for euthanasia and physician-assisted suicide have been unchanged in the Netherlands.2,3 The European Association for Palliative Care (EAPC) has defined its position in 2003 by saying that the provision of euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care.4 The EAPC paper did acknowledge that the issues around euthanasia and palliative care are receiving increasing attention in different European countries, and that active debate surrounding these issues is to be encouraged.

Against this background, the paper of Schildmann et al. on this issue5 is most interesting. It describes a survey of members of the German Association for Palliative Care (Deutsche Gesellschaft für Palliativmedizin [DGP]). General practitioners were surveyed in previous research,6,7 whereas this survey promises an insight into the palliative care community. The results are challenging. In 9 of 780 cases reported by the respondents, medications had been given by the physician to hasten the death of the patient. The participants also report that 47 of 353 patients were not involved in the end-of-life decisions, although they were competent to judge their situation and make a decision. The authors concluded that the palliative care physicians in this survey perform a broad spectrum of end-of-life practices, including hastening of death. They also concluded that the lack of inclusion of competent patients in end-of-life decision-making point to a paternalistic model of physician–patient relationship.

They state clearly that from an ethical perspective such practice runs contrary to the respect for autonomy of patients at the end of life. If this were a matter of fact, it certainly would indicate a dangerous imbalance between the ethics of autonomy and the ethics of care as core elements of palliative care.

However, the methodology of the study is open to criticism. The study used the questionnaire of the European End-of-life Decisions Consortium (EURELD), which has been challenged because of its ambiguous wording. Seale decided to re-word the key questions for his second survey in 2009, as the old version would overestimate the prevalence of certain end-of-life decisions.8 The EURELD questionnaire does not differentiate clearly whether the intent of the physician is to shorten life or whether the intent is to stop further prolongation of life in dying patients. Withdrawing or refraining from life-prolonging treatments that are not actually prolonging life but rather prolonging dying and suffering is an accepted part of end-of-life care. However, when we completed the questionnaire we found it difficult to answer the questions without being able to differentiate between these options.

The study plan had been discussed in the ethics work group of the DGP before the initiation of the study, and the work group had advised against the use of this questionnaire. However, the authors decided to use the questionnaire in spite of the drawbacks, as this would enable them to compare their results with other published studies using this questionnaire.

The authors do discuss the ambiguity of the wording of the questionnaire in the paper. However, they do not use the advantage thus gained and describe the comparable information from other studies using the EURELD questionnaire. In a comparison of six European countries and Australia the incidence of physicians administering drugs with the explicit intention of hastening death was particularly high in Belgium and the Netherlands, as was to be expected with regard to the legal situation in these countries, but was reported even in Denmark, the German-speaking part of Switzerland and Australia with an incidence between 7% and 14%, and thus much higher than the 1.2% of the survey of Schildmann et al.5 The German results
concerning this particular topic are also lower than the 7.4% of physicians that reported such intentions in a survey with medical practitioners in the UK.  

More seriously, the conclusions that the authors draw from their data do not seem to consider the drawbacks of the methodology. The data would also allow for different conclusions. We suggest that the data indicate that training in palliative care reduces the incidence of hastening death. Palliative care is accredited as a subspeciality in Germany, and physicians with this accreditation did indicate significantly less often the intent to hasten death with their interventions.

Similarly, the lack of involvement of competent patients in end-of-life decisions is also worthy of comments. This may well represent a paternalistic physician–patient relationship, as the authors have indicated. However, in our clinical experience we see patients who prefer such a relationship to the more autonomous one of shared decision-making. Asked for a choice or preference between treatment options they respond with ‘how should I know, you are the doctor, just do what is necessary and best’. The questionnaire did not assess what kind of model the patients preferred, and more research on the physician–patient relationship would be needed to answer this question.

Even if the conclusions of the authors are to be accepted, this would not mean that the normative statements of the DGP or the EAPC would have to be revised.

Schildmann et al. have completed a valuable first step with their interpretation of the data. If we do not ask, we will never know, and the discussion on issues surrounding euthanasia and hastening death has to be based on epidemiological data as well as on a discussion about current best practice. The discussion of the attitudes towards hastening death in palliative care professionals should not be a taboo, and thus their survey was well worthwhile. The authors have asked for their paper to be the starting point for further discourse, and we hope that we have contributed to that discussion.

References

Lukas Radbruch¹ and Friedemann Nauck²

¹President of the European Association for Palliative Medicine, Department of Palliative Medicine, University of Bonn, and Malteser Hospital Bonn/Rhein–Sieg, Germany; ²President of the German Association for Palliative Care, Department of Palliative Medicine, University of Göttingen, Germany

Corresponding author: Lukas Radbruch, Department of Palliative Medicine, University of Bonn, Sigmund-Freud-Strasse 25, Bonn 53127, Germany; Email: lukas.radbruch@malteser.org