There is more to end-of-life practices than euthanasia

Bregje Onwuteaka-Philipsen and colleagues (Sept 8, p 908)[1] focus mainly on euthanasia in their discussion of trends in end-of-life practices in the Netherlands. However, the sharp rise in prevalence of "intensified alleviation of symptoms" (24·7% in 2005 *vs* 36·4% in 2010) and "continuous deep sedation" before death (8·2% in 2005 *vs* 12·3% in 2010), warrants at least as much critical discussion.

Onwuteaka-Philipsen and colleagues suggest that these trends might be related to increased attention to palliative care. However, such a shift of attention is not necessarily associated with good quality end-of-life care. Instead, available evidence indicates that currently there is substantial heterogeneity with regard to the practice of palliative sedation.[2] Although there has been a call for policies as a means to reduce possible substandard care,[3] our systematic review of palliative sedation guidelines[4] suggests that this strategy has substantial limitations. The nine guidelines assessed in our review, including one from the Netherlands,[5] provide heterogeneous definitions of key concepts relevant to palliative sedation, such as "intolerable suffering" or "refractory symptoms". Additionally, there is remarkable variation regarding recommendations on the decision-making process and patients' involvement.

In light of the high prevalence of palliative sedation, the heterogeneity in clinical practice, and the limitations of current policies on this matter, we argue that narrowing down the end-of-life debate to euthanasia could have detrimental effects on the quality of end-of-life care relevant to a large number of patients.

We declare that we have no conflicts of interest.

*Jan Schildmann, Eva Schildmann
jan.schildmann@rub.de

Institute for Medical Ethics and History of Medicine, Ruhr-University Bochum, 44799 Bochum, Germany (JS); and Department of Haematology, Oncology and Tumour Immunology, HELIOS Klinikum Berlin-Buch, Berlin, Germany (ES)

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Authors' reply

We agree with Jan Schildmann and Eva Schildmann that the debate on end-of-life practices should not be limited to euthanasia. We also agree that increased attention to palliative care does not necessarily result in good quality end-of-life care. Our study[1] gives an insight into end-of-life decision making and end-of-life acts, but not into the quality of end-of-life care. Additionally, what good quality end-of-life care consists of is not that straightforward. This is certainly true for palliative sedation. Although there is an increasing body of published studies on this subject, there are controversies on terminology and ethical acceptability of the practice.[2] Guidelines are a way to try to overcome this and to improve quality of care. Yet there are many different guidelines—eg, at the institutional level and in different countries[3,4]—and the premises of national guidelines can be the subject of debate.[5] In our opinion, the role of empirical studies such as ours is to underpin the ongoing debate with information about what occurs in practice.

We declare that we have no conflicts of interest.