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Letter to the editor

End-of-life decisions in the United Kingdom

Clive Seale's recently published article on end-of-life decisions in the United Kingdom in 2007–2008 is presented as an update of earlier findings from a survey performed in 2004.[1] This 2004 survey used a questionnaire that was developed to study end-of-life decision-making practices in the Netherlands. Since 1990, it has been used in a series of follow-up studies in the Netherlands and other countries.[2–7] In his new study, Seale has reworded the key questions, 'to adjust for the potential of the original Dutch wording to overestimate the prevalence of certain end-of-life decisions'. This adaptation coincides with substantial lower rates of end-of-life decisions where hastening the end of life had not been the explicit intention of the physician as compared with 2004. Several aspects of Seale's article deserve further attention.

Seale's adaptation consists of separating three of the original seven key questions into different sub questions to distinguish acts and expectations about the consequences of these acts regarding hastening of the end of life. In the original questionnaire, acts and expectations were combined because using or forgoing treatment only involves an end-of-life decision when hastening of the end of life is an expected (or intended) effect. The four remaining questions about the physicians' intention with respect to hastening the end of life while performing these acts remained largely unchanged. Although the original questionnaire was designed to fully assess the potential impact of current medical decision making on the hastening of death, Seale's rewording seems to aim at assessing the frequency of those acts where physicians are willing to admit the potential life-shortening effect of their act in a separate question. The original wording was aimed at being broad; but the adapted wording seems to be aimed at being narrow. It should be noted that the original questions have extensively been validated not only in the 1990 and 1995 studies in the Netherlands but also in the 2001 study in six European countries. Validity was further enhanced by a guarantee of absolute anonymity for all respondents. Unfortunately, no mention is made in Seale's article of any effort to assess the validity of the new wording. Seale's conclusion that the new results more closely reflect the realities of UK end-of-life care because some of the misleading assumptions contained in the original questionnaire were removed is thus unsubstantiated.

The comparability of Seale's study with other studies is limited also because of the adaptation in the wording of key questions. All studies following the Dutch design used samples of death cases to estimate the occurrence of end-of-life decisions before death. The UK studies, in contrast, used samples of physicians, which introduces various sources of potential bias: first, physicians are asked to identify cases themselves, which may result in an overrepresentation of memorable or correct cases, and second, responding physicians may not be representative for all physicians, which is shown in Seale's study where physicians who did not reply partly felt that they did not have to because they did not normally attend dying patients. Moderate response rates in Seale's studies enhance this problem. Response rates in the studies following the Dutch design were substantially higher, which may partly be attributed to the endorsement of the studies by authoritative medical organisations.

The Dutch approach to studying end-of-life decision making is aimed at supporting caregivers in their efforts to provide careful, transparent end-of-life care, which enhances the quality of the last stage in life while fully taking into account medical, ethical and legal considerations. Even the 2007–2008 estimates in Clive Seale's study suggest that the impact of medical decision-making on dying is substantial in the United Kingdom, as it is elsewhere. Acknowledgement of this reality is very worthwhile.

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References

1 Seale, C. End-of-life decisions in the UK involving medical practitioners. *Palliat Med* 2009; **23**: 198–204.
2 van der Maas, PJ, Delden, JJM, Pijnenborg, L, Looman, CWN. Euthanasia and other medical decisions concerning the end of life. *Lancet* 1991; **338**: 669–674.
3 van der Maas, PJ, van der Waal, G, Haverkate, I, de Graaff, CLM, Kester, JGC, Onwuteaka-Philipsen, BD, *et al*. Euthanasia, physician-assisted suicide and other medical practices involving the end of life in the Netherlands, 1990–1995. *N Engl J Med* 1996; **335**: 1699–1705.
4 van der Heide, A, Deliens, L, Faisst, K, Nilstun, T, Norup, M, Paci, E, *et al*. EURELD consortium. End-of-life decision-making in six European countries: descriptive study. *Lancet* 2003; **362**: 345–350.
5 Onwuteaka-Philipsen, BD, van der Heide, A, Koper, D, Keij-Deerenberg, I, Rietjens, JAC, Rurup, ML, *et al*. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. *Lancet* 2003; **362**: 395–399.
6 van der Heide, A, Onwuteaka-Philipsen, BD, Rurup, ML, Buiting, HM, van Delden, JJM, Hanssen-de Wolf, JE, *et al*. End-of-life practices in the Netherlands under the Euthanasia Act. *N Engl J Med* 2007; **356**: 1957–1965.
7 Deliens, L, Mortier, F, Bilsen, J, Cosyns, M, Vander Stichele, R, Vanoverloop, J, *et al*. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. *Lancet* 2000; **356**: 1806–1811.