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Editorial

End-of-Life Decisions in The Netherlands, 1990–2001

Ad J.F.M. Kerkhof

Once again, new information on the practice of euthanasia and other end-of-life decisions in The Netherlands has become available—information that I think is worth sharing in light of the continuing worldwide debate on the topic. Results of a 2001 nationwide survey on the practices of medical end-of-life decisions—following on from identical surveys in 1990 and 1995—have recently been published (van der Wal, van der Heide, Onwuteaka-Philipsen, & van der Maas, 2003; Onwuteaka-Philipsen et al., 2003). These surveys allow us to monitor trends in these practices and particularly to evaluate the effects of legislation that passed the Dutch parliament in 2000 as well as the notification procedure that has been in place since 1998 (see our editorial in *Crisis* 2001, vol. 22, issue 1; Kerkhof & Connolly, 2001). The 2001 survey was carried out in exactly the same manner as those in 1990 and 1995, using 5,617 death certificates and 482 physician interviews. The methodological quality of the survey is undisputed. Here, I would like to summarize some of the most important findings.

Frequencies

In 2001 there were 140,000 deaths in The Netherlands. Dutch physicians in that year received 34,700 requests for euthanasia or assisted suicide later in the course of the disease, and 9,700 explicit requests for euthanasia or assisted suicide at a particular time. This demand had not increased since 1995. In 2001, in actual practice, 2.2–2.6% of all deaths involved euthanasia—the same percentage as in 1995 (2.3–2.4%). From 1990 to 1995, by contrast, there was a marked increase (from 1.7–1.9%).

In 2001, around 0.1–0.2% of all deaths involved physician-assisted suicide, slightly fewer than in 1995 (0.2–0.4%) or in 1990 (0.2–0.3%). The ending of life without the patient's explicit request occurred in 0.6–0.7% of all

deaths, this figure having remained more or less stable since 1995 (0.7%) and 1990 (0.8%). The frequency of physician-assisted suicide and the ending of life without the patient's explicit request has thus remained virtually unchanged throughout the years. The reduction of pain or other symptoms (while taking into account or appreciating that this may have a life-shortening effect) occurred in 18.8% of all deaths in 1990, in 19.1% in 1995, and in 20.1% in 2001 (Onwuteaka-Philipsen et al., 2003, p. 396).

Physician Involvement

Around 57% of all physicians have now performed euthanasia or assisted in suicide at some time during their working career, a figure not noticeably different from those obtained in 1995 (53%) or 1990 (54%). The proportion of physicians who were ever engaged in the ending of life without a patient's explicit request decreased from 27% in 1990 to 23% in 1995, and further to 13% in 2001 (Onwuteaka-Philipsen et al., 2003, p. 397). The unwillingness to ever do so increased from 45% of all physicians in 1995 to 71% in 2001. Physicians therefore seem to have become somewhat more reluctant in their attitude toward this practice.

Notification Procedures

The percentages of cases in which physicians adhered to the notification procedure increased from 18% in 1990 to 41% in 1995, and to 54% in 2001. Among general practitioners, the notification was properly done in 60% of cases (compared to 44% in 1995). This means that despite the legal obligation to do so, substantial numbers of physicians

still do not report their end-of-life practices as they should. Possible explanations may lie in a fear of prosecution, uncertainty about the procedure of the Regional Examination Committee, the wish not to be troubled by considerable extra work that follows notification, situations in which not all rules for careful handling were met (or could not be met) due to practical limitations, the opinion that euthanasia is something confidential between patient and physician, the wish of surviving relatives not to notify, and negative experiences with a previous notification. The number of consultations with colleagues has increased to around 75% of all cases. The introduction of a specialized team of professional consultants for physicians considering euthanasia or assisted suicide clearly increased physicians' willingness to conform to notification procedures.

Evaluation of Cases by the Regional Examination Committees (REC)

In 6% of all notified cases the REC asked the physician for more detailed written information. Apparently, in 94% of cases the information provided by the physician was deemed satisfactory. A standardized notification form (uniformity) was clearly helpful in this respect. In 0.9% of cases the physician was asked to provide more information by telephone, and in 0.5% to clarify things in person before the committee. In the period between November 1998 and January 2002, a total of 7 cases were considered to have been incorrectly handled (0.1% of all cases). The public prosecutor initiated prosecutions in two cases, one of which was dismissed, and the other of which was under investigation at the time of the survey. Physicians in general are satisfied with the 1998 notification procedure and the new bill of 2000. Their willingness to report has improved because of the new law, they say. The Dutch general public seems to be satisfied by the consequences of the new law as well.

Conclusions

The numbers of cases of euthanasia, assisted suicide, and ending of life without the patient's explicit request in The Netherlands have stabilized over the years 1995–2001. Physicians seem to have become more reluctant in their attitude toward ending life without the patient's explicit request. The notification procedure is increasingly being adhered to, though a substantial number of cases are still not being reported. Especially the ending of life without the patient's explicit request is seldom reported. Nonetheless, the care taken in medical end-of-life decisions has improved considerably. There is—once again—no proof for the slippery slope hypothesis.

The problem of ending life without the patient's explicit request is that these cases are very difficult to avoid. They bear a strong resemblance to cases of intensive alleviation of pain with probable life-shortening effects, as well as to cases of terminal sedation, in which the shortening of life is usually minimal, the patient is unconscious at the moment of the decision and had nearly always previously expressed his or her wish for euthanasia, and in most cases there were consultations with family members and medical colleagues. Clearly, the specifications in the law and in the notification procedure need to address these cases better.

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