

SELECTION from PubMed, July 2010
Made by John Willoughby, Australia

Arch Pediatr Adolesc Med. 2010 Jun;164(6):547-53.

Medical end-of-life decisions in children in Flanders, Belgium: a population-based postmortem survey.

Pousset G, Bilsen J, Cohen J, Chambaere K, Deliens L, Mortier F.

*End-of-Life Care Research Group, Vrije Universiteit Brussel, 1090 Brussels, Belgium.
geert.pousset@ugent.be*

OBJECTIVES: To estimate the prevalence of end-of-life decisions and to describe their characteristics and the preceding decision-making process in minors in Belgium.

DESIGN: Population-based postmortem anonymous physician survey.

SETTING: Flanders, Belgium.

PARTICIPANTS: All physicians signing the death certificates of all patients (N = 250) aged 1 to 17 years who died between June 2007 and November 2008 in Flanders, Belgium.

OUTCOME MEASURES: Prevalence and characteristics of end-of-life decisions and the preceding decision-making process.

RESULTS: For 165 of the 250 deaths, a physician questionnaire was returned (70.5%). In 36.4%, death was preceded by an end-of-life decision. Drugs were administered to alleviate pain and symptoms with a possible life-shortening effect in 18.2% of all deaths, nontreatment decisions were made in 10.3%, and lethal drugs without the patient's explicit request were used in 7.9%. No cases of euthanasia, ie, the use of drugs with the explicit intention to hasten death at the patient's explicit request, were reported. Poor clinical prospects (84.6%) and low quality of life expectations (61.5%) were important reasons for the physicians to engage in end-of-life decisions. Parents were involved in decision making in 85.2% of these decisions, patients in 15.4%.

CONCLUSIONS: Medical end-of-life decisions are frequent in minors in Flanders, Belgium. Whereas parents were involved in most end-of-life decisions, the patients themselves were involved much less frequently, even when the ending of their lives was intended. At the time of decision making, patients were often comatose or the physicians deemed them incompetent or too young to be involved.

Arch Dis Child. 2010 Jun 23. [Epub ahead of print]

Attitudes and practices of physicians regarding physician-assisted dying in minors.

*Pousset G, Mortier F, Bilsen J, Cohen J, Deliens L.
Bioethics Institute Ghent, Ghent University, Ghent, Belgium.*

OBJECTIVES: To investigate attitudes towards physician-assisted death in minors among all physicians involved in the treatment of children dying in Flanders, Belgium over an 18-month period, and how these are related to actual medical

end-of-life practices. Design Anonymous population-based postmortem physician survey. Setting Flanders, Belgium. Participants Physicians signing death certificates of all patients aged 1-17 years who died between June 2007 and November 2008. Main outcome measures Attitudes towards physician-assisted death in minors and actual end-of-life practices in the deaths concerned. Results 124 physicians for 70.5% of eligible cases (N=149) responded. 69% favour an extension of the Belgian law on euthanasia to include minors, 26.6% think this should be done by establishing clear age limits and 61% think parental consent is required before taking life-shortening decisions. Cluster analysis yielded a cluster (67.7% of physicians) accepting of, and a cluster (32.2% of physicians) reluctant towards physician-assisted death in minors. Controlling for physician specialty and patient characteristics, acceptant physicians were more likely to engage in practices with the intention of shortening a patient's life than were reluctant physicians.

CONCLUSIONS: A majority of surveyed Flemish physicians appear to accept physician-assisted dying in children under certain circumstances and favour an amendment to the euthanasia law to include minors. The approach favoured is one of assessing decision-making capacity rather than setting arbitrary age limits. These stances, and their connection with actual end-of-life practices, may encourage policy-makers to develop guidelines for medical end-of-life practices in minors that address specific challenges arising in this patient group.

Med Care. 2010 Jul;48(7):596-603.

The last phase of life: who requests and who receives euthanasia or physician-assisted suicide?

Onwuteaka-Philipsen BD, Rurup ML, Pasman HR, van der Heide A.

Department of Public and Occupational Health and EMGO Institute, VU University Medical Center, Amsterdam, The Netherlands.

b.philipsen@vumc.nl

BACKGROUND: When suffering becomes unbearable for patients they might request for euthanasia.

OBJECTIVE: To study which patients request for euthanasia and which requests actually resulted in euthanasia in relation with diagnosis, care setting at the end of life, and patient demographics.

DESIGN: A cross-sectional study covering all Dutch health care settings.

PARTICIPANTS: In 2005, of death certificates of deceased persons, a stratified sample was derived from the Netherlands central death registry. The attending physician received a written questionnaire (n = 6860; response 78%).

MEASUREMENTS: If deaths were reported to have been non-sudden, the attending physician filled in a 4-page questionnaire on end-of-life decision-making. Data regarding the deceased person's age, sex, marital status, and cause of death were derived from the death certificate.

RESULTS: Of patients whose death was non-sudden, 7% explicitly requested for euthanasia. In about two thirds, the request did not lead to euthanasia or physician-assisted suicide being performed, in 39% because the patient died before the request could be granted and in 38% because the physician thought the criteria for due care were not met. Factors positively associated with a patient requesting for euthanasia are (young) age, diagnosis (cancer, nervous system), place of death (home), and involvement of palliative teams and

psychiatrist in care. Diagnosis and place of death are also associated with requests resulting in euthanasia.

CONCLUSIONS: Only a minority of patients request euthanasia at the end of life and of these requests a majority is not granted. Careful decision-making is necessary in all requests for euthanasia.

Ned Tijdschr Geneesk. 2010;154(16):A1273.

[Advance euthanasia directives in dementia rarely carried out. Qualitative study in physicians and patients]

[Article in Dutch]

Rurup ML, Pasman HR, Onwuteaka-Philipsen BD.

VU Medisch Centrum, EMGO Instituut voor onderzoek naar gezondheid en zorg, afd. Sociale Geneeskunde, Amsterdam, The Netherlands. m.rurup@vumc.nl

OBJECTIVE: To study how advance euthanasia directives (AEDs) in dementia are viewed in practice in the Netherlands. **DESIGN:** Qualitative study.

METHOD: In-depth interviews on nine patients with the patients themselves and/or partners and their physicians. The patients were included from a cohort of people with an AED. All interviews were done in 2006. Cases were included with different diagnoses and at different stages of dementia.

RESULTS: Interviewed patients and their relatives had very high expectations of the feasibility of the AED. Interviewed physicians often thought of AEDs as aids in starting up a dialogue about medical decisions at the end of life, but they did not always do this in practice. Most physicians were open to adhering to AEDs in exceptional cases, on condition that the patient obviously suffered, and that communication with the patient to some extent was possible. In this study two cases were found in which adhering to the AED was seriously considered. In one case, fear of legal consequences was the only reason the physician had not adhered to the AED, while it seemed all the requirements of due care could be met. Euthanasia was not carried out in the other patient either. Several physicians mentioned the need for more detailed practical guidelines for the use of AEDs for dementia.

CONCLUSIONS: Patients had too high expectations of AEDs. It seemed that in exceptional cases the requirements for due care for euthanasia can be met in patients with dementia with an AED. It seems advisable that more detailed practical guidelines for the use of AEDs in cases of dementia be drawn up, as a first step to more clarity for patients and physicians.

Neurology. 2010 Apr 20;74(16):1303-9.

Sedation for the imminently dying: survey results from the AAN Ethics Section.

Russell JA, Williams MA, Drogan O.

Department of Neurology, Lahey Clinic, Burlington, MA 01805, USA. james.a.russell@lahey.org

OBJECTIVES: Sedation for the imminently dying (SFTID) is a controversial practice that involves the provision of sedation to imminently dying patients with the intent of relieving their suffering when symptoms are refractory to other interventions. The goal of this research was to ascertain the opinions regarding SFTID that are held by neurologists who are interested in ethics and end-of-life care.

METHODS: Members of the American Academy of Neurology Ethics Section were surveyed regarding their familiarity and experience with SFTID and their opinions pertaining to it. To determine whether their opinions varied in relationship to clinical context, a single stem question for 5 different case scenarios was used.

RESULTS: A total of 96% of respondents agreed or strongly agreed that the primary purpose of SFTID was to relieve suffering, 83% disagreed or strongly disagreed that SFTID was morally equivalent to euthanasia, and 85% disagreed or strongly disagreed that SFTID was legally equivalent to euthanasia. For the case scenarios, 92% agreed or strongly agreed that SFTID was acceptable for imminently dying patients with metastatic cancer, while 50% agreed or strongly agreed that SFTID was acceptable for patients with end-stage amyotrophic lateral sclerosis, and only 7% agreed or strongly agreed that SFTID was acceptable for posttraumatic quadriplegic patients not at risk for imminent death.

CONCLUSIONS: The overwhelming majority of neurologists surveyed endorse the concept that sedation for the imminently dying differs morally and legally from euthanasia and that it is an acceptable therapeutic option for some but not all patients who are imminently dying of a terminal illness.