

Euthanasia and physician-assisted suicide: a view from an EAPC Ethics Task Force

Lars Johan Materstvedt, David Clark, John Ellershaw, Reidun Førde, Anne-Marie Boeck Gravgaard, H Christof Müller-Busch, Josep Porta i Sales and Charles-Henri Rapin

Background

In 1991 a debate at the European Parliament on euthanasia stimulated discussion at all levels in Europe. Subsequently, the Board of Directors of the European Association for Palliative Care (EAPC) organized a working session together with two experts to help them clarify the position the organization should adopt towards euthanasia. The experts collaborated with the Board of Directors on a document and in 1994 the EAPC produced a first statement, *Regarding Euthanasia*, published in the official journal of the EAPC – the *European Journal of Palliative Care*.¹ In February 2001, the EAPC Board asked an expert group to form an Ethics Task Force to review the subject and advice the organization accordingly.

In the intervening years there have been major developments and achievements in the field of palliative care, as well as much discussion, some of it controversial, of euthanasia and physician-assisted suicide. There has also been new legislation in some countries.

It is important that the EAPC contributes to informed public debates on these issues, especially as European policy and law are becoming an increasing feature of modern life. To do so requires careful and continuing discussion. This is no straightforward task, as euthanasia and physician-assisted suicide are two of the most complex and challenging ethical issues in the field of healthcare today. This paper builds on current debates and develops a viewpoint from the palliative care perspective.

It may be noted that most patients receiving palliative care suffer from cancer. Across Europe, unfortunately only a small minority of terminally ill cancer patients has access to palliative care expertise. At the same time, some 86% of patients who die from euthanasia or physician-assisted suicide in the Netherlands also suffer from cancer.²

Address for correspondence: Lars Johan Materstvedt, PhD, Department of Philosophy, Faculty of Arts, Norwegian University of Science and Technology (NTNU), N-7491 Trondheim, Norway.
E-mail: lars.johan.materstvedt@medisin.ntnu.no

Reproduced with permission from the EAPC.

Historical trends and current situation

Around the world some important changes relating to euthanasia and physician-assisted suicide have been taking place. In 1996, for the first time in history, a democratic government enacted a law that made both euthanasia and physician-assisted suicide legal acts, under certain conditions – Rights of the Terminally Ill Amendment Act 1996, Northern Territory, Australia.³ The law was, however, made ineffective by an amendment made to the Northern Territory (Self-Government) Act 1978 of the Commonwealth by the Parliament of Australia in 1997.⁴ In the same year, physician-assisted suicide (but not euthanasia) was legalized according to the Oregon Death with Dignity Act.⁵ In April 2001, the Dutch parliament's Second Chamber made the necessary changes in the penal code to make both euthanasia and physician-assisted suicide legal under certain circumstances;^{6–8} this law took effect in April 2002.^{7,9} Shortly thereafter, Belgium followed suit; the Federal Parliament's House of Representatives voted in favour of legalizing euthanasia on 16 May 2002.¹⁰

Across Europe as a whole, however, we have seen little evidence in the last 10 years of concerted attempts to bring about the legalization of euthanasia through parliamentary processes. Indeed, in many European countries the legalization of euthanasia is opposed by a wide range of professional associations representing doctors, nurses and others, and also by palliative care organizations.

Concepts and definitions

This paper presents, in turn, definitions of 'palliative care', 'euthanasia' and 'physician-assisted suicide'. The first originated with the EAPC and was later taken up and developed by the World Health Organization (WHO); it captures some of the underlying norms and values of palliative care. The second and third say nothing about the norms and values associated with what is defined. When the expression 'killing on request' is used in connection with euthanasia this is a technical description of the act, based upon the procedure used –

usually an injection of a barbiturate to induce coma, followed by the injection of a neuromuscular relaxant to stop respiration causing the patient to die. Whether or not euthanasia may be *justified* killing on request is another matter, addressed below. A sharp distinction, therefore, exists here between what 'is' and what 'ought' to be.¹¹

Palliative care

Across Europe palliative care is an expanding and acknowledged part of healthcare. At the same time there are continuing debates over what palliative care includes and where it begins and ends (stage and type of disease, prognosis, care setting).^{12,13} Regional, national and cultural differences exist in the approach to and organization of palliative care. These different viewpoints are also reflected in professional practice.¹⁴

Nevertheless, one particular definition of palliative care has had a unifying impact on the palliative care movements and organizations of many European countries. In Spring 1989, the EAPC published a definition of palliative care in its first newsletter,¹⁵ which was endorsed by the WHO in its document *Cancer Pain Relief and Palliative Care*.¹⁶ More recently, a new, modified WHO definition has appeared:¹⁷

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications

Medicalized killing, withholding/withdrawing futile treatment and 'terminal sedation'

Many definitions of euthanasia and physician-assisted suicide have been formulated. None of the following should be seen as euthanasia within the definitions used here:

- withholding futile treatment;
- withdrawing futile treatment;
- 'terminal sedation' (the use of sedative medication to relieve intolerable suffering in the last days of life).

Medicalized killing of a person without the person's consent, whether nonvoluntary (where the person is unable to consent) or involuntary (against the person's will), is not euthanasia: it is murder. Hence, euthanasia can be voluntary only.^{18,19} Accordingly, the frequently used expression 'voluntary euthanasia' should be abandoned since it by logical implication, and incorrectly, suggests that there are forms of euthanasia that are not voluntary. In the literature, as well as in the public debate, a distinction is sometimes drawn between so-called 'active' and 'passive' euthanasia. It is our view that this distinction is inappropriate. On our interpretation, as well as according to the Dutch understanding,^{20,21} euthanasia is active by definition and so 'passive' euthanasia is a contradiction in terms – in other words, there can be no such thing.

Adoption of the following definitions is recommended.

Euthanasia is killing on request and is defined as

A doctor intentionally killing a person by the administration of drugs, at that person's voluntary and competent request.

Physician-assisted suicide is defined as

A doctor intentionally helping a person to commit suicide by providing drugs for self-administration, at that person's voluntary and competent request.

Key issues

It is the duty of EAPC to emphasize and promote the importance of caring for patients with life-limiting illness in accordance with the WHO (2002) definition of palliative care.¹⁷ Palliative care aims to prevent or reduce suffering and hopelessness at the end of life. Respect for autonomy is an important goal of palliative care, which seeks to strengthen and restore autonomy and not to destroy it. Access to high-quality palliative care must be promoted through national and international policies

that provide resources for a competent multidisciplinary palliative care workforce across Europe.

The Ethics Task Force takes the following position:

- 1) It is recognized that within Europe several approaches to euthanasia and physician-assisted suicide are emerging and active debate surrounding this is to be encouraged.
- 2) Studies of attitudes to euthanasia and physician-assisted suicide among professionals, patients and the wider public as well as studies of their experiences of these issues may inform the wider debate. Most of these studies however suffer from significant methodological weaknesses raising doubts about the evidence base. A more co-ordinated approach to these studies is recommended.
- 3) Individual requests for euthanasia and physician-assisted suicide are complex in origin and include personal, psychological, social, cultural, economic and demographic factors. Such requests require respect, careful attention, together with open and sensitive communication in the clinical setting.
- 4) Requests for euthanasia and physician-assisted suicide are often altered by the provision of comprehensive palliative care. Individuals requesting euthanasia or physician-assisted suicide should therefore have access to palliative care expertise.
- 5) The provision of euthanasia and physician-assisted suicide should not be part of the responsibility of palliative care.
- 6) 'Terminal' or 'palliative' sedation in those imminently dying must be distinguished from euthanasia. In terminal sedation the *intention* is to relieve intolerable suffering, the *procedure* is to use a sedating drug for symptom control and the successful *outcome* is the alleviation of distress. In euthanasia the *intention* is to kill the patient, the *procedure* is to administer a lethal drug and the successful *outcome* is immediate death. In palliative care mild sedation may be used therapeutically but in this situation it does not adversely affect the patient's conscious level or ability to communicate. The use of heavy sedation (which leads to the patient becoming unconscious) may sometimes be necessary to achieve identified therapeutic goals; however, the level of sedation must be reviewed on a regular basis and in general used only temporarily. It is important that the patient is regularly monitored and that artificial hydration and nutrition are initiated when clinically indicated.
- 7) If euthanasia is legalized in any society, then the potential exists for: (i) pressure on vulnerable persons; (ii) the underdevelopment or devaluation of palliative care; (iii) conflict between legal requirements and the personal and professional values of physicians and other healthcare professionals; (iv) widening of the clinical criteria to include other groups in society; (v) an increase in the incidence of nonvoluntary and involuntary medicalized killing; (vi) killing to become accepted within society.
- 8) Within the modern medical system patients may fear that life will be prolonged unnecessarily or end in unbearable distress. As a result euthanasia or physician-assisted suicide may appear as an option. An alternative is to take action through the use of 'living wills' and advance directives, contributing to improved communication and advanced care planning and thereby enhancing the autonomy of the patient.
- 9) The Ethics Task Force encourages the EAPC and its members to engage in direct and open dialogue with those within medicine and healthcare who promote euthanasia and physician-assisted suicide. Understanding and respect for alternative viewpoints is not the same as the ethical acceptance of either euthanasia or of physician-assisted suicide.
- 10) EAPC should respect individual choices for euthanasia and physician-assisted suicide, but it is important to refocus attention onto the responsibility of all societies to provide care for their elderly, dying and vulnerable citizens. A major component in achieving this is the establishment of palliative care within the mainstream healthcare systems of all European countries supported by appropriate finance, education and research. Realizing this goal is one of the most powerful alternatives to calls for the legalization of euthanasia and physician-assisted suicide.

The EAPC Ethics Task Force on Palliative Care and Euthanasia and its work

The Ethics Task Force met on three occasions: at the 7th EAPC Congress, Palermo, Italy (April 2001);²² at the Unit for Applied Clinical Research, Faculty of Medicine, Norwegian University of Science and Technology (NTNU), Trondheim, Norway (September 2001)²³ and at the Institut Universitaire Kurt Bösch, Sion, Switzerland (March 2002).²⁴

The working methods of the Ethics Task Force were as follows. A comprehensive literature review was undertaken and disseminated to the members by the secretary. Members of the task force group contributed individual written components and the consensus document was formulated and agreed at the three meetings. The document was presented to the EAPC Board in April 2002, after which some further revisions followed prior to publication. The document represents the views of the Ethics Task Force members and not of the EAPC.

During its work, the task force received two manuscripts from Nathan Cherny, MBBS, FRACP (Israel) and one from Henk ten Have, MD PhD (the Netherlands), which were most helpful. We thank both researchers for their important contribution.

We would also like to thank our hosts in Trondheim and in Sion for providing an excellent work environment.

The Ethics Task Force behind this paper had the following members (in alphabetical order after chair):

Lars Johan Materstvedt, PhD (Philosophy)
Chair & Secretary, Postdoctoral Research Fellow, The Norwegian Cancer Society, Oslo; Associate Professor, Department of Philosophy, Faculty of Arts, Norwegian University of Science and Technology (NTNU), Trondheim, Norway

David Clark, PhD (Sociology)
Professor of Medical Sociology, Division of Clinical Sciences (South), Section of Surgical and Anaesthetic Sciences, Academic Unit of Palliative Medicine, University of Sheffield and Associate Director, Trent Palliative Care Centre, Sheffield, UK

John Ellershaw, MA FRCP
Medical Director, Marie Curie Centre Liverpool; Consultant in Palliative Medicine/Honorary Senior Lecturer, Royal Liverpool University Hospitals, Liverpool, UK

Reidun Førde, MD PhD
Professor of Medical Ethics, University of Oslo; Head of the Council of Ethics, The Norwegian Medical Association, Oslo, Norway

Anne-Marie Boeck Gravgaard, MD
Specialist in Internal Medicine and Family Medicine, Vice President, SFPM, Swedish Association of Palliative Medicine, Helsingborgs Hospice, Helsingborg, Sweden

H Christof Müller-Busch, MD PhD
Priv. Doz. Ltd. Arzt Gemeinschaftskrankenhaus Havelhöhe; Abtlg. für Anästhesiologie, Palliativmedizin und Schmerztherapie, Berlin, Germany

Josep Porta i Sales, MD PhD, BA (Bioethics)
Consultant in Internal Medicine, Consultant in the Palliative Care Service, Institut Català d'Oncologia, L'Hospitalet L., Barcelona, Spain

Charles-Henri Rapin, MD PhD
Professor of Geriatrics, Médecin-chef de service, Policlinique de Gériatrie, Genève, Switzerland

References

- Roy DJ, Rapin C-H, the EAPC Board of Directors. Regarding euthanasia. *Eur J Palliat Care* 1994; **1**: 57–59. (Available in full text at: [http://www.eapcnet.org/download/Euthanasiastatement94\(E\).pdf](http://www.eapcnet.org/download/Euthanasiastatement94(E).pdf), accessed 24 January 2003)
- Haverkate I, Onwuteaka-Philipsen BD, van der Heide A, Kostense PJ, van der Wal G, van der Maas PJ. Refused and granted requests for euthanasia and assisted suicide in the Netherlands: interview study with structured questionnaire. *BMJ* 2000; **321**: 865–66. (Full text: <http://bmj.com/cgi/content/full/321/7265/865>, accessed 24 January 2003)
- Rights of the Terminally Ill Amendment Act 1996. (Full text of law: <http://www.nt.gov.au/lant/parliament/committees/rotti/rottiamentact96.pdf>, accessed 24 January 2003)
- Parliament of Australia. <http://www.aph.gov.au/>, accessed 24 January 2003.
- The Oregon Death with Dignity Act. Ballot measure no. 16. Oregon Revised Statute §127.800-127.897. (Full text of law: <http://www.ohd.hr.state.or.us/chs/pas/ors.htm>, accessed 24 January 2003)
- The Netherlands Department of Justice. Press Releases. http://www.minjust.nl:8080/c_actual/persber/index.htm, accessed 24 January 2003.
- The Netherlands Ministry of Foreign Affairs. Euthanasia Policy. http://www.minbuza.nl/default.asp?CMS_ITEM=MBZ257609, accessed 24 January 2003.
- Kimsma G, van Leeuwen E. The new Dutch law on legalizing physician-assisted death. *Cambridge Q Health Care Ethics* 2001; **10**: 445–50.
- International Task Force on Euthanasia and Assisted Suicide: Holland's euthanasia law. <http://www.internationaltaskforce.org/hollow.htm>, accessed 24 January 2003.
- Belgium legalizes euthanasia. BBC News, 16 May 2002. <http://news.bbc.co.uk/2/hi/europe/1991995.stm>, accessed 24 January 2003.
- Hume D. *A treatise of human nature*. Selby-Bigge LA ed. Oxford: Oxford University Press, 1958.
- ten Have H, Janssens R eds. *Palliative care in Europe: concepts and policies*. Amsterdam: IOS Press, 2001.
- ten Have H, Clark D eds. *The ethics of palliative care: European perspectives*. Facing death series. Oxford: Open University Press, 2002.
- Clark D, ten Have H, Janssens R. Common threads? Palliative care service developments in seven European countries. *Palliat Med* 2000; **14**: 479–90.
- The EAPC definition of palliative care. <http://www.eapcnet.org/about/definition.html>, accessed 24 January 2003.
- World Health Organization. Cancer pain relief and palliative care. Technical Report Series 804. Geneva, 1990. <http://www.who.int/dsa/cat98/can8.htm#Palliative%20Care>, accessed 24 January 2003.
- Sepúlveda C, Marlin A, Yoshida T, Ulrich A. Palliative care: the World Health Organization's global perspective. *J Pain Symp Manage* 2002; **24**: 91–96.

- 18 Materstvedt LJ, Kaasa S. Euthanasia and physician-assisted suicide in Scandinavia – with a conceptual suggestion regarding international research in relation to the phenomena. *Palliat Med* 2002; **16**: 17–32.
- 19 Griffiths J, Bood A, Weyers H. *Euthanasia and law in the Netherlands*. Amsterdam: Amsterdam University Press, 1998.
- 20 Kimsma GK. Euthanasia and euthanizing drugs in the Netherlands. In Battin MP, Lipman AG eds. *Drug use in assisted suicide and euthanasia*. New York: The Havorth Press, 1996: 193–210.
- 21 Kimsma GK, van Leeuwen E. Comparing two euthanasia protocols: the Free University of Amsterdam Academic Hospital and the Medical Center of Alkmaar. In Thomasma DC, Kimbrough-Kushner T, Kimsma GK, Ciesielski-Carlucci C eds. *Asking to die: inside the Dutch debate about euthanasia*. Dordrecht: Kluwer, 1998: 115–33.
- 22 Seventh EAPC Congress. <http://www.kenes.com/eapc/>, accessed 24 January 2003.
- 23 Norwegian University of Science and Technology (NTNU). <http://www.ntnu.no/indexe.php>
- 24 Institut Universitaire Kurt Bösch. <http://www.iukb.ch/>, accessed 24 January 2003.