

Continuous Sedation at the End of Life

Ethical, Clinical and Legal Perspectives

Edited by Sigrid Sterckx, Kasper Raus
and Freddy Mortier

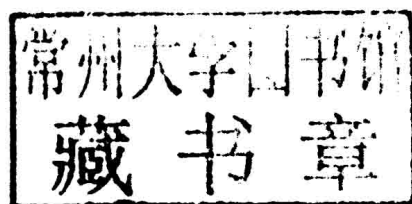


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Continuous Sedation at the End of Life

Continuous sedation until death (sometimes referred to as terminal sedation or palliative sedation) is an increasingly common practice in end-of-life care. However, it raises numerous medical, ethical, emotional and legal concerns, such as reducing or removing of consciousness (and thus potentially causing 'subjective death'), the withholding of artificial nutrition and hydration, the proportionality of the sedation to the symptoms, its adequacy in actually relieving symptoms rather than simply giving onlookers the impression that the patient is undergoing a painless 'natural' death, and the perception that it may be functionally equivalent to euthanasia.

This book brings together contributions from clinicians, ethicists, lawyers and social scientists, and discusses guidelines as well as clinical, emotional and legal aspects of the practice. The chapters shine a critical spotlight on areas of concern and on the validity of the justifications given for the practice, including in particular the doctrine of double effect.

SIGRID STERCKX is a professor of ethics at Ghent University and at the Vrije Universiteit Brussel (VUB) in Belgium.

KASPER RAUS is a postdoctoral researcher at Ghent University, Belgium.

FREDDY MORTIER is a professor of ethics at Ghent University, Belgium.

Cambridge Bioethics and Law

This series of books was founded by Cambridge University Press with Alexander McCall Smith as its first editor in 2003. It focuses on the law's complex and troubled relationship with medicine across both the developed and the developing world. Since the early 1990s, we have seen in many countries increasing resort to the courts by dissatisfied patients and a growing use of the courts to attempt to resolve intractable ethical dilemmas. At the same time, legislatures across the world have struggled to address the questions posed by both the successes and the failures of modern medicine, while international organisations such as the WHO and UNESCO now regularly address issues of medical law.

It follows that we would expect ethical and policy questions to be integral to the analysis of the legal issues discussed in this series. The series responds to the high profile of medical law in universities, in legal and medical practice, as well as in public and political affairs. We seek to reflect the evidence that many major health-related policy debates in the UK, Europe and the international community involve a strong medical law dimension. With that in mind, we seek to address how legal analysis might have a trans-jurisdictional and international relevance. Organ retention, embryonic stem cell research, physician assisted suicide and the allocation of resources to fund health care are but a few examples among many. The emphasis of this series is thus on matters of public concern and/or practical significance. We look for books that could make a difference to the development of medical law and enhance the role of medico-legal debate in policy circles. That is not to say that we lack interest in the important theoretical dimensions of the subject, but we aim to ensure that theoretical debate is grounded in the realities of how the law does and should interact with medicine and health care.

Series Editors

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A list of books in the series can be found at the end of this volume.

Contributors

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EVELIEN DELBEKE specialises in healthcare law in the broad sense of the word (e.g. medical liability, medical disciplinary rules, professional legal advice, bioethical regulations, patient rights, and the like). From 2006 to 2011, she worked as a doctoral researcher in the field of health law at the Faculty of Law of the University of Antwerp, Belgium. In 2011, she obtained the degree of Doctor of Law with a dissertation on the legal aspects of end-of-life care, in which she examined the legal aspects of the various medical end-of-life decisions (euthanasia, ending of life without request, assisted suicide, alleviation of pain and symptoms with a possible life-shortening effect, continuous deep sedation at the end of life, and the withholding or withdrawing of life-sustaining treatment). She compared Belgian law with the laws of The Netherlands, France, Luxembourg, Switzerland, the USA and the UK. She was awarded the prize André Prims for her work. Dr Delbeke is a frequently invited lecturer on these topics. Since 2012, she has been an attorney-at-law with Monard-D'Hulst, a law firm specialising in health law.

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Ethics Workbook (2010, Cambridge University Press). He is currently working on *All That Matters: Euthanasia*, which is due to be published in 2013. A long-standing participant in clinical ethics support, Richard is also a trustee of the National Council for Palliative Care, and Chair of its Ethics Forum.

DAVID ALBERT JONES is Director of the Anscombe Bioethics Centre in Oxford. He is also Research Fellow in Bioethics at Blackfriars Hall, Oxford and Visiting Professor in the Centre for Bioethics and Emerging Technologies, St Mary's University College, Twickenham. Professor Jones read Natural Sciences and Philosophy at Cambridge (1984–7), and Theology at Oxford (1992–2000). His book *The Soul of the Embryo* was short-listed for the Michael Ramsey Prize 2007. His doctorate was published in 2007 as *Approaching the End: a theological exploration of death and dying*. Professor Jones also contributed to *The Mental Capacity Act: A practical guide* and *A Practical Guide to The Spiritual Care of the Dying Person*. He is Vice-chair of the Ministry of Defence Research Ethics Committee, examiner for the Diploma in the Philosophy of Medicine run by the Society of Apothecaries, is on the National Reference Group of the Liverpool Care Pathway for the Dying Patient and was on a working party of the General Medical Council which helped draft its 2010 guidance on *Treatment and Care towards the End of Life*. His most recent book, co-edited with Calum MacKellar, is *Chimera's Children: Ethical, Philosophical and Religious Perspectives on Human-Nonhuman Experimentation*.

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JOSEP PORTA-SALES studied medicine at the University of Barcelona (1975–82). He specialised in Internal Medicine and trained in Palliative Care at St Christopher's Hospice (London). He obtained an MA in Palliative Care from the University of Barcelona (1998) and an MA in Bioethics from the Autonomous University of Barcelona (1999). Since 1987 he has been working as a palliative care consultant in various hospitals. Dr Porta-Sales is currently Head of Research and Teaching at the Palliative Care Service of the Catalan Institute of Oncology, and Senior Lecturer in Palliative Medicine at the International University of Catalonia. He has authored many national and international articles and textbooks. His main areas of interest and research are palliative sedation, opioids in cancer pain and the organisation of palliative care in acute hospitals.

TIMOTHY E. QUILL is a professor of medicine, psychiatry and medical humanities at the University of Rochester School of Medicine and Dentistry. He is also Director of the Palliative Care Program in the Department of Medicine. Dr Quill has published and lectured widely about various aspects of the doctor–patient relationship, with special focus on end-of-life decision-making, including delivering bad news, non-abandonment, discussing palliative care earlier and exploring last-resort options. He is the author of several books on end of life, including *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (2004), *Caring for Patients at the End of Life: Facing an Uncertain Future Together* (2001) and *A Midwife Through the Dying Process: Stories of Healing and Hard Choices at the End of Life* (1996), as well as numerous articles published in major medical journals. Dr Quill was the lead physician plaintiff in the New York State legal case challenging the law prohibiting physician-assisted death that was heard in 1997 by the US Supreme Court (*Vacco v. Quill*). Dr Quill received his undergraduate degree from Amherst College (1971), and his MD from the University of Rochester (1976). He completed his Internal Medicine residency in 1979 and a Fellowship

in Medicine/Psychiatry Liaison in 1981, both from the University of Rochester School of Medicine and Dentistry. Dr Quill is a Fellow in the American College of Physicians, an ABMS certified palliative care consultant, and the immediate past-President of the American Academy of Hospice and Palliative Medicine.

KASPER RAUS holds an MA in Philosophy (Ghent University, 2008) and a Ph.D. in Philosophy (Ghent University, 2013). His current research focuses on the ethical issues surrounding end-of-life decisions in general, and continuous sedation at the end of life in particular. He has published various articles on this topic in international journals. Together with researchers from the End-of-Life Care Research Group of the Vrije Universiteit Brussel he is involved in an international qualitative research study on the experiences and attitudes of physicians, nurses and relatives concerning continuous sedation at the end of life. Broader aspects, for example the possible justifications of sedation in end-of-life care, are also being addressed by this study. This research is being conducted by a multidisciplinary team of researchers in Belgium, The Netherlands and the UK.

JUDITH A.C. RIETJENS works as an assistant professor at the Department of Public Health of Erasmus Medical Centre, Erasmus University Rotterdam, The Netherlands, and as a part-time professor at the End-of-Life Care Research Group of Ghent University and Vrije Universiteit Brussel, Belgium. She is a health scientist by training and completed her Ph.D. on end-of-life decision-making in 2006. She is involved in several local, national and international studies concerning end-of-life decision-making. She was awarded a VENI grant (Innovative Research Incentives for Academic Excellence) and an EUR fellowship. She coordinates the UNBIASED study, an empirical and ethical evaluation of the practice of continuous sedation at the end of life in The Netherlands, Belgium and the UK. Her other research interests include different perspectives on end-of-life decision-making (e.g. international comparisons; comparisons of perspectives of patients, relatives and healthcare professionals) and media representations of end-of-life decisions. In 2010 she was a visiting researcher at the Department of Geriatrics of Yale School of Medicine, New Haven, USA. Judith was selected to participate in the Erasmus MC Female Career Development Program. In 2010, she was granted the Young Investigator Award (2nd prize) of the European Association of Palliative Care, and in 2012 the UNESCO/L'Oréal For Women in Science fellowship.

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SIGRID STERCKX is a professor of ethics at Ghent University and at the Vrije Universiteit Brussel (VUB) in Belgium. She lectures on courses in Theoretical Ethics, Methods in Ethics, Contemporary Continental Ethics, Global Ethics and Environmental Ethics. Her current research focuses on: ethical aspects of medical decisions at the end of life; ethical aspects of biobanking, organ transplantation and patenting of human body material (particularly genes and stem cells); ethical issues regarding human enhancement; patent law (especially in Europe and the USA); and environmental ethics and governance, focusing inter alia on climate change, global and intertemporal justice. Sigrid has (co-)authored numerous book chapters as well as journal articles. She serves on various advisory boards and commissions, including the Belgian Advisory Committee on Bioethics, and works as an ethics consultant for several EU research projects. She is also a member of the Steering Group for the UNBIASED study, an interview study exploring the perspectives of physicians, nurses and bereaved informal caregivers on the use of continuous sedation until death for cancer patients in the UK, The Netherlands and Belgium.

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Saunders, is often regarded as the birthplace of the hospice movement and the specialty of palliative care. It has both inpatient and community palliative care services, and looks after about 2,000 terminally ill people each year. Dr. Sykes' principal research interests concern gastrointestinal and end-of-life symptom management in palliative care, subjects on which he has written extensively. He is a past winner of the Evans Prize for Research in Palliative Medicine. He also teaches widely both in the UK and abroad. Previously a member of the Executive and Ethics committees of the Association of Palliative Medicine of Great Britain and Ireland, Dr. Sykes is currently a member of the Neurological Diseases Strategy Group of the UK National Council for Palliative Care. He set up the first clinical ethics committee to be located in a hospice and has spoken on television and radio, and made presentations to British parliamentary committees, on ethical issues relating to palliative care.

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Contents

| | |
|---|-----------------|
| <i>List of figures</i> | <i>page vii</i> |
| <i>Notes on contributors</i> | <i>viii</i> |
| <i>Acknowledgements</i> | <i>xvii</i> |
| 1 Introduction | 1 |
| SIGRID STERCKX, KASPER RAUS AND FREDDY MORTIER | |
| 2 Continuous sedation until death: state of the art | 29 |
| SOPHIE M. BRUINSMA, JUDITH A.C. RIETJENS AND AGNES VAN DER HEIDE | |
| 3 Death by equivocation: a manifold definition of terminal sedation | 47 |
| DAVID ALBERT JONES | |
| 4 Palliative sedation: clinical, pharmacological and practical aspects | 65 |
| JOSEP PORTA-SALES | |
| 5 Clinical aspects of palliative sedation | 86 |
| NIGEL P. SYKES | |
| 6 Understanding the role of nurses in the management of symptoms and distress in the last days of life | 100 |
| ELEANOR WILSON AND JANE SEYMOUR | |
| 7 Principle and practice for palliative sedation: gaps between the two | 116 |
| DAVID ORENTLICHER | |
| 8 The legal permissibility of continuous deep sedation at the end of life: a comparison of laws and a proposal | 132 |
| EVELIEN DELBEKE | |