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978-1-107-00756-7 - Physician-Assisted Death in Perspective: Assessing the Dutch Experience

Edited by Stuart J. Youngner and Gerrit K. Kimsma

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Physician-Assisted Death in Perspective

Assessing the Dutch Experience

This book is the first comprehensive report and analysis of the Dutch euthanasia experience over the last three decades. In contrast to most books about euthanasia, which are written by authors from countries where the practice is illegal and therefore practiced only secretly, this book analyzes empirical data and real-life clinical behavior. Its essays were written by the leading Dutch scholars and clinicians who shaped euthanasia policy and who have studied, evaluated, and helped regulate it. Some of them have themselves practiced euthanasia. The book will contribute to the world literature on physician-assisted death by providing a comprehensive examination of how euthanasia has been practiced and how it has evolved in one specific national and cultural context. It will greatly advance the understanding of euthanasia among both advocates and opponents of the practice.

Stuart J. Youngner, MD, is the Susan E. Watson Professor and Chair of the Department of Bioethics at Case Western Reserve University School of Medicine. Trained as a psychiatrist, Dr. Youngner is a nationally and internationally recognized scholar in biomedical ethics. He has published extensively on topics including end-of-life issues, organ transplantation, and the definition of death.

Gerrit K. Kimsma, MD, MPh, is a practicing physician and philosopher and co-founder of the Department of Metamedicine at the Vrije Universiteit in Amsterdam. His present affiliation is with the Department of Philosophy and Medical Ethics of the St. Radboud University Medical Center in Nijmegen. He is a nationally and internationally recognized scholar in end-of-life issues and serves on the Boards of *Cambridge Quarterly of Health Care Ethics*, *Theoretical Medicine and Bioethics*, *Medicine HealthCare*, and *Philosophy*.

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Boudewijn E. Chabot, MD, PhD, was trained as a psychiatrist and psychotherapist at the Erasmus University in Rotterdam and at the Institute of Psychiatry and Maudsley Hospital in London. He did research in psychotherapy at the University of Amsterdam and later specialized in psychiatry for the elderly. His name has been given to the Dutch Supreme Court case (1994) on physician-assisted dying in a psychiatric patient.

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Mutual Expectations, a Conventionalist Theory of Law (Springer 2002) and the editor of *The Good Life as a Public Good* (Kluwer 2000), and he has written many articles in moral, legal, and political philosophy and medical ethics. He is a member of the Dutch Health Council and of one of the Regional Review Committees for euthanasia. He is presently writing a book about medical and nonmedical decisions concerning the end of life.

John Griffiths held the chair in sociology of law in the Department of Legal Theory of the Faculty of Law of the University of Groningen from 1977 until his retirement in 2005. He studied philosophy (University of California, Berkeley) and law (Yale Law School) and taught law at, successively, Yale, the University of Ghana, and New York University before accepting his most recent appointment. His theoretical work in sociology of law has largely focused on the effectiveness of regulation. Most of his research and writing has dealt with problems of the regulation of euthanasia and other socially problematic medical behavior.

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Esther Pans has written a legal dissertation on the *Dutch Law on Euthanasia and Physician-Assisted Suicide* (Vrije Universiteit Amsterdam, 2006). This book analyzes the moral considerations underlying Dutch legislation and Dutch case law. She has written several articles on issues regarding the legal aspects of end-of-life decisions, such as physician-assisted suicide in case of dementia or being “weary of life.” She is presently working as a health care-oriented lawyer in Amsterdam and is a member of the Civil Law Department of the Vrije Universiteit Amsterdam.

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Preface

Gerrit K. Kimsma

I have had a long-standing interest in end-of-life decision making in medicine. It started well before I began my career in the early 1970s as a teacher of medical ethics and philosophy at the Vrije Universiteit of Amsterdam and as a general practitioner working in a health center near Amsterdam.

I have witnessed and participated in all the phases of confrontation, acceptance, and integration of euthanasia in the Netherlands. I received my medical degree in 1974, the year of the “first” court case, and taught students and residents about the implications and what has followed since. I ended the unacceptable suffering of a terminal patient with a brain tumor by injection in 1977; this was my first time, and it was during a period when there was neither unanimity about the practice nor regulations that would protect a physician. I have reported all my cases except this first one, and I still feel ambivalent about it. It was justified but troublesome because of the legal risks and the mixed emotions I felt. This ambivalence has never left me and is revived each time I receive a request to help someone to die.

My motivation was based on a conviction that people at the end of their lives should not suffer unnecessarily. In general, I believe that this type of suffering serves no real purpose, except to remind us of the tragic and vulnerable side of life. As a physician, I have observed that suffering may be part and parcel of diseases; nowadays, however, the well-intended but often damaging interventions of medicine may actually increase suffering. Although medicine is intended to address the cause and nature of diseases, in so doing it changes the accompanying suffering and often extends it in unforeseen ways. My personal conviction coincided with an emerging cultural discomfort with the medicalization of death and dying and a growing belief that how one dies should be a personal choice. I shared the belief that the medical profession alone is incapable of making this choice and that patient input is essential but not, by itself, decisive.

I have always maintained the position that physician-assisted death (PAD) should respect the moral position of physicians because they are not just the

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“means” of fulfilling a request; rather, they are moral agents with their own professional responsibilities, emotions, and consciences. PAD is a relational process that involves at least two individuals. It is not just an intervention to help someone die.

This friction between death under the guidance of medical technology and the option of autonomous choice has been the motivating force behind Dutch end-of-life decision making and much of what has happened since the seventies in the Low Countries. I found the Dutch national investigation on medical practices at the end of life to be brave and extremely enlightening because it did away with a lot of speculation and furnished facts. These investigations were the start of cooperative efforts between the government and the medical profession, resulting in the development of programs for euthanasia consultants and review committees. I have been intimately involved in these programs as an independent consultant, even before the new acts. I have been a teacher in the Royal Dutch Medical Society for the Advancement of Medicine (RDMA) programs for consultants since 1997. I was also a physician-member of a Euthanasia Review Committee for twelve years after 1998 (after the new acts were passed) that determines whether it is legal to end an individual's life.

From early on I have been aware of the “open ends,” risks, and dangers of these irreversible interventions by physicians. Chris Ciesielski-Carlucci and I interviewed families for the first time after the acts were passed. David Thomasma, Thomasine Kushner, and I interviewed physicians who ended the lives of their patients. We published *Asking to Die: Inside the Dutch Debate about Euthanasia* (Kluwer Academic Publishers, Dordrecht/Boston/London) in 1998 in order to open up public debate about the personal and private consequences of physician-assisted death.

I was and still am impressed by the personal involvement of physicians with their patients and families, and can assure people that they are not being or becoming indifferent, as some feared. On the contrary, everyone we interviewed was deeply touched by these decisions. As a consultant, I have witnessed the courage and strong convictions of patients who ask for an end to their suffering. I am struck by the depth of involvement of all the participants in physician-assisted dying. I have seen no hints of routinization, callousness, or a “slippery slope”; there are no studies that reflect such developments.

Even though these personal experiences and small-scale research activities were inspiring, there was reason to doubt whether they were representative or complete. There was a need for more comprehensive empirical and theoretical research on many aspects of medicine at the end of life in order to grasp the total picture of PAD.

So it was more than a lucky coincidence that Stuart J. Youngner, who is an interested but critical observer of “Dutch euthanasia,” expressed an interest similar to mine. Our professional partnership in teaching, our friendship, and our intellectual curiosity inspired this book, which is intended to present

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the next phase in Dutch empirical, legal, and ethical developments. This book includes information on how Dutch professionals of all ranks respond to the challenges of a “permissive system.” It demonstrates how they confront the “new” borders of suffering, both at the end of life, such as with Alzheimers’ patients and the elderly who are “tired of living,” and at the beginning of life, such as in the extremely problematic issues of neonatology.

I acknowledge that the system may not be perfect, that reporting may not be a hundred percent, and that Euthanasia Review Committees (ERCs) conclude that the PAD has not been “careful” in a small minority of the cases. Nevertheless, the existence of an option for patients to be allowed to die when they choose has increased the humaneness of death and made its acceptance easier, in spite of the enormous grief for anyone whose end has come and the grief of his or her dependents.

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Preface

Stuart J. Youngner

I have had a long-standing interest in end-of-life decision making within the United States. It began with my career in the early 1970s as a consultation-liaison psychiatrist, working primarily in the medical and surgical areas of the hospital.

Psychiatry had gained credibility during this period by identifying clinical depression as a potentially lethal disease. Epidemiological studies confirmed that most suicides took place in the context of mental illness and could often be prevented with timely intervention. The perception that depression was, in fact, a public health problem led to the establishment of a national network of suicide prevention centers. This, and the development of new drugs that could often effectively treat serious depression, provided new recognition and prestige for the field of psychiatry.

Another seemingly unrelated development occurred during this same period. The first intensive care units were opening in American hospitals – that is, an impressive concentration of “lifesaving equipment” and specially trained medical personnel brought together in special areas in the hospital to salvage lives that would previously have been lost. I took an interest in the psychological and social issues raised by intensive care – issues that affect patients, families, and health professionals alike. A new problem became apparent very quickly. Sometimes critical illness could not be reversed by lifesaving machines, pharmaceuticals, and invasive monitoring. Sometimes people lingered in a technological limbo in which suffering, indignity, and isolation seemed to overwhelm the noble goals of medicine.

In this context, a national discussion began concerning when death was the least worst alternative. After decades of court cases, legislation, news stories, editorials, movies, and books, American society seems to accept, though somewhat uneasily at times, that allowing death to come may sometimes be the better alternative. The social and legal discussion has focused largely on the claim that passively allowing death to come is sometimes acceptable and even desirable, whereas “actively” ending a patient’s life is *never* acceptable. Phrases

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such as “letting nature take its course” are used to characterize what is judged to be acceptable behavior; unacceptable behavior is branded with the socially toxic words “killing” and “suicide.” In fact, the toxic words were used initially to characterize the consideration of forgoing almost every lifesaving intervention. Withdrawal of fluids and nutrition can still evoke passionate accusations of “killing,” as the 2005 Terri Schiavo case illustrated.

Most psychiatrists used to see patients in their offices or in psychiatry units where they sought help for depression. These psychiatrists never ventured into an intensive care unit or cancer ward, where patients were increasingly faced with the terrible choice of life burdened either by invasive medical technology or by the diminished state in which “rescue” technology had left them. Here, death was never the first choice. The first choice was cure or recovery to an acceptable state. Unfortunately, that choice was often not available; death appeared the best choice available to many. Although this reality was accepted by a growing number of health professionals and the American public, psychiatry clung to the rigid belief that a wish to die was *always* a product of mental illness. Psychiatry’s newly found ability to understand and treat suicidal ideation and behavior as symptoms of depression too often blinded it to the plight of this new group of patients who often (though not always) chose death rationally.

Throughout our national debate about end-of-life decisions (from do not resuscitate [DNR] orders and stopping fluids and nutrition to turning off ventilators), opponents argued that we were heading down a slippery slope to the lethal injection, where there was no ambiguity between killing and letting die. They were right. Once we accepted the notion that death could be the least worst alternative and that it was cruel to keep people alive in these situations against their wishes, it was a matter of time until we considered the lethal injection.

I have often found the most vocal American critics of Dutch euthanasia to be a bit shrill and doctrinaire. They have sometimes resorted to attacking the Dutch character. The more I learned about euthanasia in the Netherlands, the more I was impressed by the thoughtfulness, the evidence-based policy, and the transparency with which it is implemented. Are there problems? Of course. But the Dutch take them seriously. Is the Netherlands heading down a slippery slope to Nazism, as some of its critics have suggested? Hardly. I view the Netherlands as a healthy, bourgeois, liberal democracy with a strong sense of social solidarity that I envy.

My own views on active euthanasia (the lethal injection by a physician) are complicated. While I am intellectually comfortable with its moral logic, I am psychologically (or culturally) uncomfortable with it. I have been asked by patients but have never complied – even in situations where I thought it would be very reasonable. Fortunately (or unfortunately), I have never practiced in a setting where lethal injection was socially and legally permissible. If I did, I cannot predict what I would do.

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Preface

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Putting this book together with Gerrit K. Kimsma has been a great learning experience. It has not, however, made it any easier for me, as a physician, to contemplate giving a patient a lethal injection. Perhaps that discomfort, which is shared by many physicians who practice euthanasia in the Netherlands, is a reassuring take-home message from this book.

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Introduction

Stuart J. Youngner and Gerrit K. Kimsma

This book affords those Dutch who have conceived, studied, regulated, and practiced Dutch euthanasia the opportunity to tell their stories in one place in their own voices. Most persons who have written about physician-assisted death (PAD) have lived in countries and cultures in which PAD is illegal and members of the medical professions are strongly opposed to it. This “limitation” results in speculation rather than analysis. The Dutch have now had experience for more than three decades, allowing an unparalleled opportunity to study and reflect about PAD both statically and as its practice unfolds over time in a specific social and cultural context.

Together, we identified and interviewed potential authors and, with them, shaped the content of the book. They were, without exception, enthusiastically cooperative and trusting. Our focus was on the practice of PAD and, therefore, we did not include authors (inside or outside of the Netherlands) who find PAD in general or Dutch PAD in particular morally unacceptable. Therefore, what follows does not serve as a representative or “balanced” discussion of the moral acceptability of PAD in general or Dutch PAD in particular. Nor was it intended to do so. We do hope that the reflections and experiences provided in this book will make a valuable contribution to the ongoing discussion of PAD for supporters and critics alike.

In using the term *physician-assisted death* (PAD), we mean to include two behaviors. The first is the unambiguous and intentional ending of a patient’s life by a physician, of which lethal injection is emblematic. The second is physician-assisted suicide, in which a physician intentionally provides the patient with the medical means to end his or her life. When the Dutch use the term *euthanasia*, they have something more restricted in mind (see Chapter 2 by Johan Legamaate). In the Netherlands, euthanasia has a specific social and legal meaning, that is, PAD with specific conditions, such as voluntariness, unbearable suffering, and certain procedural requirements. We have tried to standardize the language in the chapters that follow to avoid confusing the reader.

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The first section of the book includes “Background and History.” Contemporary historian James C. Kennedy provides a unique interpretation concerning how and why the PAD practice developed in the Netherlands at a particular point in history. He emphasizes the “anti-taboo” culture of the 1970s and 1980s, and the importance the Dutch have historically attached to *bespreekbaarheid* (the freedom to speak openly). Judicial expert Johan Legemaate discusses the importance and ongoing problems of the Dutch classification just mentioned. His discussion of palliative (or terminal) sedation suggests the persistent problem of the active/passive distinction, even in the Netherlands. In the first of her two chapters, Heleen Weyers, a sociologist of law, traces the political, legal, and social practices that shaped the current Dutch law and practice of euthanasia, including a discussion of the key legal cases. Next, lawyer Esther Pans explicates the moral underpinnings of the Dutch euthanasia law, emphasizing the importance of beneficence relative to autonomy. In her second chapter, Heleen Weyers examines positions taken by organizations representing physicians, patients, and religious denominations and how they have evolved over time. Finally, political scientists Margo Trappenburg and Hans Oversloot identify three strands in the Dutch social fabric: the consensual character of the Dutch social and political culture; the Dutch health-care system, in particular the system of general practitioners; and the trust that Dutch patients have in their doctors. They argue that these strands allow the Dutch system to be both liberal and moderate. They also discuss how recent social and political developments may threaten the stability of these strands.

The next section, “Regulation and Practice Deficiencies,” contains four chapters written by social scientist researchers who have either conducted the primary government studies or written extensively about them. Bregje D. Onwuteaka-Philipsen and Agnes van der Heide, leaders of the next generation of government studies, address the issues of unreported cases and cases in which there was no specific request for euthanasia – two issues that have motivated a great deal of the criticism of Dutch euthanasia. H. Roeline W. Pasman deals with the interesting question of cases in which physicians refuse requests for euthanasia. Finally, John Griffiths, a supporter of Dutch euthanasia in general, suggests some gaps in the methodology of the research to date.

Experience and information from early studies led the Dutch to make serious efforts to monitor and improve their system of euthanasia. In the section “Quality Assurance,” two of these efforts, a systemic approach to consultation and a nationwide review process, are described and analyzed by Gerrit K. Kimsma and philosopher Evert van Leeuwen. Next, physician-philosopher Dick Willems reports on the development of palliative care in the Netherlands in relation to euthanasia.

The section “Learning from the Practice” includes seven chapters that address difficulties identified in the course of the actual practice of Dutch euthanasia. Geriatrician-philosopher Cees M. P. M. Hertogh describes the problem of advance directives and euthanasia for persons with advanced dementia.

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Here, physicians have put the brakes on a practice that was allowed by law. Psychologist Ron Berghmans addresses the problem of competence to request euthanasia in patients with early Alzheimer's. Health services researcher Mette Rurup explores the problem of "weariness of life," that is, when patients without a clearly identified medical cause for their suffering request euthanasia. The Dutch courts have forbidden this practice. Kimsma and Chalmers C. Clark describe the impact of euthanasia on physicians by reviewing empirical studies and suggesting that the term *medical friendship* describes the ideal context for euthanasia. In contrast to some who argue that physicians "should never kill patients," they suggest that *only* physicians should do it. Psychologist Marije van der Lee discusses the complicated issue of depression and its relationship to requests for euthanasia, concluding that depression must be taken very seriously but that it hardly characterizes all requests. Pediatrician Pieter J. J. Sauer and pediatrician-lawyer A. A. Eduard Verhagen address the Groningen Protocol, which sets conditions for ending the lives of newborn infants with severe congenital abnormalities. This practice does not count as Dutch euthanasia because, obviously, infants cannot give consent. It has, therefore, stirred considerable controversy around the world. Is it the beginning of a slippery slope in the Dutch end-of-life practice? The authors address this and other questions. Finally, psychiatrist Boudewijn E. Chabot reports on his study of the hastening of death through voluntary cessation of fluids and nutrition in the Netherlands – a practice that is surprisingly common. This is the first such study reported in the world literature.

According to Dutch practice and law, patients who receive euthanasia must demonstrate "unbearable suffering." In the next sections, Henri Wijsbeck and Kimsma explore this key but quintessentially subjective term, philosopher Wijsbeck in a more theoretical way and Kimsma from the perspective of actual practice.

The book concludes with chapters by two senior scholars and longtime commentators on euthanasia in the Netherlands. Theologian Govert den Hartogh judges the success of the Dutch system of euthanasia on its own terms. Specifically, he addresses the rate of reporting, euthanasia without specific request, effectiveness of the review committees, and the newly emerging issue of the classification of terminal sedation. In her final chapter, Trappenburg echoes some of the concerns that she raised in her earlier contribution about changes in the fabric of Dutch society. In contrast, euthanasia policy is, she concludes, "something we really did right."