
Communication and Bioethics at the End of Life

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Real Cases, Real Dilemmas

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This book is dedicated to the people whose stories we share here (whose identities have been changed to protect their privacy). These stories belong not just to the patients, but also to the family members who faced unbearable situations where difficult decisions had to be made, and to the health care professionals, hospital administrators, and ethics committee members who agonized about how to do the best thing possible for each patient. We share these stories with the hope that we can all learn better ways to die and better ways to care for dying patients and their families.

Preface

This book is a collection of real-life cases exploring the complex range of issues inherent in contemporary end-of-life medical care. It is intended for physicians, medical students, residents, ethics committee members, social workers, chaplains, nurses, bioethicists, researchers, and scholars who confront ethical issues with patients and families at the end of life, and who are committed to an understanding of the ways in which things can go wrong in efforts to improve our American way of dying. Most Americans die in institutional settings, primarily hospitals, which involve a challenging set of circumstances to be considered in helping patients die well. Media saturation, concerns for privacy, institutional norms, cultural diversity, politics, technology, and advances in medical care all complicate the decision-making, communication, and ethical analysis that are part of the dying process. More individual concerns, including family dynamics, patient preferences, spirituality, and insufficient advance care planning, also confound solutions that satisfy all stakeholders.

End-of-life care is a controversial matter. The classic cases of *In re Quinlan* (1976) and *Cruzan v. Director* (1990) established the right of patients or their surrogates to refuse life-sustaining treatment, but the more recent case of Terri Schiavo (Caplan et al. 2006) demonstrated how difficult it can be to exercise this right in the face of family conflict, media coverage, and political chicanery. The same year that Schiavo lapsed into a persistent vegetative state, retired pathologist Jack Kevorkian euthanized his first patient in Oakland County Michigan (Roscoe et al. 2000). Kevorkian went on to assist the deaths of over 100 people illegally between 1990 and 1997 until his arrest, conviction, prison sentence, and eventual death. Today, 20% of Americans live in a state where physician-assisted suicide (which is a highly regulated version of what Kevorkian practiced) is legal; California is the most populous U.S. state to legalize this practice, and one of the most recent. Since Oregon passed its *Death with Dignity* statute in 1997, 1,545 terminally ill people have had lethal prescriptions written for them, and 991 have died from ingesting these medications (Oregon Public Health Division 2015). That same year, the U.S. Supreme Court heard two cases—*Vacco v. Quill* (1997) and *Washington v. Glucksberg* (1997)—and found no constitutionally protected right to die; the ruling was predicated in part by the hope expressed by Justice Sandra Day O'Connor that all Americans would be able to access high-quality end-of-life care.

The growth in the number of hospice programs in the U.S. increases the chances of receiving quality end-of-life care. This number has grown from fewer than 3000 in 1998 to over 5,800 currently, with the number of patients served increasing from 540,000 to 1,542,000 (NHPCO 2015). The median length of stay, however, has decreased slightly from 22 days in 1987, to just over 17 days in 2014 (Gage et al. 2000). Hospice care also remains an option overwhelmingly chosen by White patients; over 80% of hospice enrollees identify their race as White (NHPCO 2015). In 2006, the American Board of Medical Specialties (ABMS) officially recognized hospice and palliative medicine as a formal subspecialty of medicine in the United States focusing on symptom management, pain relief, and end-of-life care. Approximately 4,400 physicians are currently board certified or members of the American Academy of Hospice and Palliative Medicine, but it is estimated that an additional 6,000–18,000 hospice and palliative medicine physicians are needed to staff the current number of hospice- and hospital-based palliative care programs at appropriate levels (Lupu 2010). Americans spend a great deal of money on end-of-life care: nearly, 6% of Medicare patients who die each year make up 27–30% of Medicare costs (Emanuel 2013), but increased spending does not guarantee they experience the kinds of deaths they might prefer. Most Americans (75%) wish to die at home but only 20% do, with the majority dying in institutions after an explicit decision is made to limit care.¹ Only 20–30% of Americans report having an advance directive, such as a living will, that specifies their end-of-life care preferences. Even worse, only 25% of physicians in a recent study knew that their patients had an advance directive on file (Tillyard 2007). While more than 80% of patients want to avoid hospitalizations and high-intensity care at the ends of their lives, their wishes are often overridden by patient-designated surrogates and next-of-kin proxies, who incorrectly predict the patient's end-of-life treatment preferences (Shalowitz et al. 2006), and ironically even by doctors who would choose a “no-code” status for themselves but tend to pursue aggressive, life-prolonging treatment for their patients (Periyakoil et al. 2014).

Our goal in this book is to enrich the practicality and nuance of ethical analysis applied to the moral problems surfacing in contemporary end-of-life care. Each case presents a unique and ethically problematic situation in which medical care decisions at the end of life defied easy, neat, or universal resolution. While some of the lessons to be learned are generalizable, each case also reveals issues that reflect particular configurations of patient characteristics, organizational structures, political climates, medical cultures, and interpersonal relationships. There are no easy solutions or ones that will be satisfactory to all stakeholders. Each of the cases presented involved real people, with varying intentions, trying to make decisions they could live with, even after the patient died and the headlines faded. These cases provide lessons in how ethical principles, precedents, and virtues must also accommodate relationships, family dynamics, political realities, and social conventions. We believe that their casebook offers several unique things: (1) specific, real-life cases not made available heretofore; and (2) a wide-angle view of the apparent problems or issues at hand in each case, beholden to no particular “school”

or ethical approach, yet insistent upon thorough and rigorous argumentation in developing the best analysis, approach, or resolution possible.

We have both worked in the healthcare arena for more than 25 years and have been active participants in efforts to improve end-of-life care. Lori A. Roscoe is Associate Professor in Health Communication in the Department of Communication at the University of South Florida (USF) where she also earned her Ph.D. in Aging Studies. Her dissertation research examined the ethical, clinical, and psychological factors that influenced the clients of Dr. Jack Kevorkian to request his assistance in ending their lives. Her current research focuses on the communication issues that complicate end-of-life decisions. Dr. Roscoe teaches undergraduate and graduate classes in communication ethics, health communication, aging, and end of life; she spent 5 years in the Office of Curriculum and Medical Education at the USF Morsani College of Medicine developing and implementing classes in medical ethics and humanities, geriatrics, and professionalism. Dr. Roscoe is also on the Executive Committee of the Center for Hospice, Palliative Care, and End-of-Life Studies at USF, a university–community partnership research center that funds pilot grants, provides assistantships for doctoral students conducting end-of-life research, and has sponsored national conferences on end-of-life issues including a physician board review course for certification in hospice and palliative medicine.

David P. Schenck is an Emeritus Professor of USF, who earned his Ph.D. in French language and literature from the Pennsylvania State University. He followed the usual academic career path of teaching and research, responding along the way to interesting challenges that resulted in 15 years of service devoted to college and central administration. At the same time, he developed a keen interest in bioethics, pursuing this field over many years at Georgetown University, and spending most of the last decade of his career teaching biomedical ethics in both the Honors College and Department of Religious Studies at USF. Since 2000, he has also held an affiliate appointment in the USF Department of Otolaryngology as its ethicist; his research in the Head and Neck Surgery Program of that department has focused primarily on oral cancer in Hispanic migrant farmworkers.

We have each served on various hospital and hospice ethics committees over the past 25 years, both continuing service on one or more today. We are both also intimately familiar with Institutional Review Boards (IRB). Dr. Roscoe served as a member of an IRB of a large, state-supported, comprehensive, graduate, and research institution which counted, within its broad spectrum of academic divisions, colleges of medicine, nursing, and public health, as well as numerous institutes and research centers dedicated to special areas of focus in health care. Dr. Schenck is currently a member of the IRB of a large urban, private, not-for-profit, local multi-hospital system that reviews and maintains oversight of hundreds of new and ongoing funded and unfunded clinical studies annually.

We have worked closely together as colleagues for many years. In 1999, we found ourselves serendipitously housed in what was then known as “The Ethics Center” on the main (Tampa) campus of USF, where one interesting conversation led to another intriguing idea, and before a year had passed a new course in biomedical ethics had been approved and was being taught jointly by the two of us.

The success of this work led to further collaboration, including a jointly authored, delivered, and subsequently published conference paper; a subsequent joint publishing effort; joint attendance at workshops and seminars of mutual interest; additional shared presentations and research efforts; lengthy service together on a particular ethics committee; and collaborative work of various kinds with USF head and neck surgeons.

We have spent many, many hours discussing cases with which we have been intimately familiar, working through them again and again, reviewing “what went wrong” or “what could have been done better” or “how this kind of thing could be avoided next time.” We have reviewed our collaborative work tirelessly, and have bravely asked one another for critical reviews of work to be submitted for publication or funding, begging for honest, brutal candor in response, trusting that the other will indeed be forthright. We have come not only to trust one another but also to believe that we are very much in the same mode of thinking with regard to human values, the fundamental principles that should guide biomedical ethical decision-making, and the role of the virtues in this process. We share very similar views on such important issues as to what it means to be sick and to suffer; the significance behind the terms curing, healing, and wholeness; the roles of both patient and physician; and an understanding of the goals of medicine. Yet, differences in perspectives, experiences, and training have emerged as well. Bioethical concerns often give way to communication difficulties. Lack of effective communication between doctors, patients, and family members creates untenable situations for all concerned. Conversely, sometimes what appears to be competent communication between doctors and patients can mask important underlying ethical problems.

We believe that ethical dilemmas, especially those found in complex or complicated cases, may involve both bioethical issues as well as those in communication. What can sometimes appear to be an ethics case may in fact be most readily resolved by focusing on communication between the various parties such as patients, family members, physicians, nurses, and other members of the healthcare team. Yet, other cases that appear to contain intractable problems in communication might be resolved when all parties concerned focus on the ethics involved—how best to honor a loved one’s treatment preferences, for example. The principles and practices of bioethics, coupled with case analysis, allow us to focus on ways to honor patient autonomy, examine the balance between beneficence and non-maleficence, the virtues expected in the helping professions, conflicts between ethics and law, and the increasing need to focus on just resource allocation, health disparities and access to healthcare resources. Communication theory is particularly attuned to contextual features, systems, and relationships, which simultaneously complicate already complex patient care situations, and which may also provide the resources needed for a satisfactory resolution. This book brings bioethical principles, concepts, and reasoning into conversation with communication concepts such as social construction, sense-making, framing, and relational dialectics. This framework thereby provides readers with opportunities to fit themselves into the situations described in order to cultivate unique and divergent explanations that

reflect the complex realities of contemporary medical practice, including the changing relationships between patients and practitioners, shifting perceptions of the role of technology in human existence, and evolving social ideals about life and death.

The cases chosen for inclusion in this book are those we see as containing more than the usual complexity to be found in casebooks or journals presenting case discussions, where ethical dilemmas may often appear to be the product of conflicts between principles, values, cultural/national/racial/religious, or other significant differences between parties, or where seemingly problematic ethical issues may ultimately be rather easily resolved through better communication. Some might call these cases “wicked problems” because they each defied easy resolution. The cases here have been chosen because more than one kind of conflict appears to be in play, either ethical or communicative in nature, or both, especially where there may appear to be no satisfactory or acceptable resolution. The claims of multiple stakeholders had to be taken into account, almost always against a backdrop of intense scrutiny from the legal system, the media, as well as from religious organizations.

We have found all too often, however, not only among students but also among seasoned professionals, a tendency to look for answers that offer the “easy out” solution, particularly if one can point to a principle, a rule, or even a law that would seem to overrule virtually everything else, but which in fact has only the effect of so oversimplifying things that valuable nuances are lost and critical issues of human concern are not fully explored. The purpose of this book, then, is to provide opportunities for careful examination of complex cases through a broad, somewhat hybrid, approach that does not promote or embrace any particular stance, “school,” or heretofore identified critical perspective on ethics, such as principle ethics, virtue ethics, feminist ethics, or casuistry, to name a few. We do not, therefore, attempt to follow any particularly prescriptive approach to case analysis, and we certainly do not attempt to create our own method. We describe our methodology as one that is grounded essentially in the historical growth and development of principle ethics, coupled with narrative ethics and its emphasis on ethical reasoning derived from stories, in an environment that encourages “outside the box” approaches to problem-solving. Narrative ethics (Geisler 2006) is an umbrella term for ethical reasoning derived from stories, whereas principlism (Beauchamp and Childress 2012) employs and balances abstract principles such as autonomy, beneficence, non-maleficence, and justice to determine right action. Each approach makes a unique contribution to understanding moral life and the process of ethical decision-making in healthcare situations. As McCarthy succinctly states, “a good principlist has narrativist tendencies and a good narrativist is inclined toward principlism” (McCarthy 2003).

Principlism is a more traditional approach to ethical reasoning that generally takes respect for persons (or autonomy) as the principle of most importance in bioethical decision-making. The focus is on understanding and putting into practice what the patient would want for him- or herself. Other principles are brought to bear as well. Beneficence challenges us to do good for others, while non-maleficence

reminds us to “first do no harm.” The principle of justice demands that we treat everyone equally and remain mindful of issues of cost and resource allocation.

Narrative ethics regards moral values as an integral part of stories and storytelling because narratives themselves implicitly or explicitly ask the question, “how should one think, judge, and act—as author, narrator, character, or audience—for the greater good.” Our approach focuses primarily on the ethics of “the told” where we are most concerned with exploring the ethical dimensions of characters’ actions, especially in the conflicts they faced and the choices they made, and how the narrative’s plot unfolded to reveal the ethical issues faced by all individuals involved.

The cases here allow readers to practice ethics by applying both ethical principles and narrative competencies to understand, interpret, and determine right actions. The case narratives are written to expose the perspectives of multiple stakeholders and to demonstrate that medical plotlines in many end-of-life situations are far from predictable, controllable, or generalizable. The literary skills that allow readers to understand and interpret stories also help reveal the ethical issues embedded in a case narrative, while the ethical principle of autonomy helps center the questions to be resolved within the context of a patient’s individual beliefs, culture, and life events. The combined approach also allows contextual features of each case, such as family dynamics, the political scene, the conflicting priorities of various professional interests (medical specialists, nurses, social workers, and hospital administrators), and institutional cultures and practices to be taken into account. What follows are all actual cases. Permission to use them has been granted either by the institutions, or officials, or physicians involved, provided all identifiers be stripped, and every effort has been made to ensure that. In some cases, not only have names or initials been altered but dates and locations have been changed as well. The use of initials may seem to be an impersonal choice, but this was done deliberately. Names convey a great deal of information—social class, age, and ethnicity, among other characteristics. Whatever we knew about the patient is disclosed in the discussion, if not in the case description, but it can be instructive to deliberate about the ethical dimensions of a difficult case, free from attributions about certain kinds of patients. Identifying patients and other individuals by initials hopefully encourages readers to analyze the kind of inferences one may make about certain kinds of patients in certain kinds of situations.

Each case is described in some detail, but that should not be understood to mean that it would necessarily include everything a reader might wish to know, as may often be the case with real-life ethical dilemmas. Case descriptions are followed by discussion questions designed to help focus a conversation about the issues presented in the case. Following the discussion questions, we provide responses from their respective disciplines, Dr. Schenck from Bioethics, and Dr. Roscoe from Health Communication.

These cases are not examples of the application of specific ethical principles, the dilemmas that attend to particular kinds of patients, or situations that involve only certain healthcare professionals. They all involve hospitalized patients at the ends of their lives, and they are illustrations of the complexities of human

decision-making and ethical justification against a backdrop of real-life circumstances: the realities of media coverage, politics, a heterogeneous public, and the lack of civil dialogue in almost every avenue of public life. Our hope is that the sharing of these cases may help those in the trenches of health care (or those about to be) to learn about how good people, in difficult circumstances, can strive to reach ethical, legal, and medically appropriate solutions when confronted with a vast and difficult range of circumstances. None of them provides easy answers, but they should allow readers of all kinds to test their ethical judgments, moral commitments, and knowledge of the law and professional codes of conduct against the real dramas that play out every day as patients and families, physicians, and other healthcare providers attempt to navigate the rocky and difficult terrain of end-of-life care. Many of these cases are cautionary tales, and we hope that sharing them will allow better solutions to be imagined and enacted.

Notes

¹For more information, see <http://www.pbs.org/wgbh/pages/frontline/facing-death/facts-and-figures/>.

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Tampa, Florida
September 2017

Lori A. Roscoe, Ph.D.

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Tampa, Florida
September 2017

David P. Schenck, Ph.D.

Recommended References for Beginners

This casebook is composed of complicated current cases, whose analysis presupposes a basic or intermediate level of familiarity with ethical principles, case-based reasoning, and foundational cases that created the current underpinning on which to base ethical judgment. Where possible, we have included references and summaries that will assist readers in understanding the cases presented here; in addition, we include a partial list of other ethics casebooks and other volumes that provide an excellent background for interested readers.

- Beauchamp, T. L., & Childress, J. F. (2012). *Principles of biomedical ethics* (7th ed). New York: Oxford University Press.

Many bioethicists consider this to be the foundational text for understanding the history and current trends in bioethical reasoning. This edition describes in detail a principlist approach to bioethical reasoning, which we adapt in our case analysis, and which will be familiar to those who practice medicine, teach biomedical ethics in professional schools, or serve on ethics committees.

- Pence, G. E. (2004). *Classic cases in medical ethics: Accounts of cases that have shaped medical ethics, with philosophical, legal, and historical backgrounds* (4th edition). New York: McGraw-Hill.

This book is written by a professor of philosophy and begins with an overview of moral reasoning and ethical theories in medical ethics. This is an excellent casebook to familiarize students with the classic cases in a variety of areas, and the cases include details about the court cases that helped resolve these cases. Classic cases are important to understand but they do not always prepare interested persons to anticipate the outcome of more current cases in which technology, law, and medicine, among other important contextual features, have changed since these classic cases were resolved.

- Ford, P. J., & Duzinski, D. M. (2008). *Complex ethics consultations: Cases that haunt us*. New York: Cambridge University Press.

This casebook is an edited collection of 28 cases submitted by authors representing diverse disciplinary viewpoints. Each chapter includes a case narrative, professional reflections, haunting aspects, outcomes, discussion questions, and references. All

cases are presented from the point of view of the ethics case consultant who was involved with the case and who authored the case for inclusion in this collection.

- Fry, S. R., Veatch, R. M., & Taylor, C. R. (2011). *Case studies in nursing ethics* (4th edition). Burlington, Massachusetts: Jones and Bartlett Learning.

This casebook is designed specifically for students in upper level undergraduate and graduate-level nursing courses, and presents basic ethical principles and specific guidance for applying these principles in nursing practice. Each of the 150 case studies allows readers to develop their own approaches to the resolution of ethical conflict and to reflect on how the traditions of ethical thought and professional guidelines apply to the situation. This is a good resource for nurses but is not specifically focused on end-of-life patient situations.

- Gervais, K. G., Priester, R., Vawter, D. E., Otte, K. K., & Solberg, M. M. (Eds). (1999). *Ethical challenges in managed care: A casebook*. Washington, D. C.: Georgetown University Press.
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This book contains 20 case studies that present a wide range of ethical challenges that explore the goals, methods, and practices of managed care. Accompanying each case are questions for consideration and a pair of commentaries by prominent contributors from diverse fields. Through the cases and commentaries, this book clarifies the internal workings of managed care, explains relevant concepts, and offers practical, constructive guidance in addressing ethical and policy issues. It is designed primarily for those managing the delivery and financing of health care and for students and practitioners of the health professions and health administration.

- Thomas, J. E., & Waluchow, W. J. (1998). *Well and good: A case study approach to biomedical ethics* (3rd edition). Peterborough, Ontario: Broadview Press.

This book includes both real-life cases as well as classic cases, most of which involve nurses and other allied health professionals. The cases in the main body of the book are accompanied by the editors' discussions of the issues involved.

- Veatch, R. M., & Flack, H. E. (1997). *Case studies in allied health ethics*. Upper Saddle River, New Jersey: Prentice Hall.

This book contains case studies based on the actual experiences of practicing allied health professionals in various fields (such as dietetics and occupational therapy). The book is somewhat dated and does not always reflect changes in these fields, and it can be helpful to students and practitioners in allied health fields.

For readers interested in more background on family dynamics and family communication, the following are suggested references:

- Hoffman, L. (1981). *Foundations of family therapy: A conceptual framework for systems change*. New York: Basic Books.

Hoffman's classic book provides a synthesis of themes and concepts around which family theory and therapy have evolved. Starting with Gregory Bateson's ideas on social fields, the book examines concepts that have come to family therapy from general systems theory. The book also explores the major schools of family therapy.

- Vangelisti, A. L. (ed). (2003). *The Routledge handbook of family communication*. New York: Routledge.

The Routledge Handbook of Family Communication offers a comprehensive exploration and discussion of current research and theory on family interaction. It integrates varying perspectives and issues addressed by family researchers, theorists, and practitioners, and offers a unique and timely view of family interaction and family relationships. Research of issues key to understanding family interaction is synthesized, and the various theoretical and methodological choices made by researchers studying family communication are analyzed. The handbook highlights the work of scholars across disciplines—communication, social psychology, clinical psychology, sociology, family studies, and others—to capture the breadth and depth of research on family communication and family relationships.

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