

HEALTH CARE ETHICS AND THE LAW

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Preface

“A long habit of not thinking a thing is wrong, gives it a superficial appearance of being right.”

— **Thomas Paine** (1737–1809), one of the Founding Fathers of the United States, from *Common Sense* (1776)



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Authors' Vision

This text will engage students with the ethical decisions faced by health care professionals every day. Based on principles and their applications in health care ethics and the law, this text extends beyond areas that are often included in discussions of political philosophy and the principles of justice. While aware of the intimate interplay between morality and ethics, no distinction is made between the two in this text, as they can be united in a consistent manner. Far from overlooking the separation of ethics and the law, it is assumed, as U.S. Supreme Court Justice Oliver Wendell Holmes (1841–1935) articulated, that ethics and the law should not be separable; therefore, all materials addressed in the text encompass both health care ethics and the law. At the same time, what is lawful may not always be ethical, but what is ethical should always be lawful.

For many people, the fundamental questions of ethics are: “what should I do?” and “how should I act?” However, ethics seeks to provide principles in addition to standards or rules of conduct. Such principles can guide people in identifying ethical issues and making ethical decisions in those not infrequent situations that may be outside the purview of the standards and rules. In this text, the law can be understood in light of organizing principles or consideration of social policy. This approach excludes theoretical puzzles not based on observation and data analysis.

Many people are passionate adherents of the principle of utilitarianism: “Everyone is obligated to do whatever will achieve the greatest good for the greatest number.” Others are

just as devoted to the basic principle of libertarianism: “Everyone is obligated to act only in ways that respect the human dignity and moral rights of all persons.”

Ethical principles like these provide guidance for our actions; they balance stakeholder interests and personal motivations. People apply these principles by asking what is required of them when considering, for instance, whether to:

- Accept hospice care or begin a new invasive experimental treatment regime that lacks clinical evidence of its curative efficacy and may not be covered by health insurance
- Have an abortion or take to term a child that will be severely disabled, whether physically or intellectually or both

Health care professionals also apply ethical principles when they ask what is required of themselves or what is required of health care policies and organizations when considering, for instance, whether to:

- Provide affordable access to health insurance coverage to all members of society
- Limit health insurance coverage of medications and medical treatments to those that are determined to be effective based on evidence-based medicine
- Provide equal access to health care without regard to the ability to pay for such services

Ethical principles, though more general and requiring intelligent application, prevent health care ethics from being a mere list of rules and regulations. Many ethicists, in an effort to be helpful in the maximum number of cases, focus on principles so as to broaden the considerations beyond health laws and regulations, thereby preventing ethics from becoming a matter of checking whether actions are in compliance with carefully crafted rules of do’s and don’ts. This focus on principles also enables the discussion to include a very fundamental component of ethics: values. The traditional values of compassion, equality of opportunity, and justice are referred to throughout this text. These same ethicists point out that by focusing only on what people should do or how they should act ignores the more important issue of what human beings should be and what their health care systems should stand for. In other words, the fundamental questions of ethics are not what people should do, but what kind of person should they be; what social responsibilities should health care systems have as a result of their corporate existence (an existence that is derived from the people through their representative state governments)?

According to value ethics (or virtue ethics), there are certain ideals, such as a commitment to excellence, toward which everyone should strive and which allow the full development of humanity. These common ideals are discovered through reflection on what human beings have the potential to become. With this approach to ethics, one strives to grasp the core values of common ideals and then bring them to bear on everyday decision-making. The essential elements in these ideals, once identified, could hold the key to addressing true reform of the U. S. health care system.

Values are attitudes and character traits that enable people to be and to act in ways that develop their human potential. They enable the nation to pursue the ideals its people have adopted. How does a person, and then society, develop values? Values are developed through learning and through practice. People can improve their character by practicing self-discipline, while a good character can be corrupted by repeated self-indulgence. Just as the ability to run a marathon develops through disciplined training and practice, so too does the capacity to be fair or to be compassionate develop through daily effort.

Values become habits. That is, once values are acquired, they become characteristic of a person. For instance, people who develop the value of fairness are often referred to as being fair-minded because they tend to be fair in all circumstances. Moreover, people who

develop values are more disposed to act in ways that are consistent with their principles. The person who has values is the ethical person.

Habits create systems. At the heart of the value approach to ethics is the idea of systems. Ethical attitudes and character traits are not developed in isolation, but within and by the communities in which people choose to place themselves (including employers for which health care professionals choose to work). Individual personalities are affected by the ideals and values to which their communities attach importance and by the role models their communities present for imitation. This value approach urges health care professionals to pay attention to the contours of the health care systems in which they work and the habits of character that their employers encourage and instill.

Health care systems are only as ethical as the health care professionals who work within them, and vice versa. An ethical health care system will not tolerate unethical behavior by anyone associated with it, however far removed the person might be from the center. Ethics, then, is not simply a matter of having ethical principles and learning to apply them to specific situations. Health care ethics is a matter of trying to determine the kind of health care professional one should be and subsequently attending to the development of character within the health care system where one chooses to work.

Throughout this text are two strong, recurring themes: namely, that health care professionals have an obligation to be ethical and that the nation's laws should be reformed to help create health care systems that improve the quality and equality of health care for all stakeholders and members of society. A premise related to the imperative to create ethical health care systems is that the convergence of many health care sectors is rapidly changing the principles governing provider competition and regulation. These changes require the American legal system to expand the boundaries of health care ethics as it recognizes what is best and what is essential in the U.S. health care system.

While the health care industry faces unique ethical challenges, health care systems are increasingly shifting strategies to stay ahead of the curve of emerging ethical issues and government laws and regulations. Providers are constructing new breakthroughs in health care delivery and seeking to return to the common ideals of reason through modern science. All of this active change is taking place amid innovative U.S. reform initiatives. Health care ethics should challenge these dynamic changes with a stern but fair message about moral limits.

Text Approach

Real-World Knowledge

This text explores ethical dilemmas in which there are two or more valid decisions to choose from. Real-world issues are explored that are often decided based on personal ethics, such as abortion and end-of-life care. This text bridges research and practice, reflecting current issues facing the health care industry and government agencies. The ethics concepts in this text are old-fashioned practical questions of life: right and wrong and how to treat other people justly and fairly. The application of justice and compassion seeks to provide health care professionals with sufficient knowledge of ethics to become intelligent, critical thinkers in professional practice.

This is a practical ethics text relevant to undergraduate students seeking the basic management skills required to work in health care organizations, as well as graduate students currently working in health care organizations as health care industry administrators, physicians, nurses, pharmacists, therapists, scientists, and other administrative and clinical

managers. This text is also relevant to consumers of health care who are simply attempting to navigate the complex U.S. health care system. Every attempt is made within the text to support health care ethics with practical applications of ethical decisions that health care professionals face in their everyday lives.

Depth and Breadth

This text does not overwhelm students with technical language and logic; instead, it covers basic principles of ethics and then focuses on practical applications of ethics in the real world of health care delivery and practice. Challenging court decisions and current health care actions are presented. Learning experiences can be customized by selecting from 16 topical chapters or by studying a specific topic in-depth using the multiple online resources provided.

Ethical Principles

There is a focus on interpretation, insight into ideas of ethics, and the methodologies for ethical decision-making. Principles underlying the ethics of health care are woven throughout this text as reference points. Students can develop and strengthen their skills in ethical decision-making through examination of the difficult ethical considerations presented in each chapter. Traditional principles will, however, only serve as a reference. Students do not have to be confined to any one normative model or framework for making ethical decisions. Rather, students are encouraged to be disciplined and independent in their decision-making and discover new models for arriving at ethical decisions. Students can build new models that will assist them in thinking through the implications of ethical issues.

Normative Law Standards

What sets this text apart from other texts on health care ethics is its focus on the normative standards of the law in supporting the foundation for ethics. In contrast to the philosophical standards used in most traditional texts on health care ethics, in this text, the prescribed standards of conduct in almost every recent court decision of first impression are examined; cases of first impression set forth completely original issues of law for decision by the courts. This unique method of selecting court decisions to ascertain ethical underpinnings highlights the changing nature of ethics and its current effect on the health care industry. Significant U.S. Supreme Court cases, as well as landmark cases from the U.S. Courts of Appeal and highest state courts will also be examined where the decisions are still good law and relevant. Each of the selected court decisions in this text, and the accompanying Student Manual, addresses new, important, and substantive issues involving health care ethics.

Court decisions are examined with a focus on how ethical principles underlying the law are currently being applied, the correctness of traditional assumptions and choices, and what might be done differently in future similar situations. Although the role of the courts is to interpret and apply existing law, their decisions often prompt legislators to write new laws in response to new thinking and changes in society. Additionally, although it is not the role of the courts to make judgments about what is ethical or unethical, their decisions certainly contain assumptions about ethics. Therefore, in an effort to provide some help to

the reader in making ethical decisions, this textbook employs a methodology of examining recent U.S. court decisions for ideas about ethics. The courts are in no way dictating ethics, but their decisions may indicate the direction a society is moving in terms of its accepting or rejecting certain actions and whether those actions are tolerable or desirable from an ethical point of view. It should be emphasized again that legal does not equal ethical, but it provides some indications about what is considered ethical.

Models for Decision-Making

This text seeks to apply the best ethical practices to the health care industry. Students are exposed to decision-making models and their application in a health care context, whether in seeking new models to overcome the failure of markets and governments to provide health care to millions of people, or when searching for ways to better understand the nation's complex health care reforms. Students learn about key elements of ethics that allow the U.S. health care culture to operate.

State-of-the-Art Research on Health Care Ethics and the Law

This text is traditional legal scholarship written with state-of-the-art research methods, using online databases that are revolutionizing research on health care ethics and the law, including foremost:

- Knowledge@Wharton (Wharton School of the University of Pennsylvania)
- NLM (National Library of Medicine)
- Westlaw and LexisNexis
- OVRC (Opposing Viewpoints Research Center)
- ProQuest

The text reviews the philosophies of ethics and seeks common themes in the law as well as conflicts. Knowledge of the ethical considerations that arise as innovations transform global health care industry practices and public policy are clearly explained so that students can be open to new possibilities for applying what they learn when the ethical imperatives are not clear or are contradictory.

Primary Research with Health Care Professionals

Background information was obtained from a comprehensive search of published literature and reports obtained from various business, law, and medical trade journals. Secondary research of peer-reviewed journals is all-inclusive in a bibliography for each chapter; some reference is made to government reports and policy papers. This research, in turn, was supplemented with reviews by a panel of more than 30 health care professionals from all aspects of the health care industry. Their shared opinions and insights helped supplement the online databases with first-hand knowledge on current and future trends in health care ethics. They identified ethical matters that have the most social significance to them as leaders in the health care industry. This review process resulted in chapters having importance for real-world issues, present-day events, and the current state of the nation's health care reforms.

Organization of This Text

The text is divided into six general parts:

Part I, “Introduction to Health Care Ethics,” provides an overview of the ethical issues facing the U.S. health care system.

Chapter 1, *The Ethics of Health Care*, describes the ethical principles underlying the U.S. health care system; eight models for decision-making are provided to help health care professionals identify ethical issues and make the right decisions.

Chapter 2, *Values and Principles Confronting Our Health Care System*, explains how the health care industry seeks to develop systems to help it make ethical decisions; the focus of this chapter is on ten near-universal values that often govern and guide decisions when ethical dilemmas are reviewed.

Part II, “The Ethics of Access to Health Care,” addresses Americans’ resolve to obtain the best health care system for as little investment as possible; the focus is on what is fair and just.

Chapter 3, *Access to Affordable Health Insurance*, draws attention to the ethical obligation and challenge of finding a way to provide access to essential health care for all U.S. residents, especially vulnerable members of our society.

Chapter 4, *Patients’ Rights and Responsibilities*, looks at the ethical issues involved in health care reform legislation, patient rights, and universal basic coverage.

Chapter 5, *Charitable Care and Tax-Exempt Hospitals*, examines whether non-profit hospitals are required to provide mutually affordable health care in return for the substantial tax exemptions they receive; the focus of this chapter is on what is a fair health care bill.

Part III, “The Ethical Development of Human Capital,” concentrates on equality of opportunity in staffing U.S. health care organizations and the ethical issues of fairness affecting the management of employees.

Chapter 6, *Employers’ Health Care Costs*, deals with growing efforts to trim employers’ health care costs in an ethical manner. Particular attention is devoted to smoking- and weight-related behaviors and adherence to medication and treatment regimens, areas that are linked to preventable health conditions and health care cost savings.

Chapter 7, *Management and Labor Relations*, covers the ethical principles underlying the unionization of physicians and nurses, as well as newer concerns surrounding wage disparity in the health care industry.

Part IV, “Improving the Quality and Equality of Health Care,” explores areas that could combat rising health care costs and improve the quality and equality of health care.

Chapter 8, *Evidence-Based Medicine*, reviews the ethical issues confronting a discipline that has been around for a little more than a decade and is at the top of the list of improvements for improving patient safety, avoiding unnecessary medical procedures, and helping to provide more reliable and higher-quality health care.

Chapter 9, *Medical Malpractice*, considers the ethical dilemmas facing health care professionals when malpractice occurs, as well as medical standards of care and malpractice reform.

Part V, “Our Health Care System’s Ethical Response to Vulnerable Members of Society,” takes a systematic look at the intellectually disabled, people suffering from the effects of Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome (HIV/AIDS), and victims of gun violence. The emphasis is on the costs of health care for the most vulnerable members of our society.

Chapter 10, *Mental Health*, focuses on the ethical issues involved in the health care system’s response to mental illness. It seeks to address who should be responsible for the costs of living with a chronic mental disease or dangerous, severe mental disorder.

Chapter 11, *The HIV/AIDS Pandemic*, discusses the devastating HIV/AIDS epidemic; attention is focused on providing equal access to antiretroviral medications, which slow the progression of HIV/AIDS.

Chapter 12, *Environmental Safety and Gun Injury Prevention*, sets forth the ethical issues underlying the quandary of the modern U.S. health care system: while it is the most expensive in the world, Americans are neither healthier nor longer-lived than residents in other similarly situated countries.

Part VI, “Pressing Issues Facing Our Health Care System,” comprises of chapters describing pivotal ethical issues and real-world pitfalls the United States is confronting.

Chapter 13, *Women’s Reproductive Health*, spotlights the disparate provision of health care for procreation concerns. It addresses the ethical principles underlying reproductive issues against the backdrop of how abortion, the newer forms of contraception, and maternity care coverage are falling out of reach for more women in the United States.

Chapter 14, *Nutrition and Food Safety*, investigates ethical issues underlying the debate between the food industry and public health advocates over junk food, advertising, and obesity.

Chapter 15, *End-of-Life Care*, poses the ethical question of whether human beings have a right to die at a time and place of their own choosing.

Part VII, “Our Future Health Care System,” briefly overviews health care ethics within the context of health care reforms in the United States.

Chapter 16, *Our Future: A New Kind of Health Care Ethics*, offers a framework for ethical reform of the current health care system.

How to Use This Text

One of the strengths of this text is the consistent approach to topics in each chapter. Each chapter has been methodically developed so students have the opportunity to understand what the law is, as well as the ethical principles that act as a foundation for the law. This text can be used at both introductory and advanced levels by merely changing the amount of guidance provided in each chapter. The same format is used in each chapter:

- “Learning Objectives” provide an overview of what is to be learned in each chapter.
- “Key Terms” list the terminology and specialized terms used in the health care industry and its relevant law.
- “Ethical or Unethical Decision” sections at the beginning of each chapter are short vignettes pulled from in-depth articles or drawn from actual court decisions pertinent to the chapter, demonstrating that society cannot always separate right from wrong or always know what the most ethical course of action is.

- The heart of each chapter explains the basics of ethical decision-making for those with little or no training in ethics; namely, the importance of health care ethics, its basic principles, and how it applies to practical management applications. Specific court decisions illustrate how ethical issues are currently being identified and how ethical principles are being applied to decisions in the real world. Understanding the legal reasoning of these court decisions will assist in reaching the most ethical decisions, particularly when such decisions may involve transforming the current legal order.
- “Ethical Dilemmas” dispersed throughout each chapter offer students the opportunity to apply their decision-making skills on both sides of an ethical issue to rationally arrive at ethical decisions.
- The “Ethical or Unethical Decision” that introduces every chapter is revisited at the end, and applies what has been put forth in the chapter and what has been decided by the courts thus far.
- “Chapter Summary” summarizes the most important ethical issues and principles covered in each chapter. The Chapter Summary pulls together practical knowledge and insight on emerging trends in reform of the U.S. health care industry.
- “References” sections list the extensive body of research that provides the foundation of this text.

Teaching Materials

Dramatic changes in the health care industry have pushed forward new questions about value creation. Because the health care industry is a highly regulated environment, and there are genuine ethical issues that place individuals at risk, the integrity of this text is very important. This text will help students prepare for real-world challenges. The technology-enhanced learning tools accompanying this text are available in multiple formats to fit students’ learning preferences, and a range of instructional tools will meet virtually every instructor’s needs.

Study Guide

Students are provided with an online study guide as a resource to help them apply the ethical principles and concepts and to master the terminology. This guide, which will be updated periodically as the law evolves, includes:

- **Chapter Outlines.**
- **Review Questions** assess students’ knowledge.
- **Ethical Dilemmas** as they are presented in the text’s chapters, with additional thought-provoking questions intended to ask students to analyze the selected ethical issues by reference to the eight decision-making models. This is where students can reach reasoned and ethical conclusions based on ethical principles presented and discussed in each chapter.
- **Related Ethical Issues** reinforce practical insights gained in the chapter to assess or improve the outcome of ethical issues facing the U.S. health care system. These questions include emerging ethical issues addressed in recent law review articles and symposia.
- **Analysis of New Court Decisions** outlines the legal standards of conduct from emerging cases on the topics covered in each chapter.
- **You Decide** presents competing statements and counterstatements about the issues covered in each chapter. This section enables students to reach their own rational decisions on the basis of ethical principles and personal reflection on the issues.

- **Further Your Knowledge** provides detailed material citing the research supporting the chapter narrative in the main text. At times, this section expands upon the ideas described in the main text, explains important caveats, or offers additional examples of a compelling fact. This section will help students if they want to investigate certain topics in more depth, such as the relationship of a health care topic to Jodi Picoult's bestselling novels.
- **Web Links** provide the opportunity to do further research on the topics presented in each chapter.

Instructor's Resources

The Instructor's Resources are computerized tools for instructional needs. These comprehensive and convenient online materials are designed to enhance class discussion and measure student progress. They provide a wide variety of valuable items to help instructors plan their courses and implement activities by chapter. The availability of these resources in an electronic format increases their value as teaching resources. They include:

- Suggested talking points for the Ethical Dilemmas from the study guide with a focus on how the eight decision-making models could be applied, the correctness of traditional ethical principles and choices, and what different ethical principles might be used in future, similar situations
- Additional short vignettes of actual court decisions pertinent to each chapter
- Additional group and individual activities, including summaries of film and television documentaries
- Links to websites providing additional materials to research cited in the chapter References in both the text and the student guide
- **PowerPoint Presentations** are available to visually enhance lectures and aid students in note-taking.
- **Computerized Testbank** contains short-answer, multiple-choice, and true/false questions from each chapter. This versatile program enables instructors to create their own tests and to write additional questions.
- **Comprehensive Syllabus Templates** have been developed to help instructors customize specific course titles.

About the Authors

Donna K. Hammaker, a health law attorney, earned graduate degrees in law and government administration from Temple University School of Law and the Wharton School at the University of Pennsylvania, and completed graduate studies at the Hebrew University Faculty of Law and the London School of Economics. Before entering academia, Hammaker was a member of the Pennsylvania Bar, admitted to practice before the U.S. District Court for the Eastern District of Pennsylvania, and the U.S. Court of Appeals for the Third Circuit. Hammaker was also president and chief executive officer of Collegiate Health Care, the nation's first inter-university managed care organization. She has served on the adjunct faculty and taught graduate management and health law at Immaculata University, Pennsylvania State University, Rutgers University, Saint Joseph's University, and Widener University. Hammaker recently authored the textbook, *Health Care Management and the Law* with Sarah J. Tomlinson (Delmar-Cengage Learning, 2011).

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Sarah J. Tomlinson is an attorney with the Office of the General Counsel of Fox Rothschild, LLP, a national law firm with over 600 attorneys in 21 offices nationwide. The firm has extensive experience as counsel to health care facilities and organizations and advises hundreds of physicians, medical groups, and health care institutions and provides representation in litigation, corporate, regulatory, and transactional matters. Tomlinson, a member of the Pennsylvania Bar, is a doctoral student in public health with a focus on health policy at Temple University's College of Public Health, and has earned graduate degrees in law and business administration from Villanova University School of Law and Pennsylvania State University. She is also a member of the adjunct faculty at Immaculata University, where she teaches legal and social aspects of health care administration and nursing law. This is Tomlinson's second textbook publication involving health law.

Interaction with the Authors

The standard for this text on health care ethics is excellence. Our goal is for every instructor adopting this text to have an excellent experience with it, along with its ancillary teaching materials. Adopters of this text may contact the authors to ask questions regarding materials in this text, to offer suggestions, to share teaching concerns, or to seek resolution of health law and ethics disputes. If the next generation of health care managers can reclaim a supple awareness of the challenging standards of ethics, the U.S. health care system may regain some of its earlier prestige. As Tocqueville maintained in his 1840 influential text about American law and society, *Democracy in America*, the greatest task of each generation is not to erase the past and reconstruct the present, but to recognize what was best in the past, what was essential, and to carry it forward.

The U.S. health care system will thrive again when the nation learns to acknowledge the force of this insight. However, if health care ethics is seen as nothing but a collection of arbitrary rules and regulations, and social forces are treated as obstacles to be overcome, rather than as shared boundaries to be reckoned with, the U.S. health care system will stay in its current crisis mode. Health care ethics should not be a wholly owned subsidiary of any one ideology. Instead, health care ethics should challenge all ideologies, with a firm understanding of the limits of law in a democracy based on notions of ethics and morality.

Donna K. Hammaker
Thomas M. Knadig
with Sarah J. Tomlinson

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Kaymak, Yilmaz C.: Novocure	

Textbook Features



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Learning Objectives

Describes what readers should be able to do after completing each chapter.

Key Terms

Lists important terms that are defined and used in each chapter.

Ethical or Unethical Decision

Helps readers reach a judgment on the basis of ethical principles and personal reflection. The greater societal context of decisions should be considered, as opposed to yielding to more selfish drives or incremental changes that merely support maintenance of the status quo. The decisions are often derived from current headlines. Ethics should be integrated with the law instead of distinguishing between the law and ethics.

Ethical Dilemmas

Expands upon the ethical issues presented in each chapter. While Congress, state legislatures, and lower trial courts are debating these dilemmas, they have not been satisfactorily dealt with by the highest federal and state appellate courts or the U.S. Supreme Court.

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Although the nation's highest courts can provide hints and inklings about ethics, it is ultimately each individual's responsibility to make rational decisions about ethics based on fair and just criteria. Thus, while there is a lack of widely accepted agreement for or against any of the choices possible relating to the ethical dilemmas in this text, reasoned and ethical conclusions should be based on ethical principles, as well as other common standards essential for a civil society built upon just law. To avoid emotion and prejudice, it is important that decisions be made in honest consultation with others who also seek just and reasoned resolutions of ethical dilemmas.

Law and Ethics Analysis: Court Decisions

Summarizes the legal assumptions and ethical choices used by the courts (U.S. Supreme Court, U.S. Courts of Appeal, highest state courts) in their analysis of the issues presented in this text. The law necessarily involves ethical reasoning in judicial decision-making. Material in these sections presents the legal reasoning of these court decisions, many of first impression, involving questions of law which have been presented for the first time and which have never been decided before in any reported court decisions. The case summaries will assist reflections on how to reach the most ethical decisions, particularly when such decisions may involve transforming the current legal order. References, where available, at the end of each case summary provide additional commentary on the court decisions; law review articles that simply cite the court decisions (but do not make any type of analysis of the decisions) are not listed.

Chapter Summary

Provides an overview of each chapter.

References

Helps readers investigate topics in more depth. Each citation expands upon the ideas described in each chapter, explains important caveats, or offers additional examples of a compelling fact.

Foreword

Human judgment and perceptions are malleable. For instance, in one research study by Christopher Chabris and Daniel Simons, two cognitive psychologists at the University of Illinois, subjects were asked to watch a video and count the number of times players with white shirts passed a basketball (Simons & Chabris, 1999). Most of the subjects achieved a fairly accurate count of the passes, but less than half saw something more important: a person in a black gorilla costume walking right into the center of the action and then moving off. More than half the subjects were so involved in the counting task that they did not perceive the gorilla—an entire gorilla—right in front of their eyes! *See generally* Chabris & Simons, 2010; Wind & Crook, 2006.

It is sobering to consider: Focused attention creates blinders that limit what our mind perceives overall. The question to keep in mind when thinking of health care ethics is this: What parts of the U.S. health care system are blindly driven by our narrow perceptions and failure to perceive the gorilla moving through our entire field of vision?

Health care ethics is often defined in terms of rules, principles, values, and decision processes. Ethical issues are a product of what our minds determine to be ethical. A simple idea indeed: what is acted upon is more a product of shared perceptions than reality. This idea, however, has far-reaching implications, as the decisions reached and actions taken in the ongoing reform of the U.S. health care system are directly affected by our perceptions.

Different Perceptions But Shared Values

The focus of this text is how best to cultivate ethics in health care. The goal is to embark on a journey toward a higher quality and more equitable U.S. health care system by considering the nation's shared values. As the nation reforms its health care system, four questions arise:

- What wisdom is found in writings from previous centuries to the present time that helps guide us in making ethical decisions?
- What fresh perceptions can be discovered by exploring the ethics of new and different systems of delivering health care?
- What are the sources of the principles that are the foundation for the nation's collective thinking about ethics in health care?
- Which ethical principles should be retained in order to make sense of new ones?

Different perceptions about ethics in health care may be the biggest obstacle to realization of the concept of what constitutes an effective, efficient, high-quality health care system. The rightness or wrongness of the U.S. health care system is judged by generally accepted ethical principles; for instance, how right or wrong is the measure of providing affordable access to health insurance coverage to nearly all members of American society? To transform the U.S. health care system to achieve and equitably deliver quality health care may require a transformation of the American idea of what is ethical.

New Approach to the Ethics in Health Care

Changing the nation's thinking about health care ethics creates powerful opportunities for action. The health care industry plays a major role in the U.S. economy and, according to almost any objective account, a highly positive role. Admitting the current inability to

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identify a common public ethic could be the beginning of newfound wisdom with regard to health care reform. In other words, any reform of health care will first require acknowledging the gorilla in the room. The debates about the right to access health care, efficiency, and quality, not to mention the many debates surrounding such discrete health care issues as contraception, guns, and HIV/AIDS, among many others, are the players in the white shirts. The gorilla is what constitutes fairness in the allocation of the nation's limited resources.

Values Driven

We often think the world is how we perceive it and that everyone else's values are as we know them for ourselves. The principles of ethics, as illustrated in Feature Box F-1, that underlie most American values, are explained in this text along with explanations as to what they mean in a health care setting.

FEATURE BOX F-1

What is the meaning of these seven principles of ethics?

1. Ethical issues arise when actions or situations involve actual or potential harm to someone or something.
2. The action that provides the greatest benefit is the most ethical.
3. All actions should strive for the highest quality outcomes (not just high-quality outcomes).
4. Everyone must be accorded respect as human beings.
5. Individuals must always be treated as an end, not merely as a means. To treat anyone as a means is to use them to advance self-interests, but to treat everyone as an end is to respect their human dignity by allowing them the freedom to choose for themselves.
6. Individuals should be treated the same, unless they differ in ways that are relevant to the situation in which they are involved.
7. Whenever anyone is treated unequally on the basis of arbitrary characteristics, their fundamental human dignity is violated.

Motivated by Decision-Making Models

Although most Americans are driven by ethical principles, we are also driven by decision-making models, or the cognitive patterns we use to determine whether an action or situation is ethical or unethical. Consider the underlying values behind these decision-making models that could help the nation recognize and resolve the most pressing ethical issues in health care.

What do most Americans think about once they read the seven ethical principles listed in Feature Box F-1?

- What are the assumptions underlying these ethical principles and what should be investigated further to determine which situations would logically follow if the assumptions were accepted?

- Could a single, coherent principle make sense of all these assorted principles?
- Which principles underlying these values should be reexamined, and which would be simply reinventing the wheel?
- What role do the values of compassion, justice, and equality of opportunity play in the U.S. health care system?
- To what extent are the nation's leaders mindful of the decision-making process behind transforming the U.S. health care system?

Mind Barriers

We must continually examine the principles that shape the nation's thinking about ethics in health care. Americans may think health care reform is too complex or that established interests are too entrenched to change, but these barriers may simply be in the nation's mindset or collective consciousness. The nation's sense of ethics could be preventing some of the best elements of the U.S. health care system from reclaiming the ideals of reason through rational decision-making.

Today, there are three attitudes very prevalent in the nation's mindset that make it difficult to perceive ethical issues in the health care space.

- *Pluralism*: Differences in what is valued in health care make it difficult to perceive what represents an ethical issue.
- *Relativism*: Even when everyone perceives an ethical issue, there are disagreements about the relative values of competing interests.
- *Individualism*: Historical tradition in the United States places a high value on allowing individuals to act independently. In our individualistic culture, it is difficult to convince Americans that they are not, ethically speaking, completely free to pursue their own personal ends without regard to the harm their actions may cause others.

The combined attitudes of pluralism, relativism, and individualism make it difficult to perceive harm or to recognize ethical issues generally.

Testing Reality

Instead of accepting the nation's mindset as it is, extensive use of various decision-making models is needed to determine what is working best in U.S. health care and why. Some areas to explore include:

- What incentives can be created to insure the uninsured and provide affordable access to health insurance coverage to as many members of society as possible?
- How can the U.S. health care system be changed to motivate everyone to adopt behaviors that prevent or delay the onset of most chronic diseases and illnesses?
- What will induce health care providers to use evidence-based medicine that is based on the best available scientific evidence, as opposed to making decisions based on clinical experience?

Perhaps new ethical principles should be developed to achieve high-quality, equitable health care with:

- Government-funded subsidies to ensure affordability
- Mechanisms to ensure health insurance availability
- Management of risks that can prove profitable (rather than managing avoidance of risks)

Is this vision part of the nation's new collective consciousness, or is it just the tip of the iceberg on a sea of possibilities that are yet to be discovered ?

Cognitive Patterns in Our Decision-Making

Neuroscience can be helpful in understanding how our minds work to create and preserve old decision-making models and how to change the framework for decision-making in order to develop new decision-making models. We think we perceive the real world, but we actually perceive the cognitive patterns, or structured relationships and concepts stored in our minds, evoked by new external situations. We only partially perceive the new sensory stimuli we take in; we actually perceive the relationships evoked by our neural activity. *See generally* Freeman, 2000, 2001; Wind & Crook, 2006.

In other words, neuroscience has shown that we do not really perceive what we take in. As stimulation flows into our brains, it evokes a pattern that the mind uses to represent the external situation, so we are not aware that what we are actually thinking is what is already in our own minds (Chabris & Simons, 2010; Wind & Crook, 2006). Walter Freeman, a biologist, theoretical neuroscientist, and philosopher at the University of California at Berkeley, has conducted pioneering research on how the mind generates meaning. Freeman discovered that the neural activity due to sensory stimuli disappears in the brain's cortex. It disappears! We do not really perceive what we take in (Wharton, 2005). With this situation in mind, we may ask:

- How can this text be used to come up with different mindsets to view the ethics of health care?
- What ethical issues are overwhelming, and is it possible to zoom out to look at the broader social context?
- What ethical issues are limited by an overly broad perspective, and is it possible to zoom in to examine the details and their effects on individuals affected?

Once again, it is sobering to consider: we think we perceive real ethical issues, but we actually only perceive the cognitive patterns that are already in our minds (Wind & Crook, 2006).

The Neuroscience of Cognitive Patterns

If we are not aware of the power of the cognitive patterns in our minds that are used to generate new thoughts, we may just accept what we think we perceive as reality. This misunderstanding of reality can be limiting, and sometimes even dangerous, because we tend to be comfortable with and dependent upon our cognition, the actual thinking process that produces our perceptions (Wharton, 2005). When we perceive new information, we form new cognitive patterns, or modify or extend old ones. New thoughts arise from combinations of cognitive patterns that already exist in our minds. These new thoughts, in turn, shape and filter our future perceptions. This added functioning is the foundation of our thinking process. In other words, we begin with what we have in our minds and expand upon it.

Because our minds tend to resist changes in cognitive patterns, the process of generating new ideas and creating new cognitive patterns can be difficult. One instance of this conceptual inertia is health care reform; we have a hard time moving away from what we know and what we already do. This is why changing the U.S. health care system opens everyone up to uncertainty and risk, along with perhaps our jobs, or our employers' ways of doing business. Most of us are risk averse, staying within our comfort zones, even if it causes increasing problems. *See generally* Wind & Crook, 2006.

Filtered Thinking

Once we acknowledge that our views are shaped and filtered by our own sometimes out-of-date thinking, we understand why many health care professionals choose to travel down

well-worn pathways. A conscious effort is required to think about health care reforms on less traveled pathways in a way that the dominant status quo does not drown out reform ideas originating on weaker neural pathways. We must recognize the need to constantly compare the health care system the nation has against the health care system the nation should have.

In allowing a wider range of health care reforms to be brought to resolving the problems in U.S. health care, the usual filtered thinking that would otherwise be perceived as irrelevant by the dominant pathway does not occur. A wider range of views becomes available that makes possible a creative combination of existing ideas to address various questions.

- Do the medical products and health care services most Americans have meet the expectations of what they want and need?
- Does the U.S. health care system meet the needs of most Americans, and do most Americans think it will continue to do so?
- Is the continued enhancement of the U.S. health care system worth the costs, and how might the health care system look without this cost limitation?
- How can the federal government help design new experiments so the states can test the limits of shared values or gain new insights that might suggest new values and new ethical principles?

Test Decision-Making Models

There is a real need for a systematic way to approach the process of making ethical decisions in health care. Fortunately, normative standards of conduct have developed over time and across cultures as rational people of goodwill have considered human relationships and how human beings act when they are at their best. The first chapter of this text explains eight decision-making models based on the insights of major philosophers of ethics from ancient times to the present (Social Media Model, Utility Model, Rights Model, Exceptions Model, Choices Model, Justice Model, Common Good Model, and Virtue Model). These decision-making models, while rational, must still be constantly tested instead of simply relied upon as accepted frameworks to decide what is ethical or unethical. This modeling and re-modeling will help determine what the ethical principles are today and what will work best tomorrow.

As the nation decides what to do next, now that comprehensive reform of the U.S. health care system is both economically necessary and legally feasible, one decision-making model that could be used in making decisions is the Choices Model. Under this model, respect for every member of society is a priority, with a focus on how decisions are made.

- Everyone is given the freedom to choose what they value. We are not free to make our own choices if we are forced to choose something we do not value. For instance, existing health insurance laws and regulations may limit our freedom to choose the health care we want and value most.
- The Choices Model gives everyone the information necessary to know what they value most in the situation being considered. For instance, no longer is the starting point in health care reform about whether to expand insurance coverage of essential health care. The debate going forward is how to do it and how to make it affordable for everyone.
- Make an ethical decision and decide whether the new situation gives everyone the freedom and the information to choose what they value. For instance, while nearly all members of society have a right to purchase adequate health insurance, everyone must also have the freedom to decide what is adequate.

Putting the Decision-Making Models Together

While each of the eight decision-making models helps determine what standards of conduct can be considered ethical, several issues remain.

- Not everyone agrees on the content of some of the specific approaches presented in this text, especially some of the more controversial issues.
- There is a lack of national consensus on what constitutes human rights and the common good.
- There are few, if any, generally held ideas regarding the ethics in health care and proper conduct that everyone would agree are morally justified all the time.
- Implementation of the advantages and benefits of health care reform are being constantly challenged, with little national agreement on what is a benefit and what is a harm.

It is disheartening that, for all the nation's talk of reform, it appears that many stakeholders in health care still devote themselves to perpetuating their own interests, not to advancing the nation's common good, despite the health care system's formidable power to do so.

Making Ethical Decisions

Making ethical decisions requires a trained sensitivity to ethical issues and a practiced method for exploring the ethical aspects of a decision and weighing the considerations that should affect the choice of a course of action. Having a portfolio of decision-making models to call upon in any given challenging situation is absolutely essential for anyone working in the health care industry. When used regularly, the models become habitual; we can automatically work through them without consulting the specific steps.

Power of Rational Thinking

Debates in neuroscience focus on our minds as computers versus evolutionary-based biological systems subject to human error, and on the influence of nature versus nurture in shaping our thinking. Our minds constantly change and evolve over time; their architecture is not static, like machines. Over one billion neurons continually die and regenerate. Several trillion synapses are continually destroyed and re-created. Our minds select and reinforce or weaken certain synapses to forge the complex neural structures that determine our thinking. *See generally* Wind & Crook, 2006.

Practical steps to understanding, and perhaps changing, thinking about the ethics in health care include:

- Becoming explicitly aware of why we perceive, or fail to perceive, ethical issues and what that implies
- Understanding the relevance of ethical principles and deciding if they still fit or whether the principles should change and new principles ought to be generated
- Developing a portfolio of decision-making models that:
 - Minimize the risk of not following ethical principles
 - Allow the use of the decision-making models that work best for particular actions and situations
 - Prevent ethical principles from becoming dogma, an absolute transformation, or revolution
- Overcoming the inhibitors of change and reform by reshaping the decision-making infrastructure and helping others change their own thinking

- Experimenting with and continually assessing and strengthening our decision-making models

See generally, Wind & Crook, 2006.

Inattentional Blindness

Inattentional blindness, also known as *perceptual blindness*, occurs when the collective thinking of individuals is adapted at different rates (Chabris & Simons, 2010). It is the term applied to the gorilla study described earlier, where participants were so focused on the counting task at hand that they missed a glaringly obvious, unexpected, object in plain sight. Variations between what is considered ethical and unethical, right and wrong, legal and illegal are shaped by the:

- Differences in values and perceptions
- Distinction between the goals and priorities of regulators and the regulated
- Divergent views within health care delivery systems between administrative and clinical staff, and among health care professionals and consumers of health care
- Dissimilar requirements of the health insurance industry and the insured
- Differences in ethical principles and opinions as to what health care reforms are needed or not needed

The invisibility of the gorilla is a reminder that looking at something is not necessarily the same as seeing it. Paying attention to one thing often comes at the cost of missing something else altogether. It is not enough to simply change one's thinking about ethics in health care, however. The practical infrastructures and routines that support ethical decision-making must also be addressed.

- What ethical principles does the U.S. health care system currently use?
- How does the choice of decision-making models shape each health care sector's position on ethical issues and their decisions about them?

Zooming In and Zooming Out

In light of this immense complexity, we must learn to both zoom in and zoom out. When examined in detail, parts of a system, like almost any phenomenon, will seem to be unstable, even fluctuating wildly. It is important for us, as stakeholders in the U.S. health care system, to develop the ability to zoom in and zoom out our thinking. For instance, zooming in may focus on details underlying core medical technologies. Zooming out focuses on how those technologies will impact the larger health care space, such as questioning how society will pay for the advanced medical technologies being developed.

New Approach to Ethical Decision-Making

We must focus on what to do with the principles of ethics and understand the process of making ethical or unethical decisions. Health care systems, like individuals, must focus on the forces that shape and reshape their ethical principles. There are several ways to change the nation's decision-making about health care.

- The process for making sense of the ethics in health care should be understood in terms of ethical principles
- The difficulties in setting cost limits and perceiving things differently must be recognized

- The neuroscience of cognitive patterns involved in everyday decision-making must be implicitly understood and acknowledged

Only then can the national framework for decision-making be transformed.

Practical Implications of This New Approach to Ethics

The practical implications are limitless for this new approach to ethics in health care. There is great risk in changing old views about the ethics in health care, according to which health care was available based largely on the ability to pay for such care. At the same time, there are great possibilities in the unprecedented opportunities to blend the best of the old and the new so that nearly all members of society will have access to affordable health insurance coverage. In this text, always ask:

- What principles of ethics underlie the court decisions and health care actions reported?
- What are some different decision-making models for looking at the situations outlined in each chapter?
- How do different ethical principles change the options available?

The possibilities for creative thinking in reform of the U.S. health care system are endless. Once we consider what we are attempting to do—create new pathways in our minds—and how we might do it, the road seems less formidable (Weinstein & Morton, 2003). Pay particular attention to how different ethical principles often define the battle lines on ethical issues. Throughout this text, readers should consider whether the nation's shared principles of ethics in health care are promoting or limiting individual and societal interests.

By Colin Crook, Senior fellow of The Wharton School of the University of Pennsylvania and former Chief Technology Officer for Citicorp, co-author, The Power of Impossible Thinking: Transform the Business of Your Life and the Life of your Business, with Yoram (Jerry) R. Wind, also of The Wharton School.

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Introduction

If you think that our country is just as confused about our national ethical perspective on health care since the Affordable Care Act as it was before its passage, then you are about to find that you are not alone. Neither are you incorrect. That is because there is no one national ethical perspective on health care. As Americans, we are fiercely tied to and proud of our individual values and morals. How will we ever combine over 318 million viewpoints into one mindset?

As a co-author of the Affordable Care Act, this was the challenge we faced in trying to write a law that both sides of the congressional aisle would find acceptable enough to enact, and what a challenge that was! This Act finally aligns Americans with the rest of the developed world in believing that health care is a human right, not a privilege. But as everyone is already aware, we still have a long way to go.

Health Care Ethics and the Law presents readers with over 150 ethical dilemmas that have no clear resolution in either the courts of law or the court of public opinion, from macro issue questions, such as “what is holding back decisions on implementing U.S. health care reforms?” to micro issue questions, such as “is obesity, and with it diabetes, an individual and family responsibility, or do governments and public health agencies have a role in preventing diet- and weight-related diseases?” But instead of leaving readers hanging with the present state of uncertainty, this text provides readers with a framework of eight decision-making models, ten universal values, and eight principles in the American Ethic to draw upon when deciding these issues for themselves, both personally as health care consumers and professionally as health care providers. Do I ever wish I had such a roadmap when I was grappling with these issues as General Counsel at Keller Army Community Hospital!

My special friends, Donna, Thomas, and Sarah, have made a significant contribution toward helping us clarify our thinking on health care reform and its underlying ethics. As an educator myself, I value this book for its role in encouraging readers to become principled humanitarians, which is precisely the sort of health care professionals that we need to continue working toward our goal of ensuring that all Americans have the right and the means to pursue the American dream. I hope you will join me in the national conversation aimed at improving our individual health and our health care system.

Sincerely,



Honorable Patrick J. Murphy
Former Congressman, Pennsylvania 8th District

List of Abbreviations

ACA: Affordable Care Act of 2010

ADA: Americans with Disabilities Act of 1990

AIDS: Acquired Immune Deficiency Syndrome

ARVs: anti-retroviral medications

CHIP: Children's Health Insurance Program

CNA: California Nurses Association

CPR: cardiopulmonary resuscitation

CSA: Controlled Substances Act of 1970

DERP: Drug Effectiveness Review Project

DNR: do-not-resuscitate

DOJ: U.S. Department of Justice

D&E: dilation and evacuation

D&X: intact dilation and extraction

EBM: evidence-based medicine

ECs: emergency contraceptives

ERISA: Employee Retirement Income Security Act of 1974

FLSA: National Fair Labor Standards Act of 1938

FDA: U.S. Food and Drug Administration

GRAS: generally recognized as safe

GM: genetically modified

HFCS: high-fructose corn syrup

HHS: U.S. Department of Health and Human Services

HIV: Human Immunodeficiency Virus

LSMT: life-sustaining medical treatment

MEC: medical ethics committee

NEISS: National Electronic Injury Surveillance System

NICBCS: National Instant Criminal Background Check System

NLRA: National Labor Relations Act of 1935

NLRB: National Labor Relations Board

NVSS: National Vital Statistics System

OTC: over-the-counter

PDA: Pregnancy Discrimination Act of 1978

PLCAA: Protection of Lawful Commerce in Arms Act of 2005

PCORI: Patient-Centered Outcome Research Institute

PTSD: post-traumatic stress disorder

PVS: permanent vegetative state

STD: sexually transmitted disease

TB: tuberculosis

USDA: U.S. Department of Agriculture

VA: U.S. Department of Veteran Affairs

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- AT&T Corp. v. Hulteen*, 129 S. Ct. 1962 (U.S. Supreme Court 2009) (workplace accommodations for pregnant employees; see Chapter 2).
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- Thomas More Law Center, et al. v. Barack Hussein Obama, et al.*, 651 F.3d 529 (U.S. Court of Appeals for the 6th Circuit 2011), *cert. denied*, 133 S. Ct. 61 (U.S. Supreme Court 2012) (individual health insurance mandate [see Chapter 1]; fidelity or infidelity to the law [see Chapter 16]).
- Torres-Lazarini v. United States*, 523 F.3d 69 (U.S. Court of Appeals for the 1st Circuit 2008) (opportunity to sue for medical malpractice; see Chapter 9).

Tummino v. Torti, 603 F. Supp. 2d 519 (U.S. District Court for the Eastern District of New York 2009), *reconsideration denied*, *Tummino v. Hamburg*, 260 F.R.D. 27 (U.S. District Court for the Eastern District of New York 2009) (emergency contraception; see Chapter 13).

United States v. Franklin, 435 F.3d 885 (U.S. Court of Appeals for the 8th Circuit 2006), *rehearing denied* (U.S. Court of Appeals for the 8th Circuit 2006) (conditional release from involuntary commitment; see Chapter 10).

United States Citizens Association, et al. v. Sebelius, et al., 754 F. Supp. 2d 903 (U.S. District Court for the Northern District of Ohio 2010), as amended 2011 (access to health care; see Chapter 3).

Virginia ex rel. Cuccinelli v. Sebelius, et al., 656 F.3d 253 (U.S. Court of Appeals for the 4th Circuit 2011), *cert. denied*, 133 S. Ct. 59 (U.S. Supreme Court 2012) (the ethics of individual health insurance mandates [see Chapter 1]; access to health care [see Chapter 3]).

Virginia Mason Medical Center v. National Labor Relations Board, 558 F.3d 891 (U.S. Court of Appeals for the 9th Circuit 2009) (refusal to bargain; see Chapter 7).

Virginia Office for Protection and Advocacy v. Stewart, 131 S. Ct. 1632 (U.S. Supreme Court 2011) (abuse and neglect of mentally disabled patients; see Chapter 10).

Waddell v. Valley Forge Dental Associates, Inc., 276 F.3d 1275 (U.S. Court of Appeals for the 11th Circuit 2001), *cert. denied*, 535 U.S. 1096 (U.S. Supreme Court 2002) (HIV infection as a disability; see Chapter 11).