AN INTRODUCTION TO HEALTH CARE ETHICS

Theological Foundations, Contemporary Issues, and Controversial Cases

Michael R. Panicola, PhD

David M. Belde, PhD

John Paul Slosar, PhD

Mark F. Repenshek, PhD

Saint Mary's Press®

In gratitude, we dedicate this book to

Dr. Ronald P. Hamel
Friend, Mentor, Colleague, Scholar

Acknowledgments

Our thanks to the following individuals who advised the publishing team or reviewed this work in progress:

Dr. Debra Bennett-Woods, Regis University, Denver, Colorado

Dr. Janine Idziak, Loras College, Dubuque, Iowa

Dr. Karen Elliott, CPPS, Mercy College of Northwest Ohio, Toledo, Ohio

Dr. Ron Hamel, Catholic Health Association, St. Louis, Missouri

Rev. Steven O'Hala, Saint Vincent de Paul Regional Seminary, Boynton Beach, Florida

Dr. Tim McFarland, Saint Joseph's College, Rensselaer, Indiana

The publishing team included Leslie M. Ortiz, general editor; John B. McHugh, director of college publishing; prepress and manufacturing coordinated by the production departments of Saint Mary's Press.

Cover: royalty-free image from Veer Incorporated

Charts designed by Jason Spinks

Printed in the United States of America

7002

ISBN 978-0-88489-944-0

Library of Congress Cataloging-in-Publication Data

An introduction to health care ethics: theological foundations, contemporary issues, and controversial cases/Michael R. Panicola . . . [et al.].

p. cm.

Includes bibliographical references and index.

ISBN 978-0-88489-944-0 (pbk.)

1. Medical ethics. 2. Medical ethics—Religious aspects—Christianity. I. Panicola, Michael R.

R724.I63 2007

174.2—dc22 2007025889

CONTENTS

PREFACE

This book is intended as a faith-based introductory text in health care ethics geared toward college students. We believe this book offers something distinctive in that it does not assume extensive knowledge of theology, ethics, and medicine on the part of college students.

In many ways college students are only beginning to come to grips with their particular moral sensibilities. Therefore, this text provides ample opportunities for self-reflection and group discussion. It does this through interactive exercises and case studies that stimulate self-learning and class discussion. Our goal is to encourage moral reflection and moral discourse rather than resort to ready-made and proscriptive answers to concrete dilemmas. This book examines real-life concerns and issues that confront real people every day across this country. It is a realistic applied ethics textbook written by theological ethicists working in the field.

Four interdependent elements comprise the overall structure of the book: (1) a normative ethical basis; (2) examination of particular issues; (3) case studies; and (4) multimedia aides.

The normative ethical basis is presented in chapters 1–4. In our experience as college teachers and in our work within health care institutions we have learned that it is pointless to discuss controversial issues without some kind of normative framework. Without a normative framework, ethical discussion inevitably turns toward individual relativism. Our normative approach is not a moral method per se. That is, it does not provide a methodological process for ethical decision making. Instead, it presents a picture of who we ought to become as people living in community. The central concern of our normative approach is human and social flourishing. While principles and virtues are used to provide some objective basis for ethical decision making, our normative

approach is rooted in a holistic view of the person and principally concerned with the role of discernment in attaining human and social flourishing.

The issues are presented in chapters 5–12. We focus on issues that arise in clinical medicine, examining them in the light of our normative approach. This normative approach is also concerned with the social conditions that contribute to making these issues ethically problematic. We ask that students and professors take these social conditions seriously: they are not simply "add-ons" meant to increase classroom dialogue.

Within the issues section we have included case studies to give real-life relevance to the book. Some of these cases we have confronted in our daily work. They are intended to show how particular circumstances have an impact on ethical decision making. The case studies can be incorporated easily into creative teaching and learning strategies. At the end of each chapter we recommend further readings and multimedia aides such as documentaries and movies that touch on the core themes of the chapter.

This textbook is the product of four authors. In it, you will encounter four different voices and writing styles. While our normative ethical basis is grounded in some values and concepts that are central to the Catholic moral tradition—such as human dignity, justice, and human flourishing—this book is not intended as a textbook on Catholic health care ethics.

As is often the case in ethics classes, you will no doubt encounter a range of opinions and perspective. We encourage such open discourse. We also ask that you share with us your opinions and perspectives regarding this text. In particular, we would like to know how we might modify the book so that future readers may benefit from your experience with it.

CHAPTER 1

Ethics and Its Role in Health Care

Context for Understanding

Each of us encounters ethics every day, whether we are aware of it or not. We cannot avoid situations that force us to make ethical choices because ethics cuts across every facet of our lives. There really is no part of human life that is ethics-free—not politics, not sports, not journalism, not medicine, not education, not marriage, not friendships. Despite our daily experience with ethics, it remains one of the hardest concepts to define. Think about it for a minute. How would you define ethics? What descriptive words or phrases would you use?

Understanding Ethics

What Is Ethics?

Most people, when asked this question, say something about right and wrong actions and then highlight some of the sources of morality or ethics that shape how we act in concrete situations, like personal values, religious beliefs, rules, laws, customs, traditions, and feelings. How we act in concrete situations and what sources inform our decisions are definitely a part of ethics, but ethics is much more. So before we start talking about health care ethics and getting into the more complex issues of our day, we need to get a sense of what ethics is generally and what it requires. This will better prepare us for what lies ahead in this book and hopefully in life. To get us pointed in the right direction, consider the following cases.

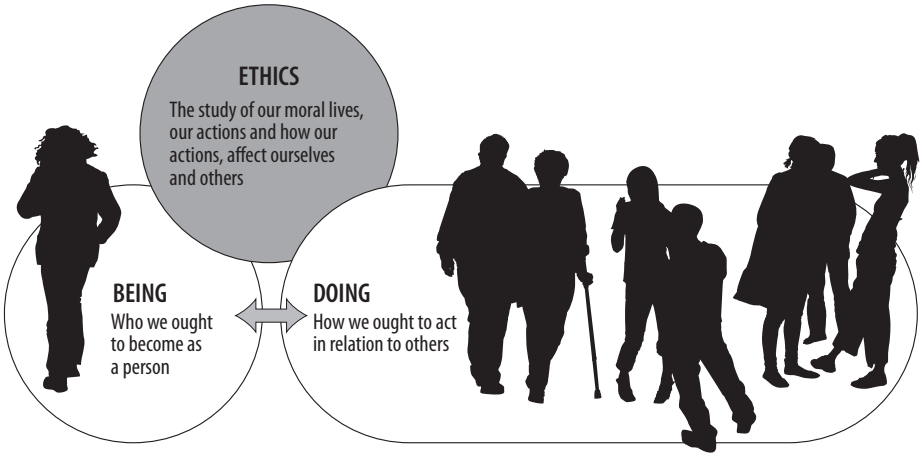
Case 1A: Last night while out on the town with your friends you witnessed your best friend's boyfriend kissing another girl. He noticed that you saw him and he immediately came over to you to beg you not to tell. He tried to explain that he and your friend have been going through tough times and that the kiss meant nothing; it was simply a dumb mistake made while caught up in the moment. The next day you see your best friend, who asks you how last night was. Do you tell her what you saw?

Case 1B: You are a mid-level executive in a fairly large, fast-moving organization. You value your job and know that you would have a difficult time finding another like it in the same place with the same salary level—which is important, given your considerable school loans and other monthly bills. One unpleasant aspect of your job is that your supervisor seems less talented than his staff and is prone to violent outbursts with some of the lower-ranking employees in the department. Just recently he berated his administrative assistant in public for not having a report completed on time, even though he had given her the necessary data at the last minute. It was obvious to everyone in the department that he was attempting to blame someone else

for his poor work habits. You would like to do something about his behavior, perhaps report him to one of his superiors. However, he has gained the favor of the president over the years, due largely to his ability to bring in the big accounts. Consequently, no one is willing to stand up to him and you will have to go it alone. You are unsure how your accusations will be handled. You fear that you will be seen as a "problem," and could even lose your job. What do you do?

Laying aside the question of what we should or should not do if we found ourselves in these situations, what do these cases tell us about what ethics *is*? Stated simply, these cases deal with ethics because any decisions made will have an impact on the well-being of people and communities. Whether we decide to tell our friend about the kissing incident or stand up to our boss will not only affect our character and quality as individuals but also that of other people and community life as a whole. This gets to the heart of what ethics is all about: the moral lives and actions of people and the impact of our actions on the well-being of others. Ethics always seeks to answer two interrelated questions: who ought we to become as people (*being*), and how ought we to act in relation to others (*doing;* see *Figure 1A*).

Figure 1A: What Is Ethics?



Consequently, ethics considers such things as:

- The ***goal(s) of human life*** and what our lives should ultimately be directed toward (e.g., love of God, right relationships, just social order)
- The ***virtues*** or character traits, attitudes, feelings, and dispositions that should define us as people and shape how we act in relation to others (e.g., love, compassion, honesty)
- The ***principles*** that should guide our decision making, conscience formation, and discernment in concrete situations (e.g., human dignity, justice, solidarity)
- The ***circumstances***, including the facts surrounding the situation and the consequences of our actions, that have an impact on our decisions

Understanding ethics in this way avoids the common misconception that ethics deals exclusively with how we act. Admittedly the focus of ethics is on our actions, which is why in ethics we tend to debate issues such as abortion, physician-assisted suicide, stem cell research, and genetic testing, all of which center on what we are doing in concrete situations. But this focus on actions tends to overshadow something that Socrates, Plato, Aristotle, Aquinas, and others took great pains to make clear, that is, our actions say something about who we are and determine to a great extent who we ultimately become as people. While we may not always act in ways consistent with who we are or ought to become, and while no one action may completely define us as a person, we cannot escape the fact that who we are affects how we act and how we act affects who we are becoming as people in relation to other people, to God, and to the creation.

Perhaps an example, using one of the cases above, will explain this a bit better. If you tell your friend about the kissing incident and consistently tell the truth in similar situations where it would be easier to lie, your actions would suggest that you value honesty and are or are on your way to becoming an honest person. The same is true in reverse. If you continuously lie when in tough spots, your actions would suggest that you are or are becoming a dishonest person—a liar. How could you claim to be anything else? The connection between the *being* and *doing* aspects of ethics is essential if ethics is to be understood properly. You cannot have one without the other because

ethics is not just about what we do but also, and simultaneously, about who we are becoming as people (and communities) through our actions.

What Does Ethics Require?

As a human endeavor concerned with who we ought to become and how we ought to act, ethics requires freedom and knowledge, reasoning and discernment, and a normative basis. Each of these elements constitutes a vital part of ethics; without any one of them it would be impossible to do ethics.

Freedom and Knowledge. In ethics, freedom is broken down into two aspects: freedom of self-determination and freedom of choice. Freedom of self-determination relates to *being;* it is that basic freedom to shape our lives and become the person we want and are called to be. Freedom of choice relates to *doing;* it is simply the ability we have to choose this or that. For example, it is the freedom we have to go out with friends versus study, or to buy Dove soap as opposed to Dial.

Some people argue that our freedom of self-determination is weakened, even crippled, by original sin, social forces, physical characteristics, or other factors. There is some truth to this; we are not *totally* free because of spiritual, social, biological, and other factors, which limit, at times, our choices and our ability to make good decisions. Yet despite these limitations, at the core of our being we are each free (barring extreme incapacity) to choose the type of person we want to become through our actions, even in the most challenging of circumstances. Viktor Frankl, a survivor of the Holocaust, provides proof of this:

> We who lived in concentration camps can remember the men who walked through the huts comforting others, giving away their last piece of bread. They may have been few in number, but they offer sufficient proof that everything can be taken away from a man but one thing: the last of the human freedoms—to choose one's attitude in any given set of circumstances, to choose one's own way.[1]

In addition to freedom, ethics requires that we have knowledge. Knowledge in ethics refers to the information we have at our disposal to make decisions in concrete situations. This knowledge can be personal, moral, or circumstantial. Personal knowledge has to do with ourselves in terms of who we are and are called to become as people in community. Moral knowledge deals with the sources of morality or ethics that guide us in making a decision. Circumstantial knowledge encompasses the circumstances surrounding the decisions with which we are faced. Obtaining the knowledge necessary to make an ethical decision may not always be easy: we may not know where to look, or may not have the energy to pursue the requisite knowledge. Nevertheless, if we have the capacity, we must seek to acquire the knowledge necessary to inform our conscience adequately.

With freedom and knowledge comes responsibility. Ethics presupposes that we have a choice in shaping our own lives through our actions in concrete situations and as such are responsible for the types of people we become and for the consequences of our actions on others. When we act with freedom and knowledge we are held morally or ethically accountable. Because our freedom or knowledge may be constrained at times, our moral responsibility can be diminished proportionately (i.e., in equal measure to our lack of freedom or knowledge).

In real-life situations, limiting factors may require us to assess our or another's accountability differently than we otherwise might. We see this all the time in law and it is no less true in ethics. When a child commits a crime with incomplete knowledge about the consequences of her actions, she is judged differently than an adult, who should know better. Or when a man is caught stealing food from a grocery store to provide nourishment for his starving family, his offense is considered less than what it might be if he were acting without this constraint.

One caution is in order: by describing how our moral responsibility can be diminished due to a lack of freedom or knowledge we do not wish to create a

loophole in ethics. We simply wish to call attention to the brokenness of human life and the limitations we all experience as human people. Living morally or ethically is not easy; at times it is painfully difficult. Nevertheless, we can never use this as an excuse for making bad decisions that negatively affect ourselves or others. We have to take responsibility for who we are as people and strive, in any given situation, to make truly ethical decisions. This is what is required of us as moral beings living out our lives within communities.

Reasoning and Discernment. Ethics also requires the ability to reason through a situation and to discern which action, among various options, best reflects who we are called to become morally as people and promotes the well-being of others. Reasoning and discernment are not simply following the orders of an authority figure, blindly applying well-known rules or principles to a case, or succumbing to desires or feelings. Rather they involve: self-reflection in which we get a sense of ourselves, our hopes, motivations, intentions, and desires; contextual analysis and investigation whereby we consult the sources of ethics and try to understand the morally relevant circumstances of the situation; and critical evaluation whereby we consider the different courses of action against some well-established moral criteria. We will say more about this in chapter 4; for now it is sufficient to point out that we cannot do ethics without the ability to reason and discern, and we cannot do these things without a normative basis.

Normative Basis. This may not be a familiar term, but the concept is something you know quite well. We all have a normative basis, though most of us never give much thought to it. If we did not have one, we would never be able to say, "I really need to be a better listener," or, "You really are a good person," or, "I should not have yelled at him like that," or, "That was nice what you did for that woman." These statements indicate that you have an idea or an understanding, no matter how unformed, of who we should be as people and how we should act toward others. This is what a normative basis is—a

framework, point of reference, or backdrop against which we judge people, actions, and the impact of actions on others. It gives us insight into the goals of human life, the virtues and characteristics that should define us as people, and the principles that should guide our actions in concrete situations.

Despite the differences we may have when it comes to specific issues or decisions (e.g., whether physician-assisted suicide is acceptable), most of us share many common thoughts about the elements that fill out a normative basis. There are many things we can say about human life and people from a normative perspective that transcend religious, cultural, ethnic, political, geographic, and other boundaries. For instance, most of us would agree with Aristotle and Aquinas that the goal of life is to flourish as people and communities. What "flourishing" means to particular people in particular times may differ, but how could one deny that this is a basic goal of life?

This is true also of the virtues or characteristics that people should strive to acquire and that constitute what is considered a good person. Who could deny that being a loving, compassionate, and courageous person is better than being a hateful, apathetic, and cowardly person? This is true also of moral principles. Although here we are getting closer to the concrete level of ethics where disagreements occur more frequently, it would be hard to argue against a principle that says "do not harm others" (the principle of nonmaleficence) or "promote the good of others" (the principle of beneficence). Likewise, it would be equally as hard to argue against a principle that says "people should be free to choose their own way in life" (autonomy) or "we should act fairly in our interactions with others" (justice). What "harm" and "good" and "freedom" and "justice" mean in different cultures or contexts might be debatable, but not the fact that we should not harm others, that we should promote the good of others, that we should be free to direct our own lives, and that we should act justly in relation to others.

These are just a few examples of commonly held, normative views. There are countless others. Yet in recent years some have questioned whether there

really is an objective normative basis, themes or elements against which we can judge people and their actions. Some go so far as to claim that everything is relative and that the only value things (or people) have is what someone attributes to them. This is a very serious matter: without some form of an objective normative basis we would never be able to say that someone was a good or bad person or acted ethically or unethically, and as a result moral responsibility and accountability would be completely destroyed. Think about the implications of this for ethics, for life. How would we be able to judge and to hold someone accountable for stealing from another, being unfaithful to a spouse, cheating on an exam, or even killing someone? On what basis would we be able to speak out against the person's actions?

To put this into perspective let us consider the attacks of 9-11. If there were no objective normative basis of any kind, how could we say that the perpetrators were wrong? On what basis could we make such claims? Perhaps you could argue that the attacks were against innocent civilians, or that the people who were killed never agreed to it, or that the attacks disrupted the social order. However, isn't this saying something on a normative level? Why can't we kill innocent people, or take someone's life without their consent, or disrupt society? These things should not matter to us if, as some suggest, there is no objective normative basis and everything is relative. But they do matter! They matter precisely because we know through our shared human experience that people are of value, that we have a responsibility to treat others with respect, and that there should be peace and stability in society because holding to these ideals aids us in our attempt to flourish as human beings and communities.

We may not all agree on the specifics of a normative basis, but at a minimum we can agree that we need one, and we can begin to sketch some of the general elements of what this would look like—as we will in chapter 3. Here we simply observe that without a normative basis ethics would cease to exist because ethics is not simply about *describing* how we live as people and how we act toward

others but *determining* how we ought to live and act as people in community.[2] This is the task of ethics, whether done personally in the context of everyday living or analytically in the context of a classroom.

Ethics Defined

With this background we can now define ethics. Ethics is the study of the moral lives and actions of people *against a normative basis* that provides insight into who we ought to become (BEING) *and* how we ought to act (DOING) in relation to others (people, God, creation).

Understanding Health Care Ethics

A Field of Ethical Inquiry

Now that we have defined what ethics is generally, we can move on to health care ethics (HCE). Before we offer a definition of HCE and outline the various ethical issues that arise in health care, it is important to get a sense of why we study the ethics of health care in the first place. What is so special about health care that people dedicate their lives to studying its ethical dimensions? Why is HCE a fixture in course catalogs at colleges and universities? Why do we have codes for nurses, physicians, and other health care professionals with strict ethical requirements? In short, why is health care a field of ethical inquiry? There are three main reasons.

First, health care is a basic need we all have and supports perhaps the most basic of all human goods: physical health and mental well-being. Without these it would be difficult if not impossible to pursue life's other important goods, such as friendships, education, family, work, recreation, and religion. As the adage goes, "Without our health, we have nothing." This separates health care from other fields of ethical inquiry. While business, journalism, education, and other fields all have ethical dimensions, the goods they promote are not as basic as the good promoted by health care.

Second, patients tend to be vulnerable in relation to their caregivers. From a moral perspective, vulnerability means that one is at risk of not being seen as a person deserving of respect and loving concern. One could argue that we are always vulnerable, no matter what the situation, because theoretically someone could always treat us poorly and not value us as people. Nevertheless, in health care situations our vulnerability is much higher than in other settings because there is far more at stake and a real imbalance in the patient-caregiver relationship.

For one thing, patients are seeking services related to their physical health and mental well-being, which is certainly more important than mere material goods. Because they often know less about their condition than their caregivers, patients are also usually completely dependent on them to provide the necessary services, and must trust that they have the proper training and are motivated to promote their patients' best interests. Furthermore, patients often have to divulge sensitive information about themselves that could be embarrassing or even incriminating. Perhaps worst of all, patients may be sick, frightened, and uncertain about the future and may have to expose themselves physically and emotionally to people they do not know very well. Customers in a grocery store, readers of a newspaper, or students in a classroom do not experience this same degree of immediate vulnerability. Patients need ethical safeguards to ensure that their dignity and well-being will be protected.

Finally, health care is a profoundly social endeavor. The decisions we make in health care—whether on the policy-making, organizational, or clinical level—affect not only those directly involved but also society at large. Consider the following case.

Case 1C: John is in a very bad car accident and transported by helicopter to a trauma center. After extensive testing, John is diagnosed with a severe head injury and sent to the intensive care unit (ICU) for close observation and treatment. After several weeks in a coma receiving aggressive treatment and round-the-clock care, it is clear that John is not going to recover consciousness

and will die sooner or later, depending on how long he is treated aggressively. The physicians suggest to John's wife that he be removed from the breathing machine because it is not improving his overall condition, and moved from the ICU to a nursing floor where he will receive comfort measures only. John's wife refuses and demands that everything be done. The physicians protest but, fearing a lawsuit, give in to her wishes.

Though this case focuses on decisions that unfold at the bedside of an individual patient, it highlights the social implications of health care. For one thing, continuing to provide aggressive treatment to John could negatively impact other patients. The resources (health care professionals, the ICU bed, the equipment, the money) being used to sustain John's life may not be available for other patients who may actually benefit from the treatment. This is not a theoretical problem. Hospitals do not have breathing machines for every patient, ICUs have only a certain amount of beds and trained staff, and emergency departments sometimes must close their doors to new patients because they cannot move their current patients to certain parts of the hospital due to lack of space.

In America we tend to think of health care resources as unlimited, a virtual bottomless pit. Yet in reality there is only so much to go around. Some people object to this because they assume that we could simply spend more money on health care. But experience shows that this would require much to be sacrificed in other areas and even then there is always a breaking point. The situation is a lot like our own finances. Every day we make decisions about the things we can and cannot afford because our checkbooks have only a limited amount of funds. We could obtain credit and go into debt for the things we desire, but this would limit us in other areas and eventually catch up to us. This is reality for most people, and it is the same reality we experience in health care.

Second, continuing to provide aggressive treatment to John could impact the lives of those caring for him. The physicians have already expressed their concerns about further aggressive treatment. Will their integrity be compromised because they went along with John's wife's demands against

their better judgment? Will it change the way they think of medicine and the role of patients and families in decision making? What about the nurses and other health care professionals? They will have to continue to provide intensive treatment to John and manage the complications that will inevitably arise. What about their feelings? It may be difficult emotionally to stop treatment for a dying patient, but it can be equally hard to continue to provide aggressive treatment to a patient who may suffer longer because of it. Front-line caregivers such as nurses often feel this emotional entanglement most because of their closeness to patients and families.

The hospital and John's health insurance plan, assuming he is insured, could also be affected. Hospitals only receive a certain amount of money for the services they provide and sometimes the costs far exceed the reimbursement. Is it fair to hospitals to provide care that is not benefiting a patient when they have to absorb the costs? What if this limits their ability to care for other patients and to provide just wages and cost-of-living salary increases to their employees? Would it be right for other members of John's health insurance plan to have to pay higher premiums because of the costs associated with his care? An additional four dollars a month may not be a lot to some, but to others it can make the difference between being insured and going uninsured.

Third, continuing to provide aggressive treatment to John and other patients in similar situations could drive up overall health care costs and have an impact on society at large. In America we already spend over two trillion dollars on health care and this number is expected to rise to over four trillion by 2015, which will represent about twenty percent of our national spending.[3] This means that for every dollar we spend as a nation, twenty cents will go to health care. While this may seem justifiable because health is such a basic good, the fact is that this limits our ability to spend money in other areas that are also important for personal and community development, such as education, defense and homeland security, highway and road improvements, agriculture, and alternative energy sources. We should also keep in mind that health care insurance is getting more and more costly and the number of uninsured in the United States alone is well over forty million. These things will only get

worse as health care costs continue to rise and the population ages as expected. Costs, limited resources, and the effect of our individual health care decisions on others are often overlooked in our individualistic society, but they constitute a vital reason why health care is a field of ethical inquiry.

Definition and Description

We can now explain what HCE is. HCE, a specialty of ethics generally, is the study of how human people and communities are affected by medicine, medical technologies, and the decisions we make in health care on various levels. Like ethics generally, HCE is done against the backdrop of a normative basis.

Though ethical issues in health care seem rather common nowadays, HCE is a relatively new phenomenon. It only became a distinct discipline and a formal area of study in the 1960s. This somewhat misrepresents the fact that concerns about the ethics of health care (or medicine) surfaced thousands of years ago, as witnessed in the Hippocratic Oath (circa fourth century BCE), and that Christian theologians dating back to the early church have dealt with problems that we tend to group under HCE (e.g., abortion, contraception, sterilization, and euthanasia).

Several factors led to the recent rise of HCE as a formal discipline, none more than advances in science and medical technology. Ethical issues have always been present in health care, but as medicine became more advanced and developed the technologies capable of diagnosing complex conditions, doing elaborate surgeries, and, particularly, sustaining life, the number and complexity of ethical issues increased considerably. It is no mistake that one of the most prominent health care ethics cases to date, that of Karen Ann Quinlan, arose in the 1970s and had to do with the question of sustaining life. Once health care obtained its technological might, which continues to expand, the ethical issues and concerns were quick to follow.

There are other factors as well. Significant changes took place in the patient-physician relationship and in health care. Traditionally, physicians made decisions for patients; they not only had the technical expertise but also assumed responsibility for deciding what was in the patient's best interests.

This approach is called "paternalism" because it is similar to how parents assume almost complete decision-making responsibility for their minor children. Strange as it may seem to us, in the past physicians knew their patients quite well, often having cared for them from birth to death. In such a context paternalism tended to work well, as the physician could adopt a course of treatment that accurately represented the views of the patient and family. As health care itself changed—from family physicians who came into the home to complex delivery networks involving multiple structures (hospitals, clinics, insurance companies, government payers) and caregivers (not just physicians) who often know very little about their patients—the close relationship between patient and physician began to break down. People in developed countries started to crave individual liberty and wanted to make their own decisions. All of these factors led to a new model of the patient-physician relationship, one that is now driven by patient autonomy versus physician paternalism. This new model, while beneficial to a point, has led to greater conflict in health care decision making, such as we saw in *Case 1C*.

Other important events gave rise to HCE, perhaps the three most important of which were the Nuremburg Tribunal, the Tuskegee Syphilis Study, and dialysis committees. At the Nuremburg Tribunal several Nazi physicians were tried for performing unethical, harmful, and sometimes fatal experiments on concentration camp victims during World War II. What came out of Nuremburg was a commitment that all research subjects must be adequately informed about the benefits and risks of participating in medical research and must give their free and informed consent before anything is done to them.

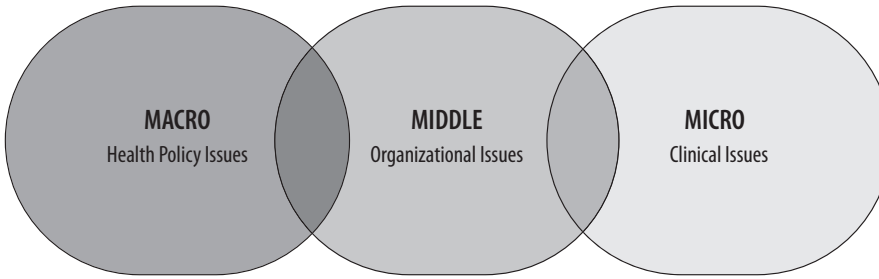
The Tuskegee Syphilis Study was conducted by the United States Public Health Service and began during the great depression around 1930 and lasted until 1972. The study was conducted on poor, uneducated African-American men who lived in Tuskegee, Alabama, where a relatively high number of people were suffering from syphilis. The researchers at Tuskegee lied to the men about the nature of the study, were not honest with them about the extent of their disease, did not tell some men who acquired the disease while in the study that they were sick, and deceived the men into thinking they were receiving the best

treatment for their condition. What is worse, when penicillin began being used effectively in 1946 to treat syphilis, the government blocked the men from receiving it. This was all exposed by a reporter for the Associated Press, whose story came out on July 26, 1972, and appeared on the front covers of most national newspapers. The story and the subsequent congressional hearings on Tuskegee opened the eyes of the American public about the danger of ethical abuses in medical research and practice.

Dialysis committees were fixtures in sophisticated acute care hospitals. They were charged with determining who, among patients with severe kidney disease, would receive a treatment known as dialysis, which essentially does the work of the kidneys outside the body by filtering the blood artificially and reintroducing the filtered blood back into the body. At the time, dialysis machines were not readily available and so hospitals could not meet the needs of all patients with kidney problems requiring dialysis. Dialysis committees "played God" by deciding who would receive dialysis and who would not—and would most likely die. This obviously raised questions of an ethical nature and people began to wonder how dialysis committees made their decisions and what criteria they used.

Advances in science and technology, changes to the patient-professional relationship and to health care generally, and landmark events such as Nuremburg, Tuskegee, and dialysis committees all contributed to the rise of HCE as a formal discipline of study. The ethical challenges posed by these developments could not be ignored and as a result people began in earnest studying the ethical dimensions of health care. At first, study was restricted primarily to the clinical level or issues related to patient care. However, it quickly became clear that HCE encompasses three interrelated levels: the macro level (health policy issues), the middle level (organizational issues), and the micro level (clinical issues). Decisions made at one level have an impact on other levels. We have already seen how decisions at the bedside might have an impact on the other levels (refer to *Case 1C*). This can also go the other way. For example, when the government started reimbursing for dialysis under Medicare, hospitals no longer had to make the difficult decision as to who would receive treatment

Figure 1B: Three Levels of Health Care Ethics



(middle—organizational level), and more patients were allowed access to the treatment and as a result lived longer than they otherwise might have (micro—clinical level; see *Figure 1B*).

Below we list the major ethical issues that arise in health care. As we move forward in this book, we will focus primarily on issues at the micro (clinical) level, but we will always keep an eye on how decisions at this level impact our relationship to others, our communities, and society at large. This is necessary because ethics is not just about who we are and how we act as individuals, but more profoundly who we are becoming in community and how our actions affect others.

Macro Level (Health Policy Issues)

1. Health care organization and reform
   - Creating a just system, ensuring access to care, defining coverage and setting limits, allocating societal resources for health care, responding to the needs of the underinsured and uninsured, and establishing adequate structures for delivering care
2. Health care financing
   - Reimbursement, controlling costs, balancing societal values, and payment mechanisms (who pays and how best to structure payment: employer, government, insurers, out-of-pocket)

3. Public health concerns
   - Immunizations, infectious disease control, disparities in health care, safety programs, health infrastructure (lead paint, toxic substances, sanitation, water supply), and health promotion and disease prevention
4. Medical research
   - Protecting research subjects, allocation of public funds, Human Genome Project, and stem cell research
5. Health care regulation and legislation
   - Insurance, government-sponsored programs, patient privacy (HIPAA, the Health Insurance Portability and Accountability Act), patient-dumping (EMTALA, the Emergency Medical Treatment and Active Labor Act), physician-assisted suicide, embryonic and fetal research, and regulation of other research applications

Middle Level (Organizational Issues)[4]

1. Health care organization as caregiver
   - Hospital staffing levels, provider shortages, clinicians and conflicts of interest, patient rights and responsibilities, admission (especially into specialty units like the ICU), providing futile or non-beneficial treatment upon request, medical mistakes, medical records, and billing procedures
2. Health care organization as employer
   - Employee strikes, union activity, justice and responsibility in hiring practices, just wages, downsizing, diversity and affirmative action, whistle blowing, sexual harassment, and executive compensation
3. Health care organization as insurer
   - Setting health benefits for a plan, reviewing appeals for denied coverage in a plan, coverage exceptions for contractually excluded benefits, prescription drug plans, covering disenfranchised populations, paying for investigational interventions for life-threatening conditions, and balancing commitment to individual enrollees with overall plan

4. Health care organization as citizen
   - Hospital closures, community needs assessment, fairness in selection of vendors, responsible advertising, environmental responsibility, mergers and acquisitions, investing (investment screens, proxy voting, and community investing), advocacy and lobbying activities, and charity care

Micro Level (Clinical Issues)

1. Allocation of scarce resources
   - Life-sustaining treatments, organ transplants, intensive medical care, genetic technologies, and the goals and limits of medicine
2. Providing care to patients unable to pay
   - Addressing the needs of the underinsured and uninsured, charity care, and cost-shifting
3. Nature of the patient-professional relationship
   - Rights and responsibilities, conflict of ethical principles (e.g., autonomy, beneficence, nonmaleficence), advance directives, informed consent, patient competency, disparities in health care, and clinicians and conflicts of interest
4. Treatment of people living with HIV-AIDS
   - Vaccinations, treatments, pastoral care, partner involvement in treatment decisions, and aiding developing nations ravaged by the disease
5. Treatment of people living with mental illness
   - Access issues, stigmatization, and patient rights
6. Definition of death
   - Heart-lung versus brain death criteria
7. Withholding and withdrawing treatment at the end of life
   - Treatment criteria, who decides, case conflict, questions about futility, professional integrity, patient rights, and cost concerns

8. Euthanasia and physician-assisted suicide
   - Personal liberty versus societal restraints, and compassion or killing
9. Care of dying patients
   - Pain management, palliative care, hospices, and recognizing limits of life and medicine
10. Care of critically ill newborns
    - Pushing limits of viability, treatment criteria, parental authority in decision making, and cost concerns
11. Organ and tissue transplantation
    - Dead versus live donors, donation after cardiac death, artificial and animal organs, cloning for organs or tissues, transplants for questionable populations, and cost concerns
12. Reproduction and reproductive technologies
    - Personal rights, societal limits, abortion, maternal-fetal conflicts, fetal surgery, assisted reproduction, embryo adoption, and human cloning
13. Genetics, genetic testing, and gene therapy
    - Access, confidentiality, insurance and employment discrimination, the goals and limits of medicine, and safety and efficacy
14. Stem cell research
    - Allocation of federal dollars, access, the moral status of embryos, and the goals and limits of medicine
15. Research and experimentation on humans
    - Informed consent, progress versus limits, protecting vulnerable populations (children, prisoners, mentally ill), and research across borders

Conclusion and Next Steps

By way of conclusion, we would like you to consider *Cases 1A* and *1B* again. This time, however, we *want* you to decide what you would do in each case. While

you are deciding, reflect on what factors are important to you as you make your decisions. For example, would you decide to tell your friend the truth because you are afraid she will find out if you do not, or because telling the truth is something you believe you are obligated to do? Would you refuse to stand up to your supervisor because you do not want to lose your job, or because you have always been told to obey your superiors? This exercise will help you prepare for the next chapter, where we will look more deeply at how we approach ethical situations, specifically what factors we consider most important when making ethical decisions.

Suggested Readings

Ashley, Benedict M., Jean deBlois, and Kevin D. O'Rourke. *Health Care Ethics: A Catholic Theological Analysis,* 5th ed. Washington, DC: Georgetown University Press, 2006.

Devettere, Raymond J. *Practical Decision Making in Health Care Ethics: Cases and Concepts,* 2nd ed. Washington, DC: Georgetown University Press, 2000.

Jonsen, Albert R. *Birth of Bioethics*. New York: Oxford University Press, 1998.

Lammers, Stephen E., and Allen Verhey, eds. *On Moral Medicine: Theological Perspectives in Medical Ethics,* 2nd ed. Grand Rapids, MI: Eerdmans, 1998.

Munson, Ronald. *Intervention and Reflection: Basic Issues in Medical Ethics,* 7th ed. New York: Wadsworth, 2004.

Walter, James J., and Thomas A. Shannon. *Contemporary Issues in Bioethics: A Catholic Perspective*. Lanham, MD: Rowman and Littlefield, 2005.

Endnotes

[1] Viktor Frankl, *Man's Search for Meaning*, trans. Ilse Lasch, rev. ed. (New York: Simon and Schuster, 1962), 65.

[2] Raymond J. Devettere describes this well in his book, *Practical Decision Making in Health Care Ethics: Cases and Concepts*, 2nd ed. (Washington, DC: Georgetown University Press, 2000), 4–6.

[3] For up-to-date information on health care expenditures and other health care related data, see the Web site of the Centers for Medicare and Medicaid Services (CMS) at http://www.cms.hhs.gov/.

[4] These issues are revised and expanded from Leonard Weber, *Business Ethics in Health Care: Beyond Compliance* (Bloomington: Indiana University Press, 2001).