Part I

Ethics in health care

Role, history, and methods

The five chapters in Part I of this volume provide a general introduction to the field of health care ethics, including its purpose, history, methods, and relation to the domains of law and culture. The account of the nature, scope, and limits of health care ethics provided in these chapters is designed to set the stage for examination of the multiple specific topics in ethics and health care in the subsequent chapters of the book.

Chapter 1, "The role of ethics in health care," begins with a description of several concepts of ethics, common sources of moral guidance, and methods for resolving moral disagreements. It then considers the relation of ethics and health care, arguing that ethical issues are especially prominent in health care. This prominence is a result both of the importance of the human interests at stake and of the complexity of many treatment decisions. Ethics can guide difficult choices in health care, but decisions also depend on factual information, and even the most careful moral reasoning may not produce a unique and definitive "correct" solution.

Chapter 2, "A brief history of health care ethics and clinical ethics consultation in the United States," describes the emergence of health care ethics as a new field of inquiry and practice in the latter half of the twentieth century. This review highlights major changes in the US health care system during this period. It also identifies three high-profile events that called public attention to moral issues in medical research and practice: investigative reports condemning the decades-long Tuskegee Study of Untreated Syphilis in poor black men, the US Supreme Court abortion decision in *Roe* v. *Wade*, and the New Jersey Supreme Court *Quinlan* decision on rights to refuse life-sustaining medical treatment. Chapter 2 also outlines the development of the practice of clinical ethics consultation in US health care facilities. From its origins in the 1970s, clinical ethics consultation has become a widely available service designed to help health care

professionals, patients, and families make difficult moral choices about medical treatment.

Chapter 3, "Methods of health care ethics," summarizes a variety of different approaches that scholars have proposed for moral reasoning in health care settings. These approaches recommend different theoretical tools and strategies to guide moral deliberation, including basic principles, paradigmatic cases, moral rules, and moral virtues. This chapter also describes a simple, step-by-step procedure for analyzing health care ethics cases.

Chapter 4, "Law and ethics in health care," is devoted to the relationship between law and ethics as guides to choice and action in health care. Recognizing that some health care professionals are inclined to look first to the law for direction, this chapter begins by considering the option of sole reliance on the law as a strategy for decision-making. It also examines a very different option, namely, sole reliance on ethics as one's guide to action. The chapter offers reasons why both of these options are unsatisfactory, and it proposes an alternative strategy, that of recognizing legal rules and standards as one among multiple morally significant but fallible action guides.

Part I concludes with Chapter 5, "Culture and ethics in health care." This chapter examines the role of cultural beliefs and values in health care. It points out the increasingly multicultural composition of contemporary societies and the growing frequency of culture-based disagreements about what health care to provide and accept. Chapter 5 describes three different responses to cultural disagreements, namely, moral imperialism, moral relativism, and moral negotiation. It considers strengths and weaknesses of each of these responses and argues for the overall superiority of moral negotiation. In order to negotiate cultural disagreements productively, Chapter 5 recommends that health care professionals adopt a "culturally humble" approach, including a respectful attitude toward patients and colleagues, attention to the cultural beliefs and values of others, and a commitment to communication in order to understand others' concerns and to seek agreement on a plan of care.

1 The role of ethics in health care

Case example

Metropolitan Medical Center (MMC) is a private, not-for-profit 500-bed acute care hospital. MMC clinicians and administrators are wrestling with a serious problem. Over the past year, MMC has admitted eight different patients who presented to the MMC Emergency Department with severely damaged heart valves that have required valve replacement surgery. In each of these patients, the damaged valve was the result of endocarditis, a bacterial infection of the inner surface of the heart, including the heart valves. All of the patients report intravenous (IV) injection of a homemade liquid preparation of Opana® (oxymorphone hydrochloride), a potent narcotic pain medication designed for oral ingestion. All of the patients are from the same nearby town, all are indigent, and none have health insurance. Despite strong warnings from their physicians that continued IV drug use would likely cause reinfection of the implanted heart valves, four of the patients have returned to MMC with recurrence of endocarditis requiring repeat valve replacement.

MMC medical staff members have sharply divided opinions about how to respond to these patients. Several cardiovascular surgeons have argued that these patients should be warned that they will not be offered repeat surgery if they continue IV drug use and present to the hospital a second or third time with damaged heart valves due to endocarditis. Several infectious disease specialists have argued that these patients are suffering from an addictive disease and that they are therefore not responsible for their condition and should receive life-prolonging surgery. A psychiatric consultant reports that these patients meet statutory criteria for involuntary commitment and treatment for their substance abuse, but that no substance abuse treatment facilities are currently willing to accept them for the extended treatment they require.

The president of MMC has charged the chief medical officer (CMO) to develop and implement a consistent approach to caring for these patients. What approach should MMC adopt?

As mentioned in the Preface, the aim of this book is to provide a concise introduction to fundamental concepts, methods, topics, and arguments in health care ethics. Each chapter begins with a case example in which health care professionals, patients, or others confront a specific moral problem or question in a health care setting, and each chapter ends with an analysis of that case. This first chapter will examine basic concepts of ethics and health care and will consider the role and significance of ethics in health care relationships and practices.

What is ethics?

One might claim that the answer to this simple question is so obvious that it needs no discussion. We frequently encounter the terms 'ethics,' 'morality,' 'ethical,' and 'moral' in our daily lives; popular media outlets regularly feature stories about moral conflict, moral failure, and, occasionally, moral heroism in health care, business, politics, and other areas of public and private life. Many times each day, we make decisions and take actions that have moral significance, although we usually do not consciously consider the moral dimension of our decisions and actions.

Despite the ubiquity of ethics in our lives, when I ask students, in the first meeting of an ethics course, to give me a concise definition of ethics, I am virtually always met with silence and puzzled looks. The students appear to share the view expressed by US Supreme Court justice Potter Stewart in a pornography case – Justice Stewart wrote that he would not attempt to define pornography, but claimed "I know it when I see it."[1]

Although they may not realize it, my students' initial reluctance to propose a definition of ethics may reflect the fact that 'ethics,' 'morality,' and related terms are commonly used in several different ways. 'Ethics' can refer to various members of a family of related concepts. Among the various concepts of ethics are (at least) the following:

1. A set of rules or principles for human behavior, as, for example, the Ten Commandments, or the American Medical Association's Principles of Medical Ethics.

[1] *Jacobellis* v. *Ohio* 1964.

2. A field of scholarly inquiry within philosophy, theology, and other disciplines, including various methods and theories (for example, Aristotelian ethics and Islamic ethics).
3. The state of a person's character, as, for example, "Mother Teresa is a paragon of ethics."
4. A feature of human choice and action, as, for example, "Abusing that disabled person was unethical."

Each of these different but related concepts of ethics will figure in this book. Although they are different, all of them address questions of what kind of people we should be, what actions we may or should undertake, and how we should relate to one another and to the world around us. Some scholars maintain that there is a significant difference in meaning between the terms 'ethics' and 'ethical' on the one hand, and 'morality' and 'moral' on the other. These terms may have slightly different shades of meaning, but I believe that they are very commonly used as synonyms, and therefore I will use them interchangeably throughout the volume.

Sources of moral guidance

If we recognize that ethics offers guidance about what kind of person we should be and how we should act, an obvious follow-up question is "Where does this moral guidance come from?" Unlike the first question mentioned above, students have a number of ready answers to this second question. Many credit their parents or teachers for providing this guidance, some cite the role of their religion and its doctrines, others recognize the influence of their peers and their cultural communities, still others appeal to social norms, especially norms embodied in the law, and a few mention the inner voice of conscience. Students with particular backgrounds may add that moral philosophy, or the moral standards and principles of their profession, offer further guidance.

In today's diverse and multicultural societies, all of these sources, and many others, offer valuable moral advice. This multiplicity of guides can encourage us to lead thoughtful and committed moral lives, but it also poses an obvious problem. In a variety of situations in which we confront a difficult moral choice, different sources of guidance on which we rely may disagree about what we should do, and none of these sources is likely to

have a convincing claim to priority or infallibility. How, then, should we determine what to do when our trusted sources of moral guidance disagree? This problem can arise for individuals seeking to make a responsible decision and carry it out, and it can obviously also arise when two or more people disagree about what joint action they should take, as, for example, a physician and patient considering what treatment plan they should adopt for that patient's illness. Because contemporary societies are culturally, religiously, and morally pluralistic, we frequently confront uncertainty and disagreement about what course of action to pursue. What can we do in such situations?

Resolving moral disagreements

Recognizing the fact of moral disagreement need not result in moral stalemate or paralysis; when we confront a difficult situation, we may recognize that doing nothing as well as taking some action is a conscious choice with significant consequences. We may, therefore, attempt to resolve the disagreement. Methods for resolving moral conflicts include rational argument, what I will call "moral persuasion," and negotiation and compromise. When these methods are unsuccessful, it may sometimes be appropriate to resort to a kind of coercion. In other situations, the parties may conclude that they cannot reach an agreement and therefore cannot engage in a joint endeavor. Let's consider each of these options in turn.

Rational argument. The most powerful method for resolving moral disagreement is appeal to a compelling rational argument. The proponent of one conclusion about how to resolve a disagreement may be able to present an argument showing that that conclusion follows, according to established rules of formal logic, from premises that both parties accept as true. Refusal to accept the conclusion of such a compelling moral argument would be an irrational decision. In many, if not most situations of moral disagreement, however, it may not be possible for either party in the dispute to construct a logically valid argument from shared premises. So, this method of resolution of disagreement will not be available in those situations.

"Moral persuasion." The proponent of one position in a situation of moral disagreement might appeal, not to a compelling rational argument, but rather to characteristics of his or her position that she believes will be attractive or persuasive to other parties, and invite them to embrace that

position because of those attractive characteristics. One might, for example, claim that a particular course of action will likely have certain beneficial consequences, or that it is the kind of action a virtuous person would choose. Even if such invitations to view the action in a positive way do not constitute a logically sound argument, they may persuade others to endorse that course of action.

Negotiation and compromise. Despite the fact of moral pluralism and the frequent occurrence of moral uncertainty and disagreement, we obviously also have strong interests in making and acting on moral choices, both individually and jointly. If health care professionals and their patients, for example, cannot agree on a treatment plan for the patient's illness, central interests and goals of both parties will likely be frustrated. When we encounter differences in moral beliefs and preferences, therefore, we often choose to examine the situation more thoroughly, in an effort to find a course of action that both parties can accept and undertake together. Such an examination may uncover shared values and goals that can form the basis for agreement, or it may motivate the parties to accept limitation of some individual preferences in order to achieve common goals. A process of moral negotiation and compromise may achieve agreement on a joint course of action that is not optimal for either party, but that does enable the parties to work together to achieve shared goals.

Coercion. If a moral disagreement cannot be resolved, one party may attempt to force the other to act in a particular way. Though such a coerced action obviously does not resolve the moral disagreement, it may be morally justifiable in certain contexts, especially contexts in which one party has legitimate authority over another. Consider, for example, the relationship of parents and their minor children. Parents and children sometimes disagree about whether the children should be permitted to act in certain ways. When these disagreements cannot be resolved, it may be permissible for parents to constrain the behavior of their children, based on the parents' considered judgment. Such authority relationships also commonly exist in employment settings. In entering military service, for example, a person may agree to be bound by the orders of a superior officer.

Agreeing to disagree. Even the best efforts of the parties to resolve moral disagreements by means of rational argument, moral persuasion, and negotiation and compromise have no guarantee of success. The moral

beliefs and values of the parties may be so deep-seated and divergent that there is little or no basis for agreement on a common course of action. Unless one party has legitimate authority over the other, therefore, the parties may decide that they can only agree to disagree. As a consequence of this decision, the parties will not be able to cooperate on a course of action in the situation about which they disagree. Patients, for example, may refuse treatments recommended by their physicians, and physicians may refuse to provide services requested by their patients.

This book will identify and examine central ethical issues and problems in health care. It will review and evaluate a variety of reasons, arguments, and procedures offered to address those issues and problems. The book is designed to give readers an understanding of the issues and arguments, and to enable them to engage in moral deliberation and to develop and defend a considered position on those ethical issues.

What is health care?

Like ethics, the concept of health care may seem so obvious and well understood that it requires little further discussion. In developed nations, virtually every resident receives health care services periodically throughout his or her life, usually beginning on or before the day of one's birth and ending on the day of one's death. Health care serves a variety of widely recognized and related purposes, including the prevention and treatment of illness and injury, the relief of pain and suffering, the preservation and restoration of physical and mental function, and the preservation and restoration of physical form. We also recognize that health care includes a variety of services in multiple settings, from physician office visits for preventive care and health maintenance, to emergency department treatment for acute illnesses and injuries, to ongoing care for chronic or progressive illnesses such as diabetes or heart disease, to major surgery and intensive care for catastrophic conditions such as multiple trauma or organ failure.

The broad scope and national prominence of the health care systems of the United States and other developed nations deserve brief mention here. Health care provides employment to millions of people in a variety of health care professions and related occupations. It is a major sector of the US economy, with projected national health expenditures of 2.9 *trillion* dollars

in 2013, or 17.2 percent of the entire US gross domestic product (GDP).[2] More than 90 percent of these expenditures are for health care services provided to individual patients, including hospital and nursing home care, the services of physicians, nurses, dentists, and other professionals, and prescription drugs and other medical products. The primary focus of this book, therefore, will be on ethical issues in personal health care. In addition to personal health care services, the US health care system also includes public health activities and biomedical research, and Chapter 19 of this volume is devoted to ethical issues in biomedical research on human subjects.

How is ethics related to health care?

Health care is clearly a major focus of human effort and resource investment in the United States and around the world, on a par with education, national security, manufacturing, agriculture, transportation, and government. Ethical issues arise in all of these areas, but judging from the number and intensity of public debates, nowhere else is attention to ethical issues more prominent than in health care. Why does ethics play such a conspicuous role in the health care arena? How can attention to ethical issues inform and guide the choices and actions of health care professionals and patients?

One probable reason for the sustained attention to ethics in health care is the significance of the values and interests health care serves. We rely on health care to protect us, if possible, from untimely death, disability, suffering, and disfigurement. These are clearly not trivial matters, but rather some of the most basic interests of every human being. Because these interests are so important, both individuals and groups are willing to devote considerable time, energy, and resources to health care decisions and practices.

Despite the importance of the human values at stake in health care, we would not need to pay much attention to ethical issues if most or all of our health care choices and their likely consequences were clear, and the best choices were obvious. More often than not, however, when basic values are at stake in health care, the opposite is true. Serious health conditions are

[2] Sisko et al. (2014).

often complex and difficult to understand. Alternative treatment plans may also be complicated, with multiple interventions and a variety of different possible consequences, both beneficial and harmful. The actual outcome of a proposed treatment for an individual patient may be very uncertain.

Consider, for example, the situation of Mr. Johnson, a 50-year-old man who seeks treatment for new symptoms of dizziness and vivid visual hallucinations. Diagnostic imaging studies reveal a brain tumor, and a biopsy confirms the diagnosis of a virulent form of brain cancer. An oncologist breaks this bad news to Mr. Johnson, explains what is known about this form of cancer, and describes several alternative treatment options, including whole brain radiation treatments, intrathecal chemotherapy (a series of injections of chemotherapy drugs directly into the cerebrospinal fluid), and provision of palliative medications designed to ameliorate the symptoms of the disease. The first two treatment plans offer a small chance of remission of the cancer and of extended survival, but they also have side effects of different kinds and significant risks of severe complications. Whole brain radiation may cause cognitive disability, and intrathecal chemotherapy may cause severe headache, nausea, and vomiting. Palliative treatments may relieve symptoms and enhance Mr. Johnson's quality of life, but only temporarily, if the cancerous tumor grows as expected. Mr. Johnson finds the prospects for success of the more aggressive, possibly life-prolonging treatment options unimpressive, in relation to their recognized complications and side effects, but his wife and two children urge him to choose the treatment that maximizes his chances of survival.

Mr. Johnson has had little experience with serious illness, and he initially feels overwhelmed by the complexity and gravity of his situation and his treatment choices. He may struggle to make treatment choices that require trade-offs between conflicting prudential and moral values. He wants to avoid a premature death, but is also reluctant to accept the pain and suffering of a long and rigorous course of treatment that offers only a limited chance of prolonging his life. His own individual preference may be to focus on palliative care to improve his quality of life, but he may not want to hurt his family members by refusing their request that he accept aggressive anticancer therapy. He may wonder how expensive the proposed treatments are, how much of those expenses his health insurance will cover, and whether he should commit his family's life savings to paying for his treatment.