

Bioethical Controversies in Pediatric Cardiology and Cardiac Surgery

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Preface to the First Edition

Bioethical controversies loom large in the field of congenital heart disease, which has emerged as a resource-consuming specialty that has major effects on the lives of patients and their families. While virtually all congenital heart defects can be surgically treated in some manner, the burdens imposed by short- and long-term survival have heightened the relevance and importance of informed consent, shared decision-making, public reporting, and clinical transparency.

The principles that govern ethical behavior in medical practice are beneficence, non-maleficence, justice, and autonomy which are grounded on the ideas that physicians are duty bound to do good, avoid harm, display fairness, and recognize that patients are free to make medical decisions for themselves. Neonates, infants, and children, however, are dependent on their parents to make decisions for them in the child's best interests. To make these issues more problematic, fetal diagnoses of complex heart disease present parents with daunting options that include consideration of women's rights to autonomy and bodily integrity, maternal-fetal conflicts, the potential burdens of long-term care associated with pain and suffering, and the possibility of postnatal comfort care rather than attempts at surgical palliation or cure. These circumstances are considered in the context of enormous advances in congenital heart procedures that, in many cases, are curative and clearly indicated.

The origin of this collection of ideas and inquiries took its roots from the multiple manuscripts that were published by the editors and contributors over a time period that witnessed significant advances in procedural techniques, changes in political social norms, and exposure of the equipoise that surrounds guidelines for parental interactions. Administrative, social, governmental, and media oversight led to increased awareness of clinical outcomes but also brought to the fore unintended consequences that shook the foundation of health care delivery for patients with congenital heart disease. In the near future, changes that might result in a universal one-payer system will challenge and refocus the ethical issues that are discussed herein and will likely signal another edition of this text.

The chapters in this book approach congenital heart disease through the lens of ethical principles. The authors encompass the breadth of contemporary medical experience and thought from surgical residents, young faculty members, philosophy faculty, and widely published, seasoned contributors. Each has an important perspective to consider. The chapters are not arranged by any organizing principle; rather they are discussions of the complex ethical issues that have formed the *raison d'être* of this collection.

The reader will find the contents of this book to be interesting, thoughtful, controversial, and poignant. Answers are not provided; rather controversy is highlighted.

Constantine Mavroudis
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Introduction to Biomedical Ethics

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1 Introduction

In the Classical Age of ancient Greece (fifth century BCE), Hippocrates and his followers established, for the first time in the West, a systematic, observation-based practice that was a recognizable ancestor of what we now call medicine. The *Hippocratic Corpus* is an impressive collection of lectures, case histories, research notes and observations, gathered over the decades and centuries [1].¹ The best-known document of the collection, though, is the Oath—a code of professional conduct that physicians of the Hippocratic tradition were expected to embrace—a revised version of which is still sworn by physicians today [2].

The Hippocratic Oath indicates a recognition that the physician occupies a special position and has special powers—powers that should be exercised responsibly. Because the physician has the power to heal and to harm, it is important that he² use that power always and only for healing. Because the physician often has knowledge of personal information about a patient, it is important that he not break confidence. Because the physician has the prestige that accompanies power and professional status, he should not use that standing for immoral purposes. These are basic common-sense guidelines of ethical behavior, applied to the singular circumstances of the physician who has special power, knowledge, access and prestige.

Modern scientific medicine endows the physician with a kind and degree of power that the ancients could never imagine. Scientific research reveals that the body is more complex (and more interesting) than Hippocratic humoral theory would suggest. Technology allows all manner of strategic interventions, with precise manipulation and control. Specialization, division of labor and institutionalization enhance the efficiency and influence of the profession. In the new world of modern medicine, the physicians' powers are increased, the responsibilities are greater, the cases are more intricate, and the social, legal and institutional context more complex.

Medical professionals today confront specific dilemmas and decisions that no one in human history has ever had to address before. Nowhere is this truer than in pediatric cardiology and pediatric cardiac surgery. Ancient physicians never had to advise a family whose newborn would need repeated open-heart operations and eventually a cardiac transplant in order to enjoy a compromised and shortened life. The ancient Athenians did not struggle to devise an effective and morally sensitive system for collection and allocation of donor organs. Hippocrates never dealt with the risks and problems associated with post-cardiotomy ECMO.³ The common-sense moral guidelines that underlie the Hippocratic Oath are no less sound today than they were in the ancient world, but they are not enough—they do not provide the kind of guidance that is required in the practice of modern medicine.

Fortunately, especially in the past three centuries, just as our theoretical understanding of biology, anatomy, and physiology has been advancing, so too has our understanding of ethics. And just as we are learning to apply our deeper scientific understanding to the art of healing, we are learning to apply a more developed understanding of ethics to the art of moral decision-making.⁴ In this chapter we will try to gain an overview and appreciation of modern bio-medical ethics by tracing these developments in our ethical understanding in three steps. First, we will consider briefly three major ethical theories, with a glance at their historical origins. As part of this discussion we will discuss the very idea of an “ethical theory” and will consider the significance of reasonable disagreements among the main contenders for the title of “the true theory of ethics.” Secondly, we will discuss the rise of specialized fields of “applied ethics”—of which bio-medical ethics is the most prominent. In this context we will consider the effort to condense the insights of ethical theories to concisely stated “principles” which can be used as analytical tools for decision making. We will conclude with some thoughts on the relationship between ethics and religion, and between ethics and the law.

2 Ethical Theories

2.1 Classical Ethical Theory: Virtue Ethics

Systematic, rational inquiry into what we call “ethics” began with the ancient Greeks in the fifth and fourth centuries BCE. Thinkers in this Classical Age asked, in a number of different contexts, “What differentiates a *good* human being from a *bad* one?” The Greek philosophers answered this central normative question by reference to a person's character. A good person is an individual of good character—possessed of certain excellent traits called “virtues” (Gr. *aretai*), among the most important of which are wisdom, courage, moderation and justice. The focus on these four virtues reflects widely accepted social and moral norms of the day. Socrates, Plato, Aristotle, *et al* sought to understand these virtues—how they relate to one another, how they can be taught and how they are unified in a virtuous person—a person of good character who lives a good life [3]. They focused on the idea of a virtuous *individual*, but there was also discussion of how actions and even institutions could, by extension, come to be called virtuous [4].

Pursuing their inquiries, these thinkers realized that in addition to the qualities that make one a good human being

simpliciter, there are also more specialized virtues required of a person in a specific social or occupational role. For example, in order to know what qualities, make one a good mother, a good shepherd or a good soldier, one would need to consider the specific functions and responsibilities of each of these roles. This occasionally led to discussion of the characteristics of a good physician, though usually just by way of example [4].

It is interesting (in light of later developments) that the focus was on the person and his/her virtuous or vicious character—not on specific behavior per se. To the extent that a specific action was discussed, it was usually as an expression of or as evidence of a person's character. The focus on the individual's character led to an emphasis on moral training and education—a central topic in ethical theory of the time.

2.2 Consequentialist Theories: Utilitarianism

The virtue-oriented approach to the study of ethics still has its adherents and is still a source of insights today.⁵ But the focus of ethical inquiry has changed over the centuries. Simply (too simply) put, current ethical reflection is more likely to concentrate on what makes an action right or wrong than what makes a person good or bad. Talk of virtue and character has largely been displaced by talk of consequences, duties and rights.

Modern ethical theories attempt to articulate what it means to say that an action is moral, and to provide criteria by which we can judge the morality or immorality of a given act. Proponents of such a theory hold that to the extent that an act satisfies the criteria, it can be said to be moral, and the agent can be said to be morally justified in performing the act. How such a theory works can best be illustrated on the basis of an example. We will begin with Utilitarianism, a theory most often associated with the names of its two famous early proponents: Jeremy Bentham (1748–1832) and John Stuart Mill (1806–1873) [5, 6].

Utilitarianism is known as a *consequentialist* theory, for it holds that whether an action is right or wrong depends on the consequences of the action. Specifically, the theory holds that an action (or a practice) is right if and only if, of the options available to the agent at the time, it produces the greatest balance of good consequences for everyone affected by the action. In succinct terms, the theory requires that in order to be moral, we must aim for “the greatest good for the greatest number.”

But how are we to understand the “good” that morality requires us to try to maximize? Bentham embraced a hedonistic answer to this question, holding that the good in question is pleasure—the pleasure of everyone affected by an action. Indeed, Bentham went so far as to propose that we could quantify pleasures (the unit of measurement would be “hedons”) and pains (measured in “dolors”), and, subtracting the dolors from the hedons, arrive at a net measure of pleasure for any given act or practice that we might be considering.⁶ This net measure of pleasure he dubbed the “utility” of the act or practice—hence the name “utilitarianism.” A political radical (for his time), Bentham advocated the use of the utilitarian criterion not only in personal decision-making, but when evaluating public policy initiatives.

J. S. Mill followed Bentham's lead in holding that the morality of an act depends on its consequences for everyone affected. But rather than embracing pleasure as the good to be maximized, he advocated happiness. Mill articulates his “principle of utility” as follows: “Actions are right in proportion as they tend to promote happiness; wrong as they tend to produce the reverse of happiness.” Unlike Bentham, Mill did not think that utility could plausibly be quantified in units of happiness. But Mill and Bentham both agreed that the utility principle should be used not only by individuals in their day-to-day moral decision-making, but by legislators and officials in their deliberations about alternative public policy proposals. The principle would dictate that those policies should be adopted whose enactment would maximize utility—for everyone and over the long run. It is important to emphasize that I must take into consideration the effects upon *everyone* affected—not just my family, my friends, my countrymen or members of my generation.⁷ This impartiality is part of what makes utilitarianism a *moral* theory and not just a prudential strategy for winning friends or keeping peace in the family.

2.3 Act and Rule Utilitarianism

According to Utilitarianism, if I am trying to decide between two acts—or two courses of action—I should try to estimate which course of action will bring about the greater amount and degree of happiness (utility) for everyone affected by my action. The one that yields the greater utility is the morally right action, and the one that I should perform. I apply the Utilitarian measure directly to the acts that I am considering, and (if I am to act morally) let my decision be governed by the utility estimations. This way of proceeding has come to be called “act utilitarianism,” because the utility test is applied directly to the acts being contemplated.

An immediate practical problem arises, however, when we think about actually putting the utilitarian guideline into effect. In many cases there is no way that I can reliably estimate who might be affected by my action and what effects my actions will (or might) have on those people. And even if it were possible to figure this out, it would take a lot of time—and often, when confronted with a morally weighty decision, we don't have much time for contemplation. In order to address this problem, some have suggested that the utilitarian calculation not be invoked in specific instances requiring a decision. Rather (the suggestion is) we should act in accordance with *rules* that we adopt in advance and resolve to abide by in all cases. But we are to decide which rules to adopt by using the utilitarian calculation. We should adopt those rules which—if everyone abided by them—would maximize utility for everyone in the long run. It might not be easy to ascertain which rules would be the best according to this measure, but we can take the needed time to reflect, discuss and research the question before we find ourselves in a pressing situation in which a decision is needed urgently. This version of the theory has come to be called “rule utilitarianism,” for the utility test is not applied to individual acts, but to rules which are then used to decide how to act.⁸

The difference between act- and rule-utilitarianism may seem like something of a technicality, but it turns out to be very important in medical ethics, as we will see when we come to discuss basic principles (below).

2.4 Deontological Theories: Rights and Duties

In modern moral theory the chief alternative to utilitarianism is a conception of ethics based on rights and duties. Such an approach is called a “deontological” theory (after the Greek term for “duty”). Advocates of this conception do not deny the importance of acting in ways that produce good consequences, but they contend that there are limits and constraints on our effort to maximize utility—constraints imposed, for example, by people's rights. We will look first at how rights function, ethically speaking, and then consider how certain rights claims might be justified.

To have a right is to have an entitlement to something. That entitlement imposes obligations on others. For example, if you have a right to life, everyone else has a duty not to take your life—i.e. not to kill you. If you have a right to speak, then all others have an obligation not to prevent you from speaking. And if you have a right to a certain piece of property (say, your home), then all others have a duty not to invade, steal, damage or interfere in your use of that property. Your rights impose duties on all the rest of us—the duty not to prevent you from enjoying and making use of that to which you have a right.

A right is best understood as a kind of ethical trump card, for it often overrides other moral claims. For example, we can imagine a scenario in which a person (Jim) is dying from heart disease, suffers from chronic pain and experiences little joy in life. It might be the case, however, that Jim's kidneys are in great shape, and that there are two potential transplant recipients (currently on dialysis) whose happiness and quality of life would be greatly enhanced if each were to receive one of Jim's kidneys. One might plausibly reason that overall utility would be increased by taking Jim's kidneys, transplanting them into the waiting recipients and letting Jim die. And according to the utilitarian, if utility would thereby be maximized, this would be the right thing to do. But most of us would find that conclusion repugnant, for the kidneys in question are not just an available resource to be distributed in accordance with utility calculations. They are not just kidneys; they are *Jim's* kidneys—parts of his body—and he has a right to decide what happens to them without unwanted interference from others. His right, in this case, overrides the good consequences that motivate the utilitarian.

The fact that rights can override considerations of utility in this way does not mean, however, that such rights are absolute. There are circumstances in which a very important common good can only be achieved by taking someone's property against her will. There are even imaginable (fortunately very uncommon) circumstances in which the catastrophic consequences of not killing someone—of respecting his right to life—are so dire that the violation of his right to life is morally imperative. Most rights theorists would grant that there are such circumstances but would emphasize that they are exceedingly rare.

The aforementioned rights are often referred to as “negative rights” because they entail that others have a duty *not* to interfere. Sometimes, however, it is claimed that we also have “positive rights” which impose upon others the positive duty to provide us with what we need in order to exercise that right. So, your negative right to life entails that I have a duty not to kill you. Your *positive* right to life (if there is such a right) would entail that I (and all others) have a positive duty to provide you with whatever is required to sustain life. This distinction becomes important in the context of health care policy debates. When one hears it said that “health care is a right,” the right in question is construed as a positive right—i.e. a right that imposes upon others the positive obligation to provide one with health care.⁹

Traditionally, negative rights have been accorded a higher and more binding status than positive rights. This is reflected, for example, in the UN Universal Declaration of Human Rights [11]. The “right to life, liberty and security of person” (negative right) has pride of place as Article 3 of the Declaration. The “right to a standard of living adequate to the health and well-being of [one]self and of [one's] family, including food, clothing, housing and medical care and necessary social services...” (positive right) does not appear until Article 25. (Interestingly, the right to property appears in Article 17.)

Where do the basic negative rights come from, and what justification is there for recognizing their force? Modern discussions of rights have their origins in the seventeenth and eighteenth centuries—especially in the works of Hobbes [12] and Locke [13]. In the *Second Treatise on Government* (1689) Locke argues that prior to the existence of a state, individuals by nature have rights to “life, liberty and estate.” This view is then reflected in the United States of America's *Declaration of Independence* (1776) where Jefferson famously writes that it is self-evidently true that, “...all men are created equal, that they are endowed by their Creator with certain unalienable rights, that among these are life, liberty and the pursuit of happiness.”

Rather than deriving rights from divine endowment (as Jefferson does), most modern rights theorists appeal to certain facts and characteristics of human beings that, according to these thinkers, indicate that we should treat them as the bearers of rights. Quinn [16] provides a clear statement of this position:

A person is constituted by his body and his mind. They are parts or aspects of him. For that very reason, it is fitting that he have primary say over what may be done to them—not because such an arrangement best promotes overall human welfare, but because any arrangement that denied him that say would be a grave indignity. In giving him this authority, morality recognizes his existence as an individual with ends of his own—an independent *being*. Since that is what he is, he deserves this recognition [14].

This passage brings together a number of important points. Quinn denies that the recognition of rights is a means to promote overall human welfare—i.e. he denies that consequential concerns underlie our recognition of rights. He also connects the notion of rights to a person's dignity, arguing that the very fact that we are individual beings with ends (projects and purposes) of our own requires that we be credited with rights.

Quinn's final point draws a connection between his view and that of another important historical thinker of the Enlightenment—Immanuel Kant [15]. Kant argues that since each of us is pursuing his/her own projects and own ends, it is inappropriate (in a sense, self-contradictory) for us to treat another person—who is like ourselves—as if she were a mere means to our own ends. Other people like ourselves (Kant would say “other rational agents”) are ends in themselves and hence cannot without self-contradiction be treated as if they were mere tools or instruments for us to manipulate for our own purposes. Rational beings are, in Kant's terminology, autonomous beings entitled to make their own decisions and form their own beliefs—and their autonomy must be respected. Thus Kant, a deontologist like Quinn, points to certain facts about us as human beings (our status as rational agents with ends of our own) and argues that these facts justify the attribution of rights to us.

Before leaving Kant, it should be mentioned that he holds that the admonition to treat others always as ends in themselves—and not merely as means—is one of four different ways of formulating his “Categorical Imperative.”¹⁰ Kant believes that this Categorical Imperative supports not only the basic rights mentioned above, but also an absolute duty not to lie or deceive others. After all, we lie to others in order to manipulate them for our own purposes, and such manipulation is the very opposite of respect for others' autonomy.

Thus far we have focused upon fundamental rights (to life, liberty and property) and on the duties (of forbearance and non-interference) that one person's rights impose upon all others. But, according to deontological theorists, duties can arise in

other ways as well. Most obviously, whenever I freely and voluntarily enter into a contract—formal or informal, explicit or implicit—I impose duties upon myself and (usually) acquire rights that impose duties on the other contracting parties. So, for example, if you and I enter into a contract whereby I agree to provide you with some professional service at an agreed-upon price, I have a duty to provide that service and you have a duty to compensate me for it. Some would say that you acquire a right to my services, and I acquire a right to a certain amount of your money in exchange. Duties and rights can thus be created by agreement between free agents.¹¹

In addition to those that arise as a result of contractual agreements, one can acquire duties and rights just by entering into certain natural or socially-defined roles. For example, by having children I take on the duties of parenthood. This might be construed as an implicit agreement, or as a kind of natural obligation, but either way I have duties that I am morally bound to fulfill. Finally—to return at last to our focus—when one assumes the role of physician, nurse, or other health care professional, one takes on certain duties defined by the profession itself and by society's understanding of the profession. When, as a health care professional, one undertakes to care for a patient, one enters into a relationship that is defined, in part, by reciprocal rights and duties. These have sometimes been spelled out explicitly in formal codes of professional conduct and (recently) several "Patients' Bills of Rights."

Before leaving the deontological theory, it should be noted that of course there can be conflicts between the rights of one individual and those of another. Familiar examples abound in contemporary discussions of controversial issues. For example, the abortion debate is sometimes cast as a conflict between the rights of the fetus (a right to life) and the rights of the pregnant woman (the right to control her own body).¹² Sometimes the debate about single payer health care insurance (financed by increased taxes on the wealthy) is cast as a conflict between a universal right to health care and the property rights of taxpayers. In order to resolve these disputes, one individual's right must be overridden by another's, and for that we need a reliable way of prioritizing rights.

Similarly, an individual can have conflicting duties. Consider a familiar case in the area of end-of-life care: a physician has a duty to relieve suffering, and also a duty not to kill. It may often be the case that the dosage of morphine required to relieve the pain of a terminal patient is likely to induce respiratory arrest. In order to address this sort of difficulty, deontological theorists eschew talk of *absolute* duties and speak instead of *prima facie* duties. A *prima facie* duty to do X obliges me to do X unless the requirements of a more serious duty override that initial (*prima facie*) duty. As in the case of conflicting rights (above), what is needed is a reliable method of weighing and prioritizing duties.¹³

Having examined briefly three ethical theories—one ancient and two modern—the reader might reasonably ask what such theories can contribute to our understanding. What are they purporting to explain? How are they related to each other? Does it make sense to ask which one of them is true?

Each of the two modern theories claims to explain our moral judgments, practices and institutions—based on the account of what makes some acts right and what makes other acts wrong. In addition, the explanation provides a criterion—a decision procedure for judging what acts are right and what are wrong. The Utilitarian says that morality consists in maximizing the good in an impartial way. Actions (and institutions—and people, for that matter) are moral to the extent that they adhere to this "principle of utility." When faced with the need to make a moral decision, we should weigh the consequences of the various options and go with the one that maximizes positive utility. A deontologist says that morality consists in respecting others' rights and doing one's duty. An action is moral to the extent that it fulfills these requirements. When we have a decision to make, we should ascertain what rights and duties are at stake, and act accordingly.

The two theories offer different accounts of what morality is all about. Is there some way in which they might be reconciled? Over the years, each side has occasionally claimed to be able to explain the appeal of the other theory—and thus subsume the other under its own purview. So, for example, J. S. Mill attempted to explain rights (and their importance) in utilitarian terms. In a sort of rule-utilitarian approach, he argued that adoption by a society of a widely accepted practice of respect for rights would provide for greater utility than a society in which there is not such a practice. And according to Mill, rights are important precisely because (and only because) respect for rights yields good consequences—i.e. greater utility.

From the other direction, deontologists have argued that we have a duty to improve the lot of our fellow human beings. This is sometimes described as an "imperfect duty"—not a duty that we have toward every person at all times (such as the duty not to kill). This is more like a duty to give to charity. We are required to do so, but not to give to everyone all the time. Rather, according to this view, we have discretion in whom we choose to help, and to what extent—but we do have a duty of this sort that we owe to others. The deontologists thus seek to subsume utilitarianism under their theory—as an exaggerated over-emphasis of this one duty, at the cost of more fundamental rights and duties.

The attempts to reconcile the two theories—by declaring one the more fundamental and the other derivative—are ultimately unsuccessful. As noted above, there are cases in which the two theories prescribe different courses of action. In the example of Jim, who is dying of heart disease but has healthy kidneys, the utilitarian might think the best thing to do is to take the miserable man's kidneys and transplant them into the two dialysis patients, greatly enhancing their quality of life and the overall happiness. The deontologist thinks this would be unacceptable, since it violates Jim's right to make decisions about his own body. In such cases it may be impossible to reconcile the perspectives and prescriptions of the two theories. In such cases, the theories cannot provide a decision procedure for the case, for one would first need a procedure for deciding between the two theories!

Each of these theories has proponents who would argue for the priority (or superiority) of one approach over the other.¹⁴ But ultimately, I think, we have to accept the fact that our ethical norms reflect both perspectives. Both of these approaches have a claim on our moral conscience. We are obliged to consider the consequences of our actions—the way in which our actions will affect others' well-being—when making decisions. And we are obliged to respect others' rights and to fulfill certain special duties that we have as mothers, soldiers, promisers or physicians—rights and duties that may sometimes put constraints on our efforts to enhance the common good. The theories under consideration here remind us that as morally conscientious agents we must consider our actions from both a utilitarian and a deontological perspective. Sometimes seeing the moral dimensions of a problem from both of these perspectives will reveal a dilemma—the two approaches yield different prescriptions about how to proceed.¹⁵

Though one would seldom hear the terms "consequentialism" or "deontology" in discussions of a case on rounds in the

ward, many of the ethical dilemmas that arise in the medical context derive from the fact that our shared moral convictions and sensibilities have a foot in both of these camps. Indeed, many of the chapters of this volume are focused on such dilemmas as they arise in pediatric cardiology and pediatric cardiac surgery. This will be more evident in the discussion of “Principles” (below).

3 Applied Ethics

The theories discussed above are intended to be comprehensive accounts of normative ethics, applicable in all cases and appropriate to all circumstances. They originated with philosophers and have been elaborated and refined over centuries, in discussions among academics, usually in a university setting or in the pages of scholarly journals. There has been some focus on concrete cases in these discussions, but usually as thought experiments—to illustrate some aspect of the theory or to “test” the theory by applying it to an imagined circumstance to see if its prescription in the case squares with our moral intuitions.

Large-scale historical events and movements are often inspired by ethical considerations, and they involve public argument and discussion of the moral and political principles at stake and their application to the situation at hand. Examples from United States history would include the revolution, the abolitionist movement, the drive for women’s suffrage, the temperance movement, and the civil rights campaign. Closer to home, almost every aspect of our lives has an ethical dimension, and ethical issues can arise anytime and anywhere. We consider our options, think about the values at stake, perhaps discuss the difficulty with a friend, decide what is right, and (sometimes at least) do it.

All of these involve the application of ethical reflection and argumentation to concrete, real-life situations. To that extent, they can be thought of as instances of applied ethics. But in recent decades—since the mid-twentieth century—a more targeted academic subdiscipline has emerged and laid claim to the title “applied ethics” [19]. The specialist in this field analyzes the ethical dimensions of specific real-life circumstances and practices, aiming to resolve tough dilemmas and establish (where possible) guidelines for ethical behavior. The applied ethicist can concentrate on any area of private or public life, but some of the most interesting work has focused on the various professions—medicine, the law, journalism, business, engineering. Given the specialized knowledge required in order to understand and address specific cases in these different professions, the field of applied ethics often involves interdisciplinary training—sometimes with several people from different fields working together.

The bio-medical fields led the way in the advance of applied ethics, and it is worth taking a moment to consider a few factors that might have influenced this development. First, there were specific historical events that triggered a troubled response and a sense of urgency.

The revelation, after the end of World War II, of the atrocities perpetrated by a few physicians in the Nazi eugenic programs and in the concentration camps, was shocking [20]. Very soon after completion of the war crimes trial, the Nuremberg Code of ethics for research on human subjects was formulated (1947)—a seminal document in the modern field of applied bio-medical ethics. Another important factor was the increasing tide of malpractice litigation in US courts since the 1960s [21]¹⁶. Resolution of these cases often hinges on the “standard of care,” and the standard of care often has an ethical dimension that must be articulated and addressed. Finally, and perhaps most important, the rapid advances in medicine and technology in the mid-twentieth century raised hitherto unimagined ethical issues and set the stage for widespread policy debates. To name just a few of these: organ transplantation (1954), fertility drugs (1967), in vitro fertilization (1978), pre-natal diagnosis via amniocentesis (1965), open heart surgery (1960), vacuum aspiration abortion (1967).¹⁷

Applied ethicists hope to provide insight that can be helpful to those responsible for devising public policy regarding the various professions. They also hope that their analyses might be concretely useful to practitioners in the field as they confront ethical dilemmas and make tough decisions. For the latter purpose what is needed is a small set of concisely stated principles that can focus the decision-maker’s attention on the moral dimensions of the case and guide her reasoning as she weighs the options. Over the years, practical ethicists in the bio-medical field have managed to agree upon a set of principles that condense the insights of the modern ethical theories and provide a convenient tool for analyzing concrete cases. These are four in number: (1) non-maleficence; (2) beneficence; (3) respect for autonomy; (4) justice. We will consider each of these in turn, but first a few thoughts on the relationship between the four principles and the ethical theories discussed above.

Utilitarians and deontologists might not agree on the exact wording of these, nor (importantly) on the order of priority that should be assigned to them, but all four are principles that could be accepted by an adherent of either of the two modern ethical theories. The first two principles are focused on doing good and avoiding harm. As such they are clearly consequentialist and encapsulate the core doctrine of utilitarianism. Still, the Kantian could accept them as expressing our duty not to harm fellow rational agents and our imperfect duty to improve the lot of others (see above). The third principle, by contrast, highlights the deontologist’s focus on people’s rights and our duty to respect those rights. A utilitarian could accept that a widespread practice of respecting autonomy might, in the long run, tend to maximize the well-being of everyone.¹⁸ The fourth principle—justice—embodies the impartiality that is central to both theories.

Employment of these principles does not guarantee that a solution to a dilemma will be found. There can be ethical issues that arise in the medical context that are not directly addressed by these principles. More importantly (and more often) two principles might point in conflicting directions with regard to a single case. Principle #1 might counsel withholding the gravity of a patient’s condition from him—“for his own good.” Principle #3 requires that he be told the unvarnished truth—out of respect for his autonomy. The set of principles does not provide a procedure for adjudicating priority disputes between the principles. Still, a decision maker can be confident that if she has conscientiously considered a given case from the perspective of each of these principles, she is awake to the important ethical dimensions of the problem and is in a position to make a morally sensitive and perceptive judgment.¹⁹

3.1 Principle #1: Non-maleficence

Often equated with the Latin admonition “Primum non nocere” (First do no harm), the principle of non-maleficence seems at first to be simple and straightforward. It obviously prohibits a person from willfully harming or injuring another “with malice aforethought.” But there are other ways in which a person can do someone harm. For example, I can injure another not intentionally but as a result of negligence, carelessness, incompetence or ignorance. In the medical context, where the

professional has a clear duty of non-maleficence, causing harm to the patient in any of these ways is a breach of that duty.

Medical professionals are expected to proceed carefully and deliberately, and to provide appropriate treatment and therapy based on reasonably current clinical knowledge and the “state of the art.” These performance expectations contribute to the “standard of due care”—a legal term used to designate what a patient can reasonably expect from his/her physician (in a given community, at a given time). If the medical professional acts (or omits to act) in a way that falls below the standard of due care, and if the patient, as a result, suffers harm, the physician is in breach of the principle of non-maleficence. In fact, the physician can be in breach of the principle even if the patient is not harmed—if the patient was subjected to unnecessary risk of harm as a result of treatment (or lack of treatment) that does not meet the standard of due care.

But of course, it is impossible to avoid all harm and all risk of harm when providing medical treatment. Sometimes the treatment itself requires that the patient be harmed. In order to perform life-saving open heart surgery, the patient’s skin must be cut, the sternum divided, and the chest exposed. Taken in themselves these would clearly be injuries to the patient, but since they are necessary conditions for completing a life-saving intervention, they do not count as harms and do not violate the principle of non-maleficence. So, the principle must be read not as prohibiting harm but as prohibiting *unnecessary* harm – harm that is not justified by a greater benefit to the patient.

The standard of due care does not require that the physician be omniscient. Sometimes it is impossible to know all of the consequences of one’s well-intended interventions. Unexpected eventualities can occur. The patient may have an unusual reaction to a medication; the minimum dose of morphine sufficient to relieve intense pain may in a given patient cause respiratory arrest; some aspect of the therapeutic regimen may trigger traumatic emotional response. The physician is not required by the principle of non-malevolence to avoid all injurious consequences—only the reasonably foreseeable ones.

Finally, there is not always agreement about what counts as a harm. A terminally ill patient who sees nothing in his future but suffering, expense and a prolonged process of dying may reasonably view the physician’s efforts to keep him alive as harmful. For such a patient, death itself is not seen as a harm.²⁰

These difficult questions arise in a number of chapters in this volume. Prenatal obstetrics and neonatal intensive care (including cardiology and cardiac surgery) are now capable of keeping alive compromised near-term fetuses and severely disabled newborns that would surely have died in the past. But the quality of life that can be expected in these cases is sometimes so profoundly compromised that it is unclear whether the interventions that kept the patient alive have benefited him or harmed him. Beauchamp and Childress [23] cite several authors who hold that keeping newborns alive in these extreme circumstances is a harm to the patient. “[Some commentators argue] ...that aggressive intervention violates the obligation of non-maleficence if any of three conditions is present: (1) inability to survive infancy; (2) inability to live without severe pain; (3) inability to minimally participate in human experience” (p. 173).²¹ It should be mentioned here, of course, that the final decision in these matters is not the physician’s alone. On the contrary, the pregnant woman or the parents of the newborn have the decisive voice—though they will of course be heavily influenced by the predictions and counsel offered by the medical professionals.

Beauchamp and Childress conclude that “Managing high-risk pregnancies nonaggressively and allowing seriously disabled newborns to die are, under certain circumstances, morally permissible actions that do not violate obligations of non-maleficence.” This conservative conclusion affirms that non-treatment is not a harm but leaves open the question of whether providing aggressive treatment in such cases *would* be a harm (and hence a violation of the duty of non-maleficence). Moreover, the phrase “Managing high-risk pregnancies non-aggressively” carefully skirts the question of the permissibility (or even obligation) of late-term abortion in such cases.

3.2 Principle #2: Beneficence

The second principle, beneficence, tells the physician to do what he can to help and improve the condition of his patients. This makes a somewhat higher demand than the principle of non-maleficence, for improving things requires more than just not making them worse.

There is some question whether we all have a duty of beneficence toward all others as a general matter of morality. Clearly, we are obligated not to hurt others, but do we have a duty to help all others? Utilitarians would certainly say yes, for seeking to maximize the good for everyone concerned is the very principle of utility itself. A deontologist would agree that we have some obligation to be helpful to others but would emphasize that this is an “imperfect” duty. We have to help some people some of the time, but we do not have to help everyone all of the time. We get some choice about whom to help and when to help them.

Fortunately, we do not have to resolve the larger question here, for it is entirely clear and entirely certain that a physician has a duty of beneficence toward his patients. Seeking to help one’s patients is definitive of what a physician is. By entering the profession, the physician assumes the obligation to improve the welfare of his patients to the extent that he can. This is true for other medical care professionals as well—nurses, therapists, et al. All have an individual obligation to promote their patients’ welfare. And maybe the profession as a whole has such an obligation toward society as a whole. Medical professionals can improve the well-being of everyone through supporting public clinics, advocating for health and wellness initiatives, and promoting research. All of these are part of the definition of being a medical professional, and the physician shares these obligations.

There are of course limits to the physician’s obligation to make sacrifices for his patients’ welfare. Servile selfless devotion is not required by the principle of beneficence, but more than members of most other professions the physician is expected to be attuned to patient needs and prepared to put his own immediate interests aside to attend to patients’ welfare. Striking this balance can be difficult, and there is no agreed upon “standard of beneficence,” on the analogy of the “standard of due care” to provide guidance in hard cases.

As we have seen elsewhere, adherence to this principle can be in tension with other obligations. Sometimes the obligation to help might call for a paternalistic intervention—either directly against the will of the patient or without the patient’s knowledge. Such an intervention might involve forcible institutionalization of a suicidal patient or refusing a patient a new and unproven treatment that she expressly requests. To focus on a more modest example, in certain cases the most helpful thing a physician can do might be to prescribe a placebo. Such a prescription might well be beneficial to the patient, but it requires deceiving the patient about the contents of the pill.²² Coercion, manipulation and deception might sometimes be effective ways of improving a

patient's condition, but it would directly conflict with the principle requiring respect for patient autonomy—an important principle to which we now turn.

3.3 Principle #3: Respect for Autonomy

The principle of respect for autonomy is deeply rooted in Western morality and hence, in bio-medical ethics. Jefferson's appeal to our God-given rights to life, liberty and the pursuit of happiness, coupled with Kant's emphasis on rational agency as the hallmark of humanity, have produced a powerful and complex moral norm.

The term "autonomy" comes from the Greek *auto* (self) and *nomos* (law or rule). An autonomous person is one who is self-governing or self-determining, whose actions are the result of her own decisions and choices. Warren Quinn, quoted above [14], explains that since a person is constituted by his mind and body, "For that very reason, it is fitting that he have primary say over what may be done to them... because any arrangement that denied him that say would be a grave indignity." The principle of respect for autonomy requires that the medical professional give the patient the "primary say over what may be done to [him]." This requires, most obviously, that there be no coercion, force or manipulation used to induce a patient to follow a certain course of treatment or to participate in a clinical study. But independent, uncoerced choice is not enough, for a long tradition in Western philosophy—reaching from Plato to Kant to Habermas—places the locus of human dignity in our ability to reason—in our capacity not just to make choices, but to make *rational* choices. This complicates (and enriches) the moral picture considerably. The emphasis on rational self-determination raises a host of interesting and important issues. We will mention three of these: truth-telling, informed consent and manipulation—and point briefly to some of the complexities involved. Individual articles in this volume will address some of these issues in greater depth, with a direct focus on pediatric cardiology and pediatric cardiac surgery. Footnotes will alert the reader to the chapters that provide a more thorough discussion of a particular question.

Rational decision-making is based on the accurate and complete exchange of information between the physician and her patient. Respect for autonomy requires that the medical professional support the patient's decision-making by providing accurate and (so far as possible) complete information about her condition, about treatment options and about likely results. In short, the physician is called upon to tell the patient the truth so that she can make informed decisions about her health care.

The requirement that the patient be told the truth assumes that there is one agreed-upon truth to be told. But when a team of medical professionals is involved in a difficult case, there may be substantive disagreement about the diagnosis, the prognosis or the likely results of various treatment options. In this context the question is, whose truth should be given to the patient, and who should deliver it?²³ Even in the case of a single caregiver, it may be that she is unsure about important aspects of the case—so that the truth is that the truth is unknown. In such a case, presumably truth-telling requires that the patient be informed of the high level of uncertainty involved in the information that is being provided. But this can be problematic, for such uncertainty seems unlikely to make the patient's decision-making any easier—or more rational. Moreover, it might have the unfortunate consequence of undermining the patient's confidence in the caregiver's expertise—a significant factor influencing the success of the treatment provided.

The last point serves as a reminder that words have power, and that what the patient is told may affect her state of mind and her state of health. For decades the norm was that patients suffering from terminal illnesses were not informed of the gravity of their condition. The justification most often given was the duty of non-maleficence. To inform a person that she will die soon can sometimes trigger fear, anxiety, depression and hopelessness—and to induce these emotional states in someone, at a time of already heightened vulnerability, is—arguably—to harm her.²⁴ This norm has of course changed (in the course of the late twentieth century), and except in the most unusual cases, full disclosure is now expected as part of the standard of due care.

It should also be mentioned that there is sometimes a kind of paradox—or at least a tension—in the simultaneous requirement that the physician respect a person's own wishes about what happens to her and also tell her the truth. Sometimes a patient may indicate that she prefers not to hear certain truths and or prefers not to be burdened with the need to participate in difficult decisions. If respect for autonomy requires letting her have the say in what happens to her and requires telling her the truth, what should the ethically conscientious professional do when a patient does not want to hear the truth?

Fortunately, in the cases that are the focus of this volume, these concerns are not usually a problem. In our cases, the patient is often not the decision-maker, so the patient will not be harmed by hearing traumatizing truths nor troubled by the burden of difficult choices. For near-term fetuses, newborns and young children, the responsibility for making decisions shifts to the pregnant woman or the parents. They are acting on behalf of the patient and are assumed (in the absence of evidence to the contrary) to have the best interests of the fetal or newborn patient at heart. In such cases the medical professional still has the duty to tell the truth—to the parents/decision-makers. This is in part a result of the universal duty we all have to respect others' autonomy (and hence to tell others the truth). The parents are people, too, and deserve not to be lied to or manipulated. But the main reason for the physician's obligation to tell the parents the truth is to ensure that the best interests of the patient are served—to do good and to avoid harm to the patient. Well-informed parents are more likely to make judicious decisions that in fact serve the interests of the patient.

There remains a danger that the parents might be overwhelmed or overburdened by the facts and by the obligation to make decisions at a very high-stress and vulnerable time. The physician or medical team remains obliged to provide the decision-makers with full and accurate information, and to do what can be done to ensure that they understand and are competent to weigh that information.

Conveying factual, useful and (as far as possible) complete information to the parents ensures that when they consent to treatment on behalf of the patient, they are giving *informed* consent. Like the obligation of truth-telling, the duty of securing informed consent is a direct corollary of the principle of respect for autonomy, and it is required by ethics and by the law. Whether the decision is to approve treatment (or refuse it), to allow the patient to participate in a clinical study, or to donate organs, informed consent is the required standard. Since the parents are not medical professionals, it can be difficult to ensure that they understand relevant technical aspects of the situation, but the medical professional is obliged to do his/her best.

The structure of the decision scenario in these cases generates an additional important uncertainty that deserves mention.

As noted above, in the case of a sick or disabled newborn or young child, there is a difference between the patient and the persons whose autonomy the physician is obliged to respect by telling the truth and securing informed consent (in most cases, the parents). Ideally, this difference will be unimportant because the parents want what is best for the child and want to avoid harming him/her, as does the physician. The physician bases her judgment of what is best for the patient on the relevant facts and shares those facts with the parents. Since both want the same thing (the patient's well-being) and are both basing their judgments on the same facts, we might hope that their judgments will coincide. And in most cases, presumably, they do.

But it can happen that the physician has a clear idea of what she thinks would be best for the patient, and the parents don't share that view. Maybe they have a different idea, or maybe they just seem unsure and vacillating. The question arises whether, in such cases, the physician can ethically undertake measures to persuade the parents—measures other than providing facts and rational argumentation. There has been much discussion recently about the use of gently manipulative (not coercive, but not rational) persuasive techniques (called “nudges”) to get a person to do the right thing. The question here is whether a physician may use such gently manipulative non-rational methods without violating her duty to respect the autonomy of those with whom she is dealing.²⁵

Finally, there are more extreme cases in which the parents refuse (on religious grounds, for example) to consent to an intervention that the physician thinks is required to prevent permanent harm or death to the patient. In such a case the physician might judge the parents to be irrational—so irrational that they have surrendered their status as autonomous beings and hence forfeited their right to have their autonomy respected. This amounts to a judgment, based on their religious beliefs and religiously based actions, that they are incompetent to make decisions. This sounds like a judgment that many medical professionals would not be comfortable making—given our tradition of respect for religious belief and tolerance of religious diversity. Moreover, if the mother were the patient and she refused life-saving treatment for herself, that refusal would normally be honored. So, it does not appear that such a refusal on religious grounds would by itself indicate that one is incompetent *simpliciter*. Still, the duty to avoid harm to the patient is paramount and requires that the physician intervene. Under current (US) law the physician or hospital can petition to have the state take temporary custody of the child—under the doctrine of *parens patriae*—and order the treatment. This measure does not require that the parents be declared incompetent but is based only on the state's responsibility to care for children's welfare when their parents refuse to do so.

3.4 Principle #4: Justice

The principle of justice is the most complex of the four. It is said to apply to societies, laws, institutions, practices and individuals. There is a separate chapter of this volume (Chap. 18 – “Ethics, Justice, and the Province of American Medicine: A Discussion of the Politicalization of the Duty to Care for Pediatric Heart Transplant Patients who are in the Country Illegally”) dedicated solely to the issue of social justice in pediatric cardiac medicine, so the discussion here will focus on conceptions of justice in general. After a brief consideration of justice in the most abstract terms, we will focus on two distinctions: (1) conservative versus ideal justice; (2) procedural versus substantive justice. By exploring these distinctions in brief, we will provide an orientation to the complexities of this principle.²⁶

It is easy to formulate the principle of justice in abstract terms, but very difficult to define more concretely. According to Aristotle, the essence of justice is found in the requirement that equals be treated equally, and unequals unequally. Also, from the ancient world comes the idea that justice consists of giving everyone that which he/she is due. These formulations provide an intuitive sense of what justice requires and suggest correctly that justice is about the allocation or distribution of benefits and burdens. But more questions are raised than answered by the vague terms employed. “Equal” in what respects? “Due” on the basis of what obligation?

Maybe, with some creative elaboration, we can derive a rule of non-discrimination from these definitions. After all, the medical services due a person are presumably related to his or her medical condition, and not to his/her race, gender, creed, etc. And presumably the relevant parameters on which equality should be judged, for medical purposes, are medical parameters, not racial or religious characteristics. We saw how both utilitarianism and the deontological view require impartiality, and a rule against discrimination on the basis of irrelevant characteristics embeds that impartiality in the requirements of justice. This is a step in the right direction but does not take us very far. The above-mentioned distinctions will take us further into the complexities.

3.4.1 Conservative Versus Ideal Justice

The Latin root from which our term “justice” derives (*ius*) means “law,” or “right,” and in the Roman context referred to one's rights as a citizen of the polity. The term is still most often used with respect to the actual established laws of the state—the “halls of justice,” the “justice system,” the “Department of Justice.” Justice, on this reading, is defined by the law of the state, and what is just is what is in accord with that law. This justice is labeled “conservative” for it preserves the way things are—the norms and practices that define society at a time. From this perspective, the phrase “unjust law” is a contradiction in terms.

But “justice” can also refer to an idealized conception of how things could be—where benefits and burdens are more equitably or fairly distributed, for example. On this view, actual laws may very well be unjust—think Jim Crow laws or the racial purity laws in Germany in the 1930s. Actual laws can be criticized from the perspective of a “higher” conception of justice based on principles of, say, fairness or equality.

Medical professionals are of course subject to the laws of the actual state in which they practice, and hence have a duty (at least a *prima facie* duty) to obey the laws of that state. But they might find that the laws, as presently in force, produce injustices and tend to conserve a system in which these injustices are perpetuated. In such cases the physician can adopt a higher standard of justice than that defined by the law and try, in his/her practice, to live up to that higher standard. (There will be more to say about ethics and the law in the final section of this chapter).

3.4.2 Procedural Versus Substantive Justice

On some conceptions, the main requirement of justice is to make sure that the rules in accordance with which goods are distributed are fair, non-discriminatory, and impartial. If the procedures are just (on this view), and if everyone acts in accordance with these procedures, then there is nothing more to be said. In a famous thought experiment the Harvard

professor Robert Nozick tells the story of Wilt Chamberlain, the legendary basketball star [30]. Wilt Chamberlain enjoys playing basketball, and ten million people are happy to pay a quarter each to watch Wilt play. So, Wilt ends up a millionaire, whereas most of his fellow citizens, by comparison, have much less. Nozick argues that since all the fans willingly gave their quarters, and no one was coerced or manipulated or deceived, the resulting distribution of money, though quite unequal, is entirely just—because it was arrived at in accordance with just procedures.

Others embrace a more substantive conception of justice, according to which the final distribution of goods can be unjust even if the procedures leading to that distribution were all acceptable in themselves. So, in the case of Wilt Chamberlain, the massive inequality that results from the exchanges is reason enough to declare the system unjust. For the proponent of the substantive conception of justice, the final distribution has to conform to a pattern based on a principle. That principle might be highly egalitarian, or perhaps based on a principle that calls for more resources for those with special needs,²⁷ or more for those disadvantaged in the past. In order to achieve justice, on this conception, it might well be necessary to redistribute goods in accordance with the justice principle.

In the case of the distribution of medical care in the United States, these two conceptions of justice might point in different directions. For the first conception, if one were to think that the economic system is basically procedurally fair, then the current distribution of health care services—where some can take for granted the very best care in the world while others go bankrupt or do without food in order to pay for medications—will seem just. For the second—substantive—conception, this distribution might seem extremely unjust, depending on one’s substantive principle of just distribution.

One might base a substantive conception of justice on the previously mentioned view that everyone possesses a (positive) right to health care. According to this account, not only do others have a duty not to interfere with a person’s efforts to acquire health care. On the contrary, on this view others have an obligation to provide a person with whatever is necessary to achieve a reasonable level of health care services. Any distribution of health care resources that leaves some without access would be, on this substantive conception, *eo ipso* unjust.

Yet this substantive position, too, raises additional issues. If a conception of justice grants a positive right to health care to everyone, one might still debate whether an individual forfeits that right if he engages in risky behaviors known to endanger his health and thus increase the likelihood that he will need to make claim on collective resources to pay for his more expensive and extensive care. Some would argue that it is unjust to require that others foot the bill for his irresponsibility. Others would respond that even foolish behavior does not entail the forfeiture of one’s basic rights.

Justice is a matter of fair distribution of benefits and burdens, of resources and services. The more scarce and costly the resources in question, the tougher the problem of just allocation. In pediatric cardiology and cardiac surgery, the resources can be costly indeed, and are often scarce. Such situations require criteria for allocation—which serve, in effect, as principles of triage. Is “ability to pay” a just criterion for allocation of resources? One might think so if one cares most about procedural justice and if one believes that the economic system that generated the distribution of economic assets was itself procedurally just. In the case of pediatric medicine, though, the patient is not the one who is paying, and it hardly seems just that the parents’ inability to pay should cost the newborn patient his life. Should the children of indigent and uninsured parents receive the same extent and quality of care as the children of the wealthy and insured? Many conceptions of justice would answer in the affirmative. But an actual program to make that happen would require a profound change in our present political and economic arrangements. The pediatric cardiologist or cardiac surgeon might, as a citizen, engage politically in support of such a change. As an individual practitioner, though, perhaps the best that she can do is to try to provide equally effective, respectful and professional care for all her patients.

4 Dealing with Conflicting Obligations

Several times we have seen that two of the basic principles of medical ethics might, in a given case, prescribe contrary courses of action. Respect for autonomy dictates that the patient be told the truth; non-maleficence requires that the patient not be harmed by hearing psychologically devastating news. Beneficence might call for doing all that one can to secure a kidney for a dialysis patient, while respect for autonomy prohibits taking it from a dying patient without his permission. The four principles themselves offer no way of adjudicating the dispute by prioritizing one principle over the other. One might appeal to the ethical theories of utilitarianism and deontology in hopes of resolving the conflicts, but in these cases the two theories point in different directions, and hence provide no resolution.

Sometimes the conflicts are merely apparent, and more careful consideration of the facts of the case or of the relevant moral principles will yield a solution. But sometimes not. There are, in the end, genuine ethical dilemmas in medicine—cases in which there is no clear “best option,” but nonetheless a decision is required. In such cases the ethically conscientious practitioner still has a useful source of moral insight to call to her aid: an ethics consultation. Most hospitals have a formalized advisory process for bringing in experienced professionals (usually medical professionals) trained in clinical ethics to discuss the case. Ethics consultation services are most often called for when there is a disagreement about treatment between physician and family (or between physicians), but they can also be of service to the individual practitioner who is unsure or conflicted about the ethical nuances of a given case.²⁸

Early in his *Nicomachean Ethics* [3] Aristotle reminds us that ethics is not an exact science like geometry. There can be ethical principles, but they do not logically entail an answer to every ethical dilemma the way the axioms and definitions of geometry provide a decision procedure for the truth or falsity of every proposed theorem. In Aristotelian terminology, ethics is a *practical* discipline, not a purely theoretical one. As a practical science it deals with human action—always immersed in the social, political, religious and biological complexity—the changing contextual detail—of human life. Learning to act ethically is not just a matter of learning and then applying rules. Rather, there is a kind of skill involved, and developing a skill requires practice and experience. We must acquire, through practice, the skills that enable us to apply our general understanding in ways that are appropriate to each occasion. A person who knows the principles and has acquired, through extensive experience, the skill and the habitual inclination to apply those principles in the right way, possesses what Aristotle calls “practical wisdom” (Greek *phronesis*) [3]. We sometimes say that for such people it is “second nature” to take seriously the ethical dimensions of a case, to discern the nuances that might be morally significant, to really hear what the family is saying,