



CHAPTER 4

Theory and Practice: From the Top Down

Abstract The bioethics movement, originating in the United States but then expanding to become a worldwide phenomenon, generated a conception of ethical reasoning that is oriented toward ethical (and legal) rights—and also, more abstractly, toward ethical principles. These modes of reasoning, though useful and even powerful tools for trained philosophers and bioethicists, do not mesh well with how clinicians think and work. The discontinuities arise in various contexts, and will often be discussed here and in subsequent chapters. In this chapter we focus on the development of the bioethical model of *principled decision making* and the notion of ethics expertise to which it gave rise.

Keywords Health care · Clinical ethics · *Salgo* · Informed consent
Patients' rights · Autonomy · Principled decision making · Ethical dilemmas · Ethics expertise

FROM RIGHTS TO PRINCIPLES

In what sociologists refer to as a process of *normative entrepreneurship*, the Hastings Center, Kennedy Institute of Ethics, and a small but growing cohort of bioethicists, as well as state courts and even the U.S. government, moved rapidly in the 1970s and early 1980s to articulate and consolidate a particular conception of ethical problems in health care and how to analyze and address them.

The conceptual center of the new bioethics movement was generally seen as involving informed consent (from the original 1957 *Salgo* decision by the California Supreme Court), patients' rights (invoking the language of President Kennedy (1962), Ralph Nader (1965), and, indeed, the larger civil rights movement of the 1960s [see Chapter 3]), or, in what would become the distinctive vocabulary of the bioethics movement, individual autonomy.

We can understand this progression as occurring in four stages.

First was the *Salgo* case, in which the California Supreme Court chose to enforce a policy that it described as "informed consent"—the need for physicians to provide patients with the information required to give their informed consent to treatment. The Supreme Court's opinion refers only once to the rights of patients, and even then, it does so only in quoting the earlier, lower court opinion in the same case.

Second was the assertion of patients' rights as such—most centrally, the right of patients to give informed consent to treatment. It was, indeed, a short step for courts to move from *Salgo*'s assertion about what doctors are required, or have a duty or obligation, to do (i.e., to *provide information* to patients so that they can make informed decisions), to the correlative assertion that patients have a *right to be given* that same information. And throughout the 1970s, as state courts were using the doctrine of informed consent as the central tool in analyzing that decade's landmark cases about death and dying, the bioethics literature was generating its own wide-ranging, but parallel, literature on informed consent. Though the legal cases nominally based their decisions on patients' legal rights, and the bioethics literature was nominally based on ethical rights, the two frameworks interacted and ran together. Court decisions were interpreted as extending the ethical understanding of patients' rights, while the ethical understanding of patients' rights, as advanced by bioethicists through their contributions to the bioethics literature, was used by courts and legislatures in articulating further legal advances. The doctrine of informed consent came to be the centerpiece of the bioethical paradigm, used to analyze and decide problems as wide-ranging as the care of the dying, at one extreme, to the ethically permissible conditions for selling genetically engineered tomatoes, at the other.

A third step, conceptually at least, was the expansion of the rights framework to include the rights not just of patients but of myriad other persons (parents, spouses, health professionals) and institutions (hospitals, insurance companies, the government, even society itself),¹ with the consequence that virtually any ethical situation could be construed in terms of conflicting rights.

A fourth, final step in the progression of bioethical thought was the move toward a more general plane, the level of philosophical discourse—that is, the level of principles. In this context, the emergence of a fully elaborated, mature bioethical model of health care ethics was marked, as noted in Chapter 2, by the 1979 publication of *Principles of Biomedical Ethics*, by Tom Beauchamp and James Childress, with its four principles of autonomy, beneficence, nonmaleficence, and justice. That book consolidated, and articulated in theoretical terms, the decade of bioethical discourse since the founding of the Hastings Center. The success of this approach can be measured by its longevity. The seventh edition of the Beauchamp–Childress volume was published in 2013. A parallel volume, with more emphasis on the law, is *Ethics and Law for the Health Professions* by Ian Kerridge and colleagues, originally published in 1998, with its fourth edition published in 2013. As noted in Chapter 3, the original set of four principles was expanded through the 2005 Universal Declaration on Bioethics and Human Rights, but the same emphasis on principles remains central, even exclusive.

Seen from the perspective of bioethics, as described above, the informal, intuitive ethical reasoning that had served health professionals (and patients) for two millennia was unacceptable, among other reasons because it incorporated built-in prejudices and biases about who decides what, and why. Health professionals needed to be guided, instead, by self-conscious ethical reasoning based on abstract ethical principles. That is, according to this bioethical model, health professionals were supposed to apply abstract ethical principles (including the principle of autonomy underlying informed consent) to concrete clinical situations, ultimately reaching particular ethical judgments. This process came to be enshrined as *principled decision making*; any other form of reasoning was deficient.² Principled decision making is a prime example of applying an abstract or theoretical framework to specific cases or problems—that is, of reasoning from the top down.

A further step in the emergence and consolidation of the bioethics movement was the involvement of the U.S. government through the work and publications of the initial President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. The Commission's many publications—twelve books published from 1981 to 1983 and coming with the authority and visibility of any presidential commission—covered such a wide range of issues, and in such depth, that they effectively consolidated the ethical framework that U.S. bioethicists and courts had been articulating over the course of the 1970s.

DISCONTINUITIES WITH CLINICAL THINKING AND PRACTICE

The product of the above developments was a body of theoretical work that reflected the intellectual frameworks and linguistic conventions of philosophers and lawyers but that paid little attention to the long-established ways in which doctors and other health professionals actually thought and acted. Nowhere is the discontinuity between clinical medicine and the bioethical model of principled decision making more apparent than in Beauchamp and Childress's treatment, in *Principles of Biomedical Ethics* (1979, 2013), of the maxim *primum non nocere*, "First, do no harm"—a principle that is well familiar to all health professionals. This principle, especially when used within concrete factual situations presenting relatively concrete, well-defined ethical problems, is generally perceived as both easy to understand and easy to apply. By contrast, in *Principles of Biomedical Ethics*, the principle morphs into something that physicians, nurses, and other health professionals—part of the intended audience for the book—would likely not recognize and would surely be unable to apply.

To be more specific, as set out in the first, 1979 edition of *Principles of Biomedical Ethics*, the familiar principle of "do no harm" is better understood as the principle of "nonmaleficence, [which] refers to the noninfliction of harm on others." The principle of nonmaleficence is then distinguished from the "principle of beneficence," which requires that one take "positive steps to help others." The principle of beneficence is distinguished, in turn, from the "principle of benevolence," which requires that one act with the *intention* to benefit others. Beauchamp and Childress (1979) continue (pp. 135–136):

Sometimes in moral philosophy nonmaleficence is used to refer more broadly to the *prevention* of harm and also to the *removal* of harmful conditions. However, since prevention and removal generally require positive acts that assist others, we shall use the term "beneficence" to refer to acts involving prevention of harm, removal of harmful conditions, and positive benefiting, while "nonmaleficence" will be restricted to the noninfliction of harm.

. . . The duty to *confer* benefits and actively prevent and remove harms is important in biomedical and behavioral contexts, and of equal importance is the duty to *balance* the good it is possible to produce against the harms that might result from doing or not doing the good. It is thus appropriate to distinguish two principles under the general heading of beneficence: the

first principle requires the *provision* of benefits, and the second requires a *balancing* of benefits and harms. The first may be called the principle of positive beneficence, while the second is already familiar to us as the principle of utility.

Finally, Beauchamp and Childress (1979, p. 101) encourage the reader to keep in mind is that the principle of nonmaleficence can be properly applied only if one also takes into account, among other things, “due care, . . . risk-benefit assessments, and . . . detriment-benefit assessments.”

Even for someone trained in moral philosophy (as is the first author [SS]), this sort of language and analysis is difficult and burdensome to sift through, made only worse by the substitution of the conceptually opaque term *nonmaleficence* for “do no harm”—a precedent set firmly in motion by Beauchamp and Childress and followed almost uniformly in the bioethics literature, in the United States and elsewhere (see, e.g., the volumes by Kerridge et al. 1998, 2005, 2009, 2013).³ Indeed, as a measure of how the principle of nonmaleficence has permeated writing and discussion on bioethics, the word *nonmaleficence* surpassed a quarter of a *million* hits on Google toward the middle of 2017 (before Google changed the manner in which it counts hits). This number of hits is, in effect, a measure of the distance that the bioethics literature has moved away from the language and concerns of clinicians. And the term itself—*nonmaleficence*—signals, in a word, that the bioethicists are the experts and that clinicians are not.

If one assumes that the intellectual contributions of bioethics should help health care clinicians to stand on their own two ethical feet by themselves, it is fair to say that the language and methods of bioethics have fallen short.

VIGNETTE: DILEMMAS AND THE QUEST FOR CLOSURE

The disconnection between theoretical and clinical contexts finds direct expression in the following example (drawn from the all-too-recent experience of the first author), where there is a parallel disconnection between the therapist’s bioethics-framed thinking and her incapacity to tap into her own clinical thinking and experience.

A therapist asked me if I could give her my opinion about an ethical problem. Without waiting for an answer, she immediately proceeded to tell me

about “an ethical dilemma” that she was trying to resolve. A patient of hers had recently lost his job and was therefore unable to pay anything for further treatment. So the question was whether (1) the therapist should continue treating the patient despite his inability to pay, or (2) whether the therapist should tell the patient that treatment must be stopped because of that same inability to pay. In favor of the first option, the therapist felt that she had a *right* to be paid for her services and should not be expected to work for free, and in favor of the second, the therapist felt that the patient had a separate *right* to receive the treatment that he needed, independent of whether he had the current means to pay for it. In the process of presenting the situation to me, it became clear that the therapist saw no other options as being available. When she had finished, I asked her if she would consider other possible solutions to her “ethical dilemma,” which she had framed as exactly the sort of irresolvable dilemma of conflicting rights that are so commonly used in teaching bioethics. Since the therapist was, I found, immediately receptive to the suggestion that there might be alternative courses of action, and not just two (the “*dilemma*”), I mentioned that her patient, with no income whatsoever at that point and no immediate prospect of employment, would qualify for free care (under the United States’ federally mandated free-care program) at one of the local teaching hospitals. Rather than being abandoned, the patient would be able to obtain continuing psychiatric care of high quality, despite his lack of economic resources, until his professional situation improved. The therapist immediately recognized that this third option would enable her to escape the no-win situation of conflicting rights that she had constructed for herself using the bioethical paradigm.

In the above situation, the solution proposed by the first author was effective and readily available, but as various people mentioned when I subsequently discussed the situation with them, the solution was certainly not unique. Various sorts of other arrangements could also have been worked out with the patient (e.g., less frequent appointments, or a promise from the patient, or even a contract, to pay when his financial circumstances improved). But the availability of multiple options serves only to emphasize the point of the example. From the perspective of how the therapist had been taught about ethics (from a bioethicist) at a leading American medical school, she was doing exactly as she should have. She construed the situation as involving an ethical dilemma—literally an ethical choice between two mutually exclusive options—and as involving a conflict between various rights and abstract principles (e.g., the therapist’s obligation to provide treatment; the therapist’s right

to be paid for services; the patient's right to obtain needed health care; the possible relevance of altruism, self-sacrifice, and the obligation to help someone in distress).

In both the academic literature and in the classroom (note: the *classroom*, not the *bedside*), “dilemmas” and conflicts involving rights or principles have always been a mainstay of bioethical discussions: witness the publication of various “case studies in” books by Robert Veatch and colleagues: medical ethics (1977), nursing ethics (1987), allied health ethics (1996), pharmacy ethics (1999), and, most recently, biomedical ethics (2010, with a second edition in 2015). But these “dilemmas” are basically unresolvable in their own terms: Should individuals with severe developmental delays be sterilized? What happens when prospective parents disagree about whether to abort a genetically defective or otherwise malformed fetus? Should patients with one chance in 25 (or 50, or 100, or 500, or 1000) of recovering be maintained on life support indefinitely? Should families with a history of abuse but a strong recent record of safety have their children removed when conflict at home creates the potential for harm? Reasonable, well-intentioned people—whether ethicists, health professionals, or laymen—will come to different conclusions. The more difficult the dilemma, the less likely that anything resembling a consensus will emerge. And *if* a consensus does emerge, it will likely be only after a long process of debate and analysis. Even then, some people are likely to have some perfectly good reasons for rejecting what has, by hypothesis, come to be the consensual view.

The basic problem here is that rights and principles, though legitimate dimensions of ethical discourse, are actually difficult to sort out when they conflict. Rights, for example, define interests that can be asserted against other persons and that typically demand a particular outcome—whatever that right requires—unless others can, in response, assert their own rights. That is, if a person legitimately asserts a right against others, the only way that the others can effectively oppose it is by asserting back their own rights or other compelling interests (e.g., public safety) that undercut or oppose the initial assertion of rights. The immediate unanswerability of an assertion of rights is what accounts for the lively classroom discussion of the ethical dilemmas that have become so common in teaching health care ethics. Veatch and colleagues, for example, self-consciously design their cases to generate conflicts among rights. Different students end up taking different “sides” and seeing different rights (e.g., those of the patient, those of the family, or those of society)

as more fundamental than others. The discussion may be lively and even combative, but within the confines of a single classroom session, reaching a reasoned consensus is unrealistic. The advantage of this approach to teaching ethics is that it does offer an opportunity to explore the complexities of the cases presented, but the disadvantage is that it provides no obvious way of moving beyond those complexities. Students are simply left at loggerheads with one another.

ETHICS EXPERTISE: WHAT IT IS AND ISN'T

The extent and depth of disagreements in such discussions is, in a small way, a reflection of what typically occurs in philosophical discourse. The philosophical literature abounds in discussions of normative ethical problems of the sorts that are also discussed in the parallel literature of the bioethics movement. As any observer realizes, however, the field of normative ethics (within the field of moral philosophy, not bioethics), for all its erudition and rigor, is characterized by virtually unending intellectual cacophony, conflict, and disagreement; closure and consensus are rare commodities. That is, the expertise of “professional” philosophers—those who teach in philosophy departments throughout the United States and the rest of the world—does not enable them to provide authoritative solutions and closure to thorny ethical problems. It is not an expertise of substantive ethical knowledge that would enable them to draw authoritative ethical conclusions from abstract ethical principles. Their expertise, instead, is fundamentally about *how* to think, not *what* to think: in the process of becoming a professional “expert” in ethics (a process that consumes nearly a *decade* in the life of a PhD philosopher), what one acquires is the capacity to ask questions and to analyze and criticize ethical reasoning.⁴

This particular, process-oriented conception of expertise is radically at odds with the notion of professional expertise current within health care. Whereas the former is oriented almost exclusively toward *how* to think, the latter is oriented almost exclusively toward *what* to think. Put in another way, the expertise possessed by health professionals in their own fields enables them to make specific clinical decisions and to exercise clinical judgment. And the more expert a person is, the more authoritative—and presumably, accurate and reliable—his or her expert opinion will be. By the same token, the reason for consulting someone with more expertise than one has oneself is to obtain reliable guidance, and

closure, in situations where one's own knowledge and expertise are perceived as inadequate. Within health care, the more difficult the problem, the more helpful, authoritative, and reliable expert consultation is apt to be, at least with regard to achieving closure, a way of going forward. Within normative ethics, however—and within bioethics, too—the more difficult the problem, the less likely that expert (philosophical/bioethical) consultation will lead directly to closure. It may well lead to a better understanding of the problem and of the various factors that render it so difficult to resolve. But it will generally not lead to closure; for all their knowledge of ethical principles and how to analyze complicated situations, philosophers with expertise in ethics—including bioethicists—cannot actually provide single, reliable, authoritative answers to difficult ethical questions.

Unfortunately, the differences between the two types of expertise—substantive expertise in *what* to think versus procedural expertise in *how* to think—is not typically recognized within clinical settings. Health professionals are apt to see bioethicists as having the same sort of substantive, authoritative expertise as those professionals have come to expect from senior colleagues in their own fields, and our own impression is that bioethicists are typically content to be perceived as having exactly the same sort of substantive expertise as experts within health care: that is, health professionals can and should rely on the opinions of bioethicists as providing the single, correct answers to whatever question has been asked.⁵ Also worth noting is that hospital administrators and department heads welcome seeing bioethicists in exactly that way: what better way could there be to escape from a messy situation than by relying on the authoritative ethical judgment of a bioethicist?

This mistaken way of perceiving bioethicists has real, and unfortunate, consequences. When clinicians perceive bioethicists as providing authoritative answers, clinicians become mere consumers of information. Their position is one of relative passivity. Clinicians are not generating knowledge or conclusions through their own intellectual activity. Instead, they are receiving information that will not be integrated, assessed, or retained in the same way as information or conclusions that they generate through our own thinking, their own ethical engagement/reflection.

The shortfall is exactly the same as what happens when someone else is driving a car and telling us how to get somewhere. It's simply not the same as what happens, and what we learn, when we are driving the car ourselves. It's only when we are in the driver's seat—when we are active

rather than passive—that we actually learn the route in a manner that will be retained. Likewise, passively consuming some information from a so-called ethics expert will possibly provide a workable way of going forward in a particular situation, but it is unlikely to result in the kind of learning that will help anyone to analyze and address ethical problems in the future. That is, a one-off encounter regarding a particular situation can be expected to produce no more than a single bit of information, useful for the situation encountered but of no further educational value.

Bioethicists have attempted to address this problem of reaching closure in various ways, including multistep processes—the subject of the next chapter. As we will argue, however, such processes promise more than they can achieve.

NOTES

1. And even to animals. In “Should We Stop Keeping Pets? Why More and More Ethicists Say Yes” (2017), Linda Rodriguez McRobbie suggests that keeping animals as pets arguably violates their “right of self-determination.”
2. This preference for reasoning from ethical principles is often taken up not just by those trained to work with such principles—such as those in philosophy, theology, and, to a certain degree, lawyers—but by scholars and practitioners intellectually grounded in other, more concrete fields. For example, when the first author was a Visiting Scholar at Yale Law School in 1994–95, he had what proved to be a remarkable conversation with Professor Jay Katz, a psychiatrist who wrote *The Silent World of Doctor and Patient* (1984) and was one of most revered and humanly sensitive bioethicists in the history of that bioethics movement. When I mentioned that I thought most doctors could and should make ethical decisions without explicitly consulting and applying ethical principles (which is, in fact, the subject of the present book), he stared at me in utter disbelief and said that he was astonished that I could hold such a view.
3. The 2005 Universal Declaration on Bioethics and Human Rights reverted to nontechnical language in its Article 4 (“Benefit and Harm”): “any possible harm to . . . individuals should be avoided.” The declaration also provided for various sorts of protections—to avoid harm—in several other articles. Despite this helpful linguistic change in such a prominent document, bioethicists have, as far as we can tell, continued to use *nonmaleficence* in their publications and on the websites to which they contribute. See, among many examples, “Ethical Frameworks: The Four Principles” (2018) on the UKCEN Clinical Ethics Network, and “Principles of Bioethics” (2013) on the University of Washington School of Medicine’s

generally informative website, Ethics in Medicine, <http://depts.washington.edu/bioethx/>.

4. In this context the first author is reminded of a conversation, long ago, with the head of a graduate training program in medicine (i.e., for residents) at a hospital affiliated with Harvard Medical School. The latter mentioned that the hospital was already being well served by a “trained” bioethicist. The person in question, a recent medical school graduate with no philosophical background, had attended a three-month summer program in bioethics at Oxford University in England. A rough estimate is that he had gained, in terms of analytical and critical skills, the equivalent of less than one year of undergraduate education in a philosophy department. Although he was consequently a mere neophyte in the field, the hospital perceived him as having gone off to Oxford to acquire substantive knowledge, and apparently three months there was deemed sufficient for him to be considered an intellectually authoritative bioethicist.
5. The use of ethical principles that were perceived as leading to determinate conclusions was also a methodology that was agreeable to doctors accustomed in thinking within the traditional biomedical model. The model of principlism stressed clarity, precision, and expertise, rather than feelings, context, and social determinants, the factors that are crucial in understanding the vignettes presented throughout the present book. We are grateful to Allan Brandt for bringing this point to our attention.

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