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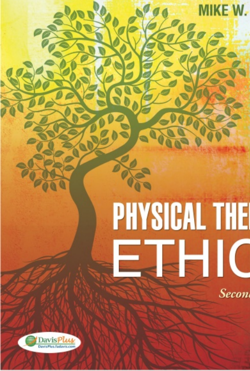

# PHYSICAL THERAPY ETHICS

*Second Edition*

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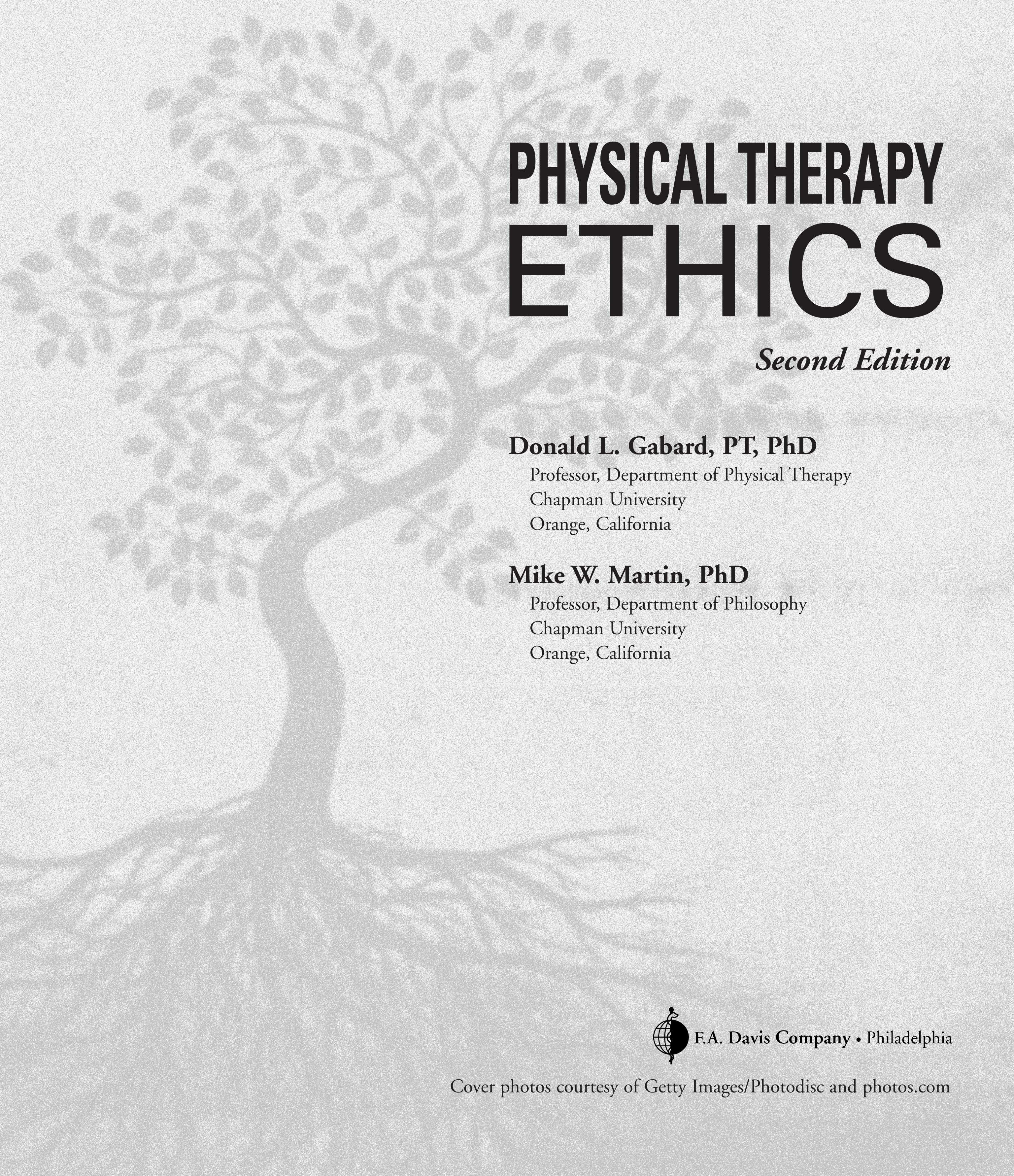

# PHYSICAL THERAPY ETHICS

## *Second Edition*

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*For Erasmo Borrego and in loving memory of Clara Mae Pardue*
*—Donald L. Gabard*

*For Shannon Snow Martin, and in loving memory of Van L. Snow and Grace Snow.*
*—Mike W. Martin*

# Preface, Second Edition

The book has been extensively reorganized and updated throughout with new concepts and cases. More subsection headings are used as are tables and figures. The book is now divided into three parts: Core Professional Concepts, Respect and Caring, and Organizations and Administration. Chapter 2—Caring, Character, and Principles—is new. The chapter on ethical theories now appears as Chapter 12, allowing instructors to deemphasize it if they choose, although many instructors will prefer to teach it immediately after Chapter 1. Many topics are given greater development, including the steps in resolving ethical dilemmas, the principles of biomedical ethics, the ethics of care, cultural competency, spirituality, and the complex interface between professional ethics and administrative ethics in the healthcare setting.

# Preface, First Edition

Ethics is the heart of professionalism. Just as much as technical skill, moral commitment enables physical therapists to provide quality services for patients, work effectively with colleagues, and maintain the trust of the public. At a more personal level, moral commitment motivates, guides, and gives meaning to work.

Physical therapists' special expertise and distinctive roles working closely and at length with patients allow them to bring a unique perspective to health-care ethics. Therapists also contribute to health-care ethics by participating in professional societies, serving on hospital ethics committees, revising health-care policies, and engaging in daily dialogue with other professionals. Hence, it is no surprise that the study of professional ethics now plays a prominent role in the curriculum and in professional settings.

Like health care itself, the exploration of physical therapy ethics is an interdisciplinary effort. This book integrates the practical interests of physical therapists with philosophical ethics—a combination of disciplines that has similarly proved fruitful in the development of other branches of health-care ethics. Practical interests are engaged in many ways: by identifying and organizing a wide array of practitioners' concerns and debates within the profession, providing numerous case studies of ethical dilemmas and responsible conduct, discussing relevant laws, and frequently referring to the American Physical Therapy Association's Code of Ethics and accompanying Guide for Professional Conduct. Philosophical approaches include attention to major ethical theories but primarily center around distinctions from and approaches to what philosophers call applied or practical ethics.

Our aim throughout this book is to provide tools for students and practitioners of physical therapy as they confront ethical dilemmas and moral controversy. Equally, our aim is to stimulate reflection on the moral significance of therapists' work, which remains a neglected area in the study of health care. Sometimes these aims are best served by withholding our views as authors, to provide balanced presentations of differing perspectives. Other times we present our position on issues, hoping thereby to provoke more discussion than would a mere summary of others' views.

Most of the chapters employ a dual organizing principle, as indicated by the chapter titles: a key value combined with a cluster of related topics in which that value plays a major role. For example, the key value in Chapter 8 is honesty, and the topics concern conflicts of interest. Usually the key value refers simultaneously to a responsibility (an obligation) and a virtue (a good feature of character). Thus, honesty is owed as a duty to patients, and it is also a virtue of caregivers. Of course, no single value operates exclusively in any one domain of a profession, but we have found this approach contributes to thematic unity and pedagogical effectiveness.

Finally, we note that the Guide to Physical Therapist Practice makes an important distinction between "patient" and "client." Physical therapist practice addresses the needs of both patients and clients through a continuum of service across all delivery settings—in critical and intensive care units, outpatient clinics, long-term care facilities, school systems, and the workplace—by identifying health improvement opportunities, providing interventions for existing and emerging problems, preventing or reducing the risk of additional complications, and promoting wellness and fitness to enhance human performance as it relates to movement and health. Patients are recipients of physical therapist examination, evaluation, diagnosis, prognosis, and intervention and have a disease, disorder, condition, impairment, functional limitation, or disability; clients engage the services of a physical therapist and can benefit from the physical therapist's consultation, interventions, professional advice, prevention services, or services promoting health, wellness, and fitness. For stylistic reasons, however, we have elected to most often use "patient," often the more vulnerable of the two categories, even though "patient/client" is in some cases most accurate.

# *About the Authors*

**DONALD L. GABARD, P.T., PH.D.,** is professor of physical therapy at Chapman University. He earned his M.S. in physical therapy at the University of Southern California, completed an additional 2-year program in interdisciplinary medicine at its University Affiliated Program, and earned an M.P.A. and Ph.D. in Public Administration with a primary emphasis in administrative ethics. He also participated in seminars in medical ethics offered by the Hastings Center and by Georgetown University. Since 1978 Dr. Gabard has practiced pediatric physical therapy in a variety of settings, including in private practice and at Pacific State Hospital, the University Affiliated Program at Children's Hospital of Los Angeles, Special Children's Center in Pasadena, and California Children's Services. In addition to publishing a number of research articles, he has been a consultant to a variety of corporate and nonprofit organizations. He also serves as a consultant and member of a major hospital ethics committee. Currently he teaches courses in physical therapy ethics, cultural diversity, and administration. His area of research is in professional ethics and education.

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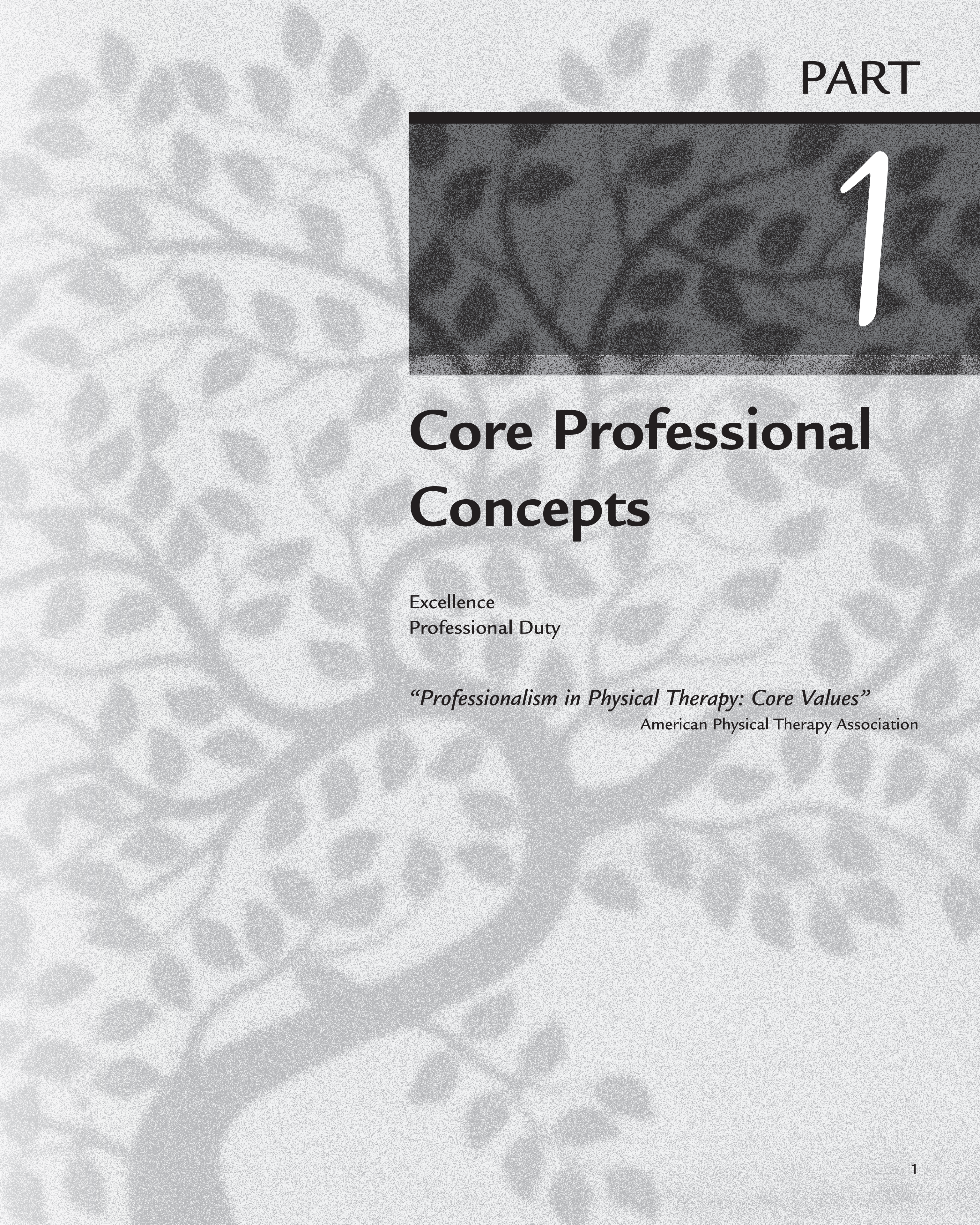


# PART 1

# Core Professional Concepts

Excellence
Professional Duty

*"Professionalism in Physical Therapy: Core Values"*
American Physical Therapy Association

# Chapter 1

# Professionalism and Ethics

*Physical therapists shall be accountable for making sound professional judgments.*

Principle 3, APTA Code of Ethics

### CASE 1.1 **Steroids in School**

Shirlaine is a physical therapist working for a public school system.[1] Her duties consist primarily in screening high school athletes during the preseason and then treating injuries caused during practice or games. Currently she is treating Donald, the school's 11th grade star wrestler and champion weight-lifter, for a minor tear in his tendon at the biceps brachii muscle insertion. She notices excessive muscle hypertrophy as the tear heals. Because she knows that anabolic steroids are a common cause of such problems, and because she had previously suspected that Donald was using illegal drugs, she asks him whether he is using any steroids. At first he denies it, but eventually he confesses to using unprescribed methandrostenolone.

Shirlaine immediately urges him to stop using the drug and informs him of its potentially life-threatening side-effects, including liver disease and cancer. He replies that he cares only about winning the state championship and begs her to keep the matter secret. He also says his competitors are using steroids, and it is unfair to deny him the opportunity to compete at their level. Moreover, he is confident he will not be caught. At one point he uses a threatening tone that makes Shirlaine feel her job might be in jeopardy if she divulges the information. In addition, Shirlaine knows the coach is an aggressive competitor who is lackadaisical about drug use.

Summarized from Bruckner J. Physical therapists as double agents: Ethical dilemmas of divided loyalties. *Phys Ther.* 1987;67(3):383-387 with permission of the American Physical Therapy Association.

Shirlaine faces an ethical dilemma, perhaps several of them. **Ethical dilemmas** are situations in which moral reasons come into conflict, and it is not immediately obvious what should be done. In this chapter, we identify the steps in resolving ethical dilemmas. Before doing so, we define physical therapy ethics and discuss why it should be studied. We also discuss how ethics and professionalism are connected and the importance of professional codes of ethics. Throughout, we understand professionalism as an umbrella value that encompasses many more specific values to which professionals should commit themselves.

## WHAT IS PHYSICAL THERAPY ETHICS?

The word "ethics" is ambiguous and hence so is "physical therapy ethics." We distinguish several primary senses, both normative and descriptive ones.

### Normative Versus Descriptive Ethics

In the main senses used in this book, ethics refers to **normative ethics,** which aims at identifying, understanding, and applying justified moral values. Moral values include what is obligatory (right), permissible (all right), good, or otherwise morally valuable. The goal is to understand and apply justified moral values to personal decisions and character, public policies and laws, and organizational procedures and structures.

In one normative sense, ethics names an area of study, the study of what is morally justified. Accordingly, as an area of study, physical therapy ethics is the normative inquiry into morally justified decisions and principles, ideals and virtues, and policies and laws concerning physical therapy. This normative inquiry is an interdisciplinary study that draws on the insights of physical therapists, other health professionals, philosophers, religious thinkers, attorneys, administrators, and members of the public.

In a second normative sense, ethics is used as a synonym for morally justified conduct, beliefs, and character. Using this sense, physical therapy ethics is the set of justified conduct, beliefs, attitudes, relationships, principles, policies, and ideals in physical therapy.

In contrast to normative senses, **descriptive ethics** refers to facts about what people believe in moral matters and how people actually act, regardless of whether their beliefs and actions are justified. In a descriptive sense, one speaks of the ethics of Christians, Jews, Muslims, Hindus, college professors, politicians, and other groups, without implying their ethics are justified. Also, under the heading of descriptive ethics, psychologists and sociologists study the origin (biological or social) and functions of what groups believe about morality, without necessarily endorsing them in any way. Using the descriptive sense, physical therapy ethics might refer to any or all of the following:

- The conduct of physical therapists (as individuals or as groups);
- The beliefs of physical therapists;
- The empirical description and explanation of the origins and functions of practices concerning morality in physical therapy.

Having distinguished normative and descriptive studies, we can appreciate their connection. Just as attending to the facts is an important part of moral decision making, scientific inquiries often shed light on how to develop and improve moral conduct and character. After all, justified moral outlooks must be psychologically realistic; that is, attuned to what is possible for human beings.[2] Moreover, information about social settings and particular contexts is crucial in making moral judgments and formulating morally justified policies.

As an example of descriptive inquiries relevant to physical therapy, we turn to challenges early in the AIDS crisis. It was common knowledge that, early on, many physical therapists as well as other health care professionals were reluctant to provide care to patients with AIDS. It was important to know if care was being withheld because of a fear of contagion, an avoidance of rendering what was perceived as futile treatment, or homophobia. If the answer had been contagion, then the profession should have dramatically increased the efforts to explain the contagion risks. If it had turned out to be an aversion to treating persons with catastrophic illnesses or terminal illnesses, then treatment of patients with AIDS needed to be viewed in comparison with treatment of patients with cancer or other life-threatening diseases. If the results had been homophobia, then the profession would have needed to increase educational efforts around diversity and duty to treat. A scientific examination of the beliefs and values of physical therapists measuring fear of contagion, attitudes about terminal care, homophobia, and resulting behaviors would have been a timely and morally useful descriptive inquiry.

## WHY STUDY PHYSICAL THERAPY ETHICS?

What can be gained from the normative study of physical therapy ethics? We will focus on the aims of courses on physical therapy ethics required for earning a degree, but the same question arises in the study of professional ethics as part of continuing education, in ethics workshops within hospitals, and even in reflecting as a practitioner on one's work.

A familiar objection to courses on ethics is that morality cannot be taught at the college level because moral values are instilled, or not, in early moral training. This objection contains an element of truth, but only an element. The essential foundation for moral behavior does begin early in life. Without that foundation, little can be done at the college level. To cite an extreme example, there is no cure for individuals (sociopaths) who have antisocial personality disorders—who enter adulthood without a moral conscience, without any sense of right or wrong. Psychiatrists estimate that as many as 3% of American males and 1% of females have this disorder.[3] Fortunately, most sociopaths are not violent, but they might engage in such behaviors as pathological lying, theft, and other crimes, without feeling guilt or shame.

Nevertheless, university courses can make a significant contribution to moral development.[4] The study of ethics is a lifelong process, and higher education provides an especially important opportunity for grappling with the complexity of moral issues in the professions. Courses on ethics strengthen capacities for dealing with moral dilemmas, vagueness (uncertainty, ambiguity), and disagreements. They do so by strengthening and refining such skills as:

- Identifying and clarifying moral issues and moral reasons;
- Weighing conflicting moral reasons;
- Forming consistent and well-developed moral perspectives;
- Maintaining imaginative awareness of alternative viewpoints and integrating conflicting perspectives;
- Using moral reasons and arguments with increased precision, both in writing and in dialogue with others.

Notice that this list centers on cognitive skills—skills of the intellect, such as perception, clarity, and reasoning. Presumably, a thoroughly immoral person could possess these cognitive skills and yet lack moral concern and respect. The person could lack desirable moral attitudes and fail to act in morally desirable ways. In fact, such a person could abuse the skills by using them to rationalize immoral conduct. Consider, then, the following additional skills as goals in studying ethics:

- Arguing in morally reasonable ways toward beliefs that are justified (acknowledging wide room for legitimate differences among morally reasonable persons)
- Manifesting attitudes of care and respect for other persons as well as for oneself
- Appreciating diversity as manifested in moral tolerance (non-coercive toward people with whom one disagrees), open-mindedness (receptive to new ideas), and broad-mindedness (acknowledging a range of morally reasonable differences)
- Acting in morally responsible ways as a professional
- Maintaining moral integrity by integrating one's personal and professional values

Should we add these five goals to our list of aims for university courses on ethics? Our answer is yes, with a caveat. Without these goals, courses on ethics would have little moral point. Devoting classroom time to ethics should be done in the conviction, or at least with the reasonable hope, that such effort will contribute to morally responsible conduct rather than to mere cleverness aimed at rationalizing immoral behavior. Moreover, when teaching ethics is linked to clinical supervision, professors can and should ensure that students are meeting appropriate standards of clinical practice.

The caveat: in our view, the direct emphases in college courses should be on increasing cognitive skills, largely presupposing a foundation of moral concern (in professors and students alike). Teaching ethics is different from preaching, and in some ways it is the opposite: teaching ethics forces us to recognize multiple perspectives and to weigh intellectually the reasoned arguments without preset judgments. As for moral commitment, professors and students are in many respects moral equals. Professors have greater practical experience and theoretical expertise, but they cannot be presumed to "have the right answers" in resolving moral issues nor even to be more deeply committed morally than students. Hence, in setting goals in courses on ethics and in grading exams and papers, professors reasonably focus on increasing skills in moral argument.[5]

Accordingly, the central aim of this book is to offer tools for students and practitioners of physical therapy to strengthen their capacities to deal responsibly with moral vagueness, ambiguity, conflicting reasons, and disagreements. These capacities contribute to defensible courses of action and habits of thinking that enhance care. We proceed in the conviction that such growth is both possible and commonplace. Although our focus is on increased cognitive skills, we address ourselves to morally concerned persons who will use these skills for ethical purposes.

## Master Clinicians and Moral Competency

There are substantial parallels between the thinking process we have just discussed and the problem-solving styles of Master Clinicians, particularly when the Master Clinician status is determined primarily by patient outcomes. Master Clinicians, whether in physical therapy or other health-care professions, are comfortable with and manage ambiguity and uncertainty. They have an intense focus on the patient as part of a true partnership in care which includes collaborative problem solving, and they engage in multiple strategies for problem solving derived from multiple perspectives.[6-13] Master Clinicians are also reflective thinkers who manifest empathy, regularly review their reasoning, and build from insight into their successes and failures.[14] Clinical competence is not, however, correlated with advanced certification, long years of clinical work, grade-point average, or MCAT scores. [6,7,15-17]

The correlations of moral reasoning and clinical competence are attributable in part to the ability to take multiple perspectives on a given situation.[14,18,19] Sheehan found that high levels of moral reasoning almost assured high clinical competence, as evaluated by faculty, and low levels almost excluded high clinical performance.[20] Baldwin found lower malpractice incidence among those with higher levels of moral reasoning.[18]

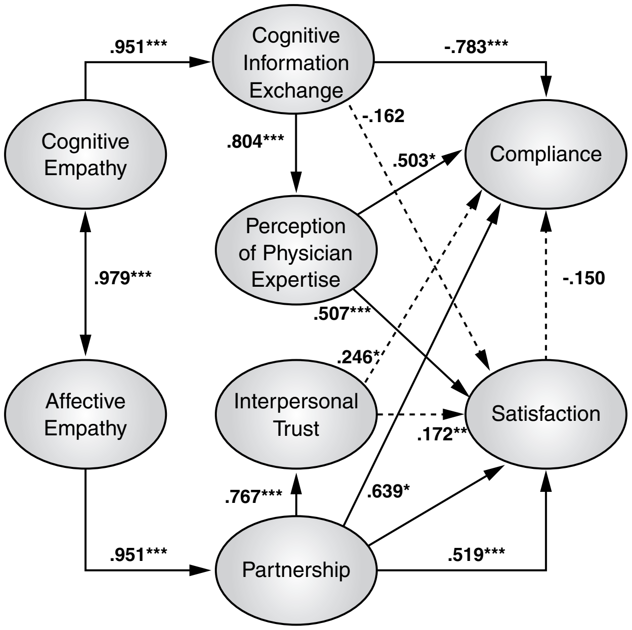
In addition to moral reasoning, empathy is also a predictor of clinical competence. Here we need to distinguish between empathy as (1) understanding another's position, and as (2) sympathy; that is, immersing one's self in the emotions of another.[21,22] Like moral reasoning, low empathy scores predict low clinical performance, and high scores predict high clinical competence. Not unexpectedly, high empathy scores were also associated with increased compliance, patient satisfaction, and more accurate diagnosis.[15,16,23,24]

In explaining the linkages between moral reasoning, empathy, and clinical outcomes, Hoffman hypothesizes some intuitive links. He suggests there is good support for the idea that empathy is innate to humans from early childhood and it goes through predictable levels of refinement.[25] Empathy allows people to add dimension and multiple perspectives into their thinking process, and in so doing they can move through the development of moral principles and reasoning. In a more limited fashion Kim, Kaplowitz, and Johnson[24] offer an interesting visual typography of the research they reviewed related to empathy **(Fig. 1–1)**. It should be noted that after her study, Hojat et al. found that physician-reported empathy and patient-reported physician empathy were similar enough for both to hold as outcome predictors.[23]

In short, the long-standing conviction that the best providers are caring and ethical providers has support from the scientific literature. Caring providers are informed by empathy and engage in responsible reasoning that reflects moral complexity and ambiguity. Their professional judgment embodies responsible moral judgment that is continually refined through clinical experience.

## MORALITY

If physical therapy ethics is the study of morality in physical therapy, what is morality? One way to approach this question is to ask, What are moral reasons? Moral reasons include honesty, fairness, integrity, respect, compassion, loyalty, and so on. A list of sample moral values, however, is not a comprehensive definition. Nor does it explain why these items appear on the list—in other words, what makes honesty and compassion moral values? It would be convenient to have a more comprehensive definition, yet providing such a definition is more difficult than first appears.



NOTE: A solid line indicates a strong effect (> .50), whereas a dotted line indicates a weak effect (< .50) between the 2 variables.
*p < .05, **p < .01, *** p < .001

**FIGURE 1–1.** Physician Empathy Model. (Redrawn with permission from Kim SS, Kaplowitz S, Johnston MV. The effects of physician empathy on patient satisfaction and compliance. *Evol Health Prof.* 2004:27[3]:237-251.)

Dictionary definitions do not help much. A dictionary might indicate, for example, that morality is about right and wrong, good and bad, and what one ought and ought not to do. The difficulty is that all these terms have applications beyond moral matters, and hence they do not pinpoint our topic. For example, we speak of the right way to use a goniometer, the wrong way to interpret the developmental quotient for a premature child, the right way to turn on a computer, and the wrong way to test for a hip flexion contracture. There is a good and bad way to grow tomatoes and to mix paint. And when someone says turn left at the signal in order to get to the restaurant, that person is not issuing a moral prescription. The point is that distinctions of right-wrong, good-bad, and ought-and-ought-not are applied in numerous contexts having no direct connection with morality.

As we try to be more specific, we are already engaged in a normative inquiry, and the resulting definition is likely to be controversial. For example, if we say that morality is simply obeying the law and other dominant customs, we are embracing the controversial view called ethical relativism. Or if we say morality is simply pursuing what is good for ourselves, we are embracing ethical egoism. If instead we say that morality is producing the most good for the most people, we are embracing the theory called utilitarianism. If we say that morality is about respecting human rights, we are embracing rights ethics. Finally, if we say that morality is about human well-being, this characterization will strike some people as too narrow and others as too broad. It is too narrow because it excludes animals and the environment as having moral significance in their own right, independently of their uses for humans. It is too broad because it neglects how additional, non-moral values also contribute to human well-being; for example the values of art, recreation, and religion. In short, an informative and comprehensive characterization of morality requires sketching an ethical theory—a theory about morality of the sort discussed in Chapter 12.

The expression "morally justified" is itself ambiguous. It might mean:

a) Morally obligatory (right, required);
b) Morally permissible (all right, although perhaps not obligatory); or
c) Morally good (desirable or ideal, even if not required).

Obligatory principles are mandatory for all physical therapists, and failing to meet them makes therapists culpable. Yet, ethics concerns more than duties and dilemmas, in physical therapy and elsewhere. Ethics also concerns personal ideals to which individuals commit themselves in their work. For example, some moral ideals are attached to religious commitments. Others are supererogatory ideals of caring and service that go beyond the minimum service required of all physical therapists. These personal ideals motivate, guide, and give meaning to the work of physical therapists (and other professionals), even when they are not morally mandatory.

## PHYSICAL THERAPY AS A PROFESSION

Regardless of how we characterize ethics, clearly ethics is integral to professions like physical therapy. What are professions? In a loose sense, professions include all ways of making a living: thus, professional athletes, spies, and even murderers. However, in a narrower sense used here, professions include only some forms of work—such as law, medicine, and teaching. Professions meet four criteria: advanced expertise and education, independent judgment, social organization and recognition, and commitment to the public good.[26] Accordingly, physical therapy is a profession if it meets these criteria, and surely it does.

1. **Advanced expertise** combines sophisticated practical skills with a strong grounding in sophisticated theory. Stated in another way, professional expertise combines practical know-how with "knowing-that" (numerous theory-based facts). The importance of practical know-how has always been clear enough in the case of physical therapy, which is quite literally a "hands-on" profession. The requirement of advanced theory-based knowledge has increased dramatically but still is in need of further refinement. The professionalization of physical therapy is manifested in the steady movement toward more advanced training in science and medicine and by the increased union between know-how and knowing-that as exemplified in evidence-based practice.

   Educationally, the profession started as certificate programs, many housed within hospitals, or free-standing, apart from universities. Over time, most programs moved to or were developed in the university setting, and the professional training occurred simultaneously with acquiring a bachelor's degree. The fairly recent emergence of the doctorate of physical therapy program as an entry-level degree has quickly replaced other entry-level programs **(Fig. 1–2)**.[27]
2. **Independent judgment** implies the need for discretion—in contrast with merely mechanical or routine procedures—in making diagnoses of problems, considering alternative solutions, and reaching sound verdicts about how to proceed. Traditionally, so-called "true professionals" were said to act independently on their own judgment, without supervision by others. That criterion has become somewhat unclear. Although it is true that 44 states and the District of Columbia have some form of direct access to physical therapy,[28] most therapists still receive a prescription/diagnosis from a physician in order to receive

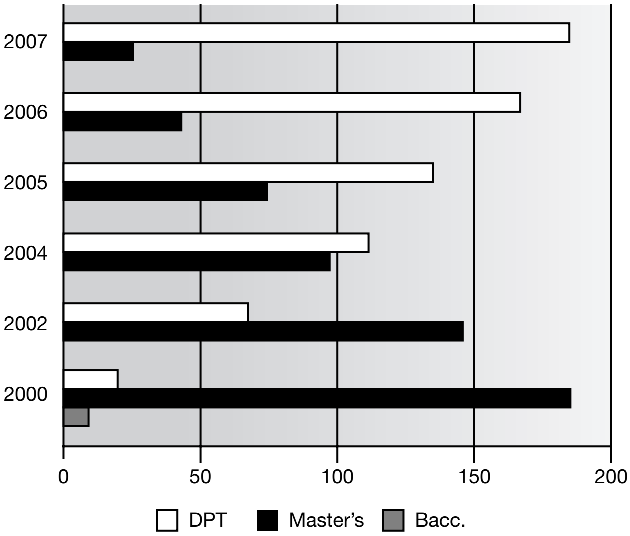


**FIGURE 1–2.** Trends by degree offered, accredited and developing physical therapy programs.

reimbursement from insurance carriers. In many locations, that prescription is often open-ended and leaves the strategy for treatment up to the physical therapists.

Historically, the first physical therapists in this country were "reconstruction aides," who were employed by the Division of Special Hospitals and Physical Reconstruction during World War I and who had relatively little independence. The American Physical Therapy Association was founded in 1921.[29] After World War I, when physical therapy began to gain social recognition, physical therapists were regarded as technicians under the supervision of physicians, who were the true professionals.[30] As such, therapists' central responsibility seemed clear and simple: obey directives from supervisors. Physical therapists remained under the direct control of physicians into the 1950s, when private practice became a genuine possibility for significant numbers of therapists. California was the first state (1968) to legally allow direct access for physical therapy evaluation, followed by the current balance of 43 states and the District of Columbia by 2008. As in other health professions, the standards of practice and education were continuously advanced as the profession became increasingly professionalized. Today, most physical therapists again work in managed-care settings, but they have a professional identity grounded in wider responsibilities than obeying physicians' orders—especially responsibilities to provide quality care to patients.

How independent must practitioners be in order to qualify as "true professionals"? Nearly all professionals currently work in situations in which they share responsibility with others, including being accountable to managers and directors of organizations. Even physicians, traditionally the most independent of all professionals, now work primarily in managed-care facilities where they are accountable to organizations. If anything, the teamwork setting in which most physical therapists conduct their work has become the norm in terms of which "independent" judgment must be understood.

3. **Social organization** typically includes one national professional society—such as the American Medical Association, the American Bar Association, and the American Physical Therapy Association—together with organizations within each state. *Social recognition* means that the profession, through its professional organization, wins support from state and national governments to educate, license, discipline, and in other ways regulate its membership. In well-established professions, the profession wins not only the permission to engage in certain tasks, but also a monopoly over services. Thus, only physicians can prescribe drugs. In the professions, such as nursing and physical therapy, monopolies are less stringent, and boundaries between professions can in some settings blur, as with occupational therapy and physical therapy treatments for the child with developmental delays. Even where there is not a vast legally granted monopoly of services, however, the license that permits practitioners to write "P.T." after their name carries a public recognition that restricts unlicensed persons from engaging in certain public services.
4. **Commitment to the public good** refers to a shared devotion to some public good or to some aspect of the good of society. The specific aspect enters into the definition of particular professions. Thus, law is aimed at justice, engineering at efficient production of technological products, education at promulgating knowledge, and the health-care professions at promoting health. Physical therapy is a health-care profession distinguished by its focus on certain aspects of health as well as by its distinctive social roles. Roughly, physical therapy focuses on functional movement, including preventing injury and reducing or relieving pain. The distinctive, if not altogether unique, ways these goods are pursued include rehabilitation and habilitation, which allow the person to enjoy a more functional, pain-free, and independent life that would not be possible without this specialized intervention.

   Commitment to the public good provides the most obvious and direct tie to professional ethics. A profession's commitment to its distinctive public good is officially signaled in its code of ethics and related guidelines for professional conduct. Indeed, the drafting of a code of ethics and its promulgation within a profession are two of the earliest signs that a profession is emerging from what was previously a domain for technicians or craftpersons. The American Physical Therapy Association's (APTA's) *Code of Ethics* was adopted in 1981 and has been revised several times since, most recently in 2010. An equivalent document for the physical therapist assistant is the *APTA Standards of Ethical Conduct for the Physical Therapist Assistant*. (Both documents are available on the APTA Web site and are reprinted in the Appendix.)

## CODES OF ETHICS

At this point we invite a close scrutiny of the APTA Code as we reflect on the contributions and limitations of the codes and guidelines promulgated within professions in general. What is the moral status of professional codes of ethics? Do these codes put into writing the standards that ought to govern the profession, or do they actually create the standards? In part, they do both.

Professional codes and guidelines are extremely important for at least five reasons.[31] First, codes provide helpful guidance to professionals. Moral problems can be genuinely perplexing. Codes articulate, organize, and concisely present the backbone of moral understanding that informs the profession as it grapples with that perplexity. Moreover, within educational settings they also provide a useful tool in teaching professional ethics.

Second, codes represent a consensus within a profession that enables practitioners to work cooperatively and to compete fairly. Individuals often disagree about how much is required. Codes seek to establish a reasonable compromise and consensus about the restraints on self-interest in pursuing income within a competitive free-enterprise system. As such, they provide an essential understanding among professionals about what should and can be expected of each other, thereby establishing a fair playing field that reduces cutthroat competition.

Third, codes give support to responsible professionals who are sometimes asked by their employers to cut (moral) corners in the name of profit. Under pressure, the isolated individual often has little recourse without the shared voice of the profession about responsible conduct.

Fourth, a code is the official statement by the profession that both individuals and the group of professionals are committed to promoting the public good—that is, the good of the wider community—and minimizing any harmful side effects. Whereas individuals differ considerably in their moral outlooks, a code expresses and establishes a consensus of shared standards in promoting the public good at a high level of excellence.

Fifth, and closely related to the fourth reason, codes and their accompanying guidelines promote public trust. Codes function as a social contract between professionals and the public about what is to be expected of professionals. The code expresses a shared commitment to seek uniform ethical standards throughout the profession, rather than a hit-and-miss approach that would provide only occasional quality.

Having underscored the importance of codes, we can now question whether they are morally sufficient. Are they all that is needed by way of guidance in the professions? In our view, codes provide the backbone of professional ethics, not its full anatomy. Codes are generally the first word, but they are not a substitute for good moral judgment, much less for the deep personal commitments that individuals bring to their work.

For one thing, the principles articulated in codes are often too vague or incomplete to resolve ethical dilemmas. For example, Principle 5E of the APTA code states: "Physical therapists who have knowledge that a colleague is unable to perform their professional responsibilities with reasonable skill and safety shall report this information to the appropriate authority." Does that mean they should sometimes engage in whistle-blowing about their employer's or colleagues' unethical conduct? If so, exactly when is whistle-blowing justified? Of course, codes can always be rendered more precise, but there are limits. If they are to be useful as concise documents, they cannot possibly comment directly on every conceivable moral problem that might arise. Hence, with good reason, the APTA Preamble to the *Code of Ethics* states: "No code of ethics is exhaustive nor can it address every situation."

For another thing, codes occasionally contain inappropriate entries. The code of the American Medical Association, as well as those in law, engineering, and other professions, once forbade advertising. The codes had to be rewritten in the late 1970s when the courts ruled that such codes were unconstitutional infringements of fair competition. Other entries in earlier codes forbade criticizing colleagues, which had the effect of silencing responsible free speech.[32]

## ETHICAL RELATIVISM

In general, it is always advisable to ask whether and why particular codes and their specific entries are justified. Codes are human documents, and they are only as sound as the judgment and foresight of the individuals and groups who write them. Suppose it were argued that a professional code is self-certifying, simply because it is written by the professional organization representing the group. Such a view presupposes that the group has final authority. In general terms, this view is called **ethical relativism:** right action consists always and only in following the customs of the group or society to which one belongs.

There are many problems with ethical relativism. One problem is that a person might be a member of many groups whose standards conflict. Thus, one might be a Catholic and a member of Planned Parenthood, groups that do not share the same views on abortion. Again, what constitutes the views of the group: complete consensus, a two-thirds majority, a simple majority, laws or other dictates of authorities within the group? The worst problem, however, is that ethical relativism could be used to justify patent immorality. To take an extreme case, it could be appealed to justifying the treatment of Jews by Nazis during the Holocaust and any number of other horrors. In fact, scholarly reflections on the Holocaust, in addition to feminist objections to the treatment of women in certain societies, have prompted some anthropologists to question the extreme forms of ethical (or "cultural") relativism on which their discipline is founded.[33] The central problem with ethical relativism, then, is that it makes nonsense of a fundamental aspect of moral reasons: Sound moral reasons can be used to evaluate and sometimes reject particular laws and customs of groups.

Although customs are not automatically the final word, they are typically morally *relevant* considerations in determining what ought to be done. Likewise, codes are vitally significant, for the reasons we gave. Neither codes nor customs, however, replace the need for good moral judgment.

## RESOLVING ETHICAL DILEMMAS

Let us now return to ethical (or moral) dilemmas, which are situations in which moral reasons come into conflict. Such dilemmas are commonplace in the professions, as elsewhere, because moral values are many and varied and enter into life in innumerable ways. The following steps are typically involved in responding to ethical dilemmas.

- **Moral Reasons.** Identify the conflicting moral reasons that comprise the ethical dilemma. Moral reasons take many forms. They include responsibilities (obligations, duties), rights (both general human rights and specific rights created by contracts), good and bad consequences, valuable relationships, ideals, and virtues (good features of character).
- **Facts.** Identify the relevant factual information—relevant in terms of the moral reasons applicable in the situation. This includes the applicable laws and policies. Identify the relevant stakeholders—that is, people and groups directly affected by how the dilemma is resolved.
- **Options and Outcomes.** Identify the realistic options in resolving the dilemma and their likely outcomes.
- **Deliberation and Decision.** Make a reasonable decision by deliberating to discover the option that most reasonably balances and integrates the moral reasons. (Occasionally more than one option can provide a reasonable solution.)
- **Action.** Take action; implement your decision.
- **Review.** Reflectively review your process, and assess the outcomes. Look for ways to improve the process by identifying procedural hurdles or barriers, and assess if procedural changes are needed for the future.

Let us illustrate how these steps apply to Shirlaine's dilemmas in Case 1.1.

1. **Moral Reasons.** The first step in grappling with an ethical dilemma is to identify and state the dilemma clearly and concisely. Identifying ethical dilemmas involves pinpointing the moral reasons applicable to a situation so as to pinpoint how they conflict or seem to conflict. Helpful resources include the *American Physical Therapy Association Code of Ethics*. Exactly which moral reasons are highlighted in formulating a dilemma are influenced by one's moral perspective, and sometimes philosophical ethical theories, of the sort discussed in Chapter 12. All these factors help in stating (as well as resolving) ethical dilemmas.

The conflicting moral reasons that enter into ethical dilemmas take different forms, and which forms we emphasize influences how we formulate dilemmas. Jan Bruckner, who developed the Shirlaine-Donald case study, suggests that Shirlaine faces a "double agent" or "dual loyalty" dilemma: "In this type of dilemma, physical therapists are forced to choose between loyalty to their employer and loyalty to their patients."[1(p383)]

"She must weigh her duty to her employer, the school system, and its interest, the team, against her duty to her patient, the athlete. The school system contracted with her to work with the coach and the team. The coach values the team's success over the welfare of the individual athletes. If Shirlaine chooses to act in loyalty to the team, she should act in a way to promote team success and probably ignore Donald's use of the contraband steroids."[1(p384)]

Certainly, this is one plausible way to formulate the primary dilemma facing Shirlaine, but there are additional ways. For example, we might formulate it in terms of rights; that is, conflicts between respecting the rights of the patient versus those of the principal and community to set school policy. Furthermore, it is not obvious that Shirlaine's duty to her employer unequivocally requires remaining silent. Suppose there is a "zero tolerance" policy within the school system to report drug use. Then, the loyalty to the school district might itself point in two directions: loyalty to the school to maintain its zero tolerance policy by reporting Donald versus loyalty to the school to help its team win by not reporting Donald. Nor is it obvious what loyalty to Donald requires. Perhaps there is a duty of loyalty to turn him in, for the sake of his long-term physical health, but also a duty of loyalty to him not to turn him in, in order to respect his expressed desire to win the state championship.

At this point it might be objected that we have switched from (1) stating the dilemmas facing Shirlaine to (2) beginning to reason about how to resolve the dilemmas, by reflecting on exactly what Shirlaine's responsibilities require in the situation. In fact, what we have discovered is that the very formulation of the pertinent dilemmas might involve discussing what one's responsibilities require in particular circumstances. In this way, the tasks of articulating ethical dilemmas and beginning to resolve them overlap. Stated another way, moral perspective shapes what is seen as dilemmas in the first place as well as how they are resolved.

Bruckner points out that Shirlaine faces another ethical dilemma, this time concerning medical paternalism. As discussed in Chapter 3, medical paternalism occurs when health professionals interfere with the autonomy (self-determination, freedom) of others with the aim of helping them. Shirlaine has a duty to promote the health of her patient; she also has a duty to respect his autonomy. Respect for Donald's autonomy seems to favor keeping his secret. In general, respect for autonomy seems to imply maintaining strict confidentiality about patients, although there are exceptions, some required by law. In contrast, the duty to promote Donald's health suggests engaging in medical paternalism by overriding his autonomy in order to prevent him from risking his health. The issue might be complicated, however, by Donald's age. He is 17 years old and hence a minor in the eyes of the law. Does his age cancel out the duty to respect his autonomy, allowing Shirlaine to act directly in his self-interest, as she interprets that interest? Or does she owe a duty to Donald's parents to inform them first, so that they, as legal guardians, can make decisions on behalf of Donald?

Shirlaine's choice might also be construed as a conflict between her self-interest and morality. Assume that her primary moral duty is to help Donald, her patient. In contrast, her self-interest, or personal well-being, might point in other directions. If she keeps quiet, most likely her job will not be affected. She would also avoid any wider repercussions for her career, such as difficulties in getting another job if her contract is not renewed. Self-interest can itself be viewed as a moral consideration, however, in that people have moral rights to pursue their self-interest, within limits. People also have duties to their families to pursue their self-interest, again within limits. Accordingly, Shirlaine's conflict can be viewed as an ethical dilemma that pits duties to others against duties to herself and to her family.

2. **Facts.** Just as one should gather as much factual information on a patient's diagnosis and history as possible, ethical dilemmas require the same type of thorough investigation. Often what seems to be a crisis is really a misunderstanding or misinterpretation of the facts. Sometimes the dilemma has already been addressed through law or company policies. These laws and policies generate moral reasons, given the general obligation to obey the law. At other times, after identifying the major stakeholders, alternative practical responses are apparent.

We also recognize the concept of "bounded rationality" pioneered by Nobel Prize winner Herbert A. Simon, which in part states that decisions are usually made with less than maximum information or time to allow thorough analysis and reflection. As an example, let us assume that Shirlaine practices in a school district with zero tolerance policies that specifically makes all employees mandated reporters of suspected drug abuse. These policies often define a narrow time frame (24 to 48 hours) for reports from the time of discovery. We want to limit the damage to Donald, the coach, the school, and Shirlaine, but policies might impose requirements that make some damage inevitable.

3. **Options and Outcomes.** Once an ethical dilemma is stated clearly and relevant information is assembled, the next step is to identify alternative practical courses of conduct in response to the dilemma. The options available are influenced by the context. In the era of managed care, it is probably rare to experience a context involving only the therapist and the patient. There are invariably organizational, legal, and even societal issues involved that shape the options.

That is not to say that people become more helpless the larger the scope of the dilemma. But as the scope of influence is expanded, it will invariably involve more stakeholders, incremental progress, and greater time to see the results. There is some merit in bearing in mind the spirit of the serenity prayer (of Alcoholics Anonymous): "God grant me the serenity to accept the things I cannot change; courage to change the things I can; and wisdom to know the difference."[34]

Especially important, *moral imagination* must be exercised in being open to the full range of options. Often a "third way" is overlooked, one that provides a better solution than what initially appears as "two horns" of a dilemma. Just as in patient care, very rarely are people limited to only two approaches in resolving ethical dilemmas. When you force yourself to identify three or more alternatives, you either find a better solution than you originally imagined, or you can support your original position with greater confidence.

Shirlaine has at least the following options:

*Option 1:* Do nothing; remain silent. The outcome might prove comfortable for everyone, or it might result in severe harm to Donald, in which case investigations might lead to Shirlaine losing her job. The publicity might make life in that town difficult if Donald blames her while defending himself. In any case, Shirlaine would have to live with what was perhaps a cowardly way out of the dilemma.

*Option 2:* Turn Donald over to the local law enforcement, reporting in writing everything she knows about the case, including Donald's threatening behavior. The consequences to Donald might be catastrophic or might improve his future behavior in ways that would lead to a more productive and considered life.

*Option 3:* Keep talking with Donald, trying to convince him, but this time have a trusted colleague present who would support and expand Shirlaine's concern and document her efforts.

*Option 4:* Talk with the coach. Present the consequences, which could occur to all the stakeholders, including his reputation and job should there be an investigation.

*Option 5:* Talk with the principal informally, without putting anything in writing, and hope for the best.

*Option 6:* Talk with the parents. As Donald's legal guardians, they have a right to know and a duty to respond. But even if they do not respond, that does not necessarily absolve Shirlaine from possible legal and related ethical responsibilities to the team, the school, and her profession.

*Option 7:* Turn Donald over to the principal with documentation, and clearly address concerns for Donald, the team, and the school.

4. **Deliberation and Decision.** The most challenging step in resolving dilemmas is—resolving them! The aim is to be sensitive to the full array of moral reasons applicable to particular situations and to integrate those reasons in morally reasonable ways in light of the relevant facts available. It is necessary to engage in responsible reflection on which moral reasons are most compelling in the situation. This involves weighing the reasons in light of the facts and with regard to the options: Which option best respects the most important moral reasons in the situation?

   Here and in all the other stages of resolving ethical dilemmas, one should be careful not to deceive oneself or to rationalize—that is, to use biased reasoning to manufacture excuses.[35] One form of rationalization is to imagine remote and unlikely outcomes that are either tailored to bring one back to a biased position or that will paralyze the decision-making process, resulting in either no action at all or action that is delayed beyond the point of prudent caution. People live daily with probabilities; the identification of some unlikely consequence is not in itself reason to abandon an option. (In 2007 there were 13.61 fatalities per 100,000 people due to traffic accidents,[36] but people still drive to school, the movies, and work.)

   Given the complexity of the world and the multiplicity of moral values, there is no mechanical procedure in resolving ethical dilemmas, no algorithm of simple rules placed in hierarchies of importance. As the novelist George Eliot commented, "the mysterious complexity of our life is not to be embraced by maxims," and there is no substitute for the "growing insight and sympathy" earned "from a life vivid and intense enough to have created a wide, fellow feeling with all that is human."[37] Good moral judgment is needed, and that is something everybody should seek to improve throughout life.

   Resolving ethical dilemmas can require grappling with moral vagueness, ambiguity, and moral disagreement, in addition to factual uncertainty. **Moral vagueness** means it is not altogether clear what a specific moral value implies in a situation; **moral ambiguity** means moral reasons might apply in different ways. For example, although it is clear that physical therapists have responsibilities to provide quality care for their patients, what exactly does that require in Shirlaine's situation? Again, therapists have responsibilities to provide loyal service to their employers, but what is loyalty in Shirlaine's context?

   **Moral disagreements** occur when individuals do not agree with each other about what is morally required in particular situations, or about which rules and policies are morally desirable, or even about which moral issues are important. Moral disagreements also play an important role in physical therapy, when therapists often share responsibility with others for health care. Physical therapists must work in unison with other health professionals, who do not always agree on the best procedure or policy in specific situations. Physical therapists also work with family members of patients, who sometimes disagree with each other. Thus, even when it seems completely clear to oneself how best to resolve a moral difficulty, disagreements among colleagues who share responsibility for making a decision can create new problems needing resolution, perhaps through reasonable adaptation and compromise. Again, as illustrated in the Shirlaine example, professionals and patients do not always see things the same way.

   In general, in situations of shared decision making where there is disagreement, work out reasonable compromises, in the positive sense of a rational reconciliation of differences, not "compromises" in the pejorative sense of betraying one's integrity.[38] In some cases, realize that more than one reasonable solution is possible; in other cases, the best solution might be to agree to disagree.[39]

   What is the most reasonable option for Shirlaine? We leave the resolution of this dilemma as a Discussion Question at the end of this chapter.

5. **Action.** Finally, take action; implement your decision. It is one thing to know what is right; it is another thing to do it. Indeed, it has been argued that the primary difficulty in professional ethics is not in knowing what is right, but in doing it.[40] **Compliance issues** arise

when it is clear what is morally right (or wrong) in a given situation and the only question is whether the professional will do it (or not do it). For example, an individual who is in financial difficulty or angry at a supervisor might be tempted to steal from an employer, even though doing so is patently immoral. In general, knowing what is right is one thing; doing it is something else. Living up to one's moral responsibilities requires having integrity, self-discipline, and commitment and avoiding apathy, weakness of will, and selfishness. In this book, we sometimes discuss compliance issues, especially in Chapter 9. The main emphasis, however, is on issues where there is some unclarity about what ought to be done, whether owing to disagreements, vagueness, or dilemmas.

6. **Review.** After action has been taken and the consequences are better known, think back on the process used to reach a decision, and decide if changes are needed. One can never know with certainty what will happen in the future, and one cannot guarantee a desired outcome. People can, however, learn from their decisions and mistakes and strengthen their skills in reasoning and decision making. People can also take further action based on reviewing their initial decision. For example, if Shirlaine finds both the coach and the principal unresponsive, then perhaps structural changes in handling student problems need to be developed and clearly outlined in a policy that is accessible to parents, students, faculty, and administrators. The new policy will not solve the problem, but it will make the decision making more uniform and transparent, which offers some protection to Shirlaine.

In concluding we note that, ironically and regrettably, ethics sometimes has a bad name. For some people, it brings to mind negative things like blaming, self-righteous hypocrisy, and congressional ethics committees that themselves sometimes act in suspect ways. Or it evinces a groan by reminding us of the seemingly intractable disagreements involved in the "culture wars" over such issues as abortion, affirmative action, and the death penalty, if not more personal battles we have had with our parents and friends. Then, too, there is the tongue-in-cheek remark reportedly made by Nobel Laureate Saul Bellow: "Socrates said, 'The unexamined life is not worth living.' My revision is, 'But the examined life makes you wish you were dead.'"[41]

Ethics does, of course, have a serious and complex side to it, and in this chapter we have highlighted its dimensions of vagueness, dilemmas, and conflict. Yet, ethics involves much more that is positive. Moral values permeate the daily practice of physical therapy as well as all other professions, even where no uncertainty or disagreement is present. All services to clients have a moral dimension grounded in caring and respect. Professionalism implies a continual sensitivity to and mindfulness of these values in ways that contribute to meaning-giving relationships with patients and other clients (such as family members, surrogate decision makers, and companies). We turn in the next chapter to a fuller discussion of relationships and caring in ethics, in addition to the role of moral principles.

## DISCUSSION QUESTIONS

1. Present and defend your view concerning (a) how best to articulate the ethical dilemmas faced by Shirlaine, in Case 1.1 and (b) how to resolve them. In developing your answer, consult the APTA's *Code of Ethics*. Which entries are directly applicable to the case, and do the entries provide the solution to any dilemmas involved? As you answer these questions and listen to others' points of view on the case, can you begin to characterize some of the values central to your view of ethics, both in personal and professional life?

2. Ethics includes moral inquiry into policies and laws as well as individual conduct, and sometimes moral dilemmas can be resolved only by shifting attention to questions of policy. Which policies would help lessen the kinds of dilemmas faced by Shirlaine? Would the policies have any negative side effects?

3. Read through the APTA *Code of Ethics.* Do all the entries strike you as reasonable? Identify the possible conflict and hence ethical dilemma that might arise between Section 11.3 and Section 9. Then identify one additional possible conflict between two additional entries.

4. Research and discuss the Realm-Individual Process-Situation (RIPS) model developed by Dr. Swisher[42] and used by Dr. Kirsch in her "Ethics in Action" column in *Physical Therapy Magazine*, and access Dr. Kirsch's articles on the APTA Web site. The RIPS model helpfully distinguishes the Realms of individual concerns, organization setting, and society in general. The Individual Process reminds you that moral sensitivity, reasoning, motivation, and courage are all part of the process of responsible decision making. The RIPS model addresses the Situation defined as ethical temptations, issues, problems, or dilemmas. Kirsch identifies four steps in resolving dilemmas: recognition, reflection, deciding,

and implementing. Compare and contrast these steps to the six steps we identified above.

5. Some social critics believe that distinguishing certain forms of work as "professions" implies elitism and social superiority. Other critics believe that professionalism is primarily a ruse designed to gain more money from clients. Are these criticisms warranted, at least in part? If so, what remedies might be offered so as to strengthen public trust in professions and professionals?

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# Chapter 2

# Caring, Character, and Principles

*Physical therapists shall be trustworthy and compassionate in addressing the rights and needs of patients/clients.*

Principle 2, APTA Code of Ethics

## CASE 2.1 A CEO's Generosity

Edward received early admission to his college of first choice on his birthday. As a double celebration, he and his brother Lyle took a skiing weekend. Around 4 p.m., Edward fell during the last ski run of the day and was seriously injured. He was airlifted to the local community hospital, where he was treated for a head injury. As soon as he was medically stable, although comatose, he was transferred to Westover Rehabilitation Hospital. There he began to regain consciousness. Within the first week of rehabilitation, he started to make progress, but his team of therapists predicted a prolonged rehabilitation process of up to a year. The HMO that carries his health insurance allows only 45 days of rehabilitation.

The CEO, George, was a physician and a rehabilitation specialist. He immediately began negotiations with the HMO to provide a longer stay, assuring their administrator that with intense and continuous rehabilitation Edward would probably return to a state similar to where he was prior to the accident. To discharge him at 45 days would severely limit his lifetime potential, although he would most likely be semi-independent in many daily living skills. The representatives of the HMO would not hear of it and stuck with the 45-day limit. The negotiations had taken nearly a month, and George realized that, in a matter of days, he had to make some decisions.

The family could not afford the extensive rehabilitation needed, without selling their modest home. George checked out all the nursing homes in the hospital's geographic area but could not find one offering the specialized therapy and team members needed to maximize Edward's recovery. There was a special fund at the hospital that could cover some of the expenses for an extended stay, but it was modest and did not come close to supporting the full time needed. The head of physical therapy and nursing believed they could rally support within the hospital to do fundraising, but it would be necessary to personalize the effort, and they were not sure the family would want their financial and medical histories on public display. Besides, in the past these efforts did not raise substantial money and served more to build community support for this very unusual private hospital with a commitment to the public good.

**At this point George called a meeting of his advisors. Westover's administrative structure was nearly flat, with George having enormous power, thanks to a board of trustees' confidence in him. He asked his risk management officer what kind of liability the hospital would incur if he discharged Edward at the end of 45 days, even though he had not reached his potential. The response was a confident "none." At that point, without hesitation, George announced the hospital would pay the bill for Edward's extensive rehabilitation. George's reasons included Edward's potential, George's duty as a physician to do no harm, and his job as CEO to make sure the patient was always the first priority. When the head of nursing asked what would happen if their razor-thin profit margin evaporated because of this patient, George replied that his first move would be to reduce the staff, not the patients. George told Edward's family his decision, and they were overjoyed. The father stated that this was the first time his prayers had been answered.**

George faced an ethical dilemma between conflicting responsibilities to Edward, to the staff, to future patients whose quality of care depends on maintaining adequate staff and other resources, and to investors. Did George make a responsible choice, and was it the best choice? Was he sufficiently sensitive to other stakeholders in the hospital, including staff, future patients, and investors?

We leave these questions as study questions. For now, we explore some of the dimensions of care and caring relationships. We begin with a relationship-centered model for thinking about caring for patients and others involved. Then we turn to Carol Gilligan's ethics of care, which introduces the issue of how good character and moral rules are related. Next we comment on caring as both a virtue and a set of moral requirements in the form of rules and principles. We conclude by commenting on moral motivation in connection with the question, "Why be moral?"

## RELATIONSHIP-CENTERED CARE

Providing health care is a complex task. Various models have been developed to highlight this complexity and identify important aspects of therapeutic interventions. Thus, biomedical-centered models emphasize technical and theoretical knowledge in restoring physical health. Patient-centered models accent patient needs and desires as the locus in healing. Code-centered models highlight the key role of a code of ethics in unifying and ensuring shared moral commitment throughout a profession. Care-centered models emphasize caring professionals who are devoted to helping patients.

Each of these models can be useful, but we find it most helpful to begin with a relationship-centered model that accents care relationships, including those between physical therapists and patients, between physical therapists and other health professionals, and between physical therapists and wider communities. The Pew-Fetzer Task Force developed such a model: "The phrase 'relationship-centered care' captures the importance of the interaction among people as the foundation of any therapeutic or healing activity."[1] The primary relationship is between the health-care professional and the patient. This relationship is important to patients and professionals alike, and it plays a key role in the healing process. Crucial, too, are relationships among health-care professionals who work in interdisciplinary teams. So are relationships with wider communities, whether the community is defined as a hospital or the profession itself.

All these relationships have legal (contractual) aspects, but essentially they are moral relationships. They embody and are guided by moral values. Thus, regarding professional-patient relationships, the Pew-Fetzer Task Force emphasizes concern for patients, sensitivity to their needs, empathy for their suffering, respect for their rights, and the value of health understood holistically, as biopsychosocial. The task force highlights the need for patients' trust and participation in the healing process. The task force moves comfortably between several meanings and dimensions of patient care: (1) **care-giving,** that is, providing health-care services (taking care of patients); (2) exercising **due care,** that is, meeting appropriate standards in providing health care; (3) **caring** for patients as persons by providing professional services with attitudes and values of concern for patients, and (4) manifesting the **virtue of caring**.

## CHARACTER AND THE VIRTUE OF CARING

Virtues are desirable features of character. They are habits or tendencies to feel, perceive, reason, and act in morally valuable ways—ways beneficial to others and to oneself. Thus, an honest person acts in certain ways—avoiding lying, cheating, and stealing—and in addition routinely tries to be truthful and trustworthy because relationships of trust are valued. A generous person gives more than is customary and does so from motives of concern for others. A courageous person confronts dangers rather than fleeing them and does so with good judgment and motivated by a desire to protect what is of value and being threatened. In contrast, vices are morally undesirable features of persons, such as dishonesty, selfishness, and cowardice.

Many virtues are relevant to health care, but the virtue of caring has special importance. With regard to patients, the virtue of caring refers to desirable habits of concern for and helping them. It refers to reliable tendencies to promote the health of patients according to appropriate standards, motivated (at least significantly) by concern for their well-being. Caring is an umbrella virtue that includes many more specific virtues, including sensitivity (perceptiveness to morally relevant features of contexts), empathy (identifying with the feelings of others), compassion (in response to suffering), kindness (nuanced and sensitive helpfulness), and conscientiousness (in meeting responsibilities).

What is the relation between virtues, as features of persons, and moral rules and principles? This is an important issue in ethical theory. "Virtue ethics," discussed in Chapter 12, regards virtues as morally primary and foundational, while moral principles and rules are secondary. Other ethical theories regard the virtues as important but secondary to principles. Here we emphasize that both virtues and rules have great importance in ethics and are interwoven. For example, an honest person will pay heed to rules such as "tell the truth" and "do not steal."[2]

There are dozens, even hundreds, of virtues, and each targets a specific aspect of life. According to their interests, ethicists organize virtues into different groups. We find it helpful to cluster virtues into three categories: self-valuing and self-directing, reciprocity between oneself and others, and caring about and for others. The categories are overlapping rather than mutually exclusive.

I. Self-Valuing and Self-Directing
    A. Self-Valuing: Self-respect, self-caring, self-love, authenticity, humility, proper pride, nobility, integrity
    B. Self-Directing
        a. Cognitive: Wisdom, prudence, foresight
        b. Volitional: Self-control, self-discipline, temperance, courage, determination, perseverance, responsibility, integrity
        c. Skill: Competence, craftsmanship, excellence
II. Reciprocity
    A. Justice, fairness, tolerance
    B. Trust: Honesty, truthfulness, trustworthiness
    C. Gratitude, cooperativeness, reliability, dependability, civility, sense of community
III. Caring About and for Others
    A. Nonmaleficence: Non-recklessness, non-negligence, non-vengefulness, non-fanaticism
    B. Beneficence: Caring, benevolence, compassion, kindness, considerateness, sensitivity, tactfulness, politeness, altruism, generosity, loyalty

We turn now to caring about and for others, focusing on its more positive dimensions (beneficence), exploring it both as a virtue and as implying a set of moral rules and principles. We begin with the context of moral development.

## GILLIGAN'S ETHICS OF CARE

The emphasis on caring in thinking about health-care ethics was greatly influenced by the psychologist Carol Gilligan. Gilligan is a specialist in moral development, that is, the psychological study of how individuals develop moral understanding. Early in her career, she noticed that previous thinkers, including her mentor Lawrence Kohlberg, understood moral development as a progression from ways of thinking in terms of rules; in addition, the studies had been conducted by males studying males. Her own studies, which used females as experimental subjects, led her to think more in terms of caring relationships. Her book, *In a Different Voice*, which appeared in 1982 at the height of the feminist revolution, drew an enormous audience, in part because of its provocative suggestion that women and men might think differently about morality, with different "voices." She suggested that women employ an ethics of care that emphasizes care-based relationships, whereas men employ an ethics of justice that is more rule-oriented. Subsequent studies provided little support for this hypothesis, but her emphasis on caring continues to be influential in both ethical theory and theories of moral development.

To elaborate, Kohlberg distinguished three levels of psychological development: preconventional, conventional, and postconventional.[3] Each level contains two stages, making a total of six stages. The stages are distinguished according to how individuals engage in moral reasoning and to which motives or reasons they respond. Thus, at the preconventional level, typical for most children ages 4 to 10, individuals are narrowly egoistic in their reasoning and motivation. This level is akin to the outlook of ethical egoism, although children at this age are not yet able to envisage their long-term good in the way required by the ethical egoist. At stage 1 they think in terms of avoiding punishment and deferring to physical power. At stage 2 they begin to pursue their desires by using stratagems to gain rewards, such as "You scratch my back, and I'll scratch yours."

At the conventional level, the emphasis is on meeting the expectations of family, organizations, and wider society. Stage 3 accents stereotypes of "good boy" and "nice girl." Stage 4 accents doing one's social duty so as to maintain the social order. The level is akin to ethical relativism. According to Kohlberg, many adults never grow beyond this level.

At the postconventional level, individuals move in the direction of autonomy, self-directing their lives in light of moral principles that are not reducible to customs of groups. Stage 5 is a social contract perspective in which principles are seen as justified when they represent agreements among rational participants in society. There is an emphasis on legal rules but not an assumption that all legal rules are reasonable. Stage 6 is reasoning in terms of abstract principles that are comprehensive, universal, consistent, and ranked in a hierarchy of importance. The general principles of justice and human rights are examples of fundamental principles.

Gilligan agreed with Kohlberg that moral development includes movement away from childlike narcissism and uncritical social conformity; it includes movement toward autonomous moral reasoning and conduct in terms of wider values. But Gilligan challenged Kohlberg's assumption that the highest stages of moral reasoning are defined by universal principles ranked in order of their general importance. To see what is at issue, consider Kohlberg's most famous example, the Heinz Dilemma.[3]

Heinz is married to a woman who is dying of cancer but who physicians believe might be saved by a very expensive radium-compound drug. A pharmacist in a European town where Heinz lives controls the drug and will provide it, but at ten times the cost to make it. Heinz cannot afford the drug, nor can he find friends who will loan him the money to buy it. After trying to convince the pharmacist to lower the price or to let him pay for it later, Heinz breaks into the pharmacy and steals the drug. The question is whether he was justified in doing so.

Kohlberg presented this and other dilemmas to people of many ages and studied how they reasoned about them. He concluded that those who said Heinz should worry about himself primarily were at the pre-conventional level. Those who argued that Heinz should not steal the drug because stealing is wrong (according to social conventions) were at the conventional stage. Those who reasoned that Heinz was justified (either permitted or obligated) in stealing the drug maintained that the rules "Save lives" or "Help one's wife" override the rule "Do not steal" illustrated higher stages of moral development.

When Gilligan began asking young females to comment on the Heinz dilemma, she noticed they often suggested talking further with the pharmacist, trying to change his mind, and perhaps encouraging others to talk to the pharmacist as well. Kohlberg interpreted such respondents as being indecisive rather than firmly principled. In contrast, Gilligan suggested that such dialogue-oriented and context-sensitive approaches, aimed at maintaining moral ties with the pharmacist and others involved, represented legitimate and perhaps even preferable responses to the dilemma.[4]

Gilligan suggested that Kohlberg largely presupposed an ethics of justice in which moral growth meant moving toward reasoning in terms of abstract, universal rules. In contrast, she invoked an ethics of care to interpret young females as growing in the direction of effectively balancing their needs with the needs of others. Gilligan adapted much of the basic structure of Kohlberg's levels of moral development, but she redescribed the three levels: (1) preconventional reasoning consists of exaggerated self-concern, (2) conventional consists of reasoning in terms of what society demands, and (3) post-conventional implies being able to reasonably balance the legitimate needs of oneself with those of others. The latter is accomplished by paying close attention to context, maintaining personal relationships, sustaining communication, and making reasonable compromises. Rather than a hierarchy of abstract rules of the sort Kohlberg emphasized, what matters for Gilligan is nuanced and responsible contextual reasoning. The contrasts between Kohlberg and Gilligan are summarized in **Table 2–1**.[5]

**TABLE 2–1. Kohlberg's and Gilligan's Schemes of Moral Development***

| LEVELS OF MORAL DEVELOPMENT | KOHLBERG'S JUSTICE PERSPECTIVE | GILLIGAN'S CARE PERSPECTIVE |
|---|---|---|
| 1. Preconventional | Self-centered, with concern for<br>(1) avoiding punishment and<br>(2) satisfying one's own needs | Self-centered: Viewing one's own needs as all that matters |
| 2. Conventional | Expectation-meeting, with concern for<br>(3) pleasing others and<br>(4) meeting society's expectations | Self-sacrificing: viewing others' needs as more important |
| 3. Postconventional | Autonomous recognition to<br>(5) social agreements and<br>(6) universal rules | Mature care ethic: able to reason toward a balance of one's own and others' needs |

*Reprinted with permission from Martin MW, *Everyday Morality,* 4th ed. Belmont, CA: Thomas/Wadsworth; 2007: 81.

We should take note of an important philosophical question about psychological theories of moral development. How can one tell whether Gilligan or Kohlberg has most accurately portrayed the highest stages of moral development? Clearly, "highest" means the most valid or justified way of reasoning. Hence, to rank the stages requires defending a moral viewpoint. Do not assume that a particular psychologist is more adept than another in determining which moral viewpoint is most justified.

In general, psychologists cannot be relied upon to indicate what the best way of moral reasoning is. Only a serious study of normative ethics can perhaps do that, and even then there can be disagreement among reasonable persons. Everyone, as morally responsible and autonomous agents, must engage in such a study and gain from the insights of others along the way. Having said that, we affirm that Gilligan's ethics of care has greatly enriched health-care ethics by bringing renewed attention to care relationships and to the virtue of caring.

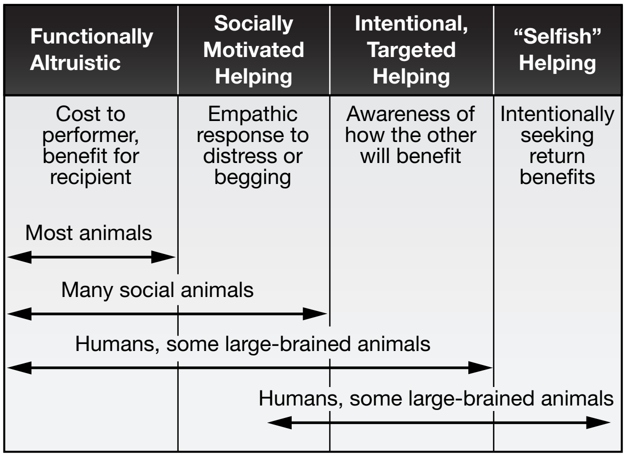
## THE EVOLUTION OF CARING

Gilligan does not speculate about the extent to which human capacities for caring are most affected by social influences or biological evolution (in addition to personal effort). Evolutionary scientists are beginning to shed light on this nature-nurture question. Their investigations are still in their infancy, but they are provocative and promising, especially in light of human genome research. According to Frans De Waal and others, evolutionary theory has been misconstrued to mean survival of the fittest defined solely as one of power or force. Instead, there is abundant evidence to support that survival of the fittest also means survival by those who are cooperative and mutually supportive. Solitary animals are the exception to survival. Communal living has offered a multitude of survival benefits not limited to procuring food and mutual protection. Indeed, the greatest evolutionary struggles have not been within species but between groups and the external environment. Qualities that support communal life have been selected and perpetuated because of the benefits they offer, and those communal qualities have been refined in a progressive gradient between species.

Moral judgment and reasoning are capacities found primarily among humans, although there are some striking vestiges demonstrated by apes. But the building blocks for those highest functions have footings and progressive development in empathy, reciprocity, and concepts of fairness that can be scientifically observed over a range of species. De Waal offers the taxonomy of altruistic behavior, shown in **Figure 2–1**, as just one of many buildings stones for moral reasoning.[6]

According to De Waal, "the vast majority of altruism in the animal kingdom is only functional altruism in that it takes place without an appreciation of how the behavior will impact the other and absent any prediction of whether the other will return the service."[6(p180)] In contrast, humans are "hard-wired" to act with some decent minimum level of help for others. The extent of this hard-wiring is a subject of ongoing scientific investigation. The new field dedicated to the discovery of these hard-wired pathways is called neuroethics. Thus far, through brain imaging studies, it appears that witnessing unethical conduct triggers an initial emotional reaction that in turn is modulated by higher reasoning centers. Although neuroethics is still in its infancy, it appears to support at least part of the theory that James Rest developed in his interpretation of Kohlberg's theory of moral reasoning. Rest maintained that moral action was contingent not only on moral reasoning but also on moral sensitivity (recognizing that something is troublesome), moral motivation (willingness to engage in problem solving), and moral courage (willingness to take a stand).[7,8] Ultimately, Rest contends that all four must be present for moral action.

Greenfield argues that moral reasoning cannot be entirely separated from emotion and that in fact the emotional responses registered in neuroethics studies that examine moral reasoning perhaps enlighten the mechanism of moral sensitivity, the recognition that people should engage in moral reasoning.[9]



| Functionally Altruistic | Socially Motivated Helping | Intentional, Targeted Helping | "Selfish" Helping |
|---|---|---|---|
| Cost to performer, benefit for recipient | Empathic response to distress or begging | Awareness of how the other will benefit | Intentionally seeking return benefits |

NOTE: Altruistic behavior falls into four categories dependent on whether or not it is socially motivated and whether or not the actor intends to benefit the other or itself. The vast majority of altruism in the animal kingdom is only functionally altruistic in that it takes place without an appreciation of how the behavior will impact the other and absent any prediction of whether the other will return the service. Social mammals sometimes help others in response to distress or begging (socially motivated helping). Intentional helping may be limited to humans, apes, and a few other large-brained animals. Helping motivated purely by expected return benefits may be rarer still.

**FIGURE 2–1.** Taxonomy of altruistic behavior. (Reprinted with permission from DeWaal F. Response. In Macedo S, Ober J. eds. *Primates and Philosophers: How Morality Evolved*. Princeton: Princeton University Press; 2006: 180.)

Emotional responses, perhaps often unintended or even unrecognized, play a daily part in clinical work and shape the way people perceive and interpret their surroundings. As such, everyone should be aware of their emotional responses, but at the same time not let emotion alone govern making a decision. Emotional responses, while valuable in identifying problems and inevitably shaping cognitive reasoning, cannot be the origin of moral decisions, to be rationalized with moral theory. Moral reasoning hears the emotional component but involves a far more complex cognitive process of deliberation and option formation informed by facts and moral reasons. But we agree with Rest in that the best moral reasoning skills without moral courage will probably not result in moral action.

## PRINCIPLES OF BIOMEDICAL ETHICS

It is frequently charged that virtues and ideals such as caring are too vague to provide much guidance. People should be caring, compassionate, kind, and so on, but exactly what does this mean in practice? At least some principles and rules specifying the content of virtues are required. In particular, in appreciating the importance of moral relationships in health care, the guidance provided by several basic moral principles widely used in biomedical ethics should be acknowledged. As Tom L. Beauchamp and James F. Childress argue, four principles have special significance.[10]Generally, they correspond to four virtues: respectfulness, nonmalevolence (minimal caring), benevolence (more positive caring), and justice (or fairness).

1. Respect for autonomy: Value the autonomy (self-determination, self-governance) of patients, and use it as a guide that limits what services may be provided to them.
2. Nonmaleficence: Do not harm patients.
3. Beneficence: Promote the good of others.
4. Justice: Treat patients fairly, not violating what they are entitled to, and support fair procedures and background institutions in health care.

These principles are broad norms and general guides that imply more specific moral *rules*. Indeed, more than one principle might imply a given rule. For example, respect for autonomy implies such rules as "obtain informed consent," "tell the truth," and "maintain confidentiality." Again, beneficence implies "be sensitive to patients' needs and fears," "alleviate suffering," and "provide health care in accord with high standards of excellence."

Some of the following chapters emphasize particular principles: for example, this chapter and Chapter 6 emphasize beneficence; Chapters 3 and 5 emphasize respect for autonomy; Chapters 4 and 8 emphasize nonmaleficence; and Chapter 11 emphasizes justice. Yet, all the principles play some role in every chapter. Certainly in life the principles overlap, limit each other, operate in concert, and shift in priority within different contexts and roles. Consider the context involved in Case 2.1. As a physician, George has an especially strong a llegiance to beneficence and nonmaleficence. At the same time, his caring for patients is limited by respect for their autonomy in deciding what happens to their bodies. As a CEO, there are issues of justice and fairness that only he can address.

## BENEFICENCE TOWARD STRANGERS

Beneficence is arguably the cornerstone of professional health care. It seems that none of the principles is more easily understood than beneficence. Quite simply, it is helping others. Yet, just how much helping is required? If the principle is understood as stating an obligation, surely there must be reasonable limits to that obligation. Society applauds and honors Mother Teresa and Albert Schweitzer, but everyone cannot be expected to achieve those levels of beneficence. Between a certain decent minimum level and exemplary levels, benevolence is defined by a continuum.

Beauchamp and Childress express this continuum of moral action as a spectrum from obligation to supererogation, as shown in **Table 2–2**.[10(p49)] Strict obligations include duties such as truth telling and not committing murder or theft. Weak obligations include behaviors such as maintaining a civil level of discourse during legitimate disagreement or not breaking in lines for self-serving purposes. Supererogatory acts span ideals beyond the obligatory to heroic ideas.

Supererogatory acts are defined by four qualities: (1) they are optional; (2) they exceed what is commonly perceived as obligatory; (3) "they are intentionally undertaken to promote

**TABLE 2–2. The Beneficence Continuum***

| OBLIGATION | | SUPEREROGATION | |
|---|---|---|---|
| Strict obligation | Weak obligation | Ideals beyond the obligatory | Saintly and heroic ideals |

*Reprinted with permission from Beauchamp TL, Childress JF. *Principles of Biomedical Ethics,* 6th ed. New York: Oxford University Press; 2009.

the welfare of others"; (4) they are "morally good and praiseworthy in themselves, not merely undertaken from good intentions."[10(p48)]

Most supererogatory acts do not put people at risk for harm or financial ruin. On a daily basis, people either perform or witness supererogatory acts, perhaps without realizing it. Volunteers in organizations throughout the world attend to unmet needs of millions without fiscal reimbursement and sometimes without simple acknowledgment. Over the past week, you have probably seen some genuine acts above the level of obligation that benefited the recipient and did not harm the giver in any significant way.

Beauchamp and Childress distinguish between specific and general beneficence. Specific beneficence refers to acts performed for partners, spouses, children, parents, and friends. General beneficence refers to acts performed for strangers. Carol Gilligan's ethics of care revealed the importance of special relationships and special obligations and commitments. General beneficence is perhaps less intuitive and less well understood. Yet everyone senses that there must be some decent minimum level that is obligatory for all citizens. Consider the following three cases.

### CASE 2.2 Refusal to Rescue

In 1998 Martin Dyckman retold the story of an event in his home state of Florida.[11] A man, self-reported to be a good swimmer, watched a young boy drown in a canal. The man looked over his back to make sure no one observed him doing nothing when a rescue would have been so easy. He later stated that he let the boy drown because he hated all people of that color, regardless of any other consideration.

### CASE 2.3 Kitty Genovese

Shortly after 3 a.m. Kitty Genovese parked her car in a space near her apartment.[12] She worked as a manager of a bar and so had learned to be careful arriving home late at night. As she walked toward her apartment, she saw something that alerted her and headed toward a police call box. Before she could reach it, she was attacked by a man and stabbed. She yelled out "Oh, my God, he stabbed me! Please help me!" A resident in the apartment threw open his window and yelled out "Let that girl alone." Lights in the apartment complex came on, and the assailant fled. Kitty struggled to get to her apartment, only to be ambushed by her attacker a second time. He initiated rape and then stabbed her again, and she yelled out "I'm dying, I'm dying." The lights came on again as people came to their windows. Again the man was frightened off. Kitty made it to the back of the building where the entrances to the apartments were located. She was weak and stopped in the second doorway. The attacker returned for the third time and stabbed her to death. In the thirty-five minutes that lapsed from her first screams to her death, 38 neighbors were aware of her struggle and not one called the police until after the final attack. When the police were finally called, it was by a man, one of the 38, who said that he deliberated and called a friend in another country for advice. He then crossed the roof of the building to the apartment of an elderly woman to get her to make the call. He explained that he went to all this trouble because "I didn't want to get involved." Later studies of this and related cases revealed that most people failed to call for help because they assumed someone else would.[13]

### CASE 2.4 Sherrice Iverson

Sherrice Iverson's father was playing slots at the Primadonna Resort on the California-Nevada border.[14] Sherrice was seven years old and probably bored. Jeremy Strohmeyer, age 18, engaged her in a game of hide and seek. Jeremy was there with his friend David Cash Jr., also age 18, who was aware of all this. But Sherrice, in an effort to get away, ran into the women's restroom. She was followed by Jeremy who cornered her in a stall and proceeded to rape and murder her. David went into the restroom and looked over the stall door and saw what was happening but could not get Jeremy's attention according to his sworn testimony. He returned every few minutes to check on his friend. Jeremy then joined David in the casino. They drove to Las Vegas to continue gambling. Jeremy told David he had killed the girl, but David told no one what was occurring or what did occur until he was interrogated.

Based on Slaying suspect's friend not seen as accomplice. *Los Angeles Times*. June 3, 1997:16.

These failures to respond to a human's need for help provoke shock and revulsion. Human instincts indicate there must be some decent minimum level of response required: if not to stop an attack, at least to call the police; if not to swim out to help, at least to toss some floatable device or call for help. Yet the law in most states does not reflect shock and revulsion.

In none of the cases above did any of the observers break any laws. Few states have exceptions to the "freedom to not act" to help others, and most of those exceptions concern: special relationships, such as in the employer-employee role or the husband-wife relationship; providing help if you caused the problem; parent-child responsibilities; property owners' responsibility for a person on their property; and contractual obligations, such as those of a lifeguard or security guard and selected others, depending on the state.[15]

Most states have Good Samaritan laws, but they apply only to those medical professionals or technicians responding to the physically injured and protect them only from civil and criminal charges if things go badly. The laws do not reward beneficence; they merely prevent misfortune for care providers. Providers are free to not respond if they so choose. The federal law has one beneficence-based law, the Bill Emerson Good Samaritan Food Donation Act, which protects donors of food from criminal and civil liability when food is donated in good faith.[16] But in the very few states where Good Samaritan laws create a positive legal obligation (between four and nine, depending on the definition), the laws are narrow in scope and rarely enforced.[17]

This reluctance to legislate positive duties is not shared internationally. Historically, ancient Indian and Egyptian laws required help for the endangered or injured, but these laws yielded to the Roman and Greek investment in expanding free will. They reemerged in the Russian Criminal Code of 1845.[17] During and after World War II, European countries began legislating a duty to help the injured. At present more than 23 European countries have such laws. But in all cases, both in the United States and Europe, the laws are crafted narrowly. They are Good Samaritan laws, not "hero" laws. In no case is a person expected to act if doing so puts him or her in harm's way. France has one of the most defined laws in that it has several elements that must be met.[18] For example, the rescuer must be capable of assisting and must believe that the victim is in true danger. Additionally, the aid that is to be administered must not put either the Good Samaritan or the injured at risk for harm or compound the problems for the victim. The French statute has most frequently been used to enforce aid to motorists who are victims in auto accidents and to force physicians to assist the injured if present at an accident. This law received enormous attention during the trials surrounding the death of Diana, Princess of Wales, secondary to an auto accident. As the Princess and her friend Dodi Fayed and chauffeur were dying, photographers who had been chasing their vehicle prior to the crash proceeded to photograph the dying victims, offering no help.[18] They were prosecuted under the French Good Samaritan Law, which carries a penalty of up to 5 years in prison and a fine.

In the United States, the persuasive arguments have largely been that imposing positive responsibilities, no matter how narrowly drawn, infringe on a citizen's autonomy. The invasiveness of these types of laws is sometimes complemented with the "slippery slope" argument that, once started, there is no stopping the legislation of any and all desirable behaviors. Examples of existing positive laws are seatbelt and helmet laws, so what next? Philosophically, the counter point is crystallized by John Stuart Mill in *On Liberty*: "the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."(Mill, cited in 17)

Pragmatically, one point of rebuttal is that Good Samaritan laws can be crafted so that minimal intrusion occurs and that the primary objective is to state a desired moral climate that is needed to curb the most egregious situations. Some people claim society needs legal grounds to prosecute "passive participants," first-hand witnesses of violent crimes who sit by and do nothing to stop the violence. This has been a common pattern in gang violence and a common frustration for prosecutors.

Some legal scholars propose model Good Samaritan laws that are narrowly drawn but go so far as to reimburse the Good Samaritans for their costs, also under strict conditions, one of which is that the reimbursement by the beneficiary cannot exceed the benefits received. The model Good Samaritan act would have to be one that any reasonable person would desire but who was not present or able to give consent for the act. If the rescuer is injured in the process of performing a rescue, again under tightly defined conditions, the medical costs are covered by public funds, as is currently done in Israel.[19,20]

Should qualified professionals be required to do more than laypersons? Professional roles are characterized not so much by a new set of values but instead by a shift in priorities. Caring relationships and the delivery of care required a priority of beneficence where in our personal lives autonomy may have the edge. Referring back to the Beauchamp and Childress schema in Table 2–2, we suggest that their proposal has an intuitive grasp of an honorable private life but the professional life would include a shift toward the right, where ideals earlier defined as being beyond the obligatory become obligations. Thus we would modify the professional model to be something more in the line with **Table 2–3**.

Supererogatory acts are reserved for those with a moral compass that demands heroic measures. They are not obligatory for the average health-care provider. The expanded obligation for health-care professionals does mean a level of beneficence that distinguishes health-care professions from some other professions. It acknowledges that health professionals enjoy a legal monopoly in part because of their self-regulation and in part because they work for the common good. They do in fact have indebtedness to the public that has funded the research

**TABLE 2–3. Professionals and the Beneficence Continuum***

| OBLIGATION | | PROFESSIONAL OBLIGATION | SUPEREROGATION |
|---|---|---|---|
| Strict obligation | Weak obligation | Ideals beyond the obligatory | Saintly and heroic ideals |

*Adapted from Beauchamp TL, Childress JF. *Principles of Biomedical Ethics,* 6th ed. New York: Oxford University Press; 2009.

that supports their professions and maintains institutions for practice. Health professionals retain those privileges and an elevated social standing based on the trust that they will go one step further than the average person, at least in their professional life.

It can be argued that more is expected of health-care professionals in their private lives also, although most young professionals have diverse opinions on this. Licensure boards do consider private acts outside the workplace as proxy statements on judgment and trustworthiness. In California, for example, a DUI (driving under the influence of alcohol or drugs) conviction incurred on a Saturday night may be enough to put a physical therapist on probation. Repeat offense can result in suspension or revocation of licensure. In the same vein, having a sexual relationship with a patient outside business hours, regardless of claims of it being consensual, can also result in actions. Boards reason that all such cases go to the heart of judgment, which does not begin or end at the employment setting.

## WHY BE MORAL?

Thus far we have focused on moral guidance in connection with ideals of virtue, development of moral reasoning, and rules and principles such as those guiding helping strangers. Moral motivation has been in the background, and we move it center stage in the remainder of this chapter. Clearly, virtues inform the emotions and desires that motivate moral conduct, and there would be no point of setting forth moral rules and principles unless people are capable of being motivated to act on them. Let us ask, then, why be moral, whether in one's profession or elsewhere?

The question can be taken in two ways. On the one hand, it might call for unfolding what is involved in the moral life, perhaps in a manner that elicits moral concern. It calls for invoking and elucidating moral values in some comprehensive way. For example, suppose the question is raised about why a person should avoid cheating or paying a bribe, even when other people are doing so. The answer might be that participating in such practices would adversely affect character. It would make a person dishonest rather than a person of integrity. In this way, the question about why one should perform certain obligatory actions is answered by appealing to the virtues defining good character.

Again, suppose the question is why should the standards of professional ethics in physical therapy be heeded. The answer might be that doing so results in responsible professionals—and that says something important about how people are, the kinds of relationships they aspire to have, and the kinds of community they seek. In this regard, the primary reason for *doing* what is required as a morally responsible professional is that health providers will *be* responsible persons in the professions. They will be persons of integrity. They will be decent and compassionate healers.

On the other hand, the question "Why be moral?" might be presented as a challenge to justify the entire moral life—not just specific moral actions, but moral character and conduct in general. It might ask, Why should people care about (value, be motivated by) any moral reasons? This question challenges the legitimacy of moral reasons and calls into question morality as a way of living. The question implies that morality must have some nonmoral justification, presumably a self-interested one. "Prove to me that morality pays," the question demands; "prove to me that morality is worthwhile in terms of my self-interest."

Many philosophers have attempted to respond to this challenge. Most notably, Plato, in his *Republic*, attempted to show that the moral person will be happier than the immoral person and, hence, that morality pays.[21] He responds to the legend of the Ring of Gyges, in which a shepherd named Gyges finds a ring that allows him to turn invisible—an idea two millennia older than H.G. Wells' science fiction tale of the invisible man. Using his magical powers, Gyges manages to gain control of the kingdom, placing all its riches under his complete control. Plato attempts to show that Gyges would of necessity become unhappy because his appetites would grow uncontrolled and overwhelm him. In contemporary terms, his mental health would be destroyed and with it his well-being. Thus, Plato concludes, "virtue is as it were the health and comeliness and well-being of the soul, as wickedness is disease, deformity, and weakness.[21(p444e)]

Other philosophers have argued that, for the most part, morality points in the same direction as an enlightened view of one's self-interest—that is, one's well-being.[22] For example, if you are selfish, you might have difficulty in love relationships; if you are callous and cruel, you will not have many friends; if you are dishonest, people will not be eager to engage in business with you; and so on. In short, moral endeavors and happiness-producing aspects of life largely overlap. If they did not, the moral life would be a nightmare of constant conflict between the natural desire to promote individual well-being and moral concerns. In fact, professional ethics and private interests generally overlap and mutually reinforce each other.

Even so, most contemporary philosophers reject the demand that morality must be justified entirely in terms of self-interest. Such a demand implies that only self-interested reasons are valid and that moral reasons must be validated in terms of them. To the contrary, as moral beings, people affirm the validity of moral values themselves, as ways to respect and care about persons (and other sentient animals). To adopt a moral point of view is to have such attitudes of respect and caring and to try to act on them. It is also to respond to other persons as having a moral worth that makes a claim on us. Indeed, it is to acknowledge moral values as especially important in how people live.

## ETHICAL EGOISM

There is one ethical theory that reduces morality to self-interest. **Ethical egoism** is the view that people ought always and only to care only about their own self-interest. This view suggests each individual ought to concentrate exclusively on his or her own well-being and happiness rather than also caring about other people for their sake.

The history of philosophy contains many attempts to refute ethical egoism. One attempt is to show it is logically inconsistent. If I value myself as having inherent worth, mustn't I, to be consistent, value other people who, after all, are similar to me in relevant respects? The difficulty with this attempted refutation is that the relevant consistency is moral and, hence, is appealing only to people who already care about and respect others.

Perhaps the most promising attempt to refute ethical egoism is to show that it is self-defeating. Its aim is to have people maximize their own long-term interests, well-being, and happiness. Yet, when people attempt to pursue their self-interest exclusively, they often fail. People become self-centered and selfish (excessively self-seeking) in ways that cut them off from the very things that promote their happiness: love, friendship, deep commitments in their professions, and additional commitments to humanitarian, environmental, spiritual, or other involvements. All these involvements presuppose that people cultivate caring for others for their sake. The crux of the matter is the nature of the "self" whose self-interests are to be promoted. When the self is defined in terms of having caring relationships with others, self-interest and morality tend to converge.[23] Most ethical egoists, however, tend to resist such expanded conceptions of the self, and it proves difficult to shake them from their narrow conceptions of the self as preoccupied with good for themselves.

## PSYCHOLOGICAL EGOISM

Instead of trying to refute ethical egoism directly, one might ask why some people find it an attractive doctrine, in order to see if there are any sound reasons for embracing it. The primary rationale for ethical egoism is a particular view about human nature called **psychological egoism.** All humans are always and only motivated by desires to get what they believe are benefits for themselves. This is called psychological egoism because it is a doctrine about what actually motivates people, by contrast with ethical egoism, which is a doctrine about how people ought to act. If psychological egoism were true, then ethical egoism would be the only plausible ethical theory. If humans are only capable of caring about their own self-interest, then the only plausible ethical theory is the requirement to take a long-term view of their interests and to engage in prudent self-seeking.

Thus, it is no surprise that defenders of ethical egoism are invariably psychological egoists, including the 17th-century philosopher Thomas Hobbes and the 20th-century novelist Ayn Rand.[24,25] A surprisingly large number of psychologists, economists, and political scientists have also embraced psychological egoism. Hence, it is worth asking what arguments support that view of human nature. Most of the arguments are simple and seductive but specious.

The first argument states that people always act on their own desires; therefore, people always and only seek something for themselves—namely, the satisfaction of their desires. Therefore, psychological egoism is true.

In reply, we can agree the premise is true: People always do act on their own desires. Even when people seek to please others, they are acting on their desires to please. Even when people do things they say they do not want to do (such as going to the dentist), they are actually acting on their desire (to maintain healthy teeth). By definition, my actions are based on my desires and my beliefs—that is simply what an action is, in contrast with involuntary reflexes or accidentally getting struck by lightning. Surely, however, this tautology cannot establish psychological egoism, which is a highly controversial view of human nature. In fact, the fallacy is easy to discern. "My desires" include desires for many different things: to get something for myself (self-seeking), to pursue my profession with excellence, and to help others who are in need of help. It is the object (target) of the desire that determines whether it is self-seeking, not the mere fact that it is my desire.

A second argument asserts that people always seek to gain pleasure for themselves (from satisfying their desires) or to avoid pain; therefore, psychological egoism is true. In reply, this time the premise is false. People seek many things, which they value for themselves—love, friendship, creative expression, and mountain climbing. People derive pleasure from these things because people value the relationships and activities. True, people often seek pleasures, but the pleasures are attached to and derive from activities, relationships, and things. If people did not value all these things in their own rights, people could not derive enjoyment from gaining or even pursuing them.

A third argument asserts as a premise that an ulterior self-seeking motive for any human action can always be imagined. Even the most seemingly self-sacrificing action might be motivated by a concern for compensation of some kind, if only posthumous awards or divine salvation; therefore, people only seek something for themselves.

In reply, the premise is obviously true: a self-seeking motive for any human action can always be imagined. It does not follow, however, that the *actual* motive is self-seeking. For example, one can imagine that soldiers who jump on grenades to save their comrades are out only to gain posthumous rewards or to escape depression or that rescuers during the Holocaust who risked their lives and their families to save strangers were thinking only about themselves. One can imagine these things, but that does not make them so.[26] One would have to be a cynic to believe that all forms of heroic and supererogatory conduct are merely variations on "looking out for number one."

A fourth argument is that when any human action is examined closely, some element of self-seeking and some kind of benefit for the agent are found; therefore psychological egoism is true. In reply, this time the premise might well be true, but it does not establish the conclusion. That is, it might well be true that every human action is at least partly motivated by self-seeking, but that does not establish that the entire or sole motive is self-seeking. It is a confusion to infer that because "one" motive for an action is self-seeking that the "only" motive is self-seeking.

## COMPLEX MOTIVATION

At this point, we leave as a discussion question whether psychological egoism can be supported by any better arguments. We conclude this section with what we consider two important and plausible claims about human motivation.

First, it is no doubt true that most people, most of the time, are primarily motivated by a concern for their self-interest. This view has been called **predominant egoism.**[24] Predominant egoism differs from psychological egoism by acknowledging a significant, albeit limited, role for caring about other people. It leaves room for the possibility that responsible professionals genuinely can and do care about the people they seek to help. Specifically, physical therapists can and do care about their patients—for the sake of their patients in addition to personal benefits to the therapists.

Second, most human actions have multiple motives, often embedded within layers of motivation, and often combine legitimate self-seeking with concern for others. For example, taking a particular college class might be motivated partly by the enjoyment one derives from it and partly, perhaps primarily, by the class's contribution to a degree. In turn, the desire for the degree is motivated by multiple interests in earning a living, finding enjoyable and challenging type of work, and being able to help others. This is the **mixed motive thesis:** much human action is motivated by a mixture of motives, including elements of self-interest and altruism.

The motives of professionals might be sorted, very roughly, into three categories: craft, compensation, and moral concern.[27] **Craft motives** are desires to meet the standards of technical excellence, as defined by state-of-the-art professionalism, as well as to seek creative solutions to technical problems. **Compensation motives** are desires to earn a living, have job stability, gain professional recognition, exercise power and authority, and other primarily self-oriented desires. **Moral concern** refers to motives specified in moral language, many of which fall into two overlapping categories: (1) integrity motives, which are desires to meet one's responsibilities and maintain one's moral integrity; and (2) caring motives, which are desires to promote the good of others, for their sake. Typically, all three types of motivation are interwoven in the life of physical therapists. Moreover, it is generally good that this mixture is found, because motives tend to reinforce and strengthen each other.

## DISCUSSION QUESTIONS

1. In Case 2.1, did George act in a way you would support as: (a) patient, (b) health-care professional employed at the hospital, (c) trustee, and (d) owners of the hospital, including investors?

   In your answer, apply the steps from Chapter 1 for solving ethical dilemmas. Did George make a morally responsible choice? Was it the best choice? Was his choice obligatory, or was it instead beyond the call of duty? Was he sufficiently sensitive to staff and future patients, not to mention to investors? If you were George, how would you have prioritized your responsibilities in the situation?

2. In Chapter 1, we emphasized that moral responsibilities and other moral reasons often come into conflict, creating

ethical dilemmas. Return to Case 2.1 to identify the virtues that conflict, or at least are in tension, in the situation.

3. Review the sampling of virtues given in the section titled "Character and the Virtue of Caring" at the beginning of this chapter. Are there any virtues you would add as germane to physical therapy and to health care in general? Can you improve on the organization of the virtues presented there?

4. What limitations, if any, do you see in Lawrence Kohlberg's assumption that the highest (best) level of moral reasoning involves an emphasis on universal moral rules, ranked in order of importance? What dangers do you see in Carol Gilligan's emphasis on contextual reasoning aimed at maintaining personal relationships, rather than relying on general moral rules? Link your answers to your view concerning how Heinz should have acted, and especially to the argument you would put forth to defend your view.

5. Ethics includes more than obligations. It also includes personal ideals of caring and service that transcend mandatory requirements, ideals that give meaning to one's career. To ask a highly personal but pertinent question, which ethical ideals do you bring to your profession? What prospects and obstacles do you anticipate in pursuing those ideals?

6. Discuss the pros and cons of Rhode Island's Good Samaritan Law: "Any person at the scene of an emergency who knows that another person is exposed to, or has suffered, grave physical harm shall, to the extent that he or she can do so without danger or peril to himself or herself or to others, give reasonable assistance to the exposed person. Any person violating the provisions of this section shall be guilty of a petty misdemeanor and shall be subject to imprisonment for a term not exceeding six (6) months or by a fine of not more than five hundred dollars ($500) or both."[20]

7. As a new member of state legislature with the support of a major political force behind you, what are elements that you would propose for a Good Samaritan law for your state?

8. (A) Is psychological egoism true? (B) Is ethical egoism true? (C) Discuss what enlightened self-interest is. Also, if "self" (the person) is defined in terms of its relationships with others, does the good of the self essentially become one with valuable relationships with others?

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# Chapter 3

# Respect for Autonomy and Control of Information

***Physical therapists shall respect the inherent dignity and rights of all individuals.***

Principle 1, APTA Code of Ethics

### CASE 3.1 **Unwanted Therapy**

Martha Sullivan is an 83-year-old widow who was admitted to a skilled nursing facility because of a broken hip caused by a fall. The hip has mended well, and now the physical therapist is working on balance skills. This was not the first fall for Mrs. Sullivan, and she has been having increasing difficulty in caring for herself since her husband's death. Her children are worried that she might be injured in her home with no one available to help her. Both her children live out of state and, since her husband's death, Mrs. Sullivan has lost interest in maintaining the friendships she had previously found rewarding.

Anna is Mrs. Sullivan's physical therapist, and the two have developed an excellent rapport. Mrs. Sullivan has been the ideal patient, doing all her home exercises. But Anna was caught by surprise when she went to Mrs. Sullivan's room 15 minutes early to find her with her face in a pillow to hush the sounds of her crying. Anna put her arm around her patient and asked why she was so upset. Mrs. Sullivan responded that she found therapy scary because she was afraid she would fall again, and she was sure she would not live through another convalescent period. All she really wanted to do was to use a walker in her room and use a wheelchair when she went outside. Anna asked her why she had not mentioned this before. Mrs. Sullivan explained that she was afraid that if she refused anything, the nursing facility would put her out or even have her declared incompetent. If they had declared her incompetent, she could be sent to a far worse location and would lose control of what little money she had left. She also stated that neither of her children wanted her with them and that she had no place else to go.

Anna feels sure she can coax Mrs. Sullivan into continuing therapy, but she also feels unsure about whether she should attempt to change Mrs. Sullivan's mind or merely stop by for social calls until Mrs. Sullivan requests more therapy.

The principle of autonomy asserts there is a responsibility to respect the autonomy (self-determination) of each person. No principle is more important to health-care ethics or indeed to all professional ethics. The principle is more complex than first appears, as the case of Martha Sullivan suggests. This chapter begins by noting how respect for autonomy has largely replaced medical paternalism. We then focus on three specific professional duties entailed by the principle of autonomy, each of which concerns the patient's control over personal information: informed consent, truth telling (veracity), and confidentiality (privacy). The goal is to develop a nuanced understanding of these duties, including their meaning, moral foundations, and the moral dilemmas that arise when they conflict with other moral principles.

## RESPECT FOR AUTONOMY

Autonomy has two aspects—one moral and one psychological. **Moral autonomy** is the moral authority or right to make one's own decisions. To respect people's moral autonomy is to recognize their moral authority to form and act on their own judgments about how to live. As such, respect for autonomy is integral to respect for the dignity and worth of persons. It implies both a respectful conduct and an attitude of valuing the liberty of others.[1] It also implies a negative obligation to refrain from controlling others and a positive obligation to encourage patients to be more independent and responsible for themselves.

**Psychological autonomy,** which is presupposed when one exercises one's moral autonomy, is the competency to make one's own decisions and the ability to reason and act rationally. Autonomous persons have the capacity to guide their lives according to their own desires, beliefs, and intentions. Infants and persons with advanced Alzheimer's disease lack autonomy in this sense.

## MEDICAL PATERNALISM

Although nearly all ethical perspectives justify a strong principle of respect for autonomy, they justify additional principles as well—in particular, beneficence (acting for the good of others) and benevolence (doing so motivated by a concern for their good), both discussed in Chapter 2. At least on the surface, beneficence can conflict with the principle of respect for autonomy, thereby creating moral dilemmas. Throughout most of the history of medicine, these dilemmas were resolved by giving priority to benevolence, or, rather, the dilemmas were not even acknowledged because it was assumed that the benevolent physician had primary authority in making treatment decisions.[2] For 2500 years, the ethic of medicine was rooted in the Hippocratic oath, which made paramount patients' health, not their autonomy. It was taken for granted that physicians knew better than patients what was good for them and that this knowledge gave physicians the authority to make decisions on behalf of their patients.

Stated another way, physicians embraced **medical paternalism,** the view that physicians are justified in promoting the well-being of patients as defined by the physician, regardless of whether the patient gives prior consent. (Paternalism is sometimes called parentalism, in order to avoid linguistic gender bias.) Paternalism takes various forms.[3] **Weak paternalism** is interfering with others' liberty to prevent them from harming themselves—for example, by forcibly stopping them from inadvertently walking into the path of an oncoming vehicle or requiring that motorcyclists wear protective helmets to prevent brain damage in motorcycle accidents. **Strong paternalism** is interfering with others' liberty for the purpose of promoting their good—for example, by using a placebo to help wean them from an addiction. The interference might mean promoting their good without their consent or even overriding their explicit choices, as when therapy is forced against someone's will.

These forms of paternalism were once widely accepted in medicine and were reinforced by the Hippocratic oath, which also forbids physicians from sharing their knowledge with laypersons, thereby further undermining patients' abilities to make decisions about their medical care. Medical paternalism, however, is declining dramatically, and the change is relatively recent. A 1961 poll of American physicians revealed that 88% of them would routinely withhold from patients a diagnosis of their terminal cancer. By 1979 a poll revealed a dramatic change: 98% of physicians polled said they would reveal that diagnosis to their patients.[4,5]

Even the defenders of paternalism now argue for restricting its role in medicine. It is still accepted as a temporary measure, such as when health-care professionals entirely take over a patient's medical decisions during an emergency—when the patient is comatose or in shock—and relatives are not immediately available. Whereas the traditional rationale was that these were instances of justifiable paternalism, they are now reconstructed as signifying an implicit respect for autonomy, based on the assumption that rational individuals would choose this care if they could.

This dramatic shift away from medical paternalism and toward an emphasis on respect for autonomy was influenced by several events during the second half of the 20th century. The Nuremberg Code of 1946, drafted in the aftermath of the Holocaust, made central a principle of informed consent to ensure patients' ability to make their own decisions when confronted with powerful social institutions. Other key forces included the social movements of the 1960s and 1970s, which accented individualism and gave rise to the patients' rights movement. During this period, several additional factors were at play: the increasing vulnerability of patients within modern health-care institutions; dramatic technological changes that extended life and made possible an ever-increasing variety of treatment options; the widening gap of understanding between patients and professionals; and the augmented power of professionals.

At the same time, feminist ethics and the ethics of care have challenged how autonomy is understood. As traditionally understood, the principle of autonomy does not recognize that self-governance has different meanings for people and that people define "self" in different ways. Carol Gilligan, discussed in Chapter 2, believed that most women and many men defined their "self" not as an isolated decision maker who should be considered competent only in the absence of the influence of others but rather as a center of relationships and responsibilities that included many other significant persons. Therefore, persons who solicit the opinions of important people in their lives on crucial medical decisions are no less autonomous than those who make their decisions alone.

Most important, feminist ethicists have raised profound questions about the impact on autonomy of the uneven distribution of power, and they question whether women and minorities have the freedom to truly act autonomously when others are in positions of power. They also question if it is possible for those in power to treat those with lesser status as equals and to respect their choices with the same commitment as they would the choices of a peer.[6]

In light of these general considerations about autonomy, we turn to the first and most important implication of respect for autonomy in health care: the duty to obtain informed consent.

## INFORMED CONSENT

Health professionals must respect the informed consent (and refusal) of their patients concerning a course of therapy. Informed consent is an ongoing process and not something that is finalized with a signature on an intake form. At every treatment point in time, the patient has a right to know and a right to refuse. For patients to give informed consent, three conditions must be met: information, voluntariness, and competence.

### Information

The first condition for informed consent is that patients be given relevant information concerning their condition and treatment options in a manner they can understand so that they can make an informed decision. "Relevant information" includes facts about what is involved in the proposed therapy and alternative therapies, risks and benefits of the proposed therapy and of alternative therapies, financial costs, and whatever additional information the patient requests concerning therapy. Giving information only on the treatment option preferred by the therapist does not meet the standard for informed consent. If the therapist is to be truly respectful of patient autonomy, information must be given for a range of choices that include alternative treatments and options. Precisely how much information is required is sometimes difficult to identify and is variously defined legally, state by state. In a practical sense, patients cannot be given all information concerning medical procedures, nor could most understand that information anyway (without a relevant health-care degree).

The difficulty comes in defining which information is relevant. There are two legally recognized standards that define which information must be given to the patient. The **medical care standard**, which is recognized in some states, defines it as the information that providers in a region agree is important for the patient to know. Other states recognize the **reasonable person standard,** or the prudent patient standard, which says that relevant information is that which any reasonable person would want before making a decision.

A more recently proposed dialogical standard, which emerged from feminist ethics, would require that providers and patients have a dialogue in which patients define what they uniquely need to know so that the decision is their own individualized decision. "The process should be individualized within the boundaries of the patient's desires for autonomy, thus reflecting true patient autonomy."[7] This differs from the reasonable person standard in that it takes into account factors that might not be shared with "any reasonable person" but that are nonetheless important and reasonable to a particular patient. For example, a mother with terminal breast cancer wants to prolong her life in a pain-free environment until after the marriage of her daughter, which will occur in 8 weeks. A generic reasonable person might not need or want such time-specific information and medical treatments. One problem, and it is a significant one, is that a person may not have enough knowledge about a medical situation to know what to ask. Therefore, to avoid unintentionally neglected information and to satisfy legal standards, it is probably best to combine the reasonable person standard with the dialogical in jurisdictions that recognize the reasonable person standard.

The information condition places requirements on how information is given as well as on what the information is. Disclosure of information in English to a person who speaks only Arabic does not constitute informed consent. Patients in emotional distress might need help in grasping even simple facts about their situation. Conveying the information requires skillful communication rather than merely passing on a list of facts. Information must be relayed in terms that the patient can understand, free of professional jargon and assumptions about what the patient ought to understand.

The tone of voice and the structure of the presentation are just two of the many subtle ways a provider may bias a patient toward one treatment or another. That is not to say that health-care providers should not express their opinions when asked. They should, however, express those opinions directly and overtly rather than covertly through a biased presentation of the relevant information. Moreover, professionals should be careful to give only information within their domain of practice. Out of respect for the autonomy of other providers and in wise recognition of the limits of their own understanding, health-care professionals should not interpret the recommendations of other disciplines unless their help has been specifically requested in informing the patient. There is, however, a responsibility to make sure that corrections are made when a patient has received mistaken information because of either provider error or patient misunderstanding, which can often be discovered by asking patients to repeat or explain the information.

What if patients state that they do not want certain information, or perhaps any information, about their medical condition? For example, suppose they say their destiny is not in their hands and that additional information will be a burden or that they prefer to follow their instincts. Does the right to informed consent include, paradoxically, a right *not* to be informed? Ultimately, patients should be free to use whatever decision matrix they prefer, be it sound reasoning, intuition, or magic. The right to self-governance implies a right to informed consent and, if one so chooses, a right not to be given certain information.

In fact, sometimes there are cogent, although unstated, reasons for refusing information. When researchers offered free counseling, educational programs, and genetic testing for a specific type of cancer to a group of high-risk individuals, only 43% elected to take the test, even though there was an 80% to 90% lifetime risk. The researchers in this particular study found that the most significant deterrent to the testing was potential discrimination by health-care insurers once the results became known.[8]

One of the most important considerations for patients in refusing information has little to do with insurance. Ethnic background can affect how much information is desired by the patient, and belief systems can influence how information should be distributed and acted upon. We discuss this in more detail in Chapter 5.

When patients request that they not be told their diagnosis, forcing this information on them can be callous. In cases in which patients indicate an unwillingness to make their own decisions, the provider should ask what information they want, which decisions they would like to make, and who they will designate to make all other decisions. In medicine, respect for autonomy locates control with the patient or designate rather than with the provider.

### Voluntariness

Voluntariness, which is the second condition for informed consent, means that patients must be free to make decisions without being coerced or otherwise manipulated. Physically forcing therapy on patients against their explicit desires is the most flagrant violation of this condition. A more common violation is the use of subtle threats or other forms of emotional manipulation. Most common of all is the use of deception to "guide" a patient to make a particular decision.

Deception is intentionally misleading a person, by lying (intentionally stating a falsehood designed to create a false belief), withholding important information, exaggerating, understating, or using pretense. Deception typically violates both the information and voluntariness conditions, and to that extent those conditions can be viewed as overlapping.

All the conditions are sometimes challenged as changes in health-care practices and institutions occur. For example, many HMOs imposed "gag orders" on physicians and other providers, forbidding them to inform patients of alternative (usually more costly) approaches to their care or to refer them to sources outside the HMO for care—such as additional sessions with a physical therapist—which would increase their maximum benefit and the HMO's expenses. Medical ethicists and the courts condemned the gag orders, but the episode highlights the fact that patient rights remain vulnerable.

Voluntariness can be undermined in many ways, including physical coercion, deception, and emotional pressure. These ways are illustrated by three examples adapted from therapist Janet A. Coy. Each example involves patient noncompliance with a recommended course of therapy.

### CASE 3.2 Coerced Therapy

Mrs. S, a 54-year-old woman, has received 2½ weeks of physical therapy during recovery from a right cerebrovascular accident. The muscle tone in her left upper extremity is improving, but the gain has brought with it increasing pain during range-of-motion (ROM) exercises. On her next visit she refuses treatment because of the pain, and she continues to refuse even after the therapist carefully explains the importance of treatment to improve arm movement and to prevent contractures. Convinced that she "cannot really appreciate the long-term implications of her refusal . . . the therapist performs the ROM exercises against Mrs. S's wishes. Meanwhile Mrs. S cries throughout the treatment session and at one point tries to gently push the therapist's hand away."[9]

Only a few decades ago the therapist's behavior might have been condoned or at least tolerated, but today it is understood as unethical coercion. In legal terms, it constitutes battery: an unlawful attack; touching done without the consent of a person. While the presence of good intentions and a genuine desire to help Mrs. S makes the behavior paternalistic rather than a malevolent assault, immoral and illegal coercion are involved nonetheless.

There can be many variations in the details of this case. For example, Mrs. S might not express her refusal until after a therapy session is under way. Thus, by arriving for her appointment, she indicates a tacit consent to proceed with the routine exercises, but she exclaims "Please stop!" when the pain catches her by surprise during therapy. Or, in pain, she indicates refusal by shaking her head as she grimaces, a response calling for the therapist to pause and talk with her. Thus, in general, consent is not always settled at the outset of either a discussion about a course of therapy or a particular therapy session. Instead, consent is part of an ongoing interaction with the patient.

## CASE 3.3 Deceiving the Patient

Mr. J, age 38, was in an accident that caused third-degree burns over his face, upper extremities, and back.[9(p46)] His skin grafts are healing successfully, and he has been cooperative during his three months of physical therapy. He starts refusing to wear his counterpressure garments, however, because he finds them uncomfortable. The therapist insists on the importance of the garments in improving his long-term appearance, but Mr. J replies that appearance is not important to him. The therapist is aware that there is considerable debate about the efficacy of the garments, but she remains convinced that they are an essential part of responsible care. Convinced that Mr. J will later deeply regret his decision, and knowing that Mr. J is strongly motivated to return to his job, she tells him that not wearing the garments might prevent sufficient recovery to return to his job as a mechanic and even jeopardize his insurance coverage. These are lies, because the garments will not affect function and, because Mr. J is compliant overall, his insurance coverage is not at risk.

As in the first example, this case involves paternalism based on a sincere belief that the patient will benefit from the therapy being declined. Unlike the first case, the therapist manipulates Mr. J into making a particular decision by using deception and threats. Mr. J quite plausibly hears the therapist's remarks as a threat—the threat that health-care coverage will be revoked (regardless of whether the therapist is directly part of that revocation). Threats undermine voluntariness by creating fears or otherwise pressuring individuals to make decisions they otherwise would not want to make. Even without threats, deception itself interferes with voluntary choices when the deception manipulates a patient's decisions.

## CASE 3.4 Pressuring a Patient

Mr. B, age 68, has chronic obstructive pulmonary disease. Unable to care for himself, he enters a long-term nursing facility where he is mobile only with the help of a wheelchair and portable oxygen. He declines physical therapy, declaring he had had it before and it did not help. The therapist, however, believes that he would function more comfortably with the help of physical therapy and tries to convince him to at least undergo an evaluation to establish baseline information. "When Mr. B continues to refuse, the therapist begins to discuss her 'genuine desire' to help him be more comfortable, the importance of following a physician's order, and the 'terrible' consequences of not participating in physical therapy and of not being as active as possible. After 20 minutes of 'discussion', during which both Mr. B and the therapist become increasingly agitated, Mr. B finally says, 'O.K., I give up. If I let you do the evaluation, will you leave me alone?'"[9(p46)]

There can be a fine line between encouraging patients to make reasonable decisions versus pressuring and harassing them. Obtaining informed consent requires more than dryly reciting facts, and a responsible therapist would undertake rational persuasion designed to convince Mr. B that it is in his interests to undergo the baseline tests. Yet getting patients to "appreciate" the importance of therapy easily shades into badgering them to make decisions through emotional agitation rather than calm deliberation. Even a tone of voice can increase or decrease rational deliberation by patients.

Case 3.4 involves a nursing facility where, as with many health-care institutions, special attention needs to be paid to subtle pressures. The courts have seen difficulties in the use of informed consent within "total institutions" (such as prisons and mental hospitals) that shape all areas of life. Nursing facilities are not generally considered total institutions, and yet some of them share striking similarities, ranging from a lack of privacy to the uniforms and hierarchy of the personnel. One could even argue that the ailments and limited fiscal resources of many elderly take away even their voluntariness (ability to choose) concerning placement in a skilled nursing organization. Living with a chronic ailment in a health-care institution for a long time can subtly affect an individual's overall sense of autonomy, leading to even more psychological dependence and vulnerability.

Especially in caring for patients who are elderly and enfeebled in long-term care facilities, providers may be tempted to confuse consent with simple compliance and to interpret lack of compliance with mental incompetence. As A. A. Guccione writes, elderly patients "who refuse to accept professional recommendations will often have their mental competency challenged."[10] The assumption is that any rational person would accept a certain course of therapy, and hence refusing it is a sign of irrationality so extreme as to call into question that person's general psychological capacities to be self-determining. In fact, sometimes this assumption is accurate. More often, however, health professionals fail to appreciate the right of patients to make their decisions in light of their moral values and intellectual outlook.

## Competence

Competence, the third condition for informed consent, means that patients must be sufficiently rational or competent to understand and make health-care decisions. Competent, autonomous adults can authorize someone to make decisions for them in the event they become incompetent to make their own decisions. The person who delegates the authority, not the surrogate decision maker, remains responsible for the outcomes of those decisions. For example, when competent patients authorize a physician or minister to make health-care decisions for them, the responsibility for the outcome rests with the patients, even though they did not directly make the decisions that produced the outcome. In such cases there is clearly the potential for abuse, but until that abuse is observed, one should respect the surrogate's decisions.

Here we focus on cases where individuals were either never competent or who lost their competency without appointing a surrogate to act on their behalf.

### Legal Competency

Although the psychological capacities and abilities that define autonomy come in many different quantities, a person must attain some threshold of substantial decision-making capacity to be allowed to make health-care decisions. The threshold is specified by law. Adults, typically those 18 years or older, are presumed legally competent until the courts declare otherwise. However, as a rule of thumb, the need to ensure competence is proportional to the importance of the decision. Competence is rarely assessed when the decision is what the patient should order for dinner, but a diligent assessment of competence is required when the consequences of a voluntary decision are life-threatening (as in undergoing some human experimentation) or irreversible (such as a request for a sex-change operation).

Determining competency is sometimes complicated, especially because there are no standardized objective tests with the appropriate reliability and validity to make that determination.[11] Thus, it is a matter of conducting an assessment that seems appropriate to the level of the decision to be rendered. Even then, there may not always be agreement, as the following case study illustrates.

### CASE 3.5 Competent to Decide?

**Ms. Cargill was born with abnormally small kidneys that eventually gave way, necessitating a kidney transplant.[12] She lives in a sheltered home environment, appropriate for her mild mental retardation. When she applied to the Oklahoma University Medical Center, she was told that she was not a candidate because she probably could not give informed consent due to her diminished capacity. This judgment was reached despite the fact that the state of Oklahoma considered her competent to make all her decisions. It was true that she was in a supervised living situation, but she held a job and did all the ordinary things people do, including having a boyfriend. As her condition worsened, her caseworker reluctantly appealed to Adult Protection Services to become her legal guardian. That agency refused, stating that she was competent. Although Ms. Cargill signed a consent form allowing the hospital to respond to reporters, following the publicity of her rejection as a transplant recipient, the hospital ruled that she was not competent to give that consent.**

The hospital's reasons may have reached beyond the concept of competency to consent to surgery and may have centered on competency to follow up on medical care. Research shows, however, that mentally challenged individuals who have received transplants do as well as the rest of the transplant population. At least medically, Ms. Cargill is the right weight, in good health, and adequately insured to support a lifetime of ongoing medications necessary to prevent organ rejection.[12]

When a court decides that a patient is not competent, it appoints a guardian—usually a spouse, close relative, or someone the individual has specified in legal documents, especially in a durable power of attorney. Guardians then exercise autonomy, in the moral sense, on behalf of the noncompetent individual. Many troublesome issues concerning respect for autonomy involve such surrogate decision makers, as can be seen in the following discussion.

### Standards for Determining Competency

There are three primary legal standards by which guardians might be asked by the government to render decisions on behalf of the patient. The first is the pure autonomy standard, and it relies on prior written or verbal statements made by the person to friends, providers, or family. It may even extend to decisions that conform to religious beliefs or even a consistent pattern of decision making when they were competent.[1(p138)] The Patient Self-Determination Act (1991) codifies in law that organizations that accept Medicare or Medicaid must inform patients that the patients can institute advanced medical directives as well as refuse care. Written advance directives are preferred, but verbal charges are to be honored also.

In recent years the law has gradually shifted toward the pure autonomy standard. For example, in California, "A health care provider or institution must comply with (a) the patient's individual health care instruction and a reasonable interpretation of that instruction by a person then authorized to make health care decisions for the patient."[13]

There are two conditions when noncompliance is permitted: (1) when the care would be contrary to accepted standards of care and (2) when the directive conflicts with the conscience of the health-care provider, assuming that conscience is expressed in a timely manner so other resources can be procured for the patient. In addition, proactive legislation protects providers from criminal and civil liabilities when they follow appropriate directives. There is an emerging argument that providers might be civilly or even criminally liable for a "wrongful life" if written directives are intentionally ignored.[14] Anyone with knowledge of these directives has a responsibility to make others on the health-care team aware of them, for both immediate and future decision making.

Under the second standard, guardians may be asked to render a substituted judgment for the patient. In this case, they use their knowledge of the patient and the patient's history of decision making to imagine what the patient would want under the circumstances. Of course, this requires that guardians have an intimate knowledge of the patient. But many of our foundational assumptions supporting this concept are being challenged. For example, the law usually designates the spouse, when available, to be the surrogate decision maker. Research, however, has indicated that nearly 33% of married people would not choose their spouse as their surrogate decision maker.[15] Compounding the problem of substituting judgments, when next-of-kin surrogate decisions are compared with patient preferences, nearly 32% fail to express the patient's choices.[16] It appears that when these failures occur, it is because the surrogate decision makers substitute their own decisions, at least those involving cardiopulmonary resuscitation versus do not resuscitate (62.5%) and extended life versus relief of pain (88.4%).[17] In addition to concerns about the fidelity of surrogate decision making, pragmatically it is becoming increasingly difficult to locate a guardian with this type of intimate knowledge. In the past 20 years, the percentage of people who had no one in whom they could confide has risen from 10% to 24.6%.[18]

Under the third standard, guardians base their decisions on what they think is in the best interest of the patient. In theory, the best interest standard can produce very different decisions from what the patient might actually have chosen to do. For example, if a person had strong religious beliefs against blood transfusions, a substituted judgment by someone aware of these beliefs would eliminate blood transfusions in care. But suppose the person was injured and those beliefs were unknown, and there was no time to find someone familiar with the patient, then the best interest standard would find a surrogate decision maker giving approval for that method of care.

Even when the best interest model applies, as in the case of young children with mental disabilities, it is not always clear whose best interest is at stake. Consider the following case study.

### CASE 3.6 Ashley's Treatment

Ashley was 6 years old when the treatment was addressed.[19] Because she has static encephalopathy, she is unable to walk, care for herself, or even control her head posture. By standard measures, her mental abilities are severely compromised. Ashley's parents approached physicians at Seattle Children's Hospital to help them achieve a series of goals, which they believed to be in Ashley's best interest. The Ashley Treatment, part of which was approved by the ethics committee of the hospital, consisted of three elements.

First, growth attenuation was initiated using estrogen to limit her height to about 4 feet 5 inches and her weight to 75 pounds for life. Doctors estimated that without the intervention she would have become 5 feet 6 inches tall and 125 pounds. The parents argued that they would like to continue to care for her as they do now, taking her on family outings and engaging with the family as fully as possible. That would not be possible, for purely physical reasons, if she were allowed to grow and gain more weight. While she would be growing, aging would simultaneously have the opposite effect on her parents.

Second, her breast buds were removed so that she would not develop breasts. The parents were of the opinion that breasts would sexualize her and make her more readily a victim of sexual abuse. They also reasoned that since she would never breast-feed, her breasts had no functional use. They also pointed out that breasts would make it harder to secure her in a car seat, her chair, or any other situation where a seat belt was needed.

**Third, her uterus was removed. The family felt it would rid her of the discomfort and the pain associated with her menstrual cycle. They also thought the removal would reduce the possibility of uterine cancer, as well as remove any possibility of pregnancy.**

The response has been mixed. The primary question raised was whose best interest was being served? And, can the two interests, Ashley's and her parents, be separated? We will leave this for a more thorough analysis in the discussion questions.

### Degrees of Competency

Children younger than 18 years are not considered competent, and their health-care decisions must be made by their parents or guardians, although occasionally special state laws allow or require exceptions. Clearly, moral and psychological competency does not magically emerge on the 18th birthday, and some 15-year-olds are more competent than some 22-year-olds. Legally, variations from the standard depend on the types of decisions in question. For example, some states have liberal laws about the age at which persons may obtain birth control and abortions, and rulings by judges can specify that minors are sufficiently "mature" to make their own decisions in these matters.

When profound consequences are involved, the state is especially protective of the emerging competency of the child, even if it means protecting the child from the parents. Parents may not refuse emergency or other essential medical treatments for a child if that refusal endangers the child's life. When parents refuse such treatments, often because of their religious beliefs, the courts intervene and assume guardianship of the child and authorize treatment. Intervention of this sort is justified by respect for the (psychological) autonomy that the child will develop with time and the moral rights the child already has. As an adult, the former child can refuse the same kind of treatment that the court enforced, but because death cannot be reversed, those decisions must wait until children are old enough to make legally autonomous decisions.

In unusual situations, the courts might grant autonomous health-care decision-making rights to a person younger than 18 years under the concept of the "emancipated minor." This award of rights usually goes to young adults whose parents refuse to act on their behalf, as is often the case with children who are "thrown away" rather than children who elect to "run away." There are also cases in which the courts have supported a minor's request to refuse medical treatment, as they did for Benito Agrelo, age 15 years. Agrelo was granted legal permission to discontinue the antirejection drugs given when he underwent a second liver transplant, even though it would mean his death. The court accepted his desire to accept an early demise over a protracted state of discomfort caused by his reactions to the drugs.[20]

Among autonomous adults, there are the concepts of limited competency and intermittent competency. People experience limited competency in everyday life. For example, few people have the training to instruct the World Bank in the execution of its duties, yet most people are competent to manage their own personal banking responsibilities. Similarly, patients might not have the capacity to make autonomous decisions in some areas of their lives even though they have adequate competency in other areas. For example, elderly patients with mild senility might not be competent to authorize participation in a research project that entails significant risk to the participants, but they can be adequately competent to select their meals from a menu.

Intermittent competency recognizes that there are times when otherwise autonomous individuals might be momentarily unable to deliberate thoughtfully and select a course of action. When under great psychological stress, a person might easily be confused and unaware of choices available or might be unable to make an appropriate choice. As an example, patients who have just learned that their diagnosis is life-threatening might, for a while, be unable to assess their treatment options and make an informed decision. Parents who were just told that their child was involved in a bicycle accident and suffered serious brain damage might not be able to give an autonomous directive to the health-care providers. In such cases, most experienced health-care providers know that they must preserve life or attend to all the patient's needs until decision makers have achieved a calmer state that allows them to understand medical information, assess their treatment options, and then make an informed decision.

## TRUTH TELLING

The duty to tell the truth to patients is also called the principle of veracity, honesty, or truthfulness. Negatively stated, it forbids deception or intentionally misleading someone. As in everyday life, deception is objectionable for many reasons. Thus, deception undermines autonomy, violates the right to the truth, tends to generate a host of bad consequences, and manifests dishonesty. In addition, professionals enter into fiduciary relationships—special relationships of trust—in which strong requirements of truth are expected. In fact, receiving medical information can be thought of as one of the services that patients pay for as part of their health care.

Obviously, the duty of truth telling largely overlaps the duty of informed consent, but nevertheless it is distinct. It is rooted in a general duty of truthfulness (veracity, honesty) and, as such, applies to all information rather than only to information about health-care procedures. In practice, however, within therapeutic contexts, the relevant application of the duty concerns health-care information.

One of the more recent concerns related to truth telling involves reporting medical errors. The incidence of medical errors has been reported most notably by the Institute of Medicine in three major reports: *To Err is Human, Crossing the Quality Chasm,* and *Patient Safety: Achieving a New Standard of Care*. Studies in various health professions have attempted to improve patient safety through better standards and reporting methods. One of the most troublesome aspects has been the reluctance of professionals to report errors.[21] Failing to report errors that affect patient safety and treatment conflicts directly with truth telling, beneficence, and respect for patient autonomy. Physical therapy, like the other health professions, must create a culture of patient safety that will require reporting and developing strategies to prevent those errors in the future.[22] To facilitate reporting, some hospitals have implemented apology policies that require a fast apology followed with a reasonable settlement in an effort to reduce the number and size of lawsuits. Five states now mandate reporting adverse events to patients, and another 29 states exclude expressions of sympathy to a patient after an adverse outcome as proof of liability.[23] Some educational institutions, such as Vanderbilt University School of Medicine, now mandate courses in communicating errors and apologizing.[24]

Moral dilemmas can arise when a physician asks a physical therapist not to convey to a patient certain information about the patient's health, particularly information that the therapist would normally not be required to divulge in obtaining informed consent about physical therapy procedures, but that has implications for the therapist-patient relationship. Ruth Purtilo presents the following case.

### CASE 3.7 **Tell a Lie?**

Andrew Gordon is a 43-year-old contractor who fractured his right tibia in a fall from a scaffold.[25] Mr. Gordon has been hospitalized for three weeks because the fracture is not healing quickly. A fever prompts tests that reveal lymphosarcoma, a cancer likely to be fatal within a year. His physician, Dr. Hammill, calls Kim Segard, the physical therapist, to say that he has talked with Mrs. Gordon and they have agreed that Mr. Gordon would not want to know the truth. The physician does, however, ask Kim whether Mr. Gordon has said anything suggesting he would want to know the truth. Kim reports that he had not. But 10 days later Mr. Gordon does say to Kim, "I have come to trust your judgment. . . . I've tried to cooperate with the doctors and everyone, but I have a feeling that something funny is going on that I can't get at. My wife and Dr. Hammill are acting strange and that is scaring me. . . . Do I have cancer or some fatal illness?"[25]

A direct lie, "No, you do not have cancer," would violate the relationship of trust between Kim and Mr. Gordon. Saying "I'm a physical therapist, not a doctor," would avoid a lie but perhaps constitute deception in the form of withholding information. Saying "You need to talk to Dr. Hammill about that part of your health care" might cause Mr. Gordon to feel additional anxiety that people are not being fully honest with him about something fearful. One way to preserve trust would be for Kim to offer to call Dr. Hammill and then get back to Mr Gordon within a day or so. This would provide the opportunity to convince Dr. Hammill that his patient wants the truth. But suppose Dr. Hammill still refuses, perhaps after talking again to Mrs. Gordon?

The case illustrates the moral complexities of working as part of a health-care team. A physician's choice to lie or otherwise deceive a patient can implicate coworkers in a web of deception. Fortunately, there is an increasing consensus that respect for autonomy creates a strong moral presumption to tell the truth, except in highly unusual circumstances. Today, the consensus would probably be that Dr. Hammill is at fault for failing to inform Mr. Gordon about his cancer. As a competent adult, Mr. Gordon has the right to be told the truth. Much is at stake: he should have the opportunity to choose how he wants to spend the remainder of his life in light of the truth. Perhaps he would want to prepare a will or take his family on a final vacation to some destination they had planned on visiting for years.

Dr. Hammill reflects the traditional strong medical paternalism that is now in decline. Is this shift in attitudes morally appropriate? Sissela Bok offers one of the strongest arguments in its favor.[26] Many of her reasons highlight the good consequences of truth telling. She cites polls showing that people usually want to know the truth, even about terminal diseases. Moreover, they need to know the truth so they can set their affairs in order, make peace with their loved ones, and seek a meaningful way to live their last months or years. While this may be true of most patients, health-care practitioners must remain sensitive to those who do not wish to know, if they so express that desire.

The reason that health-care professionals often find it difficult to inform their patients of bad news is a fear of unpleasantness and, perhaps, their own fear of death. As for the objection that telling a patient about a terminal illness could precipitate suicide, Bok emphasizes the importance of providing support services for patients. Nevertheless, she believes that patients have a right to the truth if they so desire. In some cases it could be argued that suicide can be a rational choice, especially when the option is uncontrolled pain followed by certain death (a topic we discuss in Chapter 6).

### CASE 3.8 Withholding Information

John Borrego is a physical therapist at a university teaching hospital. He was assigned a patient, Raymond Sinclair, who has low back pain of unknown origin but progressive in nature. Mr. Sinclair works for the U.S. Postal Service, which ships large packages, and he attributes his pain to job-related back strains. He has filed a worker compensation claim. John initiates a treatment plan that consists of mild stretching, abdominal strengthening, and modified positions for sleep, lifting, and activities of daily living. A week following implementation of the program, John drafts a recommendation to the physician that ultrasound be added as a treatment preliminary to stretching, to create a faster and less painful course of treatment. John notifies the patient that he is making this request and will begin as soon as approval is received.

After several days of no response from the physician, John calls. The physician says that he wishes John had not told the patient of this proposal because he is afraid to authorize it, fearing that the back pain is caused by a malignancy that has migrated into the vertebra. He is in the process of evaluating current test results and ordering additional tests, but he does not want to alarm Mr. Sinclair if his clinical judgment should prove to be incorrect. To prevent Mr. Sinclair from suspecting anything, the physician tells John to give Mr. Sinclair the usual ultrasound treatment but without turning on the switch that delivers the impulse to the application head. That way, the physician reasons, Mr. Sinclair will not notice anything out of order. Perhaps he might even be one of those patients who will experience improvement because of the placebo effect, with no harmful side effects. John immediately understands that he is being asked to be untruthful by withholding information from the patient. He is also being asked to risk the trust of a patient who has grown to respect his recommendations.

Situations will always arise in which physicians feel justified in withholding some relevant information, at least for a certain period, thereby creating dilemmas for therapists.

## CONFIDENTIALITY

The duty of confidentiality is the duty to maintain privacy of information concerning patients by not divulging it to unauthorized persons. In principle, the scope of the duty is broad and includes all information about patients obtained during professional interactions with them. In practice, this consists of any intimate and potentially sensitive information, including that concerning the immediate care provided, additional health-related information, financial information, and other potentially sensitive information.

During the past decade, the most frequently discussed example of confidentiality in health-care ethics has concerned patients with HIV/AIDS. Swisher and Krueger-Brophy offer the following illustration.

### CASE 3.9 An Inadvertent Disclosure

Larry Dulles is a 26-year-old man being treated in physical therapy for generalized weakness and neurological problems associated with acquired immunodeficiency syndrome (AIDS). One day his mother took him to therapy. After his treatment session, she remarked to his therapist that he did not seem to be improving. The therapist said, “Well, we don’t always see dramatic changes with AIDS patients.” Larry’s mother was previously unaware of his diagnosis.[27]

The therapist’s error was a casual lapse in judgment and probably well-intended, as the therapist was responding to the mother as a key family member whose involvement was both appropriate and valuable in contributing to the care of Mr. Dulles. Nevertheless, regardless of how understandable or well-intended, the therapist’s error constituted a serious violation of confidentiality.

How serious is it? Swisher and Krueger-Brophy point out that in some states the lapse would violate the laws protecting patient confidentiality and in addition violate laws specifically passed to protect HIV information. In addition, both the therapist and his or her organization would be open to major civil lawsuits for invading privacy and causing emotional distress. The therapist’s license could be at risk as well.

Suppose the therapist had inadvertently disclosed the information to Larry Dulles’s wife or life partner? Suppose the therapist happened to learn from Mr. Dulles that he engaged in unprotected sex with several partners? Confidentiality does have justifiable exceptions. Most of them are specified in the law. In particular, health-care professionals must report child abuse, elder abuse, gunshot wounds, and some contagious diseases.

Confidentiality may be compromised legally when medical records are ordered by the courts in criminal investigations. But are there justifiable exceptions beyond what the law requires or permits? Which exceptions ought to be established by law? Answers to these two questions have always been controversial. Extreme and even unforeseeable situations can arise that make it difficult to apply moral principles. In our view, the exceptions should be few, and confidentiality needs increasing safeguards.

To begin with, there is wide consensus that the duty of confidentiality is extremely important for at least four reasons.

First, control over sensitive information is required by the principle of respect for autonomy. Maintaining control over sensitive information—"sensitive" as defined subjectively by each individual and objectively in terms of risk of harm—is part of controlling people's lives. The example of Larry Dulles illustrates how one fact can influence someone's entire self-image and the image that others have of that person.

Second, professionals create a shared understanding with the public that they will take special care in maintaining confidential information. They do so, as a group, by promising the public (through their codes of ethics and other official documents) to maintain confidentiality. Like all promises, this commitment generates an obligation.

Third, in light of this shared understanding, a relationship of trust is created with each patient. Violating this fiduciary relationship is a breach of trust.

Fourth, and underlying all the previous reasons, confidentiality promotes health care (and other professional services). One reason why the fiduciary relationship is created in the first place is to ensure that patients will feel free to divulge sensitive information to health-care professionals in order to receive the health care they need. Many patients already have a general reluctance to discuss intimate details about their bodies and lives. They must be encouraged to maintain frank and honest dialogue throughout the therapeutic process in which that information is relevant to the diagnosis or treatment at hand.

## PROTECTING CONFIDENTIALITY

Despite the philosophical need for strict confidentiality, a hierarchy of legal entitlements to types of information does exist among health-care providers, based on the "need to know." Psychiatry and psychology have the greatest legal protection for the most intimate information about a person, because it is this type of information that is most important for successful diagnosis and treatment in these professions. Physical therapists, in contrast, have very limited legal entitlement to protect personal information in a court of law, aside from medical and physiological information. This is because information about a patient's personal life is usually not an essential element for creating a treatment plan and intervention. Physical therapists should restrict their inquiries into the personal lives of their patients to the information relevant to their care. They should also avoid leading patients to believe that their deepest secrets are legally protected in a court of law, unlike the situation of psychological therapists.

Confidentiality is increasingly at risk in health-care settings. During a hospital stay, a patient might assume only a physician and few other health professionals have access to confidential medical information, but in fact possibly a hundred individuals, including financial workers, have access.[28] Greater concerns have arisen concerning computer data banks that contain medical information—leading to both unauthorized uses and authorized abuses.[29] On the one hand, alarming examples of unauthorized use of medical information have been widely publicized. For example, some government employees in Maryland sold confidential medical information from the state data bank used for cost-containment purposes. The information was purchased by health maintenance organizations (HMOs) and later accessed and used by a banker to call in loans on cancer patients.[30] In one case, an HMO discovered that more than 100 employees had accessed the medical records of the famous figure skater Tonya Harding after her visit for a sprained wrist. Most of these employees had no involvement in the case. More recently, 127 employees of UCLA inappropriately accessed files of celebrity patients including Maria Shriver, Farrah Fawcett, and Britney Spears, among others, between January 2004 and June 2006.[31] One employee, with no legitimate reason, looked up the medical records of 939 patients. The breach came to light only after Ms. Fawcett complained to her physician that news of her reccurring cancer appeared in the paper before she had a chance to tell her son or other close relatives or friends.

On the other hand, authorized abuses are institutionalized and legally permissible arrangements that channel information acquired in health-care settings to non–health-care parties, such as employers and businesses marketing products. Employers motivated to reduce health-care costs for themselves and their employees, or simply to ensure a healthy workforce, often use such information in making hiring and firing decisions, unless laws specifically prohibit doing so. Pharmaceutical and health-care-equipment manufacturers use the information to target audiences in selling their products. Recently, the popular press has been releasing investigative reports alerting the public to current databases that include medical histories and future possible links through the Internet that threaten to destroy privacy.[32]

A. Etzioni calls upon health-care professionals to reshape their institutions with an eye to counterbalancing corporate abuses to ensure that sensitive information is used to provide cost-efficient health care to patients. In tune with Siegler's emphasis on "need to know" access, Etzioni distinguishes three groups: the inner circle directly involved in providing health care, the intermediate circle of health insurance and managed-care corporations, and the outer circle of employers, marketers, and insurers. The primary goal should be to prevent the outer circle from gaining sensitive information that the inner and intermediate circles must have to provide good health care. This can be accomplished by establishing "layered records and graduated release" of information to appropriate groups. In some countries, such as France, genetic information is considered so confidential that it is maintained in a separate chart and is strictly maintained by the primary-care physician.

The concerns of Etzioni and other critics led in 2003 to strengthened Health and Insurance Portability and Accountability Act regulations, requiring fuller notification to patients of their privacy rights. Among other things, it ensured patients the legal right to examine their medical records, forbid disclosure of medical records to employers without a patient's consent, and limited access of health professionals to need-to-know information about patients. Strong penalties were attached to health professionals' violations of the guidelines. Perhaps some of the strongest penalties come from accrediting agencies, such as the Joint Commission on Hospital Accreditation and the Commission on Accreditation of Rehabilitation Facilities. Licensure boards also can impose harsh penalties on providers who violate confidentiality, which in turn may make them ineligible for some types of reimbursement, such as Medicare.

To conclude, we began this chapter with the idea that respect for autonomy has replaced medical paternalism as a dominant theme in medical ethics, especially concerning the control of information. The traditional case for medical paternalism was an appeal to beneficence or benevolence. Properly conceived, however, respect for autonomy and beneficence are not inherently opposed. As Edmund D. Pellegrino and David C. Thomasma suggest, "Paternalism, whether benignly intended or not, cannot be beneficent in any true sense of that word. Beneficence and its corollary, nonmaleficence, require acting to advance the patient's interests, or at least not harming them. It is difficult to see how violating the patient's own perception of his [or her] welfare can be a beneficent act. Paternalism is obviously in a polar relationship with autonomy, but it is diametrically opposed to beneficence and nonmaleficence as well."[33]

## DISCUSSION QUESTIONS

1. Regarding Case 3.6, present and defend your view about whether the best interest standard was properly applied. Are there other ways the same objectives could be achieved? Carried to its logical conclusion, how might other, similar patient problems be addressed? More information about the case is available by searching "The Ashley Treatment" or http://ashleytreatment.spaces.live.com

2. Social isolation is an especially important concern in a democracy which is built on assumptions of social relationships that bind communities together. McPherson et al.[18] noted that one of the more concerning trends, aside from the 150% increase over two decades of those with no one in whom they could confide, was the trend for those who did have confidants to only confide in kin. In a democracy, that is problematic because kin tend to be more homogenous than the population in a community, thus not exposing people to varied perspectives and interests. They note two correlations of concern. Both cooperation and years of education are positively correlated with increasing numbers of confidants. How does this fit, if at all, with an increasing importance of the concept of autonomy understood as self-governance? What inferences can you draw?

3. Muriel Thomas is a 76-year-old widow who, as a consequence of a fall, had a hip replacement. Her only living relative is a son, who shows little interest in her. Almost everyone in the rehabilitation unit recognizes that most of Muriel's complaints are not related to the replacement but instead are thinly veiled attempts to get attention. She complains of various pains that change location and have no obvious connection to her injury, surgery, or therapy. Her functional status with a walker is nearly where it was prior to the accident. Although the physician and the therapist agree that therapy goals have almost been achieved and should be discontinued in a week or so, the physician asks the therapist to make up some kind of treatment to appease her complaints. The physician states that the attention will probably make the pains go away, at least until she is discharged. The physician also states that she will enter a diagnosis that will allow insurance to cover the therapist so that no revenue will be lost to the department. The therapist complied and started administering low levels of ultrasound to Muriel's forearm, the site of her most recent "pain." Much to the therapist's surprise, Muriel asked her directly how this therapy was supposed to help. What are the moral issues in this case, and how do you think they should have been handled?

4. Review the sections on confidentiality, truthfulness, and respect for patient autonomy in the APTA Code of Ethics. What does the code require concerning Cases 3.1, 3.2, 3.3, and 3.4? Does the code provide adequate guidance in these areas?

5. Paternalism (or "parentalism") is now widely suspect, both because of past abuses and because of the contemporary emphasis on respect for patient autonomy. Yet Gerald Dworkin argues that, ironically, some paternalism can be justified by appealing to respect of autonomy.[34] According to Dworkin, autonomy is reduced when

persons become seriously ill, and it is ended when they die. Conversely, individuals' autonomy is broadened and protected by many laws that interfere with individuals' liberty for their own good, especially by encouraging them to be more prudent in basic matters of health and safety. Examples of such laws include:

- Requiring motorcyclists to wear safety helmets;
- Requiring drivers to wear seat belts;
- Forbidding swimming at beaches when no lifeguard is on duty;
- Prohibiting use of such dangerous drugs as heroin and cocaine;
- Compelling participation in social security or other retirement plans;
- Putting fluoride in public drinking water;
- Requiring professionals (such as physical therapists) to be licensed.

Dworkin adds that the burden of proof should be on the government to justify each of these interferences with liberty and that the restrictions should be minimally restrictive. Do you agree or disagree with him, both about these examples and about his appeal to respect for autonomy as a justification for them? Would you favor further laws, such as those banning advertising of cigarettes, alcohol, and firearms?

**6.** In an article published by Clare M. Delany in the *Australian Journal of Physiotherapy* (2007, vol 53) entitled "In Private Practice, Informed Consent is Interpreted as Providing Explanations Rather Than Offering Choices: A Qualitative Study," the author reports the finding that "If the therapeutic goals of treatment were to be achieved, then the idea of patients choosing other than the therapist-recommended course of action was counter-intuitive to therapists, given their perception of their role as a professional." In your experience thus far, have you witnessed this? Would you classify it as paternalism? How could you improve the informational component of informed consent?

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Chapter

4

# Scientific Integrity and Experimentation

*Physical therapists shall enhance their expertise through the lifelong acquisition and refinement of knowledge, skills, abilities, and professional behaviors.*

Principle 6, APTA Code of Ethics

## CASE 4.1 Massaging the Data

For years, Scott Conway has resented teaching at a less prestigious school, and he also feels overdue for a promotion to full professor. To improve his chances for both a promotion and a teaching position at a more prominent university, he insists on being the first author listed in articles he develops with the graduate students he supervises. His curriculum vitae, which no one at his school has checked closely, contains misleading entries designed to make his contributions to several research projects appear significantly greater than they were, although he has never engaged in outright fabrication. The former chair of his department characterized his résumé as a fine example of "ultimate spin," making the trivial seem grand.

Currently, Conway is desperate to renew a substantial grant from a school district for research he hopes will show that participation in a school band is equivalent in exercise value to that provided by the state-mandated physical education program. This particular school district has an exceptional football team and is intent on promoting the athletic program in every possible way, including its half-time entertainment. To do this, the district wants to use Conway's research to exempt band members from state-mandated physical education units. Conway is confident the project has promise, but the results have been inconclusive so far, and he doubts that the school district will continue to fund his research unless significant results are likely. He knows there is a way to massage the data by highlighting the promising results and not reporting some conflicting data. He also knows it is unlikely that anyone will be caught. Convinced he is doing no serious harm to anyone, he quickly makes the changes and mails the grant proposal.[1]

## EVIDENCE-BASED THERAPY

The validity and usefulness of scientific studies depend on whether researchers proceed with scientific integrity. As the APTA document "Integrity in Physical Therapy Research" states, "A concern for integrity in research follows quite naturally from the dual commitment to research and professional ethics."[2] In everyday life, moral integrity (*integritas* means "wholeness" in Latin) is a complex virtue that implies respect for others, honesty, fairness, decency, and moral consistency.

In science, moral integrity implies scientific integrity, a virtue that combines and extends several key values:

1. Respect for autonomy, shown by securing informed consent from persons who participate in research projects;
2. Justice, shown by a concern about who benefits from scientific experimentation;
3. Humaneness, shown by acting with beneficence toward both humans and (research) animals; and
4. Honesty, shown by, for example, providing full disclosure of research findings as well as giving proper credit to authors of publications.

In Chapter 9 we discuss fraud—which is what Scott Conway engaged in—but the ethics of research involves many additional facets, a sampling of which we explore in this chapter.

By their very nature, the sciences seek new knowledge that can be validated objectively, and nowhere is that more important than in the health sciences.[3,4] Beliefs based on clinical experience alone, passed from generation to generation without question, will not suffice. Scientific validation of treatment techniques is increasingly required for reimbursement by government and health-care facilities,[4] but more than money is at stake.

In the past, the charge was made that much physical therapy practice was inadequately supported by objective research.[5,6] But this situation has been changing, and for good reason. First, respect for patients requires that physical therapists be able to discuss with them the likelihood of success of a particular intervention, and that information can only come from outcomes research. Patients cannot make informed decisions without relevant information.

Second, what is right for the patient in physical therapy care should be determined by professionals working with patients, not by the third-party payer. Yet, as long as practitioners say they do not know if an intervention is likely to work, the payer will make decisions about health care, and there will be little hope of a successful challenge by the professional or the patient.

Third, and most important, the worthiness of physical therapy as a profession depends on its ability to support its claims scientifically that it promotes better health, avoids harm, and is worthy of the public's investment of money, time, trust, and emotional energy. In the words of one of the editors of the journal *Physical Therapy*, "Scientifically collected data allow us to look beyond our biases at the reality of our patients, their lives, and their resources and at how they benefit from our interventions. These data allow us to lay claim to treatments that work, to shed those that do not work, and to modify those that need improvement."[7] Conversely, failure to provide evidence of efficacy in physical therapy invites other professions to develop alternative approaches to problems. If these professions can provide evidence of effectiveness and efficiency, they will likely become the providers of choice. "The cost and effect on all of us will be enormous."[8]

## EXPLOITING THE VULNERABLE

Scientific experimentation is essential in extending human knowledge. It also has an alarming history of abuse. We begin by highlighting a few episodes from that history to show why increasingly strict regulation of research has become necessary.

In the early 18th century, when immunizations were being developed, it was common for physician-researchers to use their own children, servants, and slaves as subjects.[9] Smallpox vaccination was just one of the immunizations initially tested on children. By the late 19th century, medical journals carried reports of experiments with gonorrheal cultures as applied to the eyes of children to document the progression of the disease. In 1914 Alfred Hess, who was medical director at the Hebrew Infant Asylum in New York City, said that institutionalized children offered those conducting experiments the distinct advantage of living in "conditions which are insisted on in considering the course of experimental infection among laboratory animals, but which can rarely be controlled in a study of infection in man."[9(p6)]

In Nazi Germany, human experimentation reached a previously unimagined level of horror. Jews, homosexuals, gypsies, and other oppressed minorities were used freely by the medical schools in Germany for experimentation. Additional atrocities were committed by physicians in the service of the German state in hopes of acquiring university appointments through their scientific publications.[10] Experiments included the "high-altitude experiments," in which prisoners were locked in airtight compartments and exposed to rapid pressure changes that caused tremendous pain, with death occurring during dissection of the living "subject." In the "freezing experiments," prisoners were left in the cold with no clothing between 9 and 14 hours as measurements were taken to record each phase of death. The numerous failed experiments to change homosexuality included castration and the surgical insertion of hormone briquettes, which resulted in horrible deaths.[11,12]

Although the Nazi atrocities are unparalleled in their viciousness, barbaric experiments were not limited to wartime. Deeply disturbing experiments took place in the United States during peacetime, even after dissemination of numerous international treaties on research ethics. The Tuskegee and Willowbrook experiments are among the most infamous.[13]

The Tuskegee Syphilis Study, a longitudinal study conducted by the U.S. Department of Public Health between 1932 and 1969, followed 400 black men infected with syphilis to confirm existing research on the long-term effects of untreated syphilis. Those effects included blindness and death for at least 40 of the participants. Long after penicillin was discovered to be an effective treatment for syphilis (in the 1940s), the men were given only aspirin or other ineffective treatments. They were also promised a $50 bonus for funeral expenses if they lived 25 years and agreed to an autopsy at time of death.

Major breaches of medical ethics in this study included the following[14]:

1. The experiment was redundant and scientifically pointless.
2. The research design was so flawed that meaningful results could not have been detected.
3. The participants were deceived and coerced.
4. A socially deprived and financially vulnerable population was exploited.
5. Participants were knowingly allowed to die even though life-saving treatment was available.
6. The participants were not compensated for injuries.

Almost 25 years after the initiation of the Tuskegee studies, Saul Krugman and Joan P. Giles, through the New York University School of Medicine, began the Willowbrook experiments. This research, like the Tuskegee Syphilis Study, was designed to follow the natural progression of a disease—in this case, viral hepatitis. It was also designed to test the effectiveness of a known treatment, gamma globulin. Gamma globulin was already known to be effective in treating viral hepatitis, yet it was withheld from half of the experimental group so that the natural progression of the disease could be observed. The research was conducted on mentally disabled children residing at the Willowbrook School on Staten Island, New York. The children were intentionally infected with the virus and then studied during the progression of the disease.

A particularly disturbing aspect of the Willowbrook research was that it was reviewed and approved by the New York State Department of Mental Hygiene, the New York State Department of Mental Health, the Armed Forces Epidemiological Board, and the New York University School of Medicine, in addition to the Willowbrook School. Although parental consent was given for each child, the consent was based on the school's declaration that there was room for new students at the school only in the experimental unit. Initially the study was even supported by the *Journal of the American Medical Association,* but it was judged indefensible by the *British Journal of Hospital Medicine*. At the core of the objections was the principle that children should not be used in research unless the children themselves stand to gain by the research, a concept enforced in British law at the time.

Serious attempts to protect participants in research began after World War II, on December 9, 1946, at the Palace of Justice in Nuremberg.[15] There, 23 physicians were tried for war crimes and crimes against humanity. The judges relied on 10 rules for ethical experimentation on humans, which became known as the Nuremberg Code, a document that has exerted unparalleled influence in the scientific community. In March 1960, Henry K. Beecher recommended a general code be developed to guide physicians, comparable to the Nuremberg Code. The World Medical Association's Committee on Medical Ethics had developed a document that was ratified at the 18th World Medical Assembly in Helsinki in 1964. This Declaration of Helsinki was revised in 1975, 1983, and, most recently, in 2008.

Additional guidelines were developed by professional groups, including the American Medical Association and the American Academy of Pediatrics. On May 30, 1974, the U.S. Department of Health, Education, and Welfare, now known as the U.S. Department of Health and Human Services, published guidelines for adults, and a 1977 appendix addressed the unique problems regarding children. Over the years, many revisions and competing models were offered, and in 1991 the "Federal Policy for the Protection of Human Subjects" was published and endorsed by government departments and agencies.[16]

These guidelines are quite specific and mandate an internal review board (IRB) located at every institution that engages in human research and receives federal funds.[17] The IRB must have at least five members, including one who represents nonscientific interests, such as an ethicist, attorney, or member of the clergy.[18] The U.S. Department of Health and Human Services further stipulates that one of these members must have no affiliation with the institution, directly or indirectly through marriage or other relationships. In addition, no IRB can have members of only one gender or all from one profession.[19] Typically, the IRB reviews each full research proposal before the project begins. Depending on the risk level of the project, the IRB will characterize it as:

1. Exempt from review,
2. For expedited review, or
3. For full review.

Projects typically exempt from review include surveys that are anonymous and do not deal with sensitive topics. Expedited reviews—projects reviewed by the chairperson of the IRB and at least one other member of the IRB—may be granted to research in the clinic setting that is noninvasive and to studies of normally occurring events. Full review covers all other experiments and especially those using invasive procedures.

## RECENT CONCERNS

The research arena is not free of ethical problems. Recently it was reported that physicians, psychologists, and other health officials helped design torture tactics, such as waterboarding and extreme sleep deprivation, and applied them to suspected terrorist prisoners.[20] And in cases discussed below, such as the Vioxx scandal, violations of research integrity have been costly in human lives and suffering. Such actions are infrequent violations of standards of professionalism, but some systematic problems are also of concern. They include conflicts of interests (also addressed in Chapter 8), lax oversight of research, and publication biases.

### Conflicts of Interest

Pharmaceutical companies are major funders of research, both at the institutional level and directly to individual researchers. These companies sometimes construct or help construct laboratories at educational institutions, with the expectation that their lines of research will be given priority. But direct relationships between funders and researchers are of greater concern. "Researchers serve as consultants to companies whose products they are studying, join advisory boards and speakers' bureaus, enter into patent and royalty arrangements, agree to be the listed authors on articles ghostwritten by interested companies, promote drugs and devices at company-sponsored symposiums, and allow themselves to be plied with expensive gifts and trips to luxurious settings. Many also have equity interest in the companies."[21] These relationships call into question the researchers' objectivity in what they report and what they do not report. In summary, "there is now considerable evidence that researchers with ties to drug companies are indeed more likely to report results that are favorable to the products of those companies than researchers without such ties."[21]

A dramatic illustration is the Vioxx scandal involving the pharmaceutical giant Merck & Company. Among other things, Merck created the false impression that Vioxx was safe and well tolerated, even though in its own human clinical trials it had recorded significant increases in deaths compared with the control group. Merck dismissed claims of harm, citing good performance of the drug in its animal model, the African green monkeys. Data that clearly identified an increased risk in humans was known to Merck 2 years before releasing the data to the United States Food and Drug Administration (FDA). Merck failed to notify a local IRB that oversaw a parallel clinical trial on Vioxx about the increased risk. When the FDA questioned whether the IRB had been warned, Merck representatives replied that they did not believe there was a substantial risk and therefore saw no reason to inform the IRB. The parallel study ran 2 years longer, and the Vioxx group suffered eight unnecessary deaths. In one report, where 8 of the 11 authors were employees of Merck, the company assured the readers that the drug was "generally well tolerated," but the data did not support that statement.[22]

After the courts assembled over 54 million documents and lawyers took over 2000 depositions, the approximately 47,000 people who claimed Vioxx caused their heart attack or stroke settled for 4.85 billion dollars in the United States alone.[23,24] In response, effective October 1, 2007, the FDA Amendment Act required trial findings, phase 2 to 4, be posted in a publicly available database. The *Journal of the American Medical Association* now requires that data analysis for all randomized trails be conducted by an academic statistician.[22]

Many studies are done with the intent to bring a drug, product, or service to the FDA for approval for marketing and distribution in the United States. The FDA requires researchers to reveal their stock holdings and options as well as grants and other forms of income that could bias their evaluation of the data. Often it is not clear how to assess the magnitude of such biases. Even if possible, this assessment is always done retrospectively, after the studies have been completed. It is not the job of the FDA, nor was it ever envisioned to be, to oversee research projects in process. In fact, the FDA claims that it does not have the responsibility to make available to the public studies demonstrating adverse effects.

In the approval process for the antipsychotic drug Seroquel by AstraZeneca International, the company made the FDA aware of Study 15 that AstraZeneca never published. Study 15 raised serious concerns about weight gains and related problems. The company presented different data at two conferences, claiming Seroquel helped patients lose weight. Thus far, more than 9210 lawsuits have emerged for damages from metabolic problems secondary to the drug.[25]AstraZeneca made news again when investigators discovered that it paid Dr. H. Bryan Brewer, chief of the National Heart, Lung, and Blood Institute's molecular disease branch of the NIH, $31,000 to serve on its advisory board. During this time the company was introducing Crestor (a drug to reduce cholesterol) to the U.S. market. Dr. Brewer assured physicians that there were no reasons to worry about a muscle-wasting side effect that can cause kidney failure and death. But, in fact, eight cases had been reported during clinical trials, and in the first year on the market the FDA received 78 reports of the wasting side effect and two deaths.[26]

The incident with Dr. Brewer was not a rare occurrence. In 2004, more than 530 scientists employed by NIH with taxpayer funds received fees and stock (or stock options) from the very companies whose products they were trusted to evaluate impartially.[26] The director of NIH, Dr. E. A. Zerhouni, originally defended the practice if it involved giving advice in their area and stated that it was a part of their duties. The U.S. Office of Government Ethics declared that NIH had a "permissive culture" after finding that 40% of payments to NIH scientists (randomly sampled) had not been approved or accounted for. Nearly 200 NIH researchers signed a letter to Dr. Zerhouni stating that a ban on paid consulting would make them "second-class citizens in the biomedical community," even though their salaries ranged from $130,000 to $200,000 yearly. Change started to occur when it was revealed that NIH employee Dr. P. Trey Sunderland III had received $508,050 in unreported income from Pfizer Inc., and the NIH's top blood transfusion expert, Dr. Harvey G. Klein, had received $240,200 and 76,000 stock options from companies developing products that were blood-related.[26(pA29)] In an agreement with the Office of Government Ethics and the Department of Health and Human Services, Dr. Zerhouni announced that NIH employees could no longer accept fees from drug companies, moonlight for research institutions receiving NIH funding, or hold investments in biomedical companies.[27]

Academic centers in the United States receive annual allotments of nearly $30 billion to conduct federal-grant research.[28] The relationship between NIH and Academic centers has recently been questioned. Because of public charges of repressing research findings, which could challenge grant funding by research institutions, NIH is considering new ethics regulations. Congressional findings reveal major ethical lapses among faculty at prominent institutions such as Harvard and Emory universities. In a study published in 2008, researchers found that of more than 2300 instances of misconduct observed each year in academic settings, only 24 were reported to the government's Office of Research Integrity, itself a violation of ethical requirements.[29] Even when wrongdoing is reported within university settings, the internal review process can fall far short of what one would expect.[30]

## Lax Oversight

The job of prospective approval of research projects and oversight falls to local IRBs that operate under general guidelines published by the FDA. In the university setting, depending on the size and research focus, these boards might be populated by volunteer faculty on an ad hoc basis or by a dedicated staff and faculty on a full-time basis. Because IRBs are not linked except through general guidelines, there is great variability between IRBs in the interpretation of guidelines.[31] It has also been reported that IRBs often do not oversee vital components of the research endeavors, such as subject recruitment, because they perceive such oversight to be beyond the limits of their authority. In addition, at some institutions the sheer volume of projects can overwhelm a board to the point where oversight is considered unrealistic. Other boards have reported conflicts of interest of members.[32,33] Donna Shalala elaborated on additional issues related to patient safety by acknowledging that researchers do not report adverse responses, following the protocol approved by IRBs, and they do not adequately train support staff and researchers for projects.[33]

Partially in response to pressures on researchers and inadequate oversight, the Office of the Inspector General published a statement addressing three major concerns regarding recruiting human subjects.

1. Informed consent. Information is not being presented in such a way that subjects truly understand to what they are consenting.
2. Patient confidentiality. Recruitment of subjects is occurring through electronic medical records for which there may not be consent.
3. Patient safety. Recruitment and retention includes subjects who may not truly qualify for the interventions, putting both the patient and the data at risk.[32]

## Publication Bias

The ultimate goal for outcomes research projects is twofold: the introduction of products or services to the public and publication of evidence of efficacy. As we discuss later, publications are a primary way in which faculty are evaluated for productivity. Medical journals have great influence. The standards they enforce shape the original research design. Yank discovered that prior to 1997, approximately 30% of medical journals reporting clinical trials provided neither informed consent nor IRB approval of the projects.[34] A comparison study of instructions to authors between 1995 and 2005 showed increases in requiring IRB approval (from 42% to 76%); reporting conflicts of interest (from 75% to 94%), and stating criteria for authorship (from 40% to 72%).[35] For physical therapy specifically, Henley and Frank reported that of 806 articles published between 1996 and 2001 in physical therapy journals, only 48% documented both IRB approvals and informed consent. As a consequence, they recommended making standardized ethical protections and documentation a prerequisite for publication.[36]

One of the more difficult and potentially damaging biases is the failure of researchers to submit articles on interventions that are not successful and for publications failing to publish these findings when submitted.[37,38] Health-care professionals, funders for health care, and the general public have as much to gain from knowing what does not work as they do for interventions that do work. Researchers might avoid costly repetitive studies had they known of efforts that failed, thus freeing money and time to pursue other venues and ideas. But as Maher et al. reported in *Physical Therapy*, negative results are less likely to get published, and if published they are subjected to greater delays and resubmissions before publication. The authors point out that this leads to unrealistic expectations for research in general. There may be a cultural bias at play in that the percentage of publications with statistically significant findings varies by the country or the nationality of the researchers.[39]

## RESPECT FOR AUTONOMY

Respect for autonomy is the heart of scientific integrity in research on humans. Each major ethical theory (discussed in Chapter 12) affirms respect for autonomy as an important value, whether the theory appeals to human rights to exercise autonomy (rights ethics), the good consequences of allowing people to exercise autonomy (utilitarianism), or basic duties to respect persons (duty ethics). Unquestionably, the greatest emphasis on respect for autonomy was articulated by Immanuel Kant: treat persons as autonomous rational beings who have their own purposes and never as mere means to reaching your own purposes. The "mere" here is important. In one sense, people constantly use each other in order to gain benefits. This reciprocity is essential to our lives as social creatures. Kant's point is that people must not treat each other as if people were the only available instrument—as if they were things whose value consists solely in what can be obtained from them. All persons have an inherent moral dignity rooted in their capacity (or potential) to govern their own lives. To ignore, undermine, or assault that autonomy is to degrade persons.

In one sense, to experiment on humans is to make them objects—namely, objects of scientific study—even though they are usually called "experimental subjects." The danger comes when researchers shift to a view of persons as mere objects—as mere means to achieving the aims of an experiment. Making that shift is a constant danger, because the goals of research are to maximize good consequences by discovering new knowledge, not to promote the welfare of individual participants. Respect for autonomy means that these benefits to others must never be won by sacrificing the autonomy of individuals who participate in experiments.

As noted in Chapter 3, respect for autonomy requires obtaining the voluntary informed consent of competent persons **(Table 4–1)**. Following is a review of three (overlapping) types of consent—voluntary, informed, and competent—as they apply to research.

### Voluntary Consent

Respect for autonomy means acknowledging that participation in research must be voluntary. Mere assent, whether verbal or behavioral, is not necessarily voluntary consent. For example, handing over money in response to the threat, "Your money or your life," is hardly a fully voluntary act. Voluntary means there is no coercion in the form of threats, physical force, or other objectionable pressures. This includes subtle pressures that come in the form of undue influence—that is, offering positive benefits rather than threatening harm.

Research subjects may be reimbursed for their expenses while participating, including travel and lost wages, and also given minor tokens of appreciation. But the enticements must not be substantial or "irresistible." Also, assembling prospective participants in a group to request their participation and to inform them of their rights might allow peer pressure to shadow their judgments. In cases where the researcher and care provider are one and the same, every effort must be made to separate the therapist-patient relationship from the researcher-subject relationship, including having someone else request patient participation in research. This is important because patients often feel a sense of dependency on their physical therapists, and they might believe that to preserve that relationship they must agree to the therapist's suggestion to participate in the research.

### Informed Consent

Two bodies of information are essential for patients to give their informed consent. First, for participants to exercise their rights, they must know what those right are, and participants must also be made aware of their right to give informed consent or to refuse. They must further be made explicitly aware of their right to withdraw from the research at any time without suffering negative consequences, their right to confidentiality, and additional rights formalized in a patient's "bill of rights."

Second, participants must know exactly what they are agreeing to do in the particular experiment. Lying to participants, providing them with false data, and withholding needed information are morally equivalent in this context. Most important, individuals must be provided with a detailed account of the risks—or potential harms greater than those experienced in daily life—involved in the study. Five basic

**TABLE 4–1. A Sample Informed Consent Document**

| SUBJECT | COMMENTS |
|---|---|
| Title of study | Provide a brief and accurate indication of the study. |
| Location | Include the complete mailing address. |
| Investigators | List all members of the research team, including faculty sponsor. |
| Purpose of study | Clearly and briefly state the intent of the study. |
| Participant selection | State how prospective participants were selected for the study (without this indication people are frequently unwilling to participate). |
| Institutional review board disposition | Obtain the (mandatory) approval for the study from the IRB of all participating universities. |
| Methods | State the methods in detail. |
| Risks | Make explicit all social, legal, psychological, and economic risk; the reasonableness standard compares the risk of research participation with the normal risk of daily living without participation in the study; if the research risks are greater, they must be expressed. |
| Benefits | Name the specific benefits for the subjects, such as frequent medical examinations; if there are no benefits, state that no benefits are anticipated. |
| Confidentiality | State specifically how confidentiality will be protected, noting that the designates of the FDA and the Department of Health and Human Services may inspect the records; note that if the study plan is changed or the information is to be used in ways not explained to the subject, the subject will be informed, and a separate consent will be required. |
| Financial concerns | State financial concerns directly affecting the participants and disclose funding for the research project. |
| Questions | Tell the research subjects how they can have their questions answered, including their rights or consent, by phone or in person. |
| Injury | In case of injury, tell the subjects what they should do and who will pay for the treatment or diagnosis. |
| Withdrawal and discontinuation of study | Subjects must be assured they can withdraw from the study at any time with no negative consequences to them. |
| Study design changes | State that a new consent from participants will be requested in the event that, during or after the study is completed, there is a design change that will result in the information being used in a new or different manner. |
| Concluding statement | Briefly review the intent of the study. |
| Signatures | Obtain signatures on the consent document, not on a separate sheet. |

types of risk are possible and, if foreseeable, should be assessed and expressed **(Box 4.1)**.[40]

Risk assessment is an ongoing part of research, and new risks discovered in the course of experiments must be revealed to the participants immediately. Consent is not a one-time event; it is ongoing throughout the entire research endeavor. If physical risks are involved, available medical care must be documented in the consent form.

The language of consent documents needs to be at the level of comprehension of the target population. If technical words, such as goniometer and isokinetic, are used, their meaning must be explained. In addition, it is essential that prospective participants have a way to speak personally with the researcher or someone informed about the research. Wanting to preserve the appearance of being knowledgeable, many people will be reluctant to ask

**BOX 4.1 Types of Risks**

| Type of Risk | Examples |
|---|---|
| 1. Physical | Muscle soreness, adverse reaction to drugs |
| 2. Psychological | Depression, confusion |
| 3. Social | Loss of privacy |
| 4. Legal | Revocation of the parole, prosecution |
| 5. Economic | Loss of employment |

questions unless it can be done privately. To assure voluntariness and understanding, persons must be allowed time to weigh and consider the choices and risk inherent in participation in research.

## Competent to Consent

So far we have assumed that the persons asked to participate in research are competent to make autonomous decisions. Voluntary informed consent implies this competence, but we will provide a separate discussion of it.

When the sample of participants is drawn from the general population, competence is rarely a critical issue. Typically, persons are considered competent if they can demonstrate that they understand the research methods, have weighed the benefits and risks, and can express a decision. However, the burden of proof of competency increases proportionally to the risks involved. When risk is low, as in measuring the active range of motion at the knee, then a simple assessment of the participant's understanding of the methods, combined with an explicit decision upon considering the risks and benefits, is sufficient. When the risks are severe, and the population studied is at risk for incompetence, it may be appropriate to have a psychiatrist or psychologist render a judgment using objective measurement tools. Between these extremes are other special circumstances warranting attention.

Competence is on a wide continuum and should be assessed in the specific context of the research with respect to each individual. Just because persons are substantively incompetent in one area does not mean they are incompetent in another area, such as making a decision to participate in a research project. Moreover, it is not uncommon to witness intermittent competence. That occurs, for example, when a patient or someone with whom that person has a significant relationship is given diagnostic information that either overwhelms or causes grief. For a brief period, that patient may be incompetent to make a decision.

Some research topics, such as Alzheimer's disease, require populations in which incompetence is a common occurrence. Obviously, valid research for such populations must involve its members, even though autonomous consent is not possible. If the experimental subjects are in an institutional setting, the institution's IRB will assess a request to use the patients in research. The institution must also acquire the consent of the family member or guardian who acts as the patient's surrogate decision maker. In noninstitutional settings, such as home care, courts typically appoint a legal guardian authorized to make such decisions for the patient. Even then, the World Medical Association Declaration of Helsinki, revised October 2008, states that, "When a potential research subject who is deemed incompetent is able to give assent to decisions about participation in research, the physician must seek that assent in addition to the consent of the legally authorized representative. The potential subject's dissent should be respected."[37]

Depending on the state, surrogate decisions will be made using either a "substituted judgment standard" or a "best-interest standard."[41] According to the substituted judgment standard, someone appointed by the court—typically someone who knew the patient well when the person was competent—is instructed to make a decision as the patient would have made if still competent. In contrast, according to the best-interest standard, the surrogate decision maker must weigh all possibilities and decide on a course of action that would give the highest benefit to the incompetent person. Former preferences of the patient may be considered as quality of life issues are interpreted, but the judgment is based on what will best serve the patient now.

Children are another special population legally defined as not competent. The states define legal competency by age, regardless of individual exceptions to the rule. Nevertheless, even with some legal exceptions, such as the emancipated minor who is awarded a decision-making right by the court, even a mature 14-year-old will need a parent's or guardian's consent to participate in a research project. If the risk of the research is minimal, usually only one parent's signature is necessary, but if moderate to great risk is involved, both parents must consent. (Exceptions occur when one parent has been given sole legal guardianship rights or when one parent is absent from the home and unavailable.)

When children are wards of the state—for example, abused and abandoned children living in shelters—then the relevant agency must provide institutional consent. Also, since 1983 the U.S. Department of Health and Human Services has recommended that children give assent in addition to the parent's consent. The form and content of assent are determined by IRBs and take into account the developmental level of children and their ability to understand. At the very least, the assent should be based on a simple description of the study and the procedures that will occur, together with some explanation of the risks involved and assurances of confidentiality. If the child refuses permission, the refusal must be honored. The one exception is when the parent overrides the child specifically because the child will personally profit from the research in ways greater than the risk or inconvenience.

## WHO BENEFITS?

Voluntary informed consent is the most important ethical consideration in experimentation on people, but there are other important ones as well. A cluster of issues concerns justice and fairness regarding who benefits from the research. These issues include the selection of participants for experiments, research topics, and control groups.

### Selecting Experiment Participants

The selection of participants can determine the population that reaps the primary rewards of the research. Transferring results from one population to another requires knowledge of all the variables that might affect a particular disease process and the proposed intervention. Typically, not all the important variables can be anticipated, and hence it is important to have an adequate representation of all groups that might be affected by the topic of the research. Because white adult males are frequently the only group sampled, they comprise the only population to which the results from those studies can be generalized with statistical confidence. As a result, there is a growing effort to find more equitable ways to share the benefits and burdens of scientific research with women, children, and minorities.

Having highlighted some of the abuses of children in experiments, as in the Willowbrook experiments, we want to emphasize that it would be unfair to exclude them altogether. Children are not “little adults.” Physiologically, biochemically, metabolically, and psychologically, children are very dissimilar to adults.[42] They even experience different kinds of diseases, some unique to them. Medications suitable for adults can have paradoxical effects in children, resulting in reactions that are the exact opposite to those in adults. Even when drugs have similar effects, the appropriate dosages are not always predicted by body weight.

Women are the most notable group not treated equitably in research designs, even though they constitute half the population.[43,44] For example, clinical drug trials are frequently performed with only male subjects. One often cited justification is the fear of unknown effects on a fetus should one of the female subjects become pregnant. A second frequently used justification is that if women are included, thereby adding extra variables, the sample size would have to be larger in order to achieve the same level of statistical significance that can be achieved with one sex only. In general, the physiological differences between men and women make it problematic to generalize from all-male studies to women. The additional cost and inconvenience are compromised by the far greater danger of giving women drugs that lack proven safety and efficacy for them. However, an expanded sample size may have advantages for everyone. At present the average clinical trial rarely has more than 2000 or 3000 subjects.[32] Thus, small segments of the population that have suffered adverse effects are not discovered until the treatment has been applied to tens or hundreds of thousands of women.

Minorities have also been denied inclusion in many research designs. Nearly 63% of health-related studies excluded nonwhite subjects between 1921 and 1990.[45] Worse, the use of nonwhite subjects in clinical field trial studies has actually been decreasing. As will be discussed in Chapter 5, advocating the inclusion of minorities in research designs does not imply the falsehood that races are genetically or physiologically unique. Rather, researchers can then investigate socioeconomic and sociocultural factors that might not be adequately present in a white male sample.

### Selecting Research Topics

Achieving justice in the distribution of benefits from research hinges greatly on the selection of topics, yet another place where conflicts of interests can distort fairness. Throughout much of the history of science, there was a consensus that knowledge is morally neutral and that data could be used for either good or evil, with the burden of right action resting on the user rather than the discoverer of information. Researchers have witnessed a history of horrible consequences that can evolve from the misuse of scientific findings.

In 1976, Callahan introduced what he called the imagination principle, which states that researchers have a responsibility to imagine the evil as well as the good ways in which findings might be used. In brief, if the research would produce more evil than good, as may be the case in biological warfare research, then the research should be stopped. If the results would likely be a mixture of good and evil, then the project should be structured so that the good would be maximized and the harmful results minimized. If the results would produce equal amounts of good and evil, then professional groups should be consulted, and if consensus cannot be reached at that level, the project should be presented for public scrutiny.[46]

Callahan’s approach, if broadly implemented, would bring dramatic change. Researchers have duties to ensure right decisions. Moreover, other competent persons are not exempt from responsibility for their products, and they are held accountable for negligence if unintended consequences are the result of their failure to exercise reasonable foresight. If anything, the expectations outlined by Callahan would merely equalize the playing field so that researchers would have the same responsibilities as anyone else in a similar situation. In any case, researchers are responsible for the selection of research topics. Given finite resources, researchers must establish priorities and pursue questions most likely to produce beneficial results. But beneficial studies should not be equated with studies grand in scope. Out of a sincere desire to bring needed change to the profession, therapists sometimes assume that research must approach global concerns in order to be valuable. However, an incremental approach to solving large problems offers many strategic advantages.[47] For example, decisions about the need for physical therapy are frequently based on range-of-motion findings as compared with standards. If these standards were established using adults only, they would not reflect averages in childhood. Rather than have one study attempt to establish standards for all joints in children of all ages, an incremental approach through a series of studies would be far more manageable, and beneficial.

Finally, the researcher has a responsibility to acquire the skills and knowledge to select and implement studies with effective research designs. This expectation is justified from the perspective of the patients who will receive the experimental treatment, of those who will be influenced by the findings of the study, and also of the institution that invests resources in the process.

## Selecting Control Groups

Frequently, the only appropriate study design involves a control group that receives no treatment or a placebo so that the experimental treatment can be evaluated for effectiveness. The control group may come to a clinic for the same number of visits as the experimental group but participate in activities known to have no effect on the topic under investigation. In drug tests in particular, control groups might even be given medications that will produce some amount of harm—namely, the same side effects as the experimental group has, such as dizziness, nausea, and other symptoms. Many physical therapists are reluctant to use the control-group design, believing that it would be wrong to withhold treatment.[48] The World Medical Association Declaration of Helsinki, as amended in 2008, offers some guidance with the following statement: "The benefits, risks, burdens and effectiveness of a new intervention must be tested against those of the best current proven intervention, except in the following circumstances:

- The use of placebo, or no treatment, is acceptable in studies where no current proven intervention exists; or
- Where for compelling and scientifically sound methodological reasons the use of placebo is necessary to determine the efficacy or safety of an intervention and the patients who receive placebo or no treatment will not be subject to any risk of serious or irreversible harm. Extreme care must be taken to avoid abuse of this option."[49]

Researchers must decide if greater harm will occur when treatment is withheld from a small control group or when an ineffective treatment is perpetuated in large numbers of patients in the future.

The potential clash between the dual responsibilities of the researcher—to current research subjects and to future beneficiaries of experiments—became salient during the AIDS epidemic. Activists argued that when an illness is terminal, when options are limited, and when there is reason to believe that an experimental treatment could offer some benefit, the victims of a disease had primary authority to make therapy decisions and to receive drugs still in the experimental stages of development. The final judgment about what is an "acceptable" risk of nonefficacy or of negative side effects rested with those who might benefit. In support of this argument, guidelines by the U.S. Food and Drug Administration have been streamlined to allow patients with terminal illnesses to make selections not available in less life-threatening situations. It should be noted, however, that FDA approval is still required. On January 14, 2008, the U.S. Supreme Court denied a petition that would have established a right for terminally ill patients to seek access to unapproved drugs (Abibail Alliance for Better Access to Developmental Drugs v. von Eschenbach).[50]

Of course, the individuals participating in the research should be considered. In some cases, the problems associated with control groups can be resolved by comparing one treatment with another, but often it is not known that either treatment is truly effective. One of several ways to minimize damage is to conduct continuous data analysis, preferably by someone unaware of the group designations, and to call the experiment to a halt as soon as statistical significance is achieved. The control group can then be given the experimental treatment. For example, in the early research with interventions that targeted HIV, data analysis was often done at the end of each day, and as soon as statistical significance was achieved, the study was brought to a close and the control group was given the interventions that showed a significant advantage over the control treatment.

Another design that attempts to minimize harm is structured so that each subject receives the experimental treatment for a block of time and the control treatment for another period of time. In this crossover design, one concern is the contamination by carryover effects from one block of time to the other. With staggered treatment versus control assignment at the beginning, some control can be offered. An example of a staggered treatment protocol would be to have group A receive the control treatment first followed with the experimental treatment.

Group B would receive the experimental treatment first followed by the control treatment. This way any carryover effect in group B into the control treatment can be detected and controlled.

## Placebo and Nocebo Effects

New evidence points toward a more desirable and still more complex model than the classical two-group comparison. Research into the "placebo effect" is raising a number of interesting questions and ethical dilemmas. Whereas modern medicine and evidence-based interventions are current phenomena, healing is an ancient art, originally under the purview of religious leaders in virtually all religious traditions. But many of the allegedly healing agents that were used were of no objective efficacy, beyond the belief that the healer could successfully intervene. Often that belief was supported with beneficial outcomes.

The reverse was also true. *Nocebo effects* refer to harmful consequences caused by the belief in the threatened negative outcomes.[51,52] An ancient example of the nocebo effect would be voodoo deaths, some of which are documented events. A recent example is the difference in reported side effects between one informed group and one less than optimally informed group.[53] Finasteride at 5 mg is used to reduce the risk of prostate cancer. One group, negatively disposed was given a detailed explanation of all possible side effects. A second group, less negatively disposed, was given minimal information. In reporting adverse effects, the uninformed group reported 15.3% adverse symptoms, and the informed group reported 43.6%. A similar situation occurs when patients lack trust in their provider or the treatment proposed, and invariably those patients do worse than others similarly situated but with more positive expectations. The mechanism for the nocebo effect, which has real, not imaginary, consequences, may have multiple biochemical pathways. Thus far, the two independent biochemical pathways that have been identified are different from the placebo pathways.[54,55]

The more relevant forces for our discussion are the *placebo effects,* which are the positive results from an intervention that cannot be attributed to a physical intervention or agent. Early on, it was observed that about 35% of all patients respond to placebo treatments, but that is not true in all diagnostic categories.[56] Although criticized, this percentage has not yet been refuted.[57] With the placebo effect, there appear to be two main categories of mechanisms, which are not mutually exclusive: (1) results achieved through "expectation" and (2) classical "conditioning."[58] Both are heavily dependent on context and are facilitated or inhibited by such things as the relationship with the provider, the type of instructions, the patient's psychological state, and the severity of the symptoms.

Expectations of a treatment's likelihood of success can enhance or reduce the placebo effect. Early studies in pain relief found that saline solution presented to the patient as morphine and injected in view of the patient had the same effect as 6 to 8 mg of morphine administered out of sight through an automated IV line and without the immediate knowledge of the patient.[59,60] Placebo surgeries from the 1950s to 2002 have reported same or better results for the sham interventions compared with the actual intervention, including human fetal mesencephalic transplants for parkinsonism.[61,52(pp99-107)] But as stated earlier, expectations are shaped by many variables, and one appears to be the price of the intervention. When two groups were given the same placebo for pain relief after being given the same noxious stimulus, the group that had been told that the medication cost $2.50 a pill demonstrated significant pain reduction when compared with the group that was told it cost 10 cents. Both groups, however, did show pain relief from the placebo regardless of price.[62] *The Journal of Marketing Research* reported similar findings in both performance and mental acuity.[63]

Conditioning is the second category of placebo mechanisms. When a placebo treatment (e.g., injection of saline or an inert liquid taken orally) is paired with a powerful drug treatment, the placebo will elicit the same physiological responses for a time. In these cases, it has been possible to reduce the powerful medications (including chemotherapy) and reduce the side effects by as much as 50%.[52(pp154-176)] One interesting application of this theory was an experiment that compared four groups in a physical exercise competition. All groups trained 3 weeks, with a competition in the fourth week and a post-competition control in the fifth week. Group A trained with no interventions. Group B was given a placebo treatment in week 4, being told it was morphine to raise the pain threshold and enhance performance. Group C received morphine in weeks 2 and 3 and a placebo in week 4. Group D received morphine in weeks 2 and 3 and a placebo plus Naloxone in week 4 (Naloxone abolishes the morphine preconditioning effects). Group B performed better than Group A, and Group C performed best of all. Since the winner would test clean (morphine would have been eliminated from the body in the time prior to the event) because they received only a placebo (conditioned) prior to the event the researchers questioned "Is it doping in sport competitions?"[64]

In overview, the dilemmas in this line of research are multiple. The nocebo and placebo effects are only optimal when the patient believes the interventions to be effective. Some researchers in the cited studies purposely lied to patients, and deception was an inherent element in the research. But now that this line of inquiry has been reported and the placebo effect appears to be a far more powerful force than previously believed, how should investigators respond in research design and in clinic treatment? In cases where there is no existing effective treatment already demonstrated, it would seem ideal to insist on an experimental group, a placebo group, and a no-intervention group. The no-intervention group appears to be warranted by research that has repeatedly demonstrated that the general population not receiving medication is composed of only 19% who have no symptoms over the trial time of 3 days. Thus, concerns about fatigue, lack of concentration, drowsiness, and headaches among other symptoms may be common in all three groups and not a result of the intervention.[65]

Clinically, intentional deception of patients is rarely justified, and respect for patient autonomy is legally and morally the primary value in the patient-provider relationship. It is reported, however, that physicians frequently and knowingly give placebo treatments.[52(pp11-12)] Sometimes the placebo is an inert substance, and other times it is a drug for maladies for which there is no evidence of effectiveness. Prescribing drugs "off label," not tested or approved by the FDA, has been a large source of revenue for some pharmaceutical companies. In 2009 Pfizer settled civil and criminal charges of $2.3 billion for promoting the unapproved use of several drugs.[66] These placebo "treatments" seem to reflect the strong paternalism that was prevalent in medical practice 50 years ago. For those who insist that the ends justify the means, we express our concern about what happens to the trusting relationship between patient and provider when such deceptions become known.

## ANIMAL RESEARCH

Physical therapists, like scientists in other areas of health science, use animals in much of their research and therefore must confront the moral questions about animal research that have become prominent. Since the publication of *Animal Liberation* by Peter Singer in 1975, the assumption that people have unqualified dominion over animals has been widely challenged. Since the late 1970s, two groups in the United States have argued for including animals in the "moral community" and have strongly opposed abuses in animal experimentation—animal-rights proponents and animal-welfare proponents.[67] Both groups emphasize that human beings are themselves animals and that excluding other animals from moral consideration is a form of bigotry, which they refer to as "speciesism," a term paralleling "racism" and "sexism."

Animal-rights proponents ascribe rights to nonhuman sentient (conscious) animals and use that moral framework to oppose most, if not all, animal experimentation. They draw attention to the striking parallels between human agency and the capacities of mammals to act as "subjects of experiences." Not only are sentient animals able to feel pain and pleasure, but they also have beliefs, desires, intentions, memories, and in general the capacity to act purposefully based on their preferences. Even though they lack moral autonomy, many species are capable of elaborate social interaction and display remarkably human-like forms of caring for each other, especially within their kin groups.

Animal-welfare proponents do not necessarily ascribe rights to animals, but they do see moral significance in all creatures capable of feeling pleasure and pain. They explain that even Charles Darwin was convinced there is an "emotional continuum" in animal life and that he was troubled by the suffering he knew experimentation would likely cause.[68] Some animal-welfare advocates, like Peter Singer, argue that relatively few animal experiments are justified. Others, perhaps placing greater value on the benefits people have received from animal research, stipulate that animals must be treated in a humane way so as to minimize suffering.

Opponents of these movements typically build on an exclusively human-centered moral perspective that emphasizes obligations to people. Discoveries of the causes of diseases, of vaccines to prevent disease, and of life-saving surgical techniques have all been made possible by animal research.[69] In addition, people-centered ethicists observe that, throughout the life chain, species prey on other species, and this is not considered a moral wrong.[70] That is not to say they condone wanton cruelty to animals, but the reasons given refer back to humanity. As Kant suggested, cruelty to animals degrades perpetrators of the cruelty, making them callous and sadistic in ways likely to foster cruelty toward human beings. Interestingly, these defenders of the status quo sometimes point to the benefits to animals (including endangered species) of experimentation, because they often profit from research-based advances in veterinary medicine, thereby implying that animals deserve some consideration as recipients of research benefits.

Perhaps the most widely persuasive arguments have come from scientists who base their opposition to animal testing on pragmatic reasons. The argument is based on the fact that there is no species model that consistently predicts human response. The FDA's statement that there is a 97% correlation between teratogens (agents that cause birth defects) that affect people when compared with one of five animal species is no doubt true.[71]

But the question is: which species? The FDA requires testing for medications on two species before going to phase one clinical trials (involving people). However, the difficulty is in estimating which species to use and if dosages given to animals will produce approximate human responses. Many substances in excessive amount—salt or sugar are two examples—will cause adverse effects in animals, but those levels would never be given to people. Bailey, Knight, and Balcombe, in their review of the substances that cause birth defects, conclude that "Mean positive and negative predictivities barely exceed 50%; discordance among the species is substantial; reliable extrapolation from animal data to humans is impossible, and virtually all known human teratogens have so far been identified in spite of, rather than because of, animal-based methods."[71(pp97-145)]

In other areas of research, investigators report similar objections, based most often on the poor reliability of animal models to predict bioavailability in people, which appears to be caused largely by inherent differences in metabolizing enzymes.[72] One author offers **Figure 4–1**, which summarizes prior research. The scattergram pattern of discordant findings between human bioavailability and animal bioavailability is a reminder of the false security harbored in the belief that animal results reliably predict human results. Grass and Sinko emphasize the high false-positives and high false-negatives in animal modeling. False-negatives, harmful in animals but not in people (as in the case of aspirin), are a great concern; one can only speculate at the number of effective drugs that never made it to human trials because they failed animal studies. "Sir Alexander Fleming, who discovered penicillin, remarked, 'How fortunate we didn't have these animal tests in the 1940s, for penicillin would probably have never been granted a license, and probably the whole field of antibiotics might never have been realized.'"[73] False-positives, where animal models predicted no harmful effects, have resulted tragically in fatal drugs and in delays in policy and prevention measures. Examples of false-positives were the early failures to predict the effects of cigarette smoke and asbestos[74] as well as Vioxx, which tested safe in African green monkeys. "The historical and contemporary paradigm that animal models are generally reasonably predictive of human outcomes provides the basis for their widespread use in toxicity testing and in biomedical research aimed at developing curves for human diseases. However, their use persists for historical and cultural reasons, rather than because they have been demonstrated to be scientifically valid."[75]

At the present time the FDA requires animal in vivo prior to human trials. However, the FDA's Critical Path Initiative states that the current methods for developing medical products have become increasingly inefficient and costly, so much so that a new approach is needed. At present, it costs between $0.8 to $1.7 billion to bring a new medicine to the public. As a result of rapidly increasing costs and time commitments for lengthy preparation for phase one trials (testing on a few human subjects), the number of submissions has dramatically dropped in the 10 years between 1993 and 2003. Even after all animal testing is done, 92% of all drugs fail in phase one testing in people. For the future, the "FDA recommendation on the use of human cell lines to characterize drug metabolic pathways provides a straightforward in vitro method for prediction of human metabolism, allowing developers to eliminate early on compounds with unfavorable metabolic profiles."[76] Any of the in vitro tests take a fraction of the time and money to implement compared with animal testing.

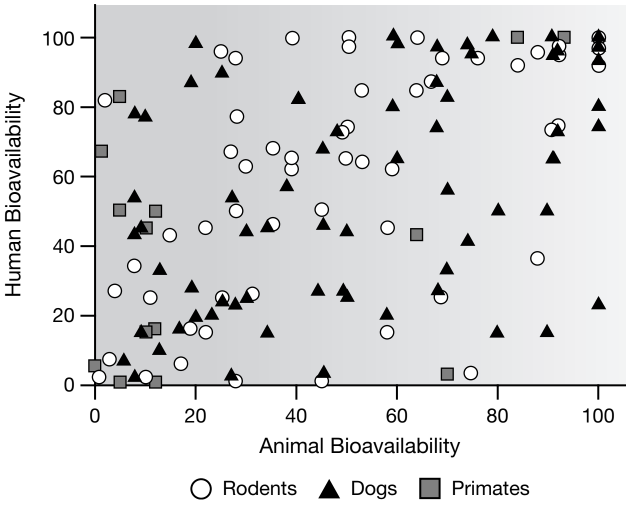

**FIGURE 4–1.** Human versus animal bioavailability. Graph generously provided by James Harris, PhD, who presented it at the Center for Business Intelligence conference titled *6th Forum on Predictive ADME/Tax,* held in Washington, D.C., September 27-29, 2006, and is adapted from data that appeared in Grass GM, Sinko PJ. Physiologically based pharmacokinetic simulation modeling. *Adv Drug Deliv Rev.* 2002 Mar 31;54(3):433-435.

Similarly, the National Academy of Sciences (NAS), in its "Toxicity Testing in the 21st Century: A Vision and a Strategy," points out that predicting human response through animal models involves assumptions and extrapolations that are highly problematic in addition to being very costly and time-consuming. The NAS states that whole-animal testing could be transformed into a system that uses cells, preferably of human origin, in a comprehensive implementation vision. However, it states that "For the foreseeable future, some targeted testing in animals will need to continue, as it is not currently possible to sufficiently understand how chemicals are broken in the body using tests in cells alone."[77]

In response to the mounting concerns, the European Union funds the European Centre for the Validation of Alternative Methods (ECVAM), which was created by the European Parliament in 1991 to "actively support the development, validation and acceptance of methods which could reduce, refine or replace the use of laboratory animals."[78] The ECVAM has validated a number of in vitro tests, which will decrease or replace whole animal testing. In 2001 it approved three in vitro alternatives (embryonic stem-cell test, micromass test, and whole embryo culture) and by 2007 it had validated an additional five new in vitro tests, including reconstructed human epidermis. It has been reported that the embryonic stem-cell test is 100% predictive for strong embryotoxic substances and overall has a 78% accuracy.[71(p132)] Coupled with Regulation, Evaluation and Authorization of Chemicals laws throughout the European Union, ECVAM estimates it will cut animal testing by as much as 50%, with a future total ban on animal testing for cosmetic ingredients.[79]

In 1997 the FDA, along with 13 other federal agencies, formed the Interagency Coordinating Committee on the Validation of Alternative Methods (ICCVAM).[80] In turn, the ICCVAM is informed by the international efforts. The FDA has for several years endorsed, especially in toxicity testing of cosmetics, alternative safety measures rather than whole-animal testing.[81] It has validated at least one in vitro test but, unlike the ECVAM, its findings have force only as recommendations. There is the hope in the foreseeable future that there will be a personalized drug compatibility test based on personal genetic material that will predict efficacy and safety as well as drug combination safety. This new field is called pharmacogenomics. The need for such a test rests with estimates of nearly 100,000 annual deaths in acute hospital settings due to adverse drug reactions, making it the fourth leading cause of death after heart disease, cancer, and stroke.[82-84]

Substantial arguments are offered on both sides of the moral debates about animal experimentation. Here we highlight several points that offer hope for some compromise by identifying a middle ground of accepting animal experimentation with strict safeguards.

First, there is an intricate web of interdependence in nature such that all living things contribute to the whole that supports individual species and lives. As people have collectively learned from their environmental mistakes, changes in a single unit can have a ripple effect over the entire fabric. For example, ozone changes have affected amphibian life, which in turn can unbalance entire ecosystems.

Second, respect for nature does not demand identical treatment of all categories of animals. The boundaries between species, including those between plants and animals, are at times ambiguous, even to experts. Nevertheless, in a general way scientists tend to divide the continuum of life into at least four major categories: human, vertebrate, invertebrate, and plant. Basic emotional responses signal differences in appropriate treatment of these groups even before we are able to give reasons justifying those responses.

Third, two general principles are widely affirmed on all sides of the debate and are now embedded in legislation. The minimal harm principle states that when harm is done, it must be justified with a good reason. The principle of proportionality calls for the least amount of harm to achieve the desired good.[85] Although these principles seem relatively simple, they have significant implications. Because suffering includes anxiety as well as the presence of pain, reducing harm means reducing anxiety, both for individual participants and for the sum of participants.

Suffering occurs at two levels for laboratory animals. The first level is composed of the husbandry conditions in which animals live on a day-to-day basis; some suffering is imposed simply by the removal or absence of an environment normal for that animal.[86] Reasonable animal husbandry will by necessity require the expertise of persons trained to recognize suffering and to appreciate species-specific conditions to reduce suffering. This staff must be held accountable through supervision by qualified and experienced staff. The staff members who manage laboratory animals daily must be accountable and monitored by qualified and experienced supervisors.

The second level of suffering is posed by the scientific procedures themselves. In keeping with the principle of proportionality, scientists must select species from the lowest level of the animal hierarchy that meets the research requirements. They must also use the best statistical procedures to assure that the fewest numbers of animals are used. With regard to those animals used, every effort must be made to minimize pain and suffering. Before the experiment begins, end points must be established so that the process is not unnecessarily prolonged. Appropriate sedation, anesthesia, and ultimately painless euthanasia are used if chronic pain cannot be relieved.

The translation of these principles into specific laws and recommendations has for the United States yielded few results and has played out over a long time compared with the process in Europe, Canada, Australia, and New Zealand. Over the past 15 years, in the effort to find alternative models for animal usage in research, Germany has spent about $6 million annually, the Netherlands $2 million, and the European Center for the Validation of Alternative Methods (established in 1992) $9 million.[68] In comparison, the United States has contributed $1.5 million per year for 3 years. Since 1985 every scientist using animals in experiments in the Netherlands has been required to take a 3-week course in correct anesthesia and techniques in animal handling and management. In general, use of animals in experimentation in Europe has slowly declined, although comparisons with the United States are difficult because U.S. legislation and accounting exempt mice, birds, and rats, which make up roughly 90% of animal research subjects.

Nevertheless, numerous steps have been taken in the United States at the federal, state, and local levels to protect animals. Additional regulations are specified by private foundations for the projects they fund. The landmark federal legislation was the Animal Welfare Act of 1966, which was revised in 1970, 1976, 1985, 1990, 2002, and 2008. More stringent standards have been established by individual federal agencies, such as the 1996 Public Health Services (PHS) Policy on

Humane Care and Use of Laboratory Animals, for projects funded by the PHS. Because they receive federal research funding, most universities are required to have an institutional animal care and use committee (IACUC), which functions in a manner similar to the IRB for human subjects. IACUC members include a veterinarian who has specific training or experience in the proper management of laboratory animals, a scientist with experience in animal research, and a person representing the general community. Veterinary medicine must be made available as needed. For details, we recommend purchasing the *Guide for the Care and Use of Laboratory Animals* from the National Academy Press (see the References for information).[87] Although various countries have different visions on how animals should be treated, at present the United States and Europe are in agreement on the 3 Rs approach:

1. Replacement: Use computer-generated models and any other in vitro models to lower the use of conscious living animals.
2. Reduction: Gather the greatest amount of information from the smallest animal population possible.
3. Refine: Minimize the pain and discomfort of all animals used in testing when there is no replacement for animals.[88]

## AUTHORSHIP

In scientific literature, authorship credit—the listing, in order, of authors of published articles or books—is taken seriously because it acknowledges the intellectual contributions and assigns credit for the findings and outcomes of the study. As stated by Pool, "Publication is the coin of the realm, and authorship is analogous to patents for inventions and copyright for creative works of literature, art, music, and computer software."[89] Decisions related to tenure, promotion, and hiring are frequently contingent on authorship and order of authorship. The perceived value of authorship itself depends on the prestige—as determined by its review process, rejection rate, and readership—of the journal that publishes the study.

Authorship would appear easy to determine, but in fact it has become increasingly difficult given the movement toward multiple authors, a movement reflecting the increased specialization of talents used in generating knowledge. Complicating matters, different journals adopt different standards. We recommend the Medical Journal Editors' "Uniform Requirements for Manuscripts Submitted to Biomedical Journals," which states that: "Authorship credit should be based on 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; 2) drafting the article or revising it critically for important intellectual content; and 3) final approval of the version to be published. Authors should meet conditions 1, 2, and 3."[90]

We note that this is essentially the same standard used by the journal *Physical Therapy*, expressed in its "Information for Authors."[91] All scientific journals agree that minor or routine contributions such as editing, data tabulations, inputting data, or typing should be acknowledged (typically in footnotes), but they do not qualify a person for authorship.[92] Most journals allow acknowledgement as an appropriate way to recognize significant efforts that do not reach the level of authorship. If acknowledgements are made, they must be with the permission (written preferred) of those involved.[38] They may have supported a part of the project but not be in agreement with the interpretation of findings and would not want to impart tacit approval to the article. Nor should personal aspects of the researchers, such as institutional position (department chair), status, or seniority, be considered. Furthermore, "acquisition of funding, collection of data, or general supervision of the research group by itself would not justify a claim of authorship."[93] The wage status of the researcher is not a relevant variable in assigning authorship, and consultants should not be disqualified as authors merely because they are paid to assist in projects, for there is no significant difference between their pay and the pay that faculty receive from universities or grants while participating. Finally, time invested in the project is not an adequate gauge for either authorship or order.[94]

Even though these guidelines are relatively clear, some key ambiguities remain. Most journals stipulate that authorship requires "professional" or "significant" contributions to the creative and intellectual components of the project, such as research design, assessment tools, interpretation of data, integration of existing theory, and development of new conceptual models. For authorship, following the guidelines from the Medical Journal Editors, one must have contributed to the design of the study or interpretation of the data, contributed to the intellectual content to the article, and given final approval of the draft to be published. The precise requirements are not always clear, but the presumption is that every effort at honesty and fairness is required by scientific integrity.

Recognition of authorship brings with it a duty. The Council on Biology Editors argues that each author must be prepared to assume public responsibility for the content of the paper.[89] The American Physical Therapy Association states that by being authors, researchers "certify that they have participated sufficiently to take public responsibility for the work."[91] At the same time, fairness requires that researchers in the study have equal opportunity to contribute in the specified areas. Denying authorship because opportunities for contribution were denied is cause for an authorship dispute and appropriate appeal.

Although authorship is itself a mark of distinction, the order of authorship can be equally important. Some universities only consider first-author publications in determining promotion, tenure, and pay. Unfortunately, the intuitive descending scale of significance in terms of contribution to the research project is not universal. In medical research the last author is frequently the senior researcher. In some fields (e.g., physics) and in some journals, authors are listed alphabetically. In most cases, however, as is usually true in physical therapy, order of authorship is in descending order based on level of contribution, with the most significant contributions having been made by the first author. Because of the way in which articles are referenced, frequently the first author is the only author listed, followed by "et al."

Authorship is also important because the authors themselves bring legitimacy to the study itself. The Vioxx scandal, mentioned earlier, exposed through court-ordered records the often difficult-to-document violations of authorship principles. Two previously known categories of offense were highlighted in the case. Guest authorship is when a person is listed as an author but does not meet the minimum criteria for authorship. Ghostwriting is when major contributors to the research or article are not recognized. Previous studies had shown guest authorship in 16% of research articles and ghostwriting in 13%.[95,96] Merck "used a systematic strategy to facilitate the publication of guest authored and ghost written medical literature. Articles related to rofecoxib [Vioxx] were frequently authored by Merck employees but attributed first authorship to external academically affiliated investigators who did not always disclose financial support."[97] In addition, Merck contracted with an outside company, Scientific Therapeutics Information, which, based on its Web-site description, is "a full service medical publishing group specializing in the development of scientific literature and…has been serving members of the pharmaceutical industry and medical associations since 1985."[97(p1083)] Ghostwriting and guest authorship are, according to the World Association of Medical Editors, dishonest and unethical.

Student-faculty research efforts are especially vulnerable to injustices in authorship distribution. The faculty member comes to the project with a disproportionate amount of knowledge about the process and significantly more power. There is a general tendency by both students and faculty to give undue credit to faculty members for their contributions.[98] Ironically, senior faculty members also tend to give more credit to students than they truly deserve. Just as students should be protected from unfair treatment by faculty, faculty has a responsibility to accurately report student authorship. Giving students more credit than they deserve falsely represents students' scholarship, gives them an unfair professional advantage compared with other students, and places them at risk for subsequent assignments that are beyond their competence.[92]

The dissertation process is qualitatively and quantitatively unlike other student-faculty research collaborations. In recognition of the difficulties in this area, the American Psychological Association Ethics Committee adopted the position that:

1. Dissertation supervisors may be only second authors;
2. Second authorship is obligatory if the supervisor designates the primary variables, makes major interpretive contributions, or provides the database;
3. Second authorship may be extended as a courtesy if the supervisor is substantially involved in developing the research design or measurement techniques/data collection, or if the supervisor substantially contributes to the writing of the publication; and
4. Authorship is not acceptable if the supervisor only gives or provides encouragement, facilities, financial support, critiques, or editorial assistance.[94]

In all cases, it is recommended that everyone meet to discuss authorship early in the development of the research project. Those most informed on the subject should share relevant articles, and the terms for authorship and order of authorship should be discussed and outlined. The agreement might have to be renegotiated at a later time, given that research projects often take unexpected turns. Even with all precautions taken, there is still the possibility that disagreements will arise. Therefore, the first meeting of the research parties should arrive at a consensus that if disputes cannot be settled amiably, arbitration will be binding on all parties. Appropriate arbitration groups vary with the committee structures in each university, but typically they include IRBs, ethics committees, or ad hoc committees composed of faculty and students not involved in the dispute.[99]

In conclusion, we have touched on only a few areas of scientific integrity, albeit important ones. The literature on research ethics is currently undergoing rapid expansion, due in part to increasing public demand for scientific integrity as well as awareness of how increasing pressures to achieve financial gain and career development encourage wrongdoing. As we noted in Chapter 2, professionals are motivated by a combination of compensation motives (money, prestige), craft motives (excellence and creativity), and moral concern (caring, integrity). Integrity can quickly fade when self-interested compensation motives become dominant. Exactly the same can be said of understanding the morally responsible conduct of professionals. At the levels of both individual character and social structures, ethics is the heart of professionalism.

## DISCUSSION QUESTIONS

1. Discuss Scott Conway in Case 4.1. What is morally troublesome about his conduct and his character, and why? Does the seriousness of misrepresenting and tampering with data turn solely on its likely consequences in the particular situation? Are there any changes in scientific or organizational practices you can recommend to discourage his type of behavior and to encourage scientific integrity in individual researchers?

2. Some critics complain that informed consent is impossible or worthless, because no one knows all the risks inherent in a project. Moreover, they say, experimental subjects lack the advanced education to fully grasp the risks that are understood by researchers. Finally, in some cases of patient care, it is permissible to engage in mild paternalism—withholding some information for a short time because immediate release would likely cause more harm. By analogy, should not the same considerations apply in research? How would you reply to these critics?

3. At present, prisoners are banned from participating in medical experiments. Those favoring the ban point to past abuses in which prisoners were not given full information about experiments and in which the hope for early parole served as undue influence. Since 1952 the House of Delegates of the AMA has insisted that prisoners not be allowed to participate because their coercive environment disqualifies them from giving full voluntary consent. Opponents argue that with proper safeguards prisoners should be allowed to participate in research because it reduces boredom, increases a sense of self-worth, and allows them to act as moral agents. Present and defend your view on whether the ban should continue, taking into account arguments on both sides.

4. Identify and discuss the ethical issues raised by the following case. Helen Mather is a junior faculty member in a highly research-oriented physical therapy department of a large university.[100] For several years she has worked closely and published articles with her mentor, Henry Goldberg, but she has begun to feel her recognition is being overshadowed by his far greater reputation. Using techniques they had developed together, but based on an experiment she had designed by herself, she writes an article invited for an international conference. The galley proofs for the article, which is to be published in the proceedings of the conference, are given to the secretary to be mailed. Goldberg happens to see the galleys and adds his name as a coauthor. When Mather confronts Goldberg, he apologizes for not telling her what he had done, but he explains that he regards the research as sufficiently belonging to him to warrant status as coauthor.

5. Present and defend your view whether ethics should be entirely people-centered or widened to recognize moral worth in other mammals and animals.

6. There is great diversity within the educational units in physical therapy in how to teach research methods and even the purpose for doing so. According to one view, students should be taught the skills necessary to review the scientific literature critically for inclusion in evidence-based practice. As part of their education, students should critique the existing literature but need not participate in conducting experiments. According to an opposing view, called the "scientist-practitioner model," students should participate in conducting experiments, by themselves or in small groups, so that practitioners know first-hand the primary issues of care. In your view, what are the pros and cons of each approach, and which would better serve the profession?

7. In 2001 Connolly, Lupinnaci, and Bush reported in *Physical Therapy* their longitudinal study on student perceptions of research in three areas, as measured at three points in the curriculum and 1 year after clinical practice. In their summary they reported, "Our findings indicate that positive changes were noted by the end of the education program but that long-lasting changes in attitudes about research have not occurred in areas such as personal desire to be involved in research and the priority that physical therapists place on research. Perhaps barriers other than familiarity with the research process (e.g., inability to give up revenue-producing time, lack of administrative financial support) continue to be the major barrier to clinical research in physical therapy."[101] Based on your experience, what barriers can you identify that prevent clinicians from engaging in outcomes research, and what strategies can you identify that might help overcome those barriers?

8. In an effort to reduce the barriers to conducting research in physical therapy, the Foundation for Physical Therapy was established with the following mission: "The mission of the Foundation for Physical Therapy, the principal and only nationwide physical therapy foundation, is to fund research that supports the development

of evidence-based physical therapist practice, enhance the quality of physical therapist services for patients and clients, and increase the number of physical therapist researchers."[102] There are a number of corporate sponsors and many gifts by physical therapists, both as outright gifts such as the $100,000 donated by Bob Deusinger, PT, Ph.D., and Susan Deusinger, PT, Ph.D., FAPTA, and planned giving donations such as the $526,000 donation by Laura K. Smith, PT, FAPTA. As students, what are some of the ways you could help further research efforts in the profession and in the future as practitioners?

9. What priority and what resources should be expended to develop more reliable in vitro models for drug toxicity and effectiveness, and why?

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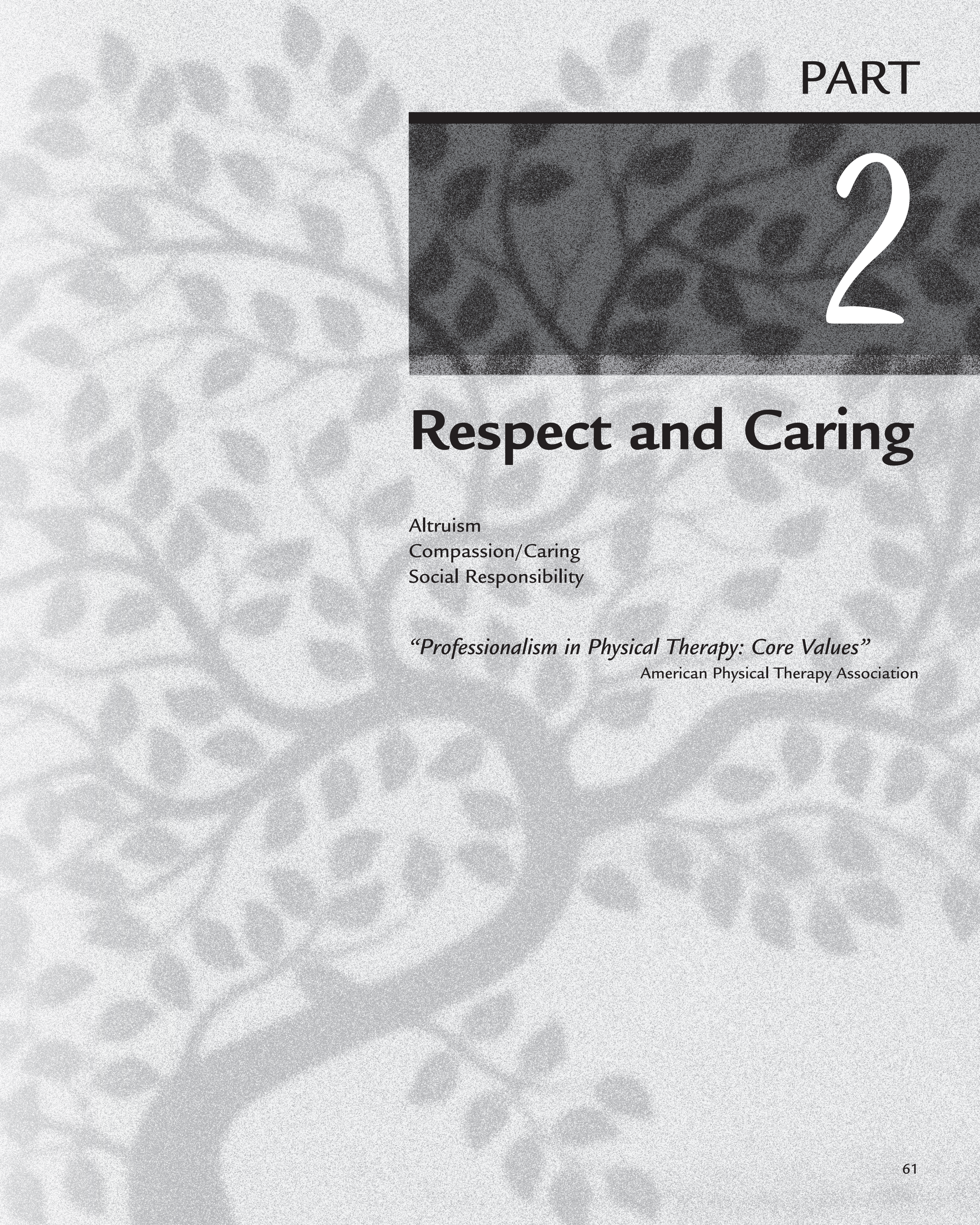
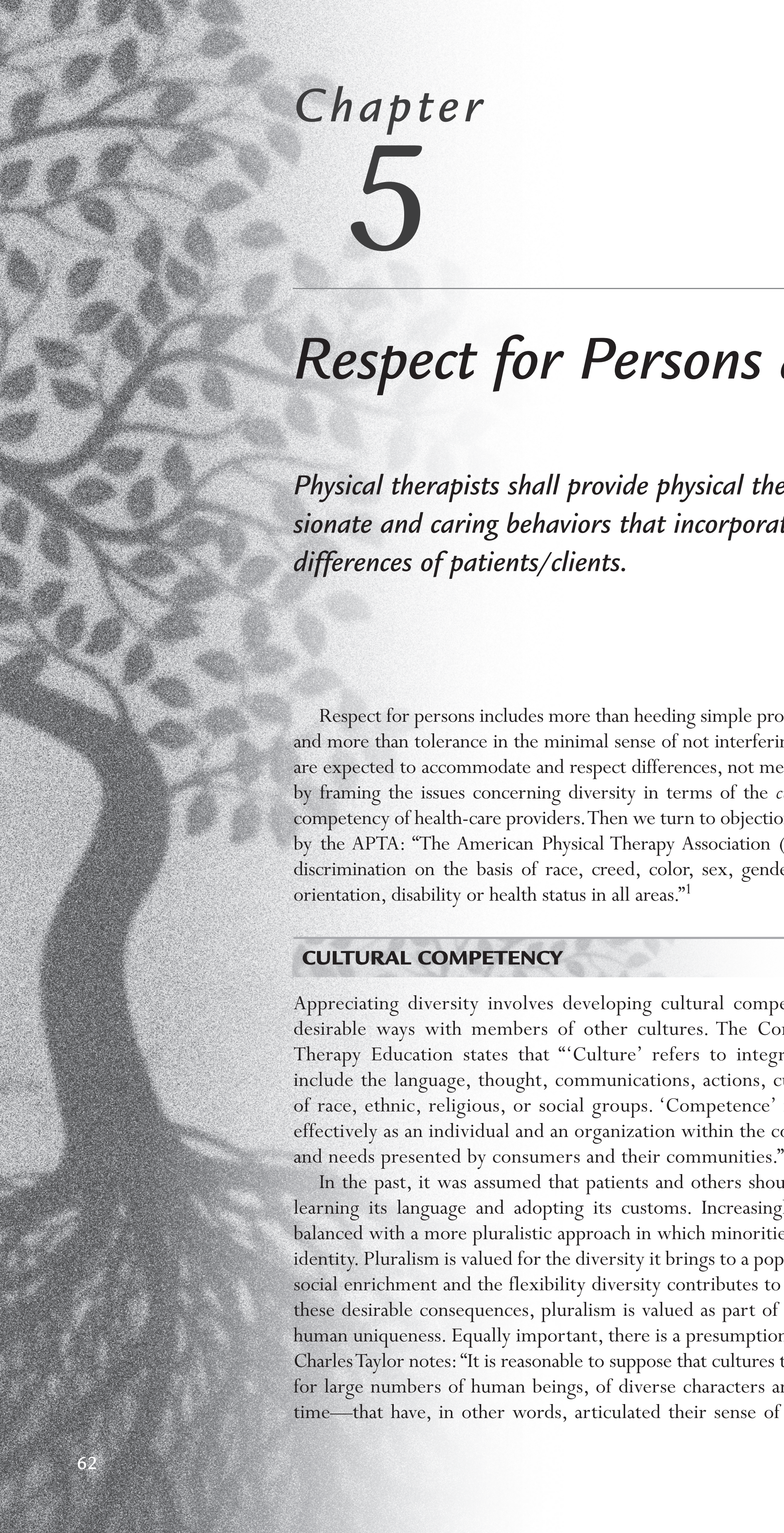


# PART
# 2

# Respect and Caring

Altruism
Compassion/Caring
Social Responsibility

*"Professionalism in Physical Therapy: Core Values"*
American Physical Therapy Association



# Chapter 5

# Respect for Persons and Diversity

*Physical therapists shall provide physical therapy services with compassionate and caring behaviors that incorporate the individual and cultural differences of patients/clients.*

Principle 2B, APTA Code of Ethics

Respect for persons includes more than heeding simple prohibitions of intentional unequal treatment and more than tolerance in the minimal sense of not interfering with others' liberty. Physical therapists are expected to accommodate and respect differences, not merely tolerate them. Accordingly, we begin by framing the issues concerning diversity in terms of the *cultural competency* required as part of the competency of health-care providers. Then we turn to objectionable forms of discrimination condemned by the APTA: "The American Physical Therapy Association (APTA) prohibits preferential or adverse discrimination on the basis of race, creed, color, sex, gender, age, national or ethnic origin, sexual orientation, disability or health status in all areas."[1]

## CULTURAL COMPETENCY

Appreciating diversity involves developing cultural competence and a willingness to interact in desirable ways with members of other cultures. The Commission on Accreditation of Physical Therapy Education states that "'Culture' refers to integrated patterns of human behavior that include the language, thought, communications, actions, customs, beliefs, values, and institutions of race, ethnic, religious, or social groups. 'Competence' implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities."[2]

In the past, it was assumed that patients and others should assimilate into the dominant culture, learning its language and adopting its customs. Increasingly, the concept of assimilation is being balanced with a more pluralistic approach in which minorities preserve basic elements of their ethnic identity. Pluralism is valued for the diversity it brings to a population, both in terms of the population's social enrichment and the flexibility diversity contributes to a global market economy. In addition to these desirable consequences, pluralism is valued as part of respect for autonomy, moral rights, and human uniqueness. Equally important, there is a presumption that different cultures possess worth, as Charles Taylor notes: "It is reasonable to suppose that cultures that have provided the horizon of meaning for large numbers of human beings, of diverse characters and temperaments, over a long period of time—that have, in other words, articulated their sense of the good, the holy, the admirable—are almost certain to have something that deserves our admiration and respect, even if it is accompanied by much that we have to abhor and reject."[3]

Patients' experience of illness as well as their response to health-care professionals depends in part on their culture. Culturally competent providers greatly enhance the likelihood that patients will engage with their provider in a joint effort to achieve better health. As examples of cultural competence in health care, consider the following cases.[4]

### CASE 5.1 Language

Mary Washington, an elderly woman, tenses slightly but noticeably and stops making eye contact with a young white male therapist who had called her Mary when they first met. In her view, the therapist's failure to address her as Mrs. Washington demonstrated a lack of respect.

Health professionals cannot be expected to guess how new patients will respond to use of their first names. Until a context of informality is established, it might be best to assume that Mr., Miss, Mrs., or Ms. is appropriate. It is also a safe assumption that members of minority groups that have suffered discrimination might have reasonable distrust about being fully respected within white-dominated hospitals and other medical facilities.

### CASE 5.2 Mr. Smith and Mr. Lee

Mr. Smith and Mr. Lee are middle-aged men recovering from similar injuries and in need of the same physical therapy interventions. Mr. Smith, however, complains far more about the pain he is experiencing and prefers lower-level exercises and more medication from the nursing staff than does Mr. Lee. The therapist assumes Mr. Smith is a whiner, and this assumption influences his treatment of the patient.

In fact, cultural differences largely explain patients' differing responses to pain. Some cultures are socialized not to express pain dramatically, and that socialization can also affect how intensely pain is experienced. The person who does not express pain is far more problematic and is the one with whom the therapist needs to discuss feedback.

### CASE 5.3 Nationality

Mr. Takahashi, a 60-year-old man, is in a hospital rehabilitation unit recovering from a stroke that significantly weakened his left side. He is doing well during physical and occupational therapy sessions, but he regresses when his wife visits. Staff members discover that when Mr. Takahashi's wife is present in his hospital room, especially for long hours, he fails to do his prescribed exercises. At those times his wife takes over all small tasks, such as brushing his teeth, shaving and dressing him, and even holding the bedpan for him, although the therapists had indicated he should begin getting up to use the bathroom. Mr. Takahashi's dependency on his wife is complemented by his barking orders at her. These behaviors are in accord with customs both he and his wife accept. While the therapists wish to respect the couple's traditions, they also speak with them to work out an agreement about limiting his wife's assistance in the room.

### CASE 5.4 Coin Rubbing in Folk Medicine

A physical therapist who practices in a children's services program, which is housed within the elementary and junior high schools of a large school district, is asked by a school nurse to work with a girl entering first grade. The girl suffers shoulder pains of unknown origin. The therapist immediately discovers dark red welts and scratches on the girl's arms, shoulders, and chest. Suspecting child abuse, he alerts the authorities. In fact, the welts are caused by coin rubbing, a traditional folk remedy. The therapy consists of vigorously rubbing a coin in prescribed patterns, typically radiating from the spine to interstices of the ribs. The coin rubbing was not the source of the child's pain—it was instead an attempt to alleviate it, and it did not itself injure the child. Today, coin rubbing is generally tolerated by Western health professionals as an "alternative" or "complementary" therapy.

Most cultural misunderstandings and gaffes can be prevented or corrected through improved communication and multicultural awareness. The following case study illustrates how awareness and communication can bridge cultural differences.[5]

### CASE 5.5 Bridging Differences

Krista had recently graduated from a physical therapy program and accepted a job in an area that served a large population of American Indians. One of her first referrals for therapy was a 4-year-old male named Jimmy who was diagnosed with cerebral palsy/hemiplegia. Following her evaluation, she requested a meeting with the mother (who was present) to discuss the treatment goals and methods, including a home treatment plan. The mother agreed with her recommendations, and at the appointed time Jimmy came to the clinic with his mother, father, uncle, and several friends. Krista was surprised by such a large group and worried about maintaining confidentiality. Uncertain how freely she could discuss the diagnosis, she asked to speak alone with the mother. The mother assured her that all these people were involved in her son's care, and the actual agreement for care would come from the child's uncle. This comment raised a new concern for Krista: consent for treatment had to come from the legal guardian, from the mother rather than the uncle. Still uncertain about how to proceed, she decided that if the mother wanted the others present, there probably was no confidentiality issue.

Krista made her presentation, explaining her findings and proposing a three-pronged approach. First, she would provide one-on-one therapy. Second, she would enroll Jimmy in a group she conducted each week. The group, she explained, was to engage Jimmy in a play setting with tasks that would complement her treatment in the individual sessions. The play would consist of games that allowed each child to compete individually with the other children in ways that motivated desirable responses. She planned to reward the children with stickers and small gifts they could select from the treasure chest when they won. Third was a home treatment program that the mother could administer to enhance the treatment sessions further. Krista alerted the family and friends that, without intervention, the child would continue to lose range of motion and have great difficulty walking or being independent in self-help skills.

The family and friends listened quietly and, when Krista finished, there was a long silence. At first Krista wondered if they had understood her, but after a while the uncle politely explained that before treatment could begin, they would seek the help of the tribal healer. When he had performed the appropriate ceremony, they would return. The uncle stated that he was happy that Krista would work with his nephew, but he objected to the type of activities she had described for the play group. The responsibility for the home program would be shared by everyone in the room, not only the mother.

Krista, confused by the responses, consulted a senior therapist, Mary, who had practiced in the area for several years. Mary explained that family, in traditional Native-American culture, is broadly defined by a concerned community rather than by biological parents alone. Grandparents often attend to the spiritual concerns of the child, and an uncle will often assume responsibility for health-care decisions. Mary stated that activities for a child that stressed individualism and competition were not acceptable to many Native Americans, who believed that those activities separated the child from others. Group activities that were cooperative and facilitated relationships would be approved, but competition and notoriety through rewards would not be accepted. Mary also explained that often the families would seek the tribal healer because they believed in multiple causes of illness, not because they disbelieved the diagnosis or thought Western medicine was ineffective. As for the warning Krista had given, in the future she should speak only about the positive outcomes. The traditional belief was that negative thoughts and fears would impede the healing process. They should not be mentioned unless in the abstract third person, so that they were not personalized by the patient.

Although Mary's information provided Krista with more understanding, it did not solve her dilemmas. Krista could yield on the confidentiality issue, but she felt conflicted about the consent for treatment coming from the uncle. She was convinced that a competitive play format would accomplish far more for the child. But perhaps most importantly, Krista believed that a frank discussion of possible negative consequences, just as much as positive outcomes, was essential to acquiring informed consent.

* * *

Sometimes the cross-cultural conflicts between provider and patient are deeply rooted. This is because cultural differences are not just beliefs but are entirely different "systems of meaning."[6] The first step in avoiding conflict is to have the provider and patient decide jointly on the goals of treatment without attending to the means by which those goals will be met. Once the goals are established, the means must be negotiated so that cultural differences are respected.

Krista solved the conflict over confidentiality by reasoning that if the mother wanted to share the medical knowledge, there was little difference between the mother telling others and their hearing it directly from Krista. In fact, there was less chance for misinterpretation if they all heard it from the same person at the same time. Likewise, Krista could reason that autonomy can be delegated to others by a competent person if the responsibility for the consequences remains with the person, not the surrogate decision maker. If the mother trusts the uncle enough to maintain this traditional decision-making pattern about health issues, then it was her autonomous choice.

Krista might feel pressured by her perception of a legal system that requires the legal guardian's consent to treat. She might choose to explain to the mother her legal entanglement and ask the mother to confirm that the uncle had the mother's permission to make health-care decisions for the child. Krista would then ask the mother to sign the required intake forms with the understanding that Krista would treat the uncle's concerns as though they were the mother's, noting that at any time the mother could resume that responsibility if she so wanted. Regarding the issue of competitive play, Krista could recognize that she could change the format to group activities where the goal was to help others and to succeed as a group rather than as an individual. As for relaying negative outcomes as well as positive ones, she might reason that autonomous persons have the right to restrict the information they receive or hear it as addressed in a general rather than personal context.

## ACQUIRING CULTURAL COMPETENCY

A variety of approaches have been developed to understand and foster cultural competency. One of the early models was a descriptive approach to cultures through listing commonly perceived attributes, customs, rituals, and traditions of a particular group. Unfortunately, those early descriptions tended to reinforce stereotypes. The descriptors often minimized differences within groups and maximized differences between groups, thereby concealing significant variations within groups and neglected commonalities. Yet, with that said, some core concepts do help people recognize patterns of values. For example, cultures in general can be sorted roughly into two categories:

1. Individualistic or
2. Collectivist.[7]

### Individualistic Cultures

Individualistic cultures focus on autonomy and individual rights. As a consequence, elements that contribute to individual security, such as competitiveness and planning for the future, are very important. Time is precise and focused so as to maximize productivity. Individualistic cultures tend to communicate with more precise language, leaving less to interpretation or chance. Thus, nonverbal communication is of minor importance and may be unnoticed by members of these cultures.

### Collectivist Cultures

Collectivist cultures are more focused on group well-being and interactions. Communities are marked by their cooperation and concern with traditions as a means of perpetuating the past into the present and future. Time is fluid, and precedence is often given to communications with friends and families. Communication is both verbal and nonverbal, with subtle and complex interactions between body language and verbal exchange.

Neither individualistic nor collectivist cultures are superior, and a pathway is needed to understand their interactions. The pathway loosely parallels some stages outlined by Kohlberg and Gilligan.[8]

### Stages of Developing Cultural Competence

There are three stages of developing cultural competency:

- Stage one: Develop knowledge of self and how one's self is influenced by one's culture and beliefs.
- Stage two: Develop awareness of people who have their own values, and a willingness to treat others as they wish to be treated.
- Stage three: Develop the ability to empathize with and to respect individuals having a different worldview.

Gradually, this willingness evolves into a nearly automatic recognition that, at a personal level, stereotypes are misleading. An individual's identity can only be assessed within the context of an ethic of care; you must be willing to personalize each and every encounter.

## PREJUDICE

Prejudice, or bigotry, is the strongest obstacle to multicultural appreciation. The Latin origin of **prejudice,** "*praejudicium,*" means to make a judgment based on prior experience. Although prejudice can involve prejudging someone favorably, such as assuming that a handsome man or beautiful woman must be talented, the greater threat to justice occurs when people prejudge negatively. When power (be it social, political, or legal) is added, prejudice is then labeled an "ism"—racism, sexism, heterosexism, ageism, and so on.[9] The inevitable consequence is to deny someone an opportunity, a service, a product, or any other desired good to which that person has a right. Arguably, most bigotry is now covert (disguised, hidden). Yet bigotry that is overt (open, obvious) is still alarmingly frequent. Consider the following case.

### CASE 5.6 Orange County Physician

In 1999 the *Los Angeles Times* reported that an Orange County (California) physician and the health maintenance organization for which he worked were being sued for causing emotional distress to a patient. The focus of the suit was a routine physical examination, during which the physician asked the patient about her means of birth control. The patient replied that she did not use birth control because she was a lesbian. Following the examination, the physician suggested that she schedule her next appointment with one of the other physicians in the office. When asked why, the physician said "he didn't approve of her gay 'lifestyle.'"[10]

Evidently, the physician believed he had a right to refuse to provide treatment to a gay person, perhaps as an exercise of his religious faith or his personal conscience or perhaps as part of the medical tradition of allowing physicians to refuse to accept individuals as patients (except in emergencies). At the very least, he was grossly insensitive in how he exercised his beliefs, given the emotional vulnerability of the patient whose body was being intimately examined by someone she thought she could trust.

We believe this case illustrates how highly intelligent and well-educated professionals can sometimes be overtly prejudiced. The case at least indicates that society has yet to reach a shared understanding of what prejudice is and the many ways prejudice is exhibited, either with or without awareness. Numerous studies suggest that this case is representative of a recurring bias in health providers.[11] For example, a study conducted in 1992 found that nearly a quarter of physical therapists in Los Angeles County who provided home health services preferred not to treat homosexual adults who were HIV-negative.[12]

In today's society, racism, heterosexism, and the other "isms" are expressed more covertly than overtly, but that does not signal an end of oppression. It just makes prejudice more difficult to recognize and correct. In addition, much bigotry manifests itself institutionally, as embedded in social practices and organizational structures. The institutionalization of prejudice often makes it difficult for individuals to recognize the extent to which they comply with the social values they have internalized. People with the best of intentions and a firm commitment to help others often mistakenly believe that the desire not to be biased automatically exempts them from prejudiced behaviors. Marilyn Frye used the metaphor of a bird cage to express the effects of cultural biases on women, but the metaphor applies to all bigotries.

"Consider a birdcage. If you look very closely at just one wire in the cage, you cannot see the other wires. If your conception of what is before you is determined by this myopic focus, you could look at that one wire, up and down the length of it, and be unable to see why a bird would not just fly around the wire any time it wanted to go somewhere....There is no physical property of any one wire, *nothing* that the closest scrutiny could discover, that will reveal how a bird could be inhibited or harmed by it except in the most accidental way."[13] The contours of the cage, and that is what a social prejudice is, emerge only by stepping back, seeing each wire as part of a wider structure.

**Ethnocentrism** is the core of much prejudice. At some level, pride in one's own group is healthy, because it adds to one's sense of well-being and belonging. But far too frequently a group elevates itself by diminishing others. One symptom of ethnocentrism gone awry is that contributions by outsiders are ignored or unrecognized. For example, only in the past few years were the contributions by African Americans to American culture included in standard history texts in public schools. Contributions of homosexual people are still not generally acknowledged. Persons born into ethnocentric groups that are in power inherit the values and even the language that helps maintain that power. More importantly, persons in the group holding power have privileges they did not individually earn, acquiring them simply because of the status of their group. They might be unaware that not everyone shares in a certain ease of living, because they have known nothing else, or they might reason that if others do not share their privileges it is because they lack initiative.

Studies in cognitive psychology reveal that prejudice serves many functions, including predicting behavior and forewarning dangers, in addition to maintaining patterns of subordination.[14] In the increasingly complex world, people use daily mental shortcuts to guide their actions. These mental shortcuts, of which stereotypes are only one type, hasten responses and contribute to survival when rapid response is critical. When the shortcuts are constructed from insufficient data to predict a particular response, people typically obtain enough feedback from the situation to improve the shortcuts. For example, in preparing for an outdoor sporting event, you notice heavy cloud cover and decide to carry an umbrella. After carrying an umbrella to an event where there are clouds but no rain, you improve your working generalization so that rain is probable only when the clouds are gray. If you had more time, you could look at a barometer, take measures of moisture in the air, temperature, and wind velocity, and calculate the probability of rain, but by then the event might be over.

In most cases, the shortcuts serve well enough. What happens, however, when these same mental shortcuts are used to estimate human behavior? Stereotypes—using limited variables to predict the behaviors of very complex beings—are often the result. They provide a certain "cognitive economy" that guides choices made.[15] For example, short haircuts on women could signify for you that such women are rude and certainly not socially refined. You decide that this person is not someone you want to know; you become unavailable and do not share activities with that person. As a consequence, the stereotype is never corrected because no new data are gathered to refute it.

To simplify choices for a course of action, stereotypes typically minimize variance within a group and then maximize differences between groups. Once these stereotypes or schemas are formed, information is filtered to accept what fits the category, and information that does not fit is either not recognized or accepted. If you should be forced to interact with a woman with short hair and you find her to be socially poised, feminine, and cordial, you might decide she is the exception to the stereotype rather than change the stereotype in your mind. As ludicrous as it is to assume knowledge of a complex human being by knowing one variable, such as length of hair, people do it all the time. Multiple studies demonstrate that bias is unconsciously present, even in those who do not want to be biased.[16] Without recognizing these unconscious biases, people cannot be genuinely fair, and they continue implicitly supporting social practices of oppression that damage the victims' self-esteem, thus creating a self-fulfilling prophecy—a newly created social reality that further disadvantages victims.

Having emphasized cognitive sources of prejudice, we should note that prejudice often serves additional desires and needs. One need is to maintain self-esteem by affirming the superiority of groups with which one identifies: "A number of classic studies have documented that [racial] prejudice is far more likely among those whose status is low or declining than among those with high or rising status, who presumably have less need to find someone to place below them."[17] Another need is simply to be accepted as part of a group, embracing the group's tradition of prejudice as simply one aspect of membership. Still another need is to provide an outlet for inner conflicts, such as insecurities about sexual identity (for example, in the case of homophobia), or guilt and shame about one's failures (for example, scapegoating of Jews by anti-Semites). With remarkable ease, people project their unacceptable desires onto other groups as a way to provide an outlet for fears, frustrations, and aggression. Finally, bigotry often functions to maintain social power and privilege, especially economic privilege.[18]

With these general reflections in mind, we comment further on three forms of prejudice—against persons with disabilities, persons of color, and women.

## PEOPLE WITH DISABILITIES

Given the nature of the work of physical therapists, it is not surprising that they have often been leaders in helping to change society's response to persons with disabilities. Therapists know first-hand the inaccuracy of stereotypes that stigmatize persons with disabilities with notions of inferiority and devaluation. At the same time, therapists are human, and they too occasionally lapse into subtle forms of prejudice.

Consider, for example, the language sometimes used to refer to patients. The climate of health-care work still leads some therapists, as well as physicians, to speak of their patients as "the quad" or "the knee," thereby reducing a person to a disability. As Susan E. Roush writes, "The problem with this language is that it is not accurate; the *person* is not the *characteristic*. In addition, this language reinforces the limiting perspectives that a stigmatizing 'mark' taints all other characteristics of a person. Another example of inappropriate language is the use of value-laden terms that again emphasize loss and negativity and ignore ability, such as 'He is confined to a wheelchair' rather than 'He uses a wheelchair for mobility.'"[19]

Editors of journals in physical therapy take special care to ensure that authors avoid such reductions. Jules M. Rothstein, for example, notes that "Our Journal [*Physical Therapy*] has long advocated the use of people-first language....People have disease, impairments, and disabilities—they are not the sum product of their medical conditions. People have paraplegia—they are not 'paraplegics'!"[20]

Language and behavior regarding people with disabilities are forms of prejudice. Everyone is vulnerable to becoming disabled in a variety of ways.[21] Rather than acknowledge that vulnerability, people lapse into insensitive language and behavior as a protective device. Responses to people with a disability range from avoidance to physical attacks. Even those from whom compassion is expected sometimes falter when it comes to disabilities. For example, a private not-for-profit center for children with disabilities eventually had to advise the parents of the children to avoid shopping at the supermarket adjacent to the center. Apparently the market attracted a large number of worshipers from a nearby church, and with great frequency members from the church approached these parents in the market and inquired what had been the nature of the sin committed by the parent to cause this disability.

The public's tolerance for disability is surprisingly low and even extends to disfigurements that have no functional significance. Consider John:

### CASE 5.7 Skin Discoloration

John was a professor who had years of experience as both a student and a teacher. He had the social skills for those settings so that he made friends easily and was rarely treated with anything but a cordial social response. During a recent visit to his dermatologist, John was advised to apply a mild topical chemotherapy lotion on his face to remove cells that appeared likely to become cancerous. The physician had never witnessed an adverse response to the medication and so failed to check John or provide guidance in case he had a reaction. John's response was atypical and violent, leaving him temporarily discolored, bleeding and swollen. John had already enrolled in a class at the local university and attended class just as he had always done. This time, however, he noticed a dramatic change in the way people responded to him. The professor and some of the students avoided eye contact with him, and only one student responded in a cordial way to his efforts to socialize. Within 4 weeks the discoloration and swelling had disappeared. The professor then began to address him in class, and the other students socialized with him as they had done in other settings for years.

If social response can be so dramatically affected by appearance, imagine the response to a functional disability and then to a functional disability in which esthetics are compromised. Historically, persons with disabilities have been forced into poverty, even when they were capable of working, because they were unable to find an employer who would hire them. Largely through the efforts of the community of persons with disabilities, legislation has been enacted to promote fairness in employment.

By far, the single most important legislation is the 1994 Americans With Disabilities Act (ADA). This act was a powerful attempt to ensure respect for the rights of individuals with disabilities, estimated at some 50 million Americans, including individuals working within the health-care professions. It covers public accommodations and employment rights of persons with disabilities. The act has enjoyed broad public support. Accordingly, our aim is to outline some of the complexities of the act.

We focus on Title I of the act, which deals with employment issues. The coverage of the ADA is broad in that it includes everything in employment from job application procedures to disciplinary action and termination. The law applies only to qualified applicants and does not advocate preferential treatment or affirmative action; nor does it excuse poor performance. Its aim is to protect the right of qualified workers who have disabilities to compete for jobs and then to be successful in applying their skills.[22]

Disability is defined broadly in three distinct ways.[23]

- First, persons are disabled if they have a physical or mental problem that substantially limits a major life activity. Examples of such activities, provided by the ADA, include walking, speaking, seeing, hearing, learning, sitting, lifting, and reading. Also included are any mental or psychological disorders. The fact that any of these conditions are controlled or cured by medications does not remove the ADA protection for that person.
- Second, all individuals who have been substantially limited in the past are covered. This includes people who have had heart disease, cancer, or mental illness, even if cured.
- Third, ADA extends to situations where a problem is created by the attitudes of others.

  For example, managers violate the ADA when they refuse to promote a person with facial scarring to a position in which the individual will have contact with the general public. They would also be in violation if they fired an employee because they believed the employee was HIV-positive. The ADA makes it illegal to refuse a job to individuals because they have a spouse or dependent with a disability, if they have a roommate or friend with a disease such as AIDS, or if they do volunteer work with an organization focused on a particular illness such as muscular dystrophy or AIDS.

Just as the ADA uses a broad definition in its coverage for citizens, it is also broad in the coverage offered in the pre-employment and employment fields. The regulations focus on issues of equality with the provision of "reasonable accommodation." Reasonable accommodation is defined by the ADA as those accommodations that enable individuals to perform tasks at a satisfactory level, such as ramps, modified work schedules, and purchased devices to aid persons with disabilities.[24] The employer should consult with the employee about which items would help in the accommodation process, because the ADA specifies that accommodation must be an "individualized analysis."[25]

Employers are not required to make accommodations that cause a hardship, either in terms of finances or if the accommodation will severely disrupt the operations of the business. For example, if someone with vision problems could be hired as a waitress only on the condition that the lighting was bright, but a restaurant needed dim lighting as part of the ambiance, then the accommodation would be justifiably too expensive to the business.[26] As another example, a physical therapist unable to lift 25 pounds could probably be reasonably accommodated in a hospital setting where aids and assistants were available, especially as hospitals are specifically listed as a "place of public accommodation" under Title III of the ADA.[27] But therapists might not be reasonably accommodated if they do home health care and the employer would have to hire or appoint an aide to accompany them on a daily basis.

In pre-employment, job offerings must be posted so as to be available to persons with disabilities, and employers' human resource departments must be accessible to them. The process of applying must also be accessible. Therefore, if an applicant is blind, the company must provide someone to fill out the application at the instruction of the applicant. During the interview process, the employer may not ask any question about a person's disability, either directly or indirectly through general questions about one's health. The employer is free to ask all applicants if they can perform all key tasks listed in the job description. Key tasks are core items in the job description, not those that could be easily done by someone else. For example, if the receptionist job description includes the task of "carrying letters to the mail room," when in reality the letters could easily be sent by the aide who goes to the mail room daily to pick up deliveries, a person with paraplegia should not be eliminated from consideration for that job.

If employers require a medical examination prior to employment, they cannot order that examination until after a conditional job offer has been made.[28] This is done to prevent employer bias. If the medical examination uncovers a disability that makes performance of the job impossible or jeopardizes the health and safety of others, then the offer can be retracted. However, this retraction is conditional on three separate factors. First, medical examinations must be required of all employees in that category, not only applicants the employers suspected of having a disability. Second, the job is such that even reasonable accommodation will not make the employee's job performance possible. Third, the health and safety factor cannot be subjective but rather one on which experts would agree, and they must be based on science where it exists.[29] Thus, physicians and any other health-care professionals cannot refuse to treat a patient who is HIV-positive because of fear of contagion. Universal precautions should be standard practice.

If someone with a disability is hired, then regulations are focused on fairness in all areas of the employment. Employees with disabilities must be given the same opportunities for job performance and promotion as all others, again with reasonable accommodation. Their privacy must also be protected. Their disabilities can be divulged only on a need-to-know basis with their supervisors, safety personnel, and officials with the ADA.[30] The employer cannot segregate employees on the basis of disability, which means that lunchrooms, restrooms, and social activities must be accessible. Employee benefits must be the same as those offered to all others. In fact, after reasonable accommodation, people with disabilities are to be treated as other employees.

Items that are not covered by the ADA vary greatly according to the reason they are not considered. Sexual orientation is not protected by the act because it is not a disability. Inability to read is not covered unless it is caused by dyslexia, and obesity is not considered unless it is the result of a glandular condition. Disabilities caused by illegal drug usage are not covered if the person is still using illegal drugs. Disabilities are covered if the person is not using drugs and has participated in any type of rehabilitation attempt, even if self-administered, or if the individual is currently undergoing drug rehabilitation.[31] Behavioral disorders, such as compulsive gambling or pyromania, and psychological characteristics, such as aggressive or threatening behavior, are not protected. Religious organizations that hire only members of their faith do not have to hire persons with a disability who are not members of their faith.

## SEXISM

The bias against women might be the most systemic bias in society because it is prevalent in every aspect of life. Historically, women "were expected to be continually dependent upon men—on fathers in childhood, on husbands as adults, and on sons in old age," writes D. Dunn.[32] This dependency was legally enforced with laws that would forbid women from owning property, testifying in court, or having credit ratings separate from those of their husbands. Even the basic right to vote was denied women until 1920, when the 19th amendment to the Constitution was passed. There is still no Equal Rights Amendment to the Constitution.

When a child is born, the first question usually asked by the husband, family, and friends is not about the child's health but the child's gender. That one variable significantly predicts a host of outcomes over a lifetime. For example, treatment of boys and girls within the education system differs greatly, starting in elementary school, where girls tend to receive less attention from teachers than do boys.[33] Gender gaps in performance and interest start early and continue to widen, especially in the sciences. Although many of the gaps have decreased, new ones have opened. Thus, while the gender gap in math narrowed between 1992 and 1998, computer science became the new "boys' club" with an enormous gender gap.[34] Graduate education did not see an equal number of women until 1984, and not until 1995 did the number of women in graduate school full time match that of males.

Sexual harassment (discussed more fully in Chapter 8) is an obstacle throughout the educational process, not only at the college level. In 1993 a poll found that four out of five girls in the eighth through eleventh grades had experienced sexual harassment, defined as "unwanted and unwelcome sexual behavior which interferes with your life."[34] Given the frequency of documented sexual harassment in the workplace, at present it appears to be a lifetime obstacle.

Education significantly affects the earning potential of job candidates, including women. Between 1970 and 2001, women increased their representation among undergraduates from 42% to 56%. It is estimated that by 2013 women will make up 57% of undergraduate enrollment.[35] Yet as recently as 2007, college-educated men in their mid-20s earned almost $7000 more than college-educated women. When the data were controlled for field of study, college selectivity, and scores on standardized tests, men still earned over $4400 per year more than women.[36] Thus, education does not always translate into earning power. By 2007, women were earning 78% of men's wages for full-time year-round workers **(Table 5–1)**.[37] Women enter the market as enthusiastically as men: in 1994, 90.3% of females and 89.9% of males stated that being successful in work was "very important" to them.[38] Nevertheless, incomes differ between the sexes in all industrialized countries. The wage gap differs more in the United States than in a number of advanced countries, especially in Canada, which has the most extensive pay equity policies in the world.

The weekly and annual earnings for women employed full-time are lower than the wages for men even with the same educational attainment, although the gap is narrowing **(Table 5–2** and **Fig. 5–1)**.[39,40] Even so, when controlled for specific occupations, the gaps are still apparent. Specifically for physical therapists, using 2000 census data, men comprise 30.1% of the workforce and women 69.9%.

Blended into salary differences, however, are considerations beyond personal bias. First, the kind of work that women do is often reimbursed at lower levels than work traditionally performed by men. This is not to say that the work is less important or less difficult. Rather, the sex of the majority of workers in a field appears to influence the reimbursement rate. Of course, there are other variables that influence wages, but something is awry when highly trained intensive care nurses earn a fraction of the salary commanded by divorce attorneys or when elementary school teachers barely earn enough to live above the defined poverty level.

Second, work behavior varies between the sexes. Men and women might have similar hourly wages, but on average men work three or more hours longer per week than women, creating a difference in annual wages.[41] Women have a greater tendency to leave jobs and remain unemployed for extended times due to events such as pregnancy and other family matters, often referred to as "sequencing."[42] In turn, this tendency affects women's seniority and work experience, which are factors in reimbursement.

Even as these explanations attempt to explain workplace bias, they only help to further define the social-family bias that women face. When a child is sick, the mother is usually expected to stay home. When either the wife's or the husband's parents are ill or in need of continuing care, the wife leaves her job to deliver the nonpaid services. Women work "double shifts"—one at their workplace and the other at home taking care of their houses, children, family finances, food preparation, and cleaning. Given these dual jobs, it is not surprising that the President's Glass Ceiling Commission found that 95% to 97% of all senior managers in the top 1000 industrial firms and the Fortune 500 were men.[43]

Women also receive disparate health care. Until recently, the nonreproductive health of women has largely been ignored, even when hormonal differences are especially relevant as in medication dosages.[44,45] Women who are hospitalized for coronary heart disease are prescribed fewer diagnostic and therapeutic procedures and are 35% less likely to undergo coronary angiography or revascularization with adjusted odds.[46] In a study of 2231 patients with myocardial infarctions, men were twice as likely as women to

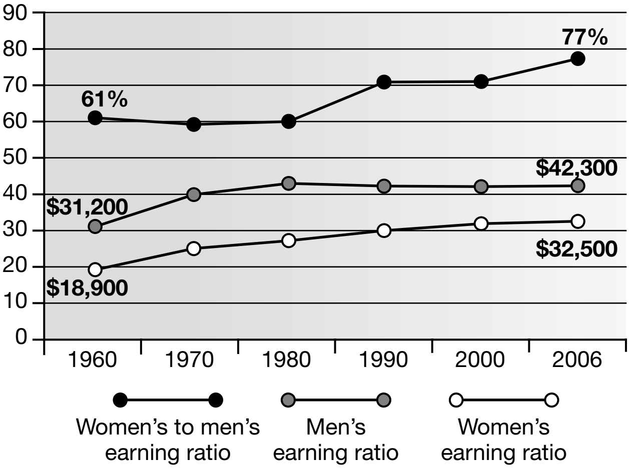
**TABLE 5–1. Earnings by Gender**

| JOB CLASSIFICATION | MEN'S EARNINGS | WOMEN'S EARNINGS |
|---|---|---|
| Legal occupations | $105,200 | $53,800 |
| Health diagnosing and treating practitioners and other technical occupations | $100,500 | $59,300 |
| Computer and mathematical occupations | $72,000 | $62,000 |
| Architecture and engineering occupations | $70,600 | $56,600 |

**TABLE 5–2. Gender Gap: Median Weekly Earnings, Full-Time Workers, 16 years and Older, 2009.**

| EARNINGS | FEMALE EARNINGS AS % OF WHITE MALE EARNINGS |
|---|---|
| All races/ethnicities | 80.2% |
| White | 79.2% |
| African American | 68.9% |
| Hispanic or Latino | 60.2% |
| Asian American | 92.2% |

Source: Institute for Women's Policy Research Compilation of Current Population Survey Labor Force Statistics, 2009 (http://www.bls.gov/webapps/legacy/cpswktab2.htm [retrieved February 25, 2010]).



NOTE: Income rounded to the nearest $100. Full-time, year-round workers. Earnings thousands (2006 dollars), ratio in percent.

**FIGURE 5–1.** Women's-to-Men's Media Earnings Ratio and Real Median Earnings: 1960 to 2007. (From U.S. Census Bureau Current Population Survey, 1961 to 2007. Annual Social Economic Supplements.)

undergo invasive cardiac procedures.[47] Similar inequities arise in medical research. For example, a study of 22,000 physicians to test the effect of an aspirin taken every other day to prevent coronary artery disease did not have a single woman in the study.[48]

Gender biases pervade everyday life in many additional ways. For example, advertising defines how women should look and behave, far more often than is done with men. The media objectify women, segmenting them into body parts and often portraying violence against women as sexy or entertaining.[49] Against this social background, it is little wonder that the feminist movement began by lashing out at men as the principal cause of social injustice. After moving through its early stages, the movement took on the productive task of identifying strategies needed to create a more just environment for women. Yet, feminists do not all speak with one voice. Indeed, an accurate short definition of feminism is now exceedingly difficult to provide, because feminism takes so many different forms.[50]

For example, feminism that highlights equal rights for women is now called "liberal feminism," referring to liberalism in the broad Enlightenment sense, emphasizing equal rights rather than its political meaning. (Many members of the Republican Party are feminists in this sense.) Feminists who link oppression to capitalism include Marxist and socialist feminists. There are postmodernist feminists, psychoanalytic feminists, multicultural feminists, and so on. Attempting an inclusive characterization, Susan Wolf suggests that "feminist work takes gender and sex as centrally important analytic categories, seeks to understand their operation in the world, and strives to change the distribution and use of power to stop the oppression of women."[51]

To illustrate just one area of strong disagreement among feminists, recall from Chapter 2 Carol Gilligan's celebration of an ethics of care, which she linked to women's moral outlooks, and the ethics of justice (and rules) that she loosely tied to male ways of thinking. Some feminists see in Gilligan's work the promise of an illuminating new ethics focused on caring relationships, which are traditionally valued by women more than by men.[52] Other feminists, however, are highly critical of her care ethic, seeing it as reinforcing old stereotypes of women as the "gentle sex." In their view, until care is a shared endeavor, it tends to perpetuate the existing power structure that subordinates women. At the same time, many feminist ethicists agree with Gilligan that the approach to ethics that depends on universal principles ignores the social reality of women and only yields truly relevant and just outcomes to men. In fact, a new ethic is needed that gives concern and support to the oppressed, not just those whose well-being is improved. Until oppression is reduced, our continued focus on autonomy might strengthen those who are already privileged and powerful.[53]

## RACE AND RACISM

Many scientists are now convinced that the idea of biologically different races—dividing up the one human race—is itself a product of racism. Indeed, the American Anthropological Association recently called for the elimination of the term "race," finding that the category of ethnicity suffices to capture the relevant groupings. There is virtually no evidence supporting the idea of multiple biological human races, and the notion of discrete genetic packages that are unique to each race is a dangerous myth. In practice, **race,** as most commonly used, is defined by skin color, hair texture, and other appearance variables. The genetic differences between the "races" is no greater than the differences between any two persons of the same race.[54-56] In particular, the only thing skin color predicts is location of one's ancestry relative to the equator. Prior health-care research, which had described racial differences in disease and treatment, had actually most often reported differences due to socioeconomic or environmental variables.

Of course, there is a "social construction" of race, according to which individuals identify themselves and others as members of what they perceive as racial groups; for example, black, white, Asian, American Indian/Alaska Native, and Native Hawaiian/Pacific Islander. There is also a "policy construction" of race that uses racial categories to validate or refute discrimination. The policy construction is evident in, for example, Article 1, Section 2, of the U.S. Constitution, which mandated that African Americans could be counted only as three-fifths of a person for purposes of tax and representation, and the Civil Rights Act of 1964, which forbids discrimination based on "race."

In fact, the perception of race by health-care practitioners has a profound influence in health-care decisions. Even after adjusting for socioeconomic factors and for the number of physician visits and health conditions, African-American and Hispanic children are less likely to receive prescription medication than white children.[57] Also, even after statistical corrections for other variables, African-American children receive fewer surgical procedures than white children.[58]

Childhood living conditions, of which medical care is a component, have a pervasive effect on well-being and can produce a lifelong vulnerability.[59] In health care, minority-identified adults fare no better than their children. Perception of race has been a primary factor in disproportionate use of resources, involving such factors as access and delivery. For an in-depth discussion of disparate outcomes, see *Unequal Treatment: Confronting Racial and Ethnic Disparity in Healthcare* published by the Institute of Medicine.

It should be noted that disparity in health care also includes health-care research. There has been a decreasing trend to include nonwhite subjects in research studies and in clinical field trial studies.[60] Even physical therapy education is not exempt. Haskins, Rose-St Prix, and Elbaum wrote about the influence of bias in evaluating PT students' clinical performance.[61] One interpretation of this disparate treatment is that health-care practitioners often have unconscious biases associated with race. All practitioners need to be vigilant and corrective for the effect biases may have in their personal and professional decisions. The greater the racial and ethnic disparity between the population and the health-care workforce, the greater the risk the provider population will not be attuned to the needs of the population.

## AFFIRMATIVE ACTION

Nowhere are uses of social and policy constructions of race, as well as attempts to overthrow sexism, more controversial than in affirmative action programs, such as those used in entrance to physical therapy programs and in hiring and promotion of professors of physical therapy programs approved by the Commission on Accreditation in Physical Therapy Education (CAPTE). Advocates of affirmative action view it as a potent way to overthrow the continuing legacy of racism as well as sexism. Critics regard it as a self-contradictory attempt to seek justice by imposing injustice.

In its original meaning, affirmative action referred to taking positive steps to ensure equal opportunity for minorities and, subsequently, women. When President Kennedy took office, he issued Executive Order 10925, which stated in part that "The contractor will take affirmative action to ensure that applicants are employed, and that employees are treated during employment, without regard to their race, creed, color, or national origin."[62] Quickly, however, affirmative action came to mean giving preferences to members of these groups, whether in hiring, promotion, education, or training programs.[63]

**Weak preferential treatment** means providing the advantage to members of these groups when they compete against white males having comparable credentials. **Strong preferential treatment** means giving women and minorities an advantage even when they are less qualified than white males with whom they are competing. Both forms, especially the strong form, are controversial.

Initially, quotas were developed for the specific percentages of jobs or college admissions that should be offered to minority candidates. The spirit behind the movement was to end the disadvantages that minorities and women had suffered for generations and to do so in a timely manner, recognizing the subtle and often covert methods of continuing discrimination. However, rigid quotas were struck down as unconstitutional in the 1978 Supreme Court case of *Regents of the University of California v. Bakke.* The court ruled that an employer or university could use race as a factor in the selection process to achieve greater racial parity, but it could not use race as the only factor. Nor could it set rigid percentages of placements. Thus, affirmative action—which is a host of agency regulations, court decisions, and legislation—has been shaped by the intersection of the Constitution, the Civil Rights Act of 1964, and the Voting Rights Act of 1965.

Currently, the Office of Federal Contract Compliance regulation states that "regulations expressly forbid quotas or giving less qualified workers preference based on their race or sex."[65] However, under current federal guidelines, any business that receives federal funds, which includes most major corporations, hospitals, and educational facilities, must keep records of the number of women and minorities at each strata of the organization and then do comparisons with the hiring pool in that area or employment catch-basin. If there is a great discrepancy between the two, then the employer may initiate preferential hiring and promotion.[64] A court can impose these practices on a private employer and on state and local governments. At present, affirmative action plans contain one or any mixture of the following.[65]

1. Outreach programs that identify and recruit qualified minorities for opportunities;
2. Aid through financial incentives or technical assistance;

3. Mentoring that guides or coaches qualified candidates;
4. Treating race as an advantaging factor in the selection process.

Some are now predicting that affirmative action is destined to be abolished by the Supreme Court.[66] Nevertheless, affirmative action continues to be vigorously debated in the United States, with some in ardent support and others in bitter opposition.

Supporters of affirmative action contend that it is a powerful way to respect the rights to equal opportunity of women and minorities. It does so by providing a counterbalance to the lingering sexism and racism in society. Institutionalized racism and sexism have not entirely disappeared, and race and gender biases continue to operate, consciously or unconsciously, in social and resource allocation. In addition, defenders of affirmative action believe the only way to overcome the unearned privileges of the white majority, which historically were largely financed by the exploitation of minorities, is to compensate through race-conscious decisions in education, employment, and political apportionment.

Opponents of affirmative action admit that the history of racial bias in the United States is a tragedy, but they contend that the past cannot be corrected by using the same methods that created the disparity. In their view, violating the rights of white males merely compounds injustice, as two wrongs do not make a right. To be sure, specific individuals who have been wronged have a right to compensation but not by giving advantages to entire groups. The victims of the past are rarely the beneficiaries of corrective actions today, and those victimized through lost opportunities were rarely the perpetrators. Moreover, preferential treatment programs are an insult to minorities: these programs create the social stigma that minorities and women cannot successfully compete without an advantage. The hostility these actions cause in whites, combined with the feelings of inferiority internalized by minorities by these methods, only deepen the race-conscious feelings. In the long run, affirmative action promotes rather than opposes racism by generating a backlash of resentment and hostility.

Whether the supporters or opponents have the stronger case will be left as a Discussion Question, but we add a few further comments about the social controversy. At present, the social, political, and business responses to affirmative action vary widely. In 1997 California, in Proposition 209, amended the state constitution to forbid affirmative action preferences in hiring, contracting, and education. The state of Washington has taken a similar action. Eastman Kodak and many other companies have voluntarily initiated affirmative action programs because they believe it is imperative to match their consumer base in order to be market savvy.[67] Proctor & Gamble has a voluntary aggressive affirmative action program that not only recruits and hires minorities but also creates career pathways to move minorities up the management ladder.[68] Most universities remain convinced that racial diversity on campus has an important place in the educational process. *Academe*, which is the Bulletin of the American Association of University Professors, reports that nearly two-thirds of faculty believe that students benefit from racial and ethnic diversity on campus and that their universities value that diversity.[69]

The Supreme Court has offered several comments to the effect that diversity on a college campus is a legitimate goal. For example, Justice Powell asserted that diversity is vital to the "robust exchange of ideas" and that the selection of diverse students, who are expected to contribute to the academic community, was a permissible constitutional goal.[70] Former Justice Sandra Day O'Connor stated in *Wygant v. Jackson Board of Education* that "a state interest in the promotion of racial diversity has been found sufficiently 'compelling' at least in the context of higher education, to support the use of racial considerations in furthering that interest."[70]

Some have argued that academic programs for health-care professionals have a special and perhaps compelling need for affirmative action. K. Deville proposes that there are three related reasons why diversity in medical education may be considered a "compelling state interest":

- It will increase the number of physicians who serve traditionally underserved patients and specialty areas,
- It will promote the robust exchange of ideas in medical education, and
- It will result in better medical care for minorities.[70]

At least five recent major research studies conducted since the 1978 Bakke case consistently show that minority physicians tend, in far larger percentage than their white colleagues, to practice in minority communities where there are insufficient primary care physicians and where they are more likely to serve Medicaid and uninsured patients.[71-75] Because the health of citizens is a compelling concern for government, then methods aimed at unmet needs should be supported when congruent with the law.

The profession of physical therapy might have especially compelling reasons for pursuing an affirmative action plan with regard to race. Although the United States is becoming more ethnically diverse, the field of physical therapy does not have proportional diversity among its practitioners. According to 1993 U.S. Bureau of Labor statistics, only 8.7% of physical therapists were from minority groups. Unlike nursing training programs (15.4% minority), physician assistant programs (17.5% minority), and chiropractic programs (12.6% minority), which have similar prerequisites, similar curricula, and entry-level health-care degrees, there were proportionally fewer minority students enrolled in physical therapy programs (3.7% minority).[76] By 1999 the minority membership in the APTA was 8.9%, and the minority student enrollment for 1999–2000 was 12.9%.[77] Although there were undoubtedly multiple factors at play, at least part of the success must be attributed to affirmative action strategies compiled and offered to all physical therapy educational institutions by the APTA. These strategies included various outreach programs, such as informational sessions targeted to minorities, and minority recruitment efforts. Still, these data suggest that minorities remain underrepresented in physical therapy.

Although progress has been made, there is a growing difference between the population composition by race and ethnicity than is currently represented in physical therapy. **Figure 5–2** gives the expected population percentages for 2010.[78] **Figure 5–3** addresses the racial and ethnic components of the physical therapy population as recorded by the 2000 census.[79] **Figure 5–4** demonstrates that the student population will not likely change the 2000 ethnic mix in physical therapy in the foreseeable future.[80] **Figure 5–5** compares physical therapy with other health professions.[81]

To conclude, cultural competency requires far more than simple tolerance. It requires an understanding that can only be achieved by recognizing institutional, cultural, and personal biases. These biases negatively affect some individuals and unfairly advantage others. Whether overt or covert, prejudice can affect health-care decisions unfairly. Such errors perpetuate the cycle of oppression that has prompted such remedies as affirmative action and the Americans With Disabilities Act.

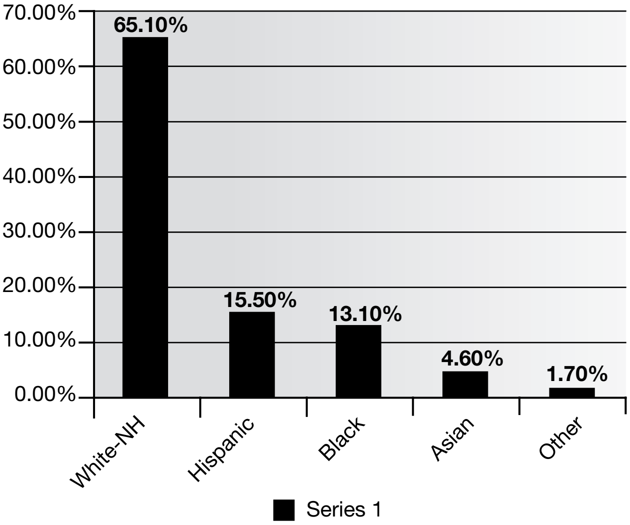


**FIGURE 5–2.** U. S. Race and Ethnicity 2010. (Adapted from U.S. Census Bureau, U.S. Interim Projections by Age, Sex, Race, and Hispanic Origin: 2000–2050. Available at www.census.gov/population/www/projections/usinterimproj/)

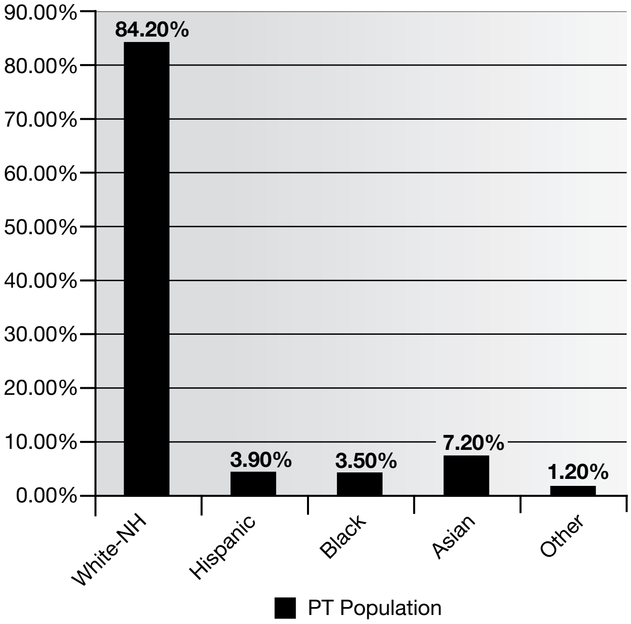


**FIGURE 5–3.** Physical Therapy Race and Ethnicity 2000. (Adapted from U.S. Census Bureau, Census 2000 EEO Data Tool: EEO Residence Data Results for Total U.S. Available at 222.census.gov/cgi-gin/broker)

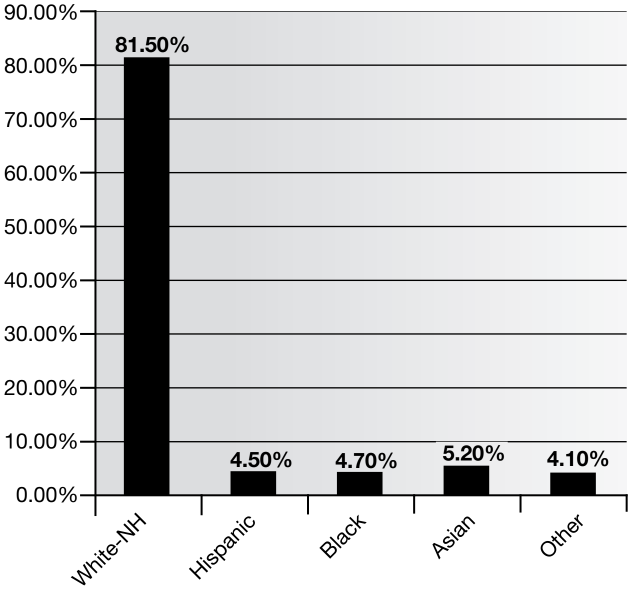


**FIGURE 5–4.** Student PT Race and Ethnicity. (Adapted from CAPTE, Fact Sheet 2007–2008. Available at http://www.apta.org/AM/Template.cfm?Section=Logout&TEMPLATE=/CM/ContentDisplay.cfm&CONTENTID=51040)

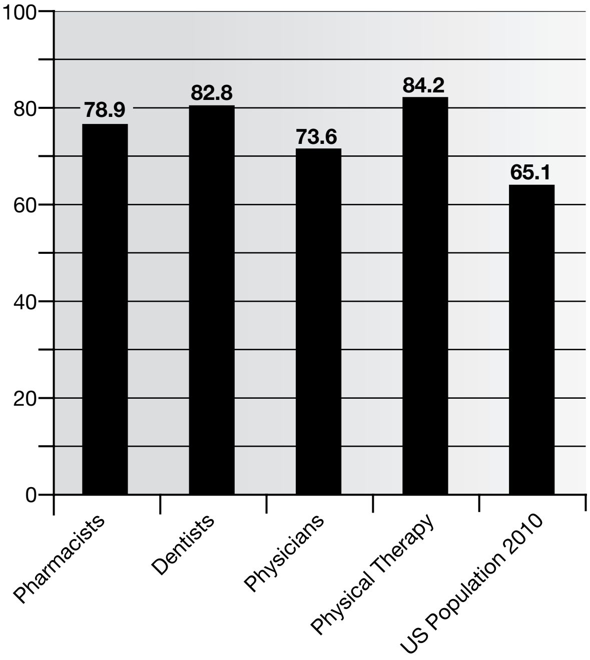


**FIGURE 5–5.** White Non-Hispanic Population of Selected Health Professionals. (Adapted from US Census Bureau, EEO Residence Data Results for Total U.S. Available at 222.census.gov/cgi-gin/broker)

## DISCUSSION QUESTIONS

1. How is cultural diversity treated on your campus, and how have you experienced it in hospital and rehabilitation settings up to this point in your education? Specifically, was diversity avoided, tolerated, or celebrated, and were different elements of diversity treated differently? For example, have you seen disparate treatment at your university and in hospital or rehabilitation settings for women, African Americans, Latinos, Asians, and gays and lesbians?

2. Discuss the Orange County physician in Case 5.6 who declined to provide future health care to his patient. Is a health professional who feels uncomfortable touching a gay person prejudiced and homophobic, in the sense of having an irrational fear or hatred of gays? Is your answer the same about a health professional who is uncomfortable about touching Jewish people? Can it reasonably be argued that the physician has a right to exercise his beliefs about homosexuality, particularly if his attitudes are linked to religious beliefs that homosexuality is "unnatural"? Exactly what does "unnatural" mean in this context, and is calling homosexuality "unnatural" itself a sign of bigotry, whether at the level of individuals or organizations (such as religions)?[82]

3. Discuss the kinds of questions a feminist might raise with respect to the following case: "A seventy-two-year-old woman with leukemia is considering whether she should refuse a second course of chemotherapy and wait for death with only home care and no further medical intervention."[83] The medical staff serving the woman is mostly male. The woman has spent a lifetime of service to others and feels reluctant to be a burden on her daughter.

4. Present and defend your view about whether affirmative action, in any form, is morally justified or unjustified, both in general and in regard to physical therapy. Whatever your position, take into account alternative proposals for remedying the lingering effects of racism and sexism in society.

5. In the following case, written by Katharine Parry, discuss how therapy might become complicated due to the patient's religious beliefs. How might those complications be dealt with in a manner that respects the patient's beliefs while providing quality care? "An elderly Cuban woman is diagnosed with rheumatoid arthritis. As a priestess in the Santeria sect, she believes that the cause of her disease was a spell—cast by another person—that she had 'stepped into' by mistake. She believes that by her accidental intervention, she prevented the death of the individual for whom the spell was intended. She believes her personal power reduced the power of the spell to something less dangerous."[84]

6. Critics argue that society has gone too far in the direction of demanding "political correctness" by sanctioning an officially proper way of talking. They contend, for example, that there is nothing wrong with speaking of a person as "a victim of" or "suffering from" multiple sclerosis (instead of saying "has multiple sclerosis"). They acknowledge that this manner of speaking accents the disability and the problems it causes, but in fact those problems are genuine, and politically correct language only leads to an elaborate game of pretense that disguises genuine problems and tragedies. Also, critics suggest it is perfectly acceptable, as a convenient abbreviation, to speak of "the stroke" in the next room or in intensive care, as long as such language is not used in front of the person involved or other patients. What would you say in reply to these critics?

7. Some critics argue that the productivity and competitive edge of American business is being seriously damaged by

excessive government regulations, including those of the ADA. What moral arguments can be marshaled for and against their position, and what is your view?

8. In small groups, make a list of the unearned privileges enjoyed by white males in society. How much consensus do you find in your group on this issue?

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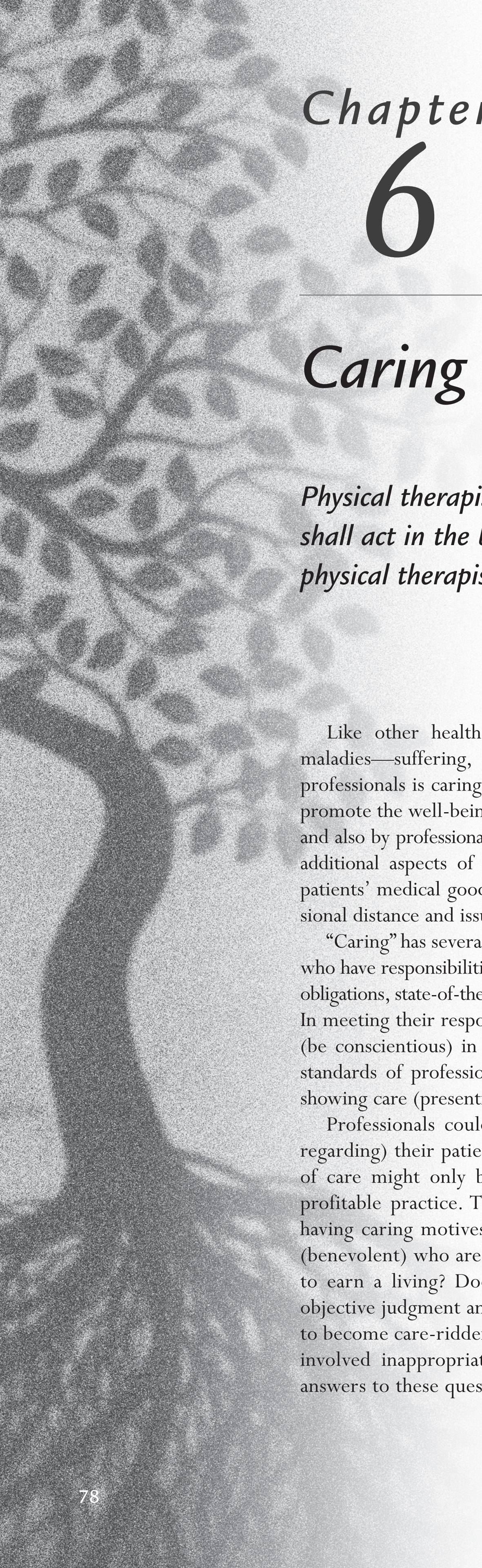

# Chapter 6

# Caring for Patients

***Physical therapists shall adhere to the core values of the profession and shall act in the best interests of patients/clients over the interests of the physical therapists.***

Principle 2A, APTA Code of Ethics

Like other health-care professions, physical therapy exists as a caring response to human maladies—suffering, disease, injury, and disability. Accordingly, the central norm for health-care professionals is caring, or what is called the **principle of beneficence:** the moral requirement to promote the well-being of patients. Caring for patients implies and is limited by respect for autonomy and also by professional standards of "due care," as discussed in chapters 2 and 3. Here we take up several additional aspects of caring for patients: patients' experience of illness; the interaction between patients' medical good and their total good; and spirituality. We also discuss questions about professional distance and issues of character and the role of caring motives in promoting health care.

"Caring" has several relevant meanings. Health-care professionals are caregivers (service providers) who have responsibilities to take care of patients (provide appropriate services) according to contractual obligations, state-of-the-art standards of competency in the profession, and respect for patients' autonomy. In meeting their responsibilities, therapists must be careful (cautious) in dealing with risks, take care (be conscientious) in meeting responsibilities, and exercise due care (reasonable caution) to meet standards of professional competence. Their work requires developing good "bedside manners" in showing care (presenting themselves as concerned and considerate).

Professionals could "show care," however, without genuinely caring about (being benevolent regarding) their patients—in other words, without having positive attitudes toward them. A show of care might only be an elaborate game of appearances and pretense aimed at maintaining a profitable practice. That is, professionals could engage in helping actions (beneficence) without having caring motives and character (benevolence). Should therapists aspire to be caring persons (benevolent) who are genuinely concerned to help patients for the sake of patients, and not simply to earn a living? Does such caring tend to interfere with the professional distance needed for objective judgment and successful coping with the stresses of work? Does caring cause professionals to become care-ridden (burdened with anxiety), to be debilitated by "compassion fatigue," and even involved inappropriately (either emotionally or sexually) with patients? We will work toward answers to these questions in this chapter.

## EXPERIENCES OF ILLNESS

It will be helpful to distinguish between a malady and an illness.[1,2] A **malady** is a negative medical condition, such as pain, disability, injury, disorder, loss of freedom, loss of pleasure, dying, or an elevated risk of suffering such harms. An **illness**—or feeling ill—is how a malady (or what one believes is a malady) is experienced by an individual. Accordingly, persons might be diseased or injured but not ill. For example, a person may have degenerative lumbar disk disease but not experience low back pain or other symptoms of illness, and a person might have hypertension without conscious symptoms of the disease. Conversely, persons can be ill but not diseased, which is true of hypochondriacs, who genuinely suffer distress even though they have no actual physical malady.

The distinction between maladies and illnesses is blurred, and some maladies are partly defined by experiences of illness. Thus, many mental disorders are defined by experiences such as chronic depression, paranoia, or phobia. Severe physical pain can be both a symptom of a disease and a critical component of the illness experienced. In theory, however, there is a difference between disease or injury (which is objectively defined) and experience of illness (which is subjectively defined). Of special interest is the fact that individuals might experience essentially the same malady in strikingly different ways, depending on attitudes, culture, emotions, and beliefs.

Pain is one of the most important determinants used in a therapist's decision about both intensity and duration of treatment, making the clinician's understanding of a patient's perception of pain an important factor. Sometimes, for example, chronic-pain sufferers have an elevated pain threshold, resulting in the underreporting of pain. This, in turn, misleads therapists to believe they are operating within normal physiological limits, when in fact they are overtreating. Conversely, there are patients with such a low threshold for pain that the equivalent of a needle prick prompts them to discontinue therapy. Understanding pain is critical to appropriate health-care delivery.

It is important to distinguish suffering from physical pain. Just as illness is the way in which a malady is experienced, suffering is one way an illness is interpreted by individuals. While physical pain can be explained by neurology, suffering is the interpretation of physical pain by the individual, and hence it is better illuminated by the psychologist. Suffering, Cassell suggests, is "the severe distress associated with events that threaten the intactness of person."[1(p33)] More fully, "suffering occurs when an impending destruction of the person is perceived; it continues until the threat of disintegration has passed or until the integrity of the person can be restored in some other manner. It follows, then, that although it often occurs in the presence of acute pain, shortness of breath, or other bodily symptoms, suffering extends beyond the physical. Most generally, suffering can be defined as the state of severe distress associated with events that threaten the intactness of person."[1(p33)]

In our view, Cassell's definition focuses on the most severe forms of suffering, but there are many milder forms as well. His definition does, however, help us clarify a phenomenon often seen in patients following a severe trauma. The idea of suffering as a threat to the entire person applies to many patients treated by the physical therapist, because patients often feel threatened by a change in their physical functioning. When they are without the core of their familiar self, which can be drastically changed by pain or disability, they are confused and disorganized and experience what Cassell calls a "loss of central purpose." They are unable to focus on creating a revised (long- or short-term) self-definition until the suffering is relieved or diminished.

The first step in reducing suffering and pain is to acknowledge their presence. Even when the therapist cannot fully understand another person's suffering, the therapist can be respectful of it and offer hope, both through compassion and the application of professional skills. Once suffering is reduced to a manageable level, the patient can effectively undertake the rehabilitation process.

The way to initiate an assessment of pain and suffering is through an **illness narrative**—a verbal account of an illness, whether brief or extended, written or spoken.[3-6] Narratives, in general, are stories (interpretations) about events and relationships, challenges and achievements, and other aspects of life. Meaning (or significance) is a combination of intelligibility and value; it is a making sense of life in light of one's values. Illness narratives, then, are interpretations of experiences of health problems.

As an illustration of the manner in which caring for patients involves sensitivity to their experiences of illness and suffering, consider Oliver Sacks' illness narrative, *A Leg to Stand On*, aspects of which are described in the following case.

### CASE 6.1 Dr. Oliver Sacks

Dr. Sacks, a distinguished psychiatrist, underwent his first major experience as a patient when he severely injured his left leg, tearing the quadriceps from the patella, ripping the cruciate ligaments, and causing major nerve damage that paralyzed the entire leg with the exception of some motion in the toes. The accident occurred during a solitary hike on a mountain in Norway. Encountering an enormous bull, he ran in panic and was injured falling from a cliff. He managed to drag himself for hours until he was rescued by some hikers. Airlifted to England, he underwent a major operation.

For a frightening 2 weeks he was left without any sensation in the injured leg, although he could wiggle his toes. Indeed, he experienced the leg as an alien appendage, something attached to his body but not part of it. This strange experience had a deep impact on his general self-conception, dislocating his sense of who he was. These odd and alarming feelings were compounded by being thrust for the first time into the passive role of a hospital patient governed by prison-like requirements of impersonal clothing, identification bracelets, and strict structuring of his time. Fortunately, sensation in the leg gradually returned, followed by quick flashes of extreme pain. At that time he began a course of physical therapy that would eventually restore normal function. The experience of recovery transformed both him and his understanding of the role of health professionals.

Despite his years of experience in medicine, he was shocked to encounter in his surgeon a brusque “mechanic” who had no interest in him as an individual. When Sacks tried to convey his alarming sense of alienation, both from the leg and from his sense of self-identity, the surgeon “didn’t even listen to me. He showed no concern. He doesn’t listen to his patients—he doesn’t give a damn.”[7] In the few and brief times the surgeon visited, he dismissed Sacks’ attempts to communicate his fears and uncanny feelings, bluntly saying he was a busy and a practical man and then walking out of the room. In retrospect, Sacks believed he might have been somewhat unfair to the surgeon and that perhaps their formal roles were preventing both of them from making human contact.

* * *

We do not know how Sacks’ physician would respond to this assessment, but we can imagine that he might have responded that he did indeed care about Sacks; it was just that he had many additional patients who also needed his time. If he engaged with patients and spent more time with each, fewer patients would be seen. Although those fewer patients might feel better about him, his surgical performance probably would not have been enhanced by the exchange. He might contend that he should consciously focus his time only on that which is relative to his task, surgery, which is based in anatomy and physiology. Certainly in the current managed care environment with its high demands on productivity, professional detachment might serve to achieve the completion of some tasks most efficiently, as we discuss more fully later in this chapter.

Patients generally expect, or at least hope for, personal concern from health-care professionals. That concern might mean empathy, sympathy, compassion, and caring. **Empathy** is sympathetic identification with others. It combines cognitive understanding of what others are feeling with at least some tendency to respond with interest rather than indifference. As one writer states, “empathy means ‘I could be you,’” but it also implies something more than indifference or cruelty.[8] In some contexts empathy involves vicariously experiencing what others are feeling and thinking, but it need not always mean having emotions paralleling what others are feeling. (In a weaker sense, empathy is simply understanding what others are feeling, without any sympathetic response to them. In this sense, sadists might have empathy for their victims.)

**Sympathy** is an emotion of concern for others’ difficulties and especially a sharing of their sorrows or suffering. **Compassion** is deep caring in response, specifically, to suffering. Empathy, sympathy, and compassion are all manifestations of caring, an emotion of direct concern for others’ well-being, with an active disposition to contribute to their well-being.

All these forms of personal concern were manifested by the physical therapists who worked with Sacks. For example, when the day came to attempt his first walk, the therapists gently urged him to stand, encouraging him with both practical advice and good humor suitable to the occasion and to the particular patient: “Come on, Dr. Sacks! You can’t stand there like that—like a stork on one leg. You’ve got to use the other one, put weight on it too!”[7(p138)] When he was seized by terror as he began to fall, he cried out to the therapists, “Hold me, you must hold me—I’m utterly helpless.” The therapists calmed him: “Now steady yourself—keep your eyes up.” Sacks replied that he was unable to move the leg and, to his astonishment, he had utterly forgotten how one walks. In response, one therapist “wordlessly moved my left leg with her leg, pushing it to a new position, so that it made, or was made to make, a sort of step. Once this was done, I saw how to do it. I could not be told, but could instantly be shown.”[7(p143)] Throughout the process, the therapists were gentle but persistent, conveying a firm sense that “one must ‘get on with it,’ one must proceed, one must take the first step.”[7(p142)]

When Sacks finally managed to take that first step, motion returned rapidly. Full convalescence, however, took many weeks of gradually strengthening both muscles and physical self-control. It also required grappling with emotional disturbances that for Sacks were out of character. As his earlier terror diminished, he felt venomous spite, bouts of anger and irritation, and resentment at the more healthy patients in the convalescent center. Here again he credits a physical therapist with helping him: “When I started on the physiotherapy program, and the therapist was affirmative and profoundly encouraging, giving me the feeling that I might hope for a virtually complete recovery, I discovered that the hateful feeling was gone.”[7(p178)]

Sacks concludes his illness narrative by reflecting on how modern medicine, with its fixation on physiological processes, has lost contact with "the experiencing, suffering patient."[7(p205)] He calls for something like a "neurology of the soul" to restore an appreciation of listening to patients, of engaging their experiences as part of the therapeutic encounter. For the patient, convalescence is more than a matter of improving muscle tone and range of movement; it is also a matter of confronting fear, suffering, and vulnerability and of needing help in summoning realistic hope.

Physical therapists are not trained as psychotherapists. It would be presumptuous for them to take on the role of "neurologists of the soul," although they should have an awareness of when patients need help from a psychotherapist. Yet, like all health professionals, physical therapists treat their patients as people when they are sensitive to emotional aspects of suffering, in addition to physical pain. A comprehensive ethical framework requires that therapists attend to the whole person, not just to body parts or systems in need of repair. From this perspective, caring is not a "bonus" in good health care but is, instead, essential, for two reasons. First, caring makes the therapist attentive to patient needs and leads to the subtle individualized feedback that is essential for personalized and effective treatment. Second, caring enhances therapists by continually expanding the ability to feel a connectedness with patients—and indeed with the profession.

## MEDICAL GOOD AND TOTAL GOOD

One important dimension of caring is sensitivity to how patients' medical good relates to their total good. For each profession, a **profession-specific good** can be defined by the relevant professional service; for example, in law it is a client's share of legal justice; in education it is a student's growth in understanding and skills; and in investment professions it is a client's growth in income.[9] Patients' **medical good,** then, is the patients' well-being measured in terms of health. In contrast, patients' **total good** is their overall, unified well-being. It includes health but also involves many more elements such as happiness, valuable personal relationships, meaningful work, financial security, enjoyment of beauty, and, for many, religious or spiritual involvements.

Clearly, the contrast between medical and total good depends upon what is meant by "health." Conceptions of health differ, in both general outline and specific detail, and these differences reflect different understandings of the appropriate scope of health care. At one extreme is the World Health Organization (WHO), which defines health as complete physical, mental, and social well-being. This definition essentially collapses the distinction between medical and total good. At the other extreme is the concept of health as simply the absence of organic maladies.

We will not attempt a precise definition of health, leaving that definition as a discussion topic. We endorse, however, a holistic conception of health as biopsychosocial and as involving more than the mere absence of disease and injury. Nevertheless, health does not encompass the entirety of well-being, contrary to the WHO definition, because health does not include all aspects of such things as financial well-being or happiness in relationships.

Allan H. Macurdy's illness narrative will help clarify the distinction between medical and overall good as well as raise questions about how they are related.

### CASE 6.2 Allan H. Macurdy

At age 8 years, Macurdy was diagnosed with Duchenne's muscular dystrophy. His parents were told that the deterioration of his muscles would likely cause his death by age 15. His childhood remained relatively normal, punctuated by monthly visits to a physical therapist and an orthopedist. By adolescence, however, the normal challenges of becoming independent were compounded by frustration when he would fall down climbing stairs and need help to regain his stability. For a while he was consumed with rage and bitterness, believing he had only a few years to live. Gradually these feelings subsided, and by the end of junior high school he was learning to cope with his disability. The early death sentence turned out to be mistaken. He completed college, earned a law degree, and become a practicing attorney.

Macurdy reports that one experience in particular became a parable for him about how health professionals often fail "to consider the person behind the symptoms."[10] Two days before he was scheduled to take the bar exam, he had extreme difficulty breathing and was diagnosed with pneumonia. Antibiotics and chest physical therapy proved insufficient to restore breathing. Given the complications caused by the muscular dystrophy, the physician decided to place him in an iron lung. Already frightened, Macurdy became terrified and claustrophobic. The physicians who might have alleviated his fear failed to offer even minimal words of comfort. Instead they "trivialized and excluded" him with perfunctory remarks and "chattered on among themselves with great enthusiasm about arterial blood gas levels, titer volumes, and the comparative advantages of negative versus positive pressure ventilation."[10(p11)] Only one nurse intervened to talk with him and lower his anxiety, responding to him as a person rather than merely an interesting medical problem.

Macurdy's narrative reminds us that to provide health care for people requires listening to them, engaging them as participants in a healing process, and respecting their autonomy in making decisions about the course of their therapy. It also reminds us that listening to patients can be integral to treating their medical conditions. Macurdy's terror when he was placed in the iron lung compounded his difficulty in breathing, and his convalescence depended in part on being helped to manage his anxiety and strengthen his capacity for self-determination. The narrative also introduces the distinction between a patient's medical good and total good. Good health tends to promote one's total good (in addition to being part of it), but it does not always do so. Unless one elevates health to a supreme value that overrides all other values—a morally dubious gambit—maintaining health must sometimes be weighed and balanced against other goods. Macurdy writes, "Health care is a means to a full and meaningful life; it is not an end in itself. But because the professionals deal only with the medical aspects of my life, they often lose sight of the impact of their recommendations on my career, home life, and relationships."[10(p14)]

In particular, his care providers continually urged him to exercise greater caution. For example, because he had a tracheostomy, Macurdy is especially susceptible to infections, and because his chest muscles have deteriorated, infections easily develop into pneumonia. But carried to their logical extreme, the attempt to eliminate all risk would lead to life in a bubble: "I would not be able to teach, represent clients, see friends, have an intimate life with my wife, play with my nephews and godchildren, or hug my dog. In other words, all those things that give my life value, purpose, and meaning would be sacrificed in order to protect me from infections that might kill me."[10(p15)]

Should the goal of health-care professionals, then, be to promote patients' total good or simply their medical good? Robert Veatch suggests that both goals are problematic in some respects: "If the goal is total well-being, no physician can be expected to be able to be skilled in all aspects of living well. But if the goal…is medical well-being, one has to recognize that no rational patient wants to maximize his or her medical well-being at least if it comes at the expense of other goods in life."[11] That is, on the one hand, health professionals are not trained to promote patients' overall good, the good that involves all major aspects of life, from finances and law to family and friendship. On the other hand, solely to maximize medical well-being would constitute a kind of fanaticism regarding only one aspect of life, however important that aspect is.

The resolution of the conundrum, as we see it, is that patients have the right and the responsibility to balance medical good against other goods, in forming their autonomous views about what is reasonable for them. For their part, health professionals must respect the autonomy of patients. Thus, a physical therapist should encourage patients to sustain a rigorous regimen to restore maximum function of an injured limb, just as a physician should urge patients to stop smoking and exercise more. But therapists and physicians alike must accept the patient's right to weigh these medical goods against other important demands, such as earning a living. Therapists cannot, however, expect patients to make the cognitive leap from selected treatments to functional outcomes. Care for patients involves explaining the relationships between what the therapist does and the patient's defined total good.

## SPIRITUALITY

Spirituality has re-emerged as an important topic regarding the healing process. We say "re-emerged" because, in its earliest forms, medicine was practiced by healers who were usually religious leaders as well. This was certainly true of the American Indians, and it was also the practice in Europe.[12] As medicine developed a separate identity rooted in science and technology, it tended to focus on physical well-being in abstraction from psychological and spiritual well-being. In addition, especially in the United States, the entrepreneurial model of health-care delivery superimposed a business relationship over the traditional healing partnership.[13] Medicine became increasingly successful at remedying physical ailments but sometimes left anxiety and suffering unabated.

It became clear, however, that physical well-being and recovery are often linked to the psychological state of the patient. The mind-body connection underscores the profound ways in which attitudes and behaviors influence physical ailments and recovery. More recently, some theorists and practitioners find the mind-body model inadequate because it neglects the spiritual domain (or reduces it to the psychological domain). "Holistic" medicine increasingly recognizes the interrelatedness of body, mind, and spirit. This recognition of spirituality is part of respect for patient autonomy and is required in a model of health-care delivery that is culturally competent and relationship based.

In elaborating on the body-mind-spirit concept of holistic care, scholars distinguish between religion, religious spirituality, and spirituality **(Fig. 6–1)**. Religion is a shared set of beliefs and practices, formalized through an institutional structure. Religious spirituality is a subset of spirituality that is guided by the institutional religion's beliefs and practices. What, then, is spirituality?[14,15] According to one definition, it is "the human propensity to find meaning in life through self-transcendence, a sense of relatedness to something greater than the self which may or may not include formal religious participation."[15]

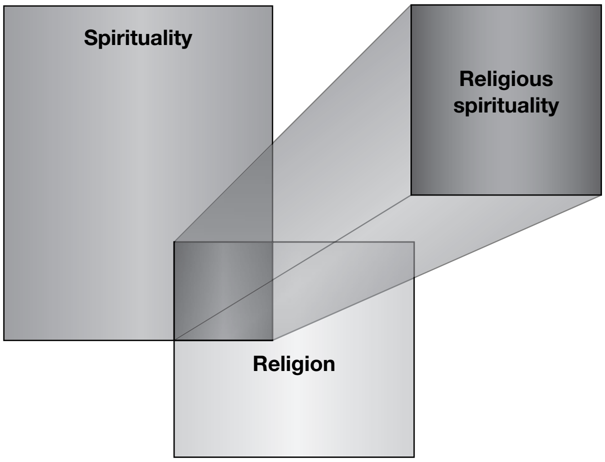

**FIGURE 6–1.** The relationship between spirituality and religion.

The relevant self-transcendence need not involve belief in a supernatural deity; there are entirely secular forms of spirituality, such as what Robert Solomon calls "the thoughtful love of life."[16] As such, spirituality centers on three major themes:

- Transcendence, a theme that is usually, although by no means always, joined with a belief in a divine consciousness or universal spirit that goes beyond the immediate in time or space.[17,18]
- Self-awareness that evolves over a person's lifespan.[17,18]
- Connectedness between oneself and all others, often including all nature. This connectedness relates to transcendence and is a part of self-awareness.[14,15,19]

Additional themes include the following:

- Spirituality is both deeply personal and at the same time universal; everyone shares in a sense of spirituality regardless of religious beliefs or lack thereof;[13,15,18,20]
- Empathy, trust, and gratitude;[19]
- Spirituality is often the core of how people define their purpose and meaningfulness in the world and is a source of inner strength;[17,20,21]
- All things are interconnected, a theme partly unfolded in Einstein's theory of relativity and the development of quantum physics.[15]

If one accepts a broad scientific platform for understanding the world, patients cannot be divided into discrete compartments.[22] For example, physical therapists might not be trained in nutrition, but they can hardly afford to ignore it.[23] Likewise, a therapist might not be religious, but that therapist cannot ignore patients' concerns and beliefs related to their spiritual well-being. This brings us to a broader understanding of relationship-based care discussed in Chapter 2.[22,24] In relationship-based care, there are three crucial relationships:

1. A deep respect and concern for the patient that expresses itself as a partnership commonly demonstrated by master clinicians;
2. Self-knowing and self-caring that include knowing one's own beliefs and feelings—the first step in cultural competence;
3. Interdependency of the health-care team, which increasingly includes shared responsibilities for holistic well-being, including social, emotional, physical, and spiritual well-being.

Links between religion and health have been under investigation for decades. Most studies showed positive influences when religion was used as the independent variable. All the great world religions had similar health-care outcomes.[25] Better outcomes within the religion communities, however, were among those groups that were inclusive, meaning they believed the Supreme Being is beneficent and forgiving. Worse outcomes occurred when the religion was exclusive, meaning members believed the Supreme Being is vindictive and punishing. To be sure, there were some cases where religious teachings produce very negative health effects. Examples of religious beliefs with negative and sometimes catastrophic health results are: refusing blood transfusions, refusal to accept medical help or immunizations, and rituals that withheld care or induced punishments that would rise to meet most standards of abuse and torture.

There were significant confounding variables that, once identified and controlled, changed the trend in some research outcomes. These variables included behavior prescriptions common to most religions; for example, promotion of exercise, cleanliness, dietary restrictions, avoidance of harmful drugs and alcohol to excess as well as forbidding sexual promiscuity.[26] Other variables had the added benefit of imparting hope and teaching patients how to induce relaxation through prayer and meditation. Both optimism and relaxation positively influence the immune responses and other recognized physiological pathways.[25] In addition, social support contributes to health care. But none of these variables are exclusive for the religious experience.

One could enjoy all these benefits without the structure of religion, although perhaps with greater individual effort. Moreover, once the level of scientific inquiry became more sophisticated and refined, some identified religious behaviors proved to be inconsequential (by themselves). For example, the relationship between church attendance and outcomes proved insignificant. Intercessory prayer—prayers that plead to God to intervene on the behalf of another—had no effect in most cases.[27] Prayer became more effective if persons are aware they are being prayed for, which obviously engages a new set of psychological variables.[28]

Early research tools to define and measure spiritual interactions between patients and therapists have undergone extensive revision or replacement with more reliable and valid instruments.[14,15,19,29] One of the advancements focused on the interrelatedness of all life, and now experiments are being conducted on nonhuman primates.[30] But the weight and trend of thousands of studies to date (most of which do not separate religion, religious spirituality, or spirituality) suggest there may well be an association between spirituality and health outcomes.[31] Is the association valid? "Probably."[31] "Is it causal? Maybe."[31] In his review of 1200 scientific studies and 400 review articles, Koenig found that in nearly two-thirds of cases, there was a significant correlation with mental and physical health.[25] The National Institute for Healthcare Research convened an expert panel that "concluded that spiritual/religious involvement has demonstrated to be consistently related to positive health outcomes across a variety of health domains."[28(p439)] Obviously, how these results are interpreted—are they a subset of the psychological or of additional spiritual factors?—depends on the interpreter's spiritual beliefs and attitudes. What is important is to appreciate their relevance to patients and to healing.

Given that the health system is both outcome- and consumer-driven, it is worth noting that nearly 94% of patients with religious beliefs think their spiritual needs should be addressed by their health provider when they are gravely ill, and nearly 45% of those who deny any religious beliefs agreed.[32] Patient preferences plus the weight of the evidence that correlates spiritual/religious states with health-care outcomes have caused a health systems response similar to that given when there were proven linkages between culture and health-care outcomes. As a matter of course, health-care practitioners are expected to be culturally competent, and compliance is being assured through educational and institutional accreditation, among other routes. At present, similar steps are being taken in areas of spirituality to ensure that patient needs are met appropriately. The Joint Commission currently requires the administration of a spiritual assessment.[33] Among those suggested elements (specifics are left to the facility) are questions such as the following[34]:

1. Who or what provides the patient with strength and hope?
2. How does a patient express spirituality?
3. What type of spiritual/religious support does the patient desire?
4. What helps the patient get through this health-care experience?

Health-care educational programs have responded: more than half the medical schools in the United States offer courses in spirituality that typically include instruction in conducting a spiritual assessment, including chaplains and clergy in the health-care team, and providing course content that identifies the major world-religion elements that affect health-care outcomes. A "theosomatic model" has been developed to include topics of spirituality, which include among other elements:

1. "Reviewing scientific findings on the epidemiology of spirituality and religion;
2. Reviewing case studies that illustrate harmful effects of religious beliefs;
3. Helping students explore their own spiritual perspectives as a means of promoting greater self awareness;
4. Developing skills mindful of spiritual issues in addressing the chronically ill and dying patients."[26]

Physical therapy education has also responded, driven by accreditation and patients' concerns. The majority of clinical physical therapists investigated in a doctoral study believed that spirituality was an important component of physical therapy care and that it should be included in the educational curricula.[35] Approximately half the physical therapy program in the United States had already included spiritual concepts into their curricula[36] and, given the new CAPTE accreditation standards, that number will steadily increase. New York University's physical therapy program has been a leader in the inclusion of spirituality content. The curriculum's objectives are to:

1. Promote self-understanding through defining values and biases;
2. Have students become aware of the spiritual background of their patients;
3. Incorporate a sensitivity to spiritual issues in treatment plans;
4. Apply clinically the respect that spiritual issues demand.

There are some specific ways to honor patients' spiritual and religious concerns.

1. Schedule patient treatment times around religious observances and when spiritual leaders visit patients.[37]
2. Be cognizant of spiritual issues and be prepared to refer to the appropriate resources, a chaplain if available.
3. Simply listening attentively and respectfully goes a long way in relaying respect, especially when patients speak of their spiritual resources. Understand that respect and awareness of spiritual issues does not entitle health-care providers to offer spiritual counseling.
4. Chaplains and clergy should be recognized as legitimate members of the health-care team. They deserve respect and inclusion in a holistic medical model that is relationship-based.
5. Medical team members may be requested, individually or with another provider, to do a spiritual assessment using one of many such standardized tools.[14,15,19,29]

Most frequently this falls within the duties of a chaplain, but with increasingly limited resources a medical team may have to cover some areas it has not traditionally attended. When this occurs, medical team members must be very careful not to be perceived as proselytizing any particular religious or spiritual perspective.

6. It is not uncommon for patients to request medical team members participate in prayer with them. The extent to which members comply depends on individual comfort levels. For those who do not share the patient's beliefs or spiritual resources, it is best to listen respectfully or offer to locate the appropriate spiritual resource.
7. "Medicine is not sometimes an art and sometimes a science. It is always simultaneously both art and science. Individual maladies afflict the whole person."[12]

## PROFESSIONAL DISTANCE

Not all forms of caring are desirable within professional relationships; some forms are harmful to those relationships and undermine professional distance. **Professional distance** is the idea of not becoming inappropriately involved, emotionally or behaviorally, with clients and others involved in one's work. It does not mean indifference. Instead, it is what Aristotle called a mean between extremes: neither excessive or inappropriate involvement with clients (underdistancing) nor absence of caring engagement (overdistancing).[38,39] Professional distance is both a moral concept that refers to heeding professional responsibilities and a psychological concept that alludes to managing emotions and attitudes.

Oliver Sacks' surgeon illustrates overdistancing. The surgeon had difficulty relating to his patients as persons. Perhaps he treated them as little more than interesting technical problems to challenge his medical skills; in any case, he did not listen with sympathy. A more subtle example of overdistancing is pity, which should not be confused with compassion and sympathy. Compassion and sympathy are caring responses to other human beings as moral equals. Compassion and sympathy are based on a sense of human solidarity, a sense that the patient is in an unfortunate situation that might also happen to the health-care provider and that the patient would benefit from concern for renewed well-being as a fellow human. In contrast, pity is a distorted form of caring that involves looking down on patients, often as a way of overdistancing oneself from their plight.

Underdistancing can cause equally severe problems, as professionals become emotionally enmeshed in their patients' suffering. Health professionals often deal with patients who suffer great pain, are disfigured, or are severely disabled. These problems are often compounded by personal crises involving finances, family relationships, and psychological traumas. Caring professionals may be drawn too deeply into these problems in ways that can harm professionals and patients alike. Patients might be harmed by professionals' loss of objectivity in making therapeutic judgments, and professionals might inadvertently foster harmful forms of dependency rather than encouraging independence. In turn, professionals might be harmed by becoming so preoccupied with their patients that they take their work home with them in ways that undermine a healthy personal life. "Compassion fatigue" is a familiar consequence of excessive emotional involvement with patients.

As an example of just how subtle the loss of professional distance can be, consider the following case.

### CASE 6.3 Health Care as Reassurance

Karen Jarvis is a 78-year-old woman who has spent the last two years in a nursing home.[39(p209)] During the past two months, following a stroke, she received physical therapy for gait training with a walker and for acquiring more functional activities of daily living. Her physical therapist, Steve Clayton, knows that Mrs. Jarvis has reached a plateau stage in which continued physical therapy is unlikely to have any physical benefits, and he informs Mrs. Jarvis of his assessment. Mrs. Jarvis protests, insisting that she feels much improved after each therapy session and implores Steve to continue working with her. Steve is willing and eager to do so. He knows that Mrs. Jarvis has no family or other visitors and that the therapy he offers undoubtedly has a positive impact on Mrs. Jarvis's overall health. He also looks forward to working with her, simply because he enjoys doing so. Medicare will continue paying the bills for physical improvements but not for mere psychological reassurance. At the same time, Steve believes he is working in the gray area where a patient's positive attitude and sense of well-being can themselves bring physical improvements or at least slow down physical deterioration.

As this case suggests, the skills of physical therapists include more than applying medical knowledge. They include constructive personal responses to patients in establishing, modifying, and ending clinical encounters. Clinical competence includes both knowing and caring. As the example also suggests, caring is a complex idea that can point in conflicting directions. Would the caring response be to focus on therapies directly linked to physical benefits, or is it permissible to consider the psychological benefits of therapeutic procedures?

Partly from fear that health-care professionals will lose objectivity, Curzer argues that they "should be no more emotionally attached to their own patients than to someone else's patients or to the proverbial man on the street."[40] In order to have a good bedside manner, they should learn to pretend to care for their patients without actually caring: they "should act *as if* they are significantly emotionally attached [to their patients], but in fact should involve their feelings relatively little....They should hug patients who need to be hugged. But they should not really care."[40(p62)]

Curzer directs his arguments to physicians in hospitals, but they pertain to many additional health-care contexts. He argues that caring generates problems in at least six ways. We believe he identifies genuine dangers, but in each case we find his conclusions unpersuasive.

First, Curzer argues that forming emotional attachments, unwanted by patients, invades patients' privacy.[40(p56)] In reply, respect for patients' autonomy includes respect for their desires not to have emotional expressions and demands forced on them. But that merely indicates that some expressions of emotion are inappropriate, not that the emotions themselves are undesirable. Imposing emotional involvement against a patient's desires shows insensitivity and an absence of the virtue of caring.

Second, Curzer argues that caring threatens patient autonomy. On the one hand, caring tends to make some people think they can control the lives of others in order to help them, thereby increasing the frequency of inappropriate paternalistic deception as well as making it hard for professionals to convey bad news about medical conditions. On the other hand, he says, caring can foster undesirable dependency of patients on the caregiver. In reply, we agree that the emotions of caring can be hurtful in the absence of respect for autonomy, including awareness that some forms of dependency undermine patient autonomy. But the virtue of caring is manifested in attitudes of respect for persons and for their autonomy. Power, not caring, is the primary motive (usually a disguised one) that generates objectionable instances of paternalism. As a virtue, caring opposes that power impulse and respects patient autonomy.

Third, Curzer contends that health-care professionals "ought to be as impartial as possible toward patients" because emotional investment invites bias and favoritism, even discrimination based on sex, race, age, or religion.[40(p58)] In reply, we agree that professionals should be impartial in the sense of not allowing their emotions to bias and distort medical treatment, and bigoted attitudes should be rooted out. Impartiality, however, does not require emotional indifference. Teachers often like some students more than others, but professionalism requires setting these attitudes aside when grading. Similarly, professionalism in providing health care requires discipline but not total lack of emotion.

Fourth, because caring about patients leads one to seek the best treatment for them, Curzer claims caring can cause inefficiency and injustice through indifference to other patients by driving up the cost of health care as one goes all out for unnecessary and perhaps even inappropriate services for one's patients, thereby skewing the distribution of limited health-care supplies within one's hospital. In reply, we agree that *excessive* emotional attachment to patients does distort good medicine. Anytime professionals have reason to believe their judgment is compromised, they should seek the medical opinions of other colleagues; in extreme cases they should withdraw from a case. However, believing that emotional attachment generally destroys the capacity for good judgment implies believing that friends and family can never help each other.

Fifth, Curzer states that "emotional ties to patients tend to compromise the objectivity of professionals" in ways that threaten accurate diagnosis and treatment decisions.[40(p60)] In reply, we believe that insofar as caring leads to trying to get the best for one's patients, it is desirable. In rare instances in which caring for particular patients threatens another role one may have, perhaps as a hospital administrator, then one should be self-critical about conflicts of interest and take appropriate action to meet one's wider responsibilities to the public.

Finally, Curzer indicates that it is difficult to leave emotions behind at the end of the workday and that emotional involvement with patients can carry into one's personal life in disruptive ways and use up limited emotional resources. Emotional investments are especially harmful in health-care careers because of the frustrations felt by clinicians when patients suffer, die, or ignore medical advice. Even the ideal of caring can generate guilt when one is unable to live up to it. In reply, we agree that caring health professionals are indeed at special risk for burnout. Yet burnout is not solely or primarily due to patient contact; it comes largely from organizational structures and management that strip providers of a sense of control and purpose. It can also come from systematically stifling emotional responsiveness to patients who are the focus of one's professional life.

In the helping professions, a sense of meaning in one's work is sustained through at least some direct caring relationships with people. As one nurse reports, "The people I've cared about, felt something for, become close to, the people I've invested a certain amount of myself in—these are the people I've learned something from. They are the reason I stay in nursing."[41] It is only in being whole, being genuine, that health-care providers can fully experience the intrinsic rewards of the profession rather than spending most days pretending to care. In addition, systematic emotional indifference to patients can easily become an emotional habit and carry over to relationships with other health professionals, with patients' family members, and even with one's own family.

In short, although Curzer identifies genuine dangers about how inappropriate caring can distort judgment, his arguments do not warrant abandoning ideals of caring in the health professions. Too much would be lost in doing so. In Chapter 9 we will extend this discussion of professional distance by focusing on one area of special concern: inappropriate sexual behavior, a topic that pertains to relationships among colleagues as well as professional-patient relationships. There, from another direction—family violence and abuse—we return to the theme of caring for patients in light of their wider good rather than always focusing on a narrowly defined medical good.

## DISCUSSION QUESTIONS

1. According to the World Health Organization (WHO), "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity."[42] In effect, this definition equates patients' medical good (health, in the ordinary sense) with their total good. Do you find this definition inviting, given its "holistic" approach to health? Or do you agree with critics that the WHO definition distorts understanding of health and threatens to give health professionals too much authority in areas of life where their training gives them no expertise?[43]

2. In the managed care environment, productivity is measured in billable hours or other such methods that maximize the time of the physical therapist relative to earned salary. This, in turn, limits time with patients. (A) Given these time pressures, what are methods you have seen in the clinic by which physical therapists maximize their time with patients and continue to provide the kind of care discussed in this chapter? (B) What other models of reimbursement can you envision that maximize the outcomes physical therapists achieve while being fiscally responsible? (Revisit this question in Chapter 11.)

3. Identify what you see as the primary dangers that tend to lead to burnout among health-care professionals. Are the dangers due primarily to caring for patients, inappropriate ways of caring, locus of control, organizational management of providers, or to other factors? What countermeasures can professionals take in order to avoid burnout and to deal with it when it occurs? You might consult the interesting literature on burnout among professionals.[44-47]

4. If you were a therapist in a skilled nursing home and the patient you are starting to treat asks you to spend a moment with her in prayer before treatment, what would you do? How would you respond to parents making the same request before you treat their child with severe burns?

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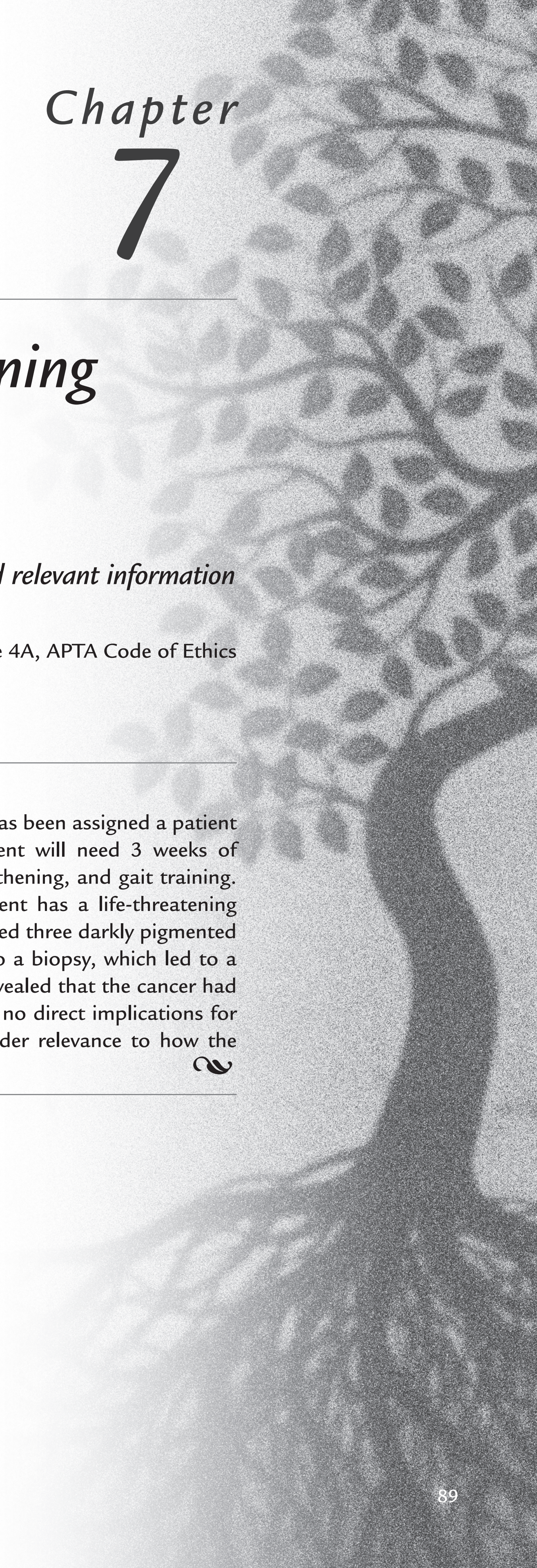

# Chapter 7

# Caring and Life-Threatening Illness

*Physical therapists shall provide truthful, accurate, and relevant information and shall not make misleading representations.*

Principle 4A, APTA Code of Ethics

### **CASE 7.1 An Unwanted Discovery**

Jim Yonemoto is a physical therapist employed at a hospital. He has been assigned a patient recovering from surgery for a total hip arthroplasty. The patient will need 3 weeks of therapy that will include active range-of-motion exercises, strengthening, and gait training. Everything looks typical until the therapist learns that the patient has a life-threatening cancer. The nursing staff, in administering routine care, had noticed three darkly pigmented moles on the patient's back. A dermatologist was called in to do a biopsy, which led to a diagnosis of multiple-site, stage four, melanoma. Further tests revealed that the cancer had invaded the lymph nodes. The information about the cancer has no direct implications for the services provided by the therapist, but does it have any wider relevance to how the therapist will or should interact with the patient?

Some physical therapists rarely work with patients who have life-threatening illnesses, and other therapists, such as those in hospice care or in skilled nursing facilities, work with many. Either way, the topic of death is not incidental to therapists. Life-threatening diseases multiply anxieties in patients and their families, and sometimes they affect the therapeutic regimen. Moreover, therapists need to understand their own responses to death in order to communicate effectively with patients and to provide emotional support. Further, what should physical therapists do on learning that a patient is planning assisted suicide or when patients with whom they have a long-term relationship "sound out" their views on assisted suicide?

We begin by setting a wide context about the meanings of death. Invariably, those meanings are linked to meaningful life—not in the sense in which all human beings have moral significance, but in the sense in which individuals experience their lives as worthwhile, rather than as worthless, pointless, or futile.[1] Why do people fear death? Which fears are reasonable? How should physical therapists respond to those fears in themselves and others?

Next we turn to practical questions about understanding and communicating with patients who have life-threatening diseases. We also discuss the dynamics of interacting with family members, especially when the patient is a child. We conclude by discussing suicide and assisted suicide, issues that are becoming increasingly relevant to all health professionals.

## FEAR AND ACCEPTANCE OF DEATH

Most people calmly acknowledge the need for death. An immortal species would quickly overpopulate the biosphere, destroying ecosystems that make possible ongoing cycles of new life. But with regard to oneself and the people whom one loves, accepting death is more difficult. Most of the time fear of death remains muted, as in the case of Ivan Ilych, the protagonist in Leo Tolstoy's *Death of Ivan Ilych*. Ilych lived a comfortable, busy life in which his death was either inconceivable or at most an abstract possibility. Then, suddenly, he was struck with a life-threatening illness. "In the depth of his heart he knew he was dying, but not only was he unaccustomed to such an idea, he simply could not grasp it, could not grasp it at all. The syllogism he had learned from Kiesewetter's logic—'Caius is a man, men are mortal, therefore Caius is mortal'—had always seemed to him correct as applied to Caius, but by no means to himself. That man Caius represented man in the abstract, and so the reasoning was perfectly sound; but he was not Caius, not an abstract man; he had always been a creature quite, quite distinct from all the others."[2]

Ilych gradually comes to comprehend and accept that he is dying. In doing so, he undergoes a moral transformation that deepens his appreciation of love and caring relationships. Initially, the appreciation is accompanied by regret about having failed to live a better life, but gradually it brings a reassuring sense that it is never too late to change how one relates to others. At the same time, Ilych becomes tormented by the pretense of his family, friends, and even his physician, who have implied that he is simply ill, not dying, and will eventually return to normal life. Instead of providing hope and optimism, the pretense hinders the honest communication that Ilych desires, beginning with the simple acknowledgment that he is dying. It also leads others to stay away from him at a time when he needs compassion and comfort.

Only Gerasim, a young household assistant, is able to provide support. Unobtrusive, yet willing to listen whenever Ilych wants to talk, Gerasim reassures him that he wants to help in any way he can. Sometimes what helps most are simple things, such as elevating Ilych's legs or touching him gently with a reassuring firmness. Other times, Ilych's mood improves when he looks forward to the regular return of Gerasim, with his confident and reassuring presence. Gerasim's caring has a further influence in leading Ilych to reflect on the values that give life meaning.

## WHY DO PEOPLE FEAR DEATH?

This "why" is ambiguous: it might be a request for causes (influences, explanations) or for reasons (justifications). Undoubtedly, the *causes* include genetic factors: fear of death manifests the biological will to survive and develop. The causes might also include social influences. Callahan outlines the evolution of the social responses to death.[3] Before modern medicine, illnesses leading to death were typically of short duration, in contrast to the chronic conditions experienced frequently today. The approach of death was something that was acknowledged, with death taking place at home among friends and relatives. By the 20th century, nearly a complete reversal had occurred. When death appears imminent, the dying are removed from their familiar surroundings to the sterile isolation of a hospital room. After death, their bodies are immediately taken to a funeral home, which applies a veneer of cosmetics to hide the appearance of death.

Another major social influence that profoundly affects the view of death is contained in the military metaphors used to define the purpose of medicine and how patients think about disease.[4] For example, medicine "wages war" on leukemia and "battles" Alzheimer's disease, suggesting that it might eventually "win a war" against death itself. Medicine often sees death as a defeat, an embarrassment to be ignored, disposed of quickly and quietly. But, of course, death is inevitable and natural.

The causes that explain why people fear death are of great interest, but we are even more concerned with reasons. What reasons are there that justify fearing death, and are they good reasons? There are many different types of fears of death, some rational and some not. We sort them into three general categories: fear of dying prematurely, fear of the process of dying, and fear about being dead. Cutting across these groupings is a distinction between fear about one's own well-being (based on self-interested reasons) and fears about the well-being of others (based on altruistic reasons).

The first category, fear about dying prematurely, comprises fears about dying before completing a full and satisfying life. Needless to say, these fears are eminently healthy and rational. It is tragic when young children die before they have a chance to develop fully and when young adults are killed before they have a full opportunity to develop their talents. It is also tragic when adults in their prime die before experiencing fulfilling love, meaningful work, or raising their children, and in general before living out a reasonable life plan. However, people fortunate enough to find inexhaustible joy in life might regard death at any time as "premature." Yet most people, upon reflection, accept the prospect of a "natural lifespan" that concludes with a "tolerable death," as Callahan suggests. "My definition of a 'tolerable death' is this: the individual event of death at that stage in a life span when (a) one's life possibilities have on the whole been accomplished; (b) one's moral obligations to those for whom one has had responsibility [especially one's children] have been discharged; and (c) one's death will not seem to others an offense to sense or sensibility [at least after a usual period of mourning], or tempt others to despair and rage at the finitude of human existence.... A 'natural life span' may then be defined as one in which life's possibilities have on the whole been achieved and after which death may be understood as a sad, but nonetheless relatively acceptable event."[3(p66)]

The second category of rational fears is focused on the process of dying and includes fears of pain, disability, and suffering. It also includes fears about loss of control and self-determination; for example, anxieties about having to leave one's home to live in a medical facility. In most cases, pain can be controlled within tolerable limits with proper medical management, but loss of control renders one profoundly vulnerable and dependent, frequently inducing a sense of shame or, at least, embarrassment. Like pain, death is intensely private, but in the context of a medical facility privacy is lost. The constant unwanted intrusion of strangers threatens whatever dignity one might hope to keep until the very end.[5]

Some fears concerning the process of dying are linked to relationships with people for whom one cares. Will I become an emotional or financial burden on my family? Who will care for my children if I am hospitalized? Will I become isolated and lose close contact with my family, because they have jobs (and lives) to maintain? Some of these fears are exaggerated and can be alleviated by assuring patients they will receive support from caring professionals. While other fears about family and loss of control might be entirely justified, even then caring professionals can help simply by listening sympathetically when patients wish to talk (without intrusively forcing them to talk).

Perhaps the most complex fear about the process of dying is fear of suffering, which encompasses more than physical pain. Callahan distinguishes between two levels of suffering[6]: at level one he places the fear and dread of coping with the illness, which affects how that illness will impact the person's life and wholeness; at level two he places the more fundamental suffering that occurs as individuals try to find a purpose in their existence. Level one seems self-explanatory; level two is more complex. When the values and assumptions of a lifetime fail to coalesce into a meaningful unity, individuals undergo "spiritual suffering" that minimizes all other concerns about health care, including advance directives.[7,8]

The third category of fears concerns those about being dead. For some people, these fears center on uncertainties about what happens after death. Is there life after death, and how is it? The uncertainties also include specific fears about the individual's own circumstances. What is my fate and the fate of people I love; perhaps heaven, or something else? Still another cluster of fears concern anxieties about the possibility of one's sheer nonexistence.[9] These fears also surround the permanent ending of one's present activities, relationships, and other interests that give life significance.

## THE HEALTH PROFESSIONAL'S RESPONSE

Health professionals sometimes find it comfortable to avoid emotional engagement with death, even though (and partly because) they deal with it more often than most people. To some extent this emotional reserve functions as an aspect of professional distance that enables therapists to cope in difficult roles without burnout. Yet, overdetachment is not the only or best alternative in caring for patients.

Much has been written about why physicians in particular too often abandon patients once death becomes certain. Nuland's observations are insightful. "[O]f all the professions, medicine is the one most likely to attract people with high personal anxieties about dying. We become doctors because our ability to cure gives us power over the death of which we are so afraid, and loss of that power poses such a significant threat that we must turn away from it, and therefore from the patient who personifies our weakness. Doctors are people who succeed—that is how they survived the fierce competition to achieve their medical degree, their training, and their position. Like other highly talented people, they require constant reassurance of their abilities. To be unsuccessful is to endure a blow to self-image that is poorly tolerated by members of this most egocentric of professions."[10]

Nuland adds that physicians have a powerful need to exercise control, and the threat of their patients' deaths comes as the ultimate threat to that sense of control. What is needed is a greater humility in the teeth of inexorable realities as well as a form of medicine that keeps the patient's welfare paramount, not the ego of professionals.

Without being sentimental, many health professionals report that caring for dying patients can evoke and be guided by positive emotions of peace and acceptance of death as a natural process. Some even express a sense of privilege in being able to help people during their final hours.[11] They also report that the deepest frustrations that cause burnout come when medical care is used in situations where there is no hope of benefit to the patient or when an aloof physician who spends little time with patients is insensitive to their suffering.[11(p128)] Here, as is so often the case, healthy emotions are indicators of good medical care.

## HELPING PATIENTS WHO HAVE CANCER

"Cancer" is a frightening word. Because cancer is characterized by malignant tumors that potentially have unlimited growth and expansion, "cancer" connotes a life-threatening disease. However, cancer is not one thing. Like bacterial or viral diseases, there are over a hundred forms of cancer that vary greatly in form and severity. Many cancers are now curable or allow many years of healthy life. Others are more serious, as in the case of Marilyn French, the feminist activist and author of the bestseller *The Women's Room*.

### CASE 7.2 **Marilyn French**

French was diagnosed with metastasized esophageal cancer in 1992, when she was 61 years old. At the time, only one in five patients survived nonmetastasized esophageal cancer, and no one survived metastasized esophageal cancer. Her oncologist told her that, even with chemotherapy, she had only 1 year to live. The oncologist was mistaken: French would prove to be one of those "miracle patients" who overthrow what medicine "knows" at a given time, possibly because she was given an experimental combination of concurrent chemotherapy and radiation. Yet, as suggested by the title of her memoir published 6 years later, *A Season in Hell*, she was to undergo a terrible ordeal. The chemotherapy and radiation treatments caused multiple side effects, including brain seizures that led to a 12-day coma, a heart attack, diabetes, severe arthritis, and spinal fractures when she went to a masseuse to relieve pain. It is likely she will need physical therapy for the rest of her life.

During her coma, an emergency room physician informed her family that she was dead, indicating once again that medicine is something less than an exact science. Her living will specified no further medical interventions at that point, but her family ignored the document. Later, during an especially difficult time, she would express anger that the document had been ignored. Still later, after her condition improved, she would be grateful it had been ignored.

A central theme in French's memoir is the importance of maintaining hope when confronting serious illness. She found herself surprised by her own determination to survive: "In fierce blind insistence, I decided I had a chance to survive and would count on that."[12] She was also surprised by her capacity for hope well beyond what the evidence seemed to make reasonable. Within hours of being informed that she had terminal cancer, she erased the word "terminal" from her consciousness and never used the word in thinking about her disease or communicating with others about it. Although she prided herself on being a person who prizes truth, she engaged in what she later confessed was blatant self-deception about her chances of survival.

Another theme in French's memoir is the importance of health professionals' support of a patient's hope.[12] To be sure, professionals must be honest in dealing with patients, whose fears are magnified only when they sense that essential information is being withheld. Nevertheless, French urges that the focus be on conveying an attitude of hope. She reports that her oncologist was exceptionally skilled but unnecessarily dour and pessimistic in dealing with patients, no doubt because most of his patients died. In sharp contrast to Ivan Ilych, she found herself in desperate need of health professionals who conveyed, through manner and style as well as words, a sense that events would improve.

French contrasts two physical therapists, selected from dozens who worked with her during years of chronic illness. One was the therapist who worked with her while she was hospitalized for 20-minute sessions several times a week during recovery from her coma. Unable to support her head or sit up by herself, she was reduced to helplessness by muscles that were severely weakened. She needed emotional support as much as physical support, but the therapist provided only the latter: "She was young, efficient, and mechanical; she made no personal connection with her patients—not at least with me—and had no affect whatever. I am sure that to her I was just one more helpless elderly woman, but I have since met so many warm, devoted, caring physiotherapists that I wonder if she was in the wrong field. Still, she did her job. She urged me to walk holding on to a walker."[12(p149)]

Despite the fact that her weight increased enough for her to return home, she continued to need assistance, as her mobility was limited. She described herself as traumatized and as grieving for herself. A team of nurses and physical therapists were central to her recuperation. Michael, the first therapist sent by the hospital, "was militantly cheerful and personally seductive; he employed charm to help his patients, especially elderly women. But I did not dislike him: his style was more agreeable than the mechanical style of the therapist in the hospital."[12(p157)] He also liked to give orders to the nurses about the requisite exercises; some of these orders French chose not to heed. Yet French came to trust his expertise and his commitment to her well-being. She continued to seek his help and trust his judgment for many years.

At one point, French suddenly developed severe arthritis, which neither drugs nor electrical acupuncture helped. Michael said he could help her regain the use of her arm and hands, but the process was going to involve great pain. Without hesitation, French said "Do it." The therapy consisted of sessions of an hour of exercises followed by a brief "torture time," in which Michael bent the joint until she heard the adhesions cracking. After 4 months she regained normal flexibility.

Professional manner and personal style in part reflect a therapist's unique personality, but in large measure they are the product of professional growth in communication and caring skills in responding to the special needs and personalities of patients. That growth takes time, of course, but it can be hastened by insights such as Flomenhoft offers. Flomenhoft, who is a physical therapist and a cancer survivor, points out that fears of saying the wrong thing or of revealing too much can lead to the far worse effects of avoidance that make patients feel both isolated and rejected. "The content of the response, the specific words, is usually not important. The gesture of reaching out to the patient can speak far louder than words."[13(p1232)]

Flomenhoft's specific recommendations about caring responses in helping patients who have cancer include:

- "[View] cancer as a chronic illness that most people live with for a long time can help to keep the disease in proper perspective" by focusing on "living with cancer" rather than the usual thought of "dying of cancer."[13]
- Cultivate a confident bedside manner, one that communicates that one can and will help. This bedside manner includes body language in the form of eye contact and a confident grip in touching a patient.
- Learn to be aware of your own feelings in order not to let disruptive feelings interfere with helping. It is normal in caring for some patients to feel moments of anger, irritation, and frustration as well as fear and self-doubt.
- Listen actively. When patients ask the hard questions, such as "Why me?" they do not expect health professionals to have the answers; instead they are expressing their grief, frustration, and anger. The appropriate response is supportive listening.
- Ask what a patient is feeling rather than assuming you know. Kübler-Ross provided valuable studies about five stages of adjustment to death: denial, anger, bargaining ("If God will let me live, I will...."), depression, and acceptance.[14] These stages are not sequential or universal. A patient might experience states of anger, depression, denial, and any number of other emotions over the course of a month or even a day.
- Rather than feel pressure to initiate a conversation about cancer, pick up on patients' cues that they want to talk. When appropriate, adopt the patients' way of talking; for example, if they use the word "tumor" rather than "cancer," follow their lead.
- Touch matters. Like others, therapists vary in how demonstrative they are. Even at difficult moments, hugging might not be appropriate. Flomenhoft recalls how much it meant to her that when her physician had to convey the news that her tumor was malignant, he touched and stroked her ankle as he looked into her eyes.
- Echoing Marilyn French's observations, find a way to be both honest and hopeful, realistic and positive, at the same time. Hope is both curative and adds meaning to the time remaining. Do not force a patient to "be realistic" when the individual chooses even false hope as a way of coping.
- "Be careful not to isolate a patient, especially as death approaches. People are alive until the very moment of death, and time is particularly precious when it is limited."[13(p1234)] Even after treatment stops, try to maintain some contact, especially if you have worked for a long period with a patient, in order to prevent the patient from feeling abandoned.

## REFUSING THERAPY

As discussed in Chapter 3, the general right to autonomy gives competent patients, or their designated surrogates, the specific right to refuse unwanted therapy. Unwanted therapy includes life-essential therapies as well as routine physical therapy during a terminal illness.

### CASE 7.3 Encourage Further Therapy?

Henry is 76 years old and lives in a private facility that combines skilled nursing and assisted living and that takes both Medicare and private paying patients. He is there to receive care and physical therapy following a total hip replacement. Henry's wife of 58 years died 2 years ago, and he has one surviving son who lives in another state. The son is married and has no children, and there has been no communication between them since the death of Henry's wife. Their relationship had always been distant, preserved largely to please his wife. Before his retirement, Henry owned a small but reasonably successful printing shop. There he worked long hours, including most weekends. During this time he developed no meaningful hobbies or social networks.

His therapist, Sonia, saw immediately that he was withdrawn but capable of sustained conversations that demonstrated an uncommon level of self-awareness. During their early sessions Henry revealed many aspects of his life with surprising candor. He told Sonia that he did not follow any particular religion, but he considered himself to be spiritual and was trying to decide what was best for him at this time of life. The therapy progressed at a reasonable pace, but Henry became progressively less interested in ambulation and more interested in talking socially with Sonia. After a month, Henry told Sonia that he did not want to do therapy any longer, but he would appreciate her stopping by occasionally for conversation.

Sonia explained that without therapy he was unlikely to become independent again. He would also run an increased risk of respiratory infection by remaining sedentary. Patients who do nothing, she added bluntly, fail to survive very long. She felt confident he would reconsider. Instead, he confided that he did not wish to live much longer. For him, life lost its meaning when his wife died, and now he could foresee only an increasingly dependent life. Although he had private insurance and a retirement portfolio more than adequate to meet his needs, he preferred to leave his money to his son, partly as repayment for his absence during his son's youth.

Sonia admitted to herself that over the years she has seen a number of men and women who just seemed to give up after the death of a partner, and no amount of therapy seemed to make a difference. She sensed that Henry was approaching death, but she was unsure of her professional role in helping him. Should she use their relationship as leverage to persuade him to continue therapy?

We leave this to the Discussion Question section of this chapter, turning now to a broader context for understanding the moral and legal rights to refuse life-extending treatments. Legal recognition of this moral right has been established gradually, through several decades of court rulings. Here are a few highlights.[15]

*1976:* The New Jersey Supreme Court ruled that the parents of Karen Ann Quinlan had a "right to privacy," which permitted them to have her removed from a respirator. A year earlier Karen had stopped breathing and slipped into an irreversible coma. Her parents requested that the respirator be removed, but because Karen was over the age of 21 they had to go to court to be appointed her legal guardians and to seek authority to remove her from the respirator. Although the request was denied by a lower court, the New Jersey Supreme Court overruled the denial. The respirator was removed, setting the legal precedent for allowing patients to refuse even the most essential life-saving technology. Contrary to expectation, Karen did not die. She lingered for 10 years in a vegetative state, sustained by intravenous nutrition and hydration.

*1977:* California passed the Natural Death Act, which authorized competent adults to sign "living wills" expressing their desires regarding "artificial" life support if they become terminal and "death is imminent." Other states quickly followed in establishing "advance directives."

*1981:* The *Report of the President's Commission for the Study of Ethical Problems in Medicine* recommended a "whole-brain" concept of death, and the recommendation quickly shaped new state laws. Prior to this, the traditional legal definition used a heart-lung concept: persons are dead when cardiopulmonary activity stops permanently. The new concept defined death as the cessation of all electrical activity in the brain. At that time, a person is considered legally dead, such that removal of life support is permissible. The new concept and laws have other legal implications, including the permissibility of transplanting organs (if so authorized by the individual or family), burial, cessation of health-care insurance, distribution of inheritance according to a will, and payment of life insurance to a beneficiary.

*1990:* The U.S. Supreme Court ruled in the Nancy Cruzan case that the Fourteenth Amendment's "liberty interest" provides a constitutional basis for advance directives, such as living wills and durable power of attorney documents (which designate a surrogate decision maker if one becomes incompetent to make decisions about medical procedures). For the first time, the Court included intravenous nutrition and hydration as "medical procedures."

*1991:* A federal statute, the Patient Self-Determination Act, required health-care facilities that receive federal funds to inform newly admitted patients about relevant state laws concerning refusal or discontinuation of medical treatment.

As these rulings suggest, the law has slowly moved toward recognizing greater legal rights of individuals to control treatment at the end of their lives. A living will, by itself, is not legally binding; it merely relays the patient's wishes. The durable power of attorney, however, has legal authority, and typically it is stipulated in the living will that the designated surrogate decision maker is to follow it.

Nevertheless, in practice, individuals often lack the control they believe they have. Relatively few advance directives are being respected, for a variety of reasons: "People lose or forge them; living wills are too vague to interpret; relatives disagree about what the patient wanted; hospital staff members mistakenly fear prosecution for terminating life support; or doctors overrule the family and refuse to stop treatment."[16]

One such case attracted national press coverage and generated two videos, "Please Let Me Die" and "Dax's Case." These videos documented the refusal of medical personnel to stop treatment at the request of a competent patient, Dax Cowart.

### CASE 7.4 Dax Cowart

Dax Cowart was a pilot who was severely burned over two-thirds of his body in a propane gas explosion. He lost his sight and use of his hands. Painful treatments continued for over a year, and throughout this time he demanded that treatment cease and that he be allowed to die. He was examined by a psychiatrist who confirmed that he was competent, yet his demands were ignored. Although he later became a successful attorney, he still maintains that it was wrong to ignore his request to discontinue treatment.[17]

Cowart's case is not unusual. In a study involving 9105 patients who were seriously ill, with approximately half receiving care before the enactment of the 1991 Patient Self-Determination Act and half after its enactment, it was "found that ADs [i.e., Advance Directives] did not result in a clinically relevant impact on resuscitation decision-making, even among those cases where intervention dramatically increased their documentation."[18]

### CASE 7.5 Advance Directive

A 71-year-old man with a history of lung and colon cancer was admitted to the hospital with ataxia and headaches. An MRI was performed, and a brain tumor and hydrocephalus were discovered. With the help of a staff social worker, the patient completed a living will and informed his grandson that he did not believe that he would live and did not want surgery.

The patient began to exhibit new symptoms consistent with hydrocephalus, and emergency surgery was performed. He experienced respiratory failure and developed an extensive infection with a gram-negative organism in his spinal fluid. It was recorded in his chart, as was the existence of his living will, that the hospital's SUPPORT prognostic model predicted only a 10% chance of his surviving the next 6 months. Despite both documents, he spent 14 of his next 23 days of life in the ICU. "His wife noted that he would not 'want this,' but also that she 'could not bear to lose him.'"[18(p506)] At no point did the medical records reveal any discussion about his advance directive.

As this case suggests, and as noted in Chapter 3, the most difficult issues surrounding informed consent involve surrogate decision making on behalf of noncompetent adults and children. Yet there are also difficulties in the case of competent adults; for example, in interpreting DNR orders.

If the DNR has been decided by the team because efforts to revive the patient would be futile—that is, not prolong life for any substantive time—then patient consent is not necessary. If the DNR order is issued without the consent of the patient or legal surrogate when the resuscitation effort would likely be successful, it would be considered by most to be indefensible. When a physical therapist sees a DNR in the chart, deciding to honor it should be contingent on the answers to the following questions.

1. Was the order given because of medical futility?
2. If the DNR was ordered for reasons other than medical futility, did the patient consent?
3. Is the DNR signed and dated, and does it have the patient's name on the same page?[19]

Clearly, the first two items must be confirmed with the originator of the DNR, not the patient. If there is any reason to doubt the authenticity of the response to the second item, the doubts can be resolved by talking with the patient. The third item is important because the therapist needs to determine that the DNR was correctly intended for this patient and that it was entered in the chart by someone in authority to issue the order. In addition, one should ask whether the order is dated, because relevant facts might change, rendering the order inappropriate. Unfortunately, some convalescent and skilled nursing homes inappropriately insert DNR orders into charts without the consent of patients or their legal surrogates.

## IS SUICIDE EVER MORALLY PERMISSIBLE?

What should physical therapists do on learning or coming to suspect that a patient is planning suicide? The specific context must be considered, as the following case suggests.

## CASE 7.6 Assist in a Suicide

Mark was a 28-year-old Latino professional employed at the managerial level at the largest live theater complex in Los Angeles. He worked long hours, and at first he attributed his fatigue to the pressure of a new theater season and a last-minute cancellation by a leading celebrity. When he discovered a dark discoloration on his forearm, however, he decided to see his dermatologist. The physician took a biopsy sample and questioned Mark about his HIV status. Mark said that he had not been tested because he had been sexually inactive for 2 or 3 years. He admitted that after his partner of 5 years left him with no explanation and no communication, he fell into a depression that work helped to alleviate. Recently he had considered dating again, but he lacked the energy for a social life. The dermatologist asked if he could draw a blood sample to be tested for HIV, and Mark agreed. At his next appointment the physician informed him that he had Kaposi's sarcoma, a relatively rare skin cancer that was most often seen in persons with advanced HIV, which the blood test confirmed he had.

Because he was in an advanced stage of AIDS and because he could not tolerate the primary drug offered at the time, due to adverse reactions, Mark's condition deteriorated quickly. The sarcomas appeared on his face and legs as well as his back. Radiation and chemotherapy helped, but the lesions were still disfiguring. Fearing the effect on sales, his employer limited Mark's exposure to the public and essentially isolated him in his office. Mark decided that he simply did not have the energy to pursue legal redress, so he requested and received disability. The following week he called his parents, whom he had not seen—at their request—since he "came out" to them. They stated that they were sorry, but he had brought this on himself and they would not be able to offer financial or other support. They also said that they would appreciate it if he would not say anything to their friends or his brothers and sisters.

Over the next 2 months the sarcomas re-emerged with renewed vigor and caused a blockage in the lymphatic system in his legs, resulting in swelling. His physician recommended physical therapy for activities of daily living (ADLs) and to assist with independent ambulation. Mark called on an old friend, Dan, who was a pediatric physical therapist to help him find someone. Dan called several therapists working in home health care, but upon hearing Mark's diagnosis they stated that they did not think a patient could profit from their professional skills or that they were booked. Dan challenged two therapists who said that physical therapy would be ineffective for patients with AIDS, asking the therapists how a patient with AIDS differed from a patient with cancer, the elderly, or any other classification of patient in need of ADL and ambulating. The therapists said that they would not work with gay men, even if they were HIV-negative.

Out of sheer frustration, Dan volunteered to help Mark after he left the pediatric center where he was chief physical therapist. Instructions in positioning and using a walker, wheelchair, toilet lift, and shower bench, along with gait training using crutches and a walker, helped Mark achieve enough independence to manage. His friends provided some support, but they also had other commitments. As his T-cell count dropped below 50, Mark became terrified. He was disfigured, terrified of dying alone, and even more terrified of being dependent on others. He had neither the resources at this age nor the social support to anticipate much more than a protracted and painful death. The only person he really trusted was Dan, who had been reassuring and reliable and with whom he had developed a deep friendship.

One day Mark informed Dan that he had requested and received 20 Seconal pills for back pain from two physicians. He told Dan how much he had appreciated his help and his caring but that he would like him to skip the next day. Dan knew what this meant, and he was unsure what to do. He could search for the Seconal and remove them, or he could call the physician and inform him about what he thought Mark was going to do. Dan also considered staying with Mark until he died so that he would not be alone.

What should Dan do? Possible answers will be explored in the Discussion Question. Here we consider broader issues, beginning with the question: What is suicide? The answer would seem clear enough: suicide is the intentional and voluntary (not accidental) killing of oneself. Yet in practice, what one counts as suicide depends in part on one's moral views about when killing oneself is justified.

Suppose a physician's intention is to alleviate pain, at a patient's request, by requesting an increased morphine drip, and both the physician and patient know that it will kill the patient within a few days. This is considered an act of suicide by some, but others see it merely as an act of alleviating pain. For example, the Catholic tradition, which takes a strong stand against suicide, would justify the increased morphine dosage by appealing to a "rule of double effect," meaning, roughly, that an act that has a good and bad consequence is justified if the intent is solely to reach the good consequence (alleviating pain), not an unavoidable bad consequence (death). Under the rule of double effect, it is not the outcome that defines the rightness or wrongness of the action but rather the intent.[20]

Is suicide ever morally permissible? Liberals emphasize freedom and being allowed to make one's own choices in matters that primarily concern oneself.[21] Conservatives emphasize life as a gift that one has no right to misuse. Liberals justify some suicides by emphasizing the principle of respect for autonomy. Clearly, there are many considerations facing a patient in determining how life should end. The quality of one's life might fall well below anything one finds tolerable. There can also be great suffering, including physical pain that, in some cases, is controllable only through heavy sedation. The cost of extended medical services might place a great financial burden on one's family. Liberals believe that because there is no one mandatory way for all reasonable persons to balance such complexities, individuals should be allowed to make their own decisions.

Conservatives often ground their opposition to suicide in appeals to religious faith. For example, Catholics appeal to the natural law doctrine that says that humans have a "natural" (God-given) desire and goal of survival, which is violated by suicide and euthanasia. In the arena of public discourse, however, conservatives have more influence when they argue that life is sacred and to be treasured no matter what one's religious beliefs. They reinforce this argument with the concern that the widespread practice of suicide, or even its toleration, will erode respect for human life.

The differences between liberals and conservatives are deep-seated, and it is unlikely that these opposing emphases will ever be reconciled. Perhaps some progress might be made, however, by distinguishing between types of situations in which individuals might consider suicide as an option. Hill argues that suicide sometimes violates rational autonomy and other times manifests respect for it. Shifting from duty language to the language of ideals and virtues, in particular self-respect, he argues for this principle: "A morally ideal person will value life as a rational, autonomous agent for its own sake, at least provided that the life does not fall below a certain threshold of gross, irremediable, and uncompensated pain and suffering."[22]

Hill distinguishes seven types of suicide, the first four of which describe situations in which individuals fail to value themselves properly. They violate the ideal of respect for oneself as a rational person.

1. Impulsive suicide: Persons commit suicide as a result of a brief but intense emotion, such as grief in losing a spouse or life partner, despair in losing one's job, or fear on learning one has a serious illness.
2. Apathetic suicide: Persons commit suicide because of severe depression, whether temporary or chronic.
3. Self-abasing suicide: Persons are filled with self-loathing and commit suicide as a form of self-contempt or self-punishment.
4. Hedonistic calculated suicide: Persons commit suicide because they calculate that the future will probably bring more pain than pleasure.[23]

Hill contrasts these situations with the following circumstances in which, he believes, suicide manifests, rather than violates, self-respect.

5. Suicide to prevent subhuman life: Persons have good reason to believe that they will survive an illness physically alive but mentally destroyed, with life reduced to the level of a lower animal or vegetable.
6. Suicide to end severe irremediable suffering: Persons in intense pain that can no longer be controlled by medication, short of rendering them constantly unconscious.
7. Morally principled suicide: Persons act on justified commitments central to their moral integrity in order to help others and preserve that integrity.[23] An illustration of this category is when prisoners of war kill themselves rather than being forced to reveal military secrets to an enemy.

## IS ASSISTED SUICIDE EVER PERMISSIBLE?

One's views about suicide, of course, largely shape one's views about assisted suicide. If all suicide should be opposed, then so should assisted suicide; if instead some suicide is morally permissible, then presumably some instances of assisted suicide will be too. Yet assisted suicide raises new complexities, and one's belief that an instance of suicide is permissible by no means establishes one is obligated to assist in it. In most states, assisting suicide is considered murder. However, laws are changing, and we conclude with the debate over whether to legalize assisted suicide for consenting adults who have a terminal illness. In what follows, we understand assisted suicide to include any action that helps persons intentionally bring about their own death. We also note that while the debate is usually framed in terms of "physician-assisted suicide," other health professionals are sometimes asked to participate, if only indirectly.[24-26]

Only a few decades ago, opinion polls showed most people strongly opposed suicide and assisted suicide under almost all conditions. In contrast, currently the opinion polls show a marked shift in attitudes, almost a complete reversal statistically. The courts have moved in a similar direction, as suggested by the above list of court rulings about refusal of life support. The following are several additional rulings that are especially relevant to the present debate over assisted suicide.

***1997:*** The Supreme Court ruled there is no constitutional "right to die." It left open the possibility, however, that the Court might in the future consider (carefully written) state laws allowing physician-assisted suicide as compatible with the Constitution.

***1998:*** Oregon's law legalizing physician-assisted suicide went into effect. During 1998, 15 people with terminal illnesses used legally prescribed overdoses of drugs to kill themselves. The Oregon law (the Death With Dignity Act) was passed in 1994 but had to survive lengthy legal challenges after the presidential election of 2000. Stringent conditions of the law include the need for both a primary-care physician and a consulting physician to agree that a patient has 6 months or fewer to live. It is also required that patients make two oral requests, followed 15 days later by a written request. The physician is then authorized only to prescribe a lethal dose of drugs and to indicate how to take them, not to use more active means such as lethal injection.

***1999:*** Dr. Kevorkian was convicted of second-degree murder for giving a lethal injection to a man with amyotrophic lateral sclerosis. Dr. Kevorkian had successfully avoided prosecution for assisting in the suicides of about 120 people during the 1990s. The public was divided about his campaign to legalize assisted suicide. Some viewed him as heroic; others saw him as reckless, especially given his brief contact with the patients he assisted. He might have continued with his campaign for many years, but instead he decided to emphasize his cause by moving from assisted suicide to active euthanasia and then sending the tape of the proceedings to the television show *60 Minutes*, which broadcast excerpts from it.

## SHOULD ASSISTED SUICIDE BE LEGAL?

The same clash of conservative and liberal outlooks concerning suicide arise regarding legalizing assisted suicide, but additional factors need to be considered. Given the strong differences between conservatives and liberals, whatever social policies and laws emerge will be partially a matter of compromises among people having reasonable differences and partly politics within a democratic setting. Compromises, however, presuppose that opponents can discern evidence of cogent reasoning on the other side of the issue, even if one does not agree with the reasoning.

Within democracies, the centrality of individual autonomy would seem to favor the liberal position, which is to pass laws giving individuals maximum freedom to make their own decisions about suicide. At the same time, legalizing assisted suicide invites abuses and new dangers. Thus, it is not uncommon for some individuals who disapprove of assisted suicide to favor laws that allow it (as with abortion). Nor is it uncommon for individuals who approve of assisted suicide in some situations (for example, extreme and unremediable suffering) to oppose legalizing it. They are not upset that some physician-assisted suicide occurs behind closed doors, but they fear that a public law would tend to invite abuse and erode respect for life. Their critics insist that abuse is more likely behind closed doors. In the *Washington v. Glucksberg* case, the Supreme Court appeared heavily swayed by the fear of abuse. "In legitimating the state's fear that legalizing assisted suicide would simply be the first step on a slippery slope leading to involuntary euthanasia, the Court cites statistics demonstrating the high proportion of cases in the Netherlands in which patients were killed without their explicit request or consent."[27]

In general, what are the possible abuses and dangers? Individuals might choose suicide based on mistaken diagnoses or prognoses, the sort illustrated in the Marilyn French example. Greedy family members might pressure individuals into a suicide decision they otherwise would not make or even bribe a dishonest physician to influence the patient to choose an early death. A climate of harsh and intimidating "managed care" might create subtle pressures to "choose" assisted suicide as a felt obligation. Some thinkers argue there can be a "duty to die," a belief that if widely endorsed would add additional pressure in direction on suicide.[28]

Even without abuses, some are alarmed by the prospect of physicians changing from their traditional role of healer to the role of expediter of death. They fear an adverse affect on professional commitments and negative changes in patients' attitudes toward their physicians. Nearly everyone agrees that health professionals should never be required to assist in a suicide, when doing so violates their moral convictions. But would legalization put pressures on health professionals to participate in acts with which they disagree, especially when they have long-term relationships with patients?

All involved in the debate agree that the possibility of abuses and adverse side effects is genuine. However, those who favor legalization point out that all laws are imperfect, but when balancing the positive aspect of individual freedom with any negatives, individual autonomy tips the scale. With stringent regulations, the abuses can be minimized, and proponents of legislation believe that any abuses can be balanced against the greater good through the legal system. They point to the likelihood that assisted suicide will be chosen by only a few individuals, as now occurs in Oregon and in the Netherlands, where knowing that it is an option brings comfort to many who are terminally ill, although they opt to continue to live.

Opponents of legalization object that the risks are simply too great, that legalizing assisted suicide will merely speed the "slippery slope" toward increasing dehumanization and callousness about life or the belief that suicide is inherently immoral.

Callahan, who we noted has argued for greater acceptance of death in society, nevertheless has expressed great concerns about efforts to legalize assisted suicide. He proposes that, as an alternative, all patients be informed that there are at least five stages in treatment that they could choose, in each of which relief of pain must be available. In stage one, the patient can refuse all health-care intervention, including prevention measures, and seek only relief of pain. In stage two, a patient can experience the diagnostic phase of treatment but refuse any curative efforts. In stage three, the patient can participate in the diagnostic phase of care and pursue medical treatment only if it promises a high probability of positive results with minimal unpleasant side effects. In stage four, diagnosis and any treatment that offers even a low probability of success can be pursued but with the understanding that, if in the course of treatment there are any unexpected negative reactions, treatment will stop. In stage five, all medical treatments can be sought even if there is only a remote chance they will be successful.[6(pp204-205)]

To conclude, we have focused in this chapter on issues about meaningful life and death because of their inherent human interest and their occasional central importance, even though they do not arise in the everyday work of most physical therapists. We also focused on these issues because they highlight the interplay of the medical and total good of patients, a theme also important in the previous two chapters. In the next chapter we will turn to more mundane but still crucial concerns about honesty at the workplace and conflicts of interest.

## DISCUSSION QUESTIONS

1. Regarding Case 7.3, discuss what Sonia should or might permissibly do regarding her patient Henry, who refuses treatment.

2. Regarding Case 7.6, discuss what Dan should or might permissibly do regarding his patient Mark, whom he knows is planning suicide. In doing so, present and defend your view concerning when, if ever, suicide is morally permissible. Take into account the different kinds of situations distinguished by Hill.

3. Regarding Case 7.2, consider a hypothetical situation in which Marilyn French discusses the topic of suicide with Michael, the physical therapist who had provided home care for her for several years. Assume that French is competent and not clinically depressed. Which of the following options are morally permissible for Michael to pursue and why? (A) Say nothing, perhaps with an accompanying raised eyebrow, alarmed glance, or sharp glare. (B) Interpret her remarks as an expression of momentary frustration, and immediately help restore her hope by saying that things are all right and she is improving. (C) Alert her physician or a family member, urging that a psychotherapist be found immediately to help French, or even recommend institutionalizing her (actions that some might consider a betrayal of her and others might view as in her best interests). (D) Discuss the topic calmly with her, expressing himself in a manner that makes clear that her views are what matter in the situation. (E) Offer to help, perhaps in helping her find a physician willing to assist her suicide or perhaps become further involved himself—an option that might have very serious legal repercussions and involve risking his career.

4. A 12-year-old boy who suffered burns over 70% of his body was not expected to live. The hospital's physical therapy staff performed the débridement (removal of dead and contaminated tissue) while the boy was placed in a whirlpool on a stretcher. The staff then performed range-of-motion exercises to keep the boy's joints mobile. The parents, who were in denial and believed their son would survive, gave consent for the procedures. They supported any treatment offering hope that the child might live and make a functional recovery. The child screamed and pleaded with the therapists to do nothing but the whirlpool, to leave the dead skin on and not hurt him. The nursing staff believed the physical therapists should be less diligent in removing the skin and as a consequence cause less pain. The physician, however, expected the same quality of care given to everyone else.

   When asked by the therapists to witness the suffering that the aggressive débridement was causing, the parents replied that they could not bear to watch their child in pain. The physical therapists followed the physician's directives, but later, after the boy died, they questioned whether they had made the right decision and whether they should have done more to heed the child's requests. What more could the physical therapists have done? Should they have been less aggressive in their therapy, even though doing so defied both the physician's orders and the parents' wishes?

5. How might the rule of double effect be applied to the following example? Jody and Mary are conjoined twins who shared one heart and one set of lungs. Mary was born with severe brain damage and survived only because of Jody's healthy heart and lungs. Surgeons wanted to separate the twins, because without the separation both twins would die within 6 months. If they are separated, however, Mary will almost certainly die. The family members are devout Catholics, and they cite their religious faith in opposing the surgery. They cannot condone the killing of Mary to advantage Jody.[29]

6. According to the law, people used to be dead when their heart and breathing stopped (the "heart-lung" criterion for death), but now people are considered legally dead when they lack all brain activity (the "whole-brain" criterion). Critics insist that the issue is moral and that the current legal definition is far too narrow to allow individuals to express their moral convictions on the issue.[14(p206)] Some of these critics argue that persons are dead when they permanently lose consciousness (the "higher brain" criterion), even if some electrical activity in the brain continues. Others argue that persons are dead when they lose all ability to interact in meaningful ways with the world, even if they retain consciousness (the "personhood" criterion). What is your view, and what arguments can be offered to resolve the issue?

7. Regarding Case 7.2, Marilyn French urged that health professionals should never squelch a patient's hopes. She does not distinguish different objects of hope, such as hopes for survival, hopes for a meaningful future (however brief), or hopes for specific improvements. Distinguish some hope-preserving and hope-destroying ways of conveying such news to a patient, marking the distinction between different kinds of hopes.

8. For some time, active euthanasia has been practiced in the Netherlands. Research and assess the recent literature about the extent of abuses and other undesirable side effects that have occurred, and apply it to current debates about U.S. laws. Take into account that virtually no social policy can escape some abuses, and abuses are already occurring secretly in the United States.

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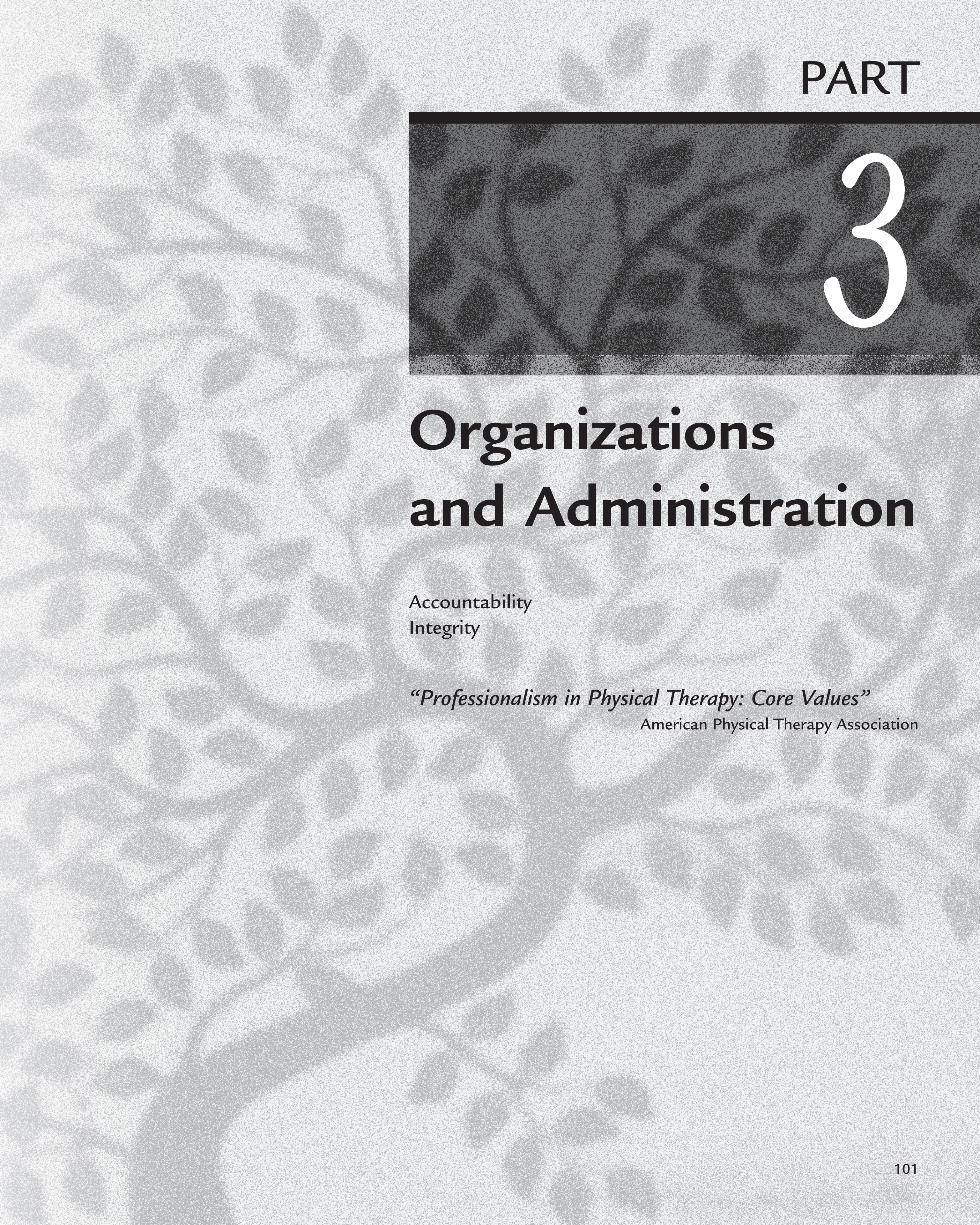
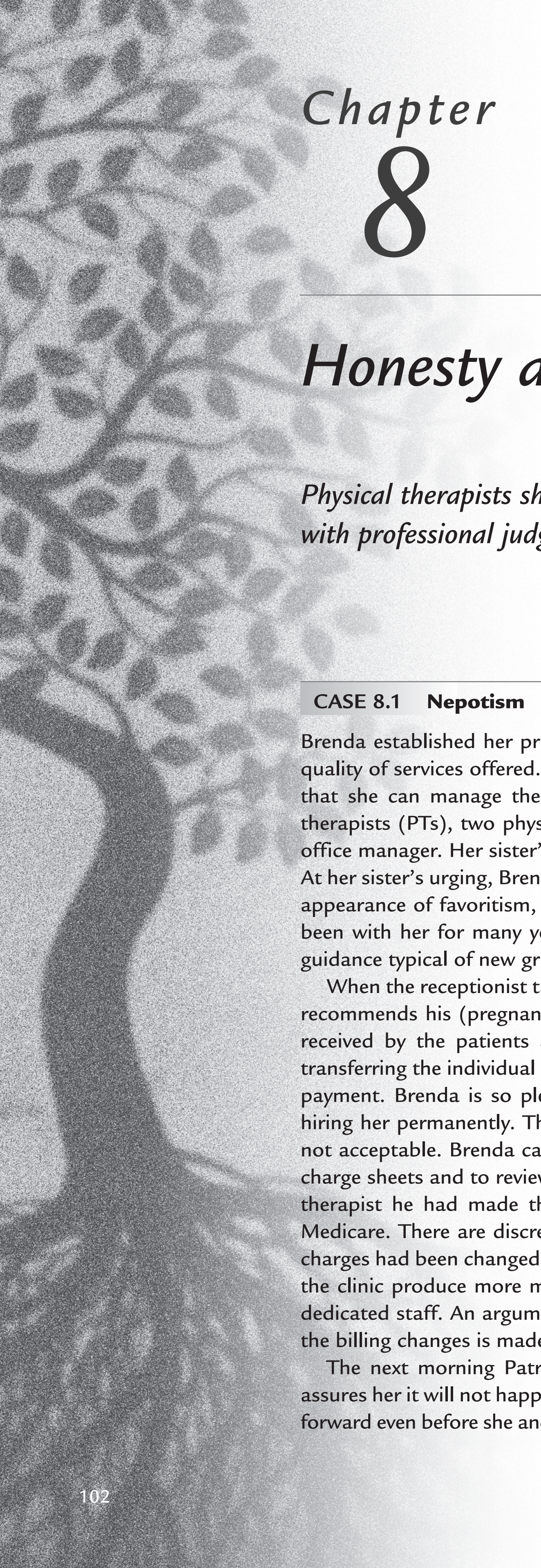


# PART 3

# Organizations and Administration

Accountability
Integrity

*"Professionalism in Physical Therapy: Core Values"*
American Physical Therapy Association



# Chapter 8

# Honesty and Conflicts of Interest

*Physical therapists shall not engage in conflicts of interest that interfere with professional judgment.*

Principle 3D, APTA Code of Ethics

## CASE 8.1 **Nepotism**

Brenda established her private practice 20 years ago, and it has prospered because of the quality of services offered. Her role as a treating therapist has been reduced to half-time so that she can manage the business side of the practice. She has three full-time physical therapists (PTs), two physical therapy assistants (PTAs), two aides, a receptionist, and an office manager. Her sister's son, Patrick, just graduated with his degree in physical therapy. At her sister's urging, Brenda hires Patrick, although she is aware that she needs to avoid the appearance of favoritism, which would erode the morale of the other therapists who have been with her for many years. He is an excellent therapist, in need of the mentoring and guidance typical of new graduates but diligent and a quick learner.

When the receptionist takes an extended leave of absence to help her ailing father, Patrick recommends his (pregnant) girlfriend Kelly as a temporary replacement. Kelly, too, is well received by the patients and staff. She assumes new duties, such as filling charts and transferring the individual billing sheets for Medicare to the practice summary submitted for payment. Brenda is so pleased with Kelly's work that she wrestles with the possibility of hiring her permanently. Then Brenda receives notice from Medicare that some charges are not acceptable. Brenda calls the staff together and urges them to be more careful on their charge sheets and to review Medicare standards for billing. Patrick, worried that as the new therapist he had made the errors, compares his billing sheets with those forwarded to Medicare. There are discrepancies. That night he asks Kelly if she knows how some of the charges had been changed, and she readily admits she had changed them. She did so to help the clinic produce more money, hoping this would generate pay raises or bonuses for the dedicated staff. An argument ensues, and Kelly threatens to leave Patrick if any mention of the billing changes is made to Brenda.

The next morning Patrick talks with Brenda and claims that he made the errors and assures her it will not happen again. Brenda is surprised but encouraged that Patrick stepped forward even before she and the office manager had found out what happened. Later that day, however, Brenda calls Patrick into her office. Her office manager had already started a review of the financial records and found that, in addition to the Medicare problem, there was a discrepancy in the "cash pay" patient and product revenue. Although the cash pays were difficult to track, the debit and credit swipes were greater than the posted prices. The overall revenue was greater than it should have been. The office manager also told her that Patrick's billing slips had been correct and transferred incorrectly to the billing statement. Only one person, Kelly, had access to both.

Conflicts of interest are sometimes difficult to discern, especially when they involve self-interest that distorts good judgment. We begin by providing a definition of conflicts of interest, not with the hope of removing all vagueness, but to highlight key areas where vagueness and ambiguity arise in practice. Next we distinguish some of the systemic conflicts of interest within a managed-care environment. Then we sample some recurring conflicts of interest: physician referral, equipment and supplies, gifts, and teaching and research.

## DEFINING CONFLICTS OF INTEREST

**Conflicts of interest** are situations in which individuals have interests that threaten their role responsibilities or that would do so for a typical person in their role.[1] Three features of this definition need clarification: role responsibilities, interests, and typical persons.

**Role responsibilities** are duties attached to formal assignments within organizations or social practices, such as the health-care professions. In the present context, role responsibilities refer both to the particular duties assigned to PTs at their jobs and to therapists' general professional duties.

**Interests** include all benefits to the professional as well as altruistic and other concerns the professional might have, such as friendships and family relationships. Most conflicts of interest involve competing interests in business or professional life, such as accepting personal inducements from a salesperson to use a particular product, doing part-time work for a competitor's company, or making a heavy financial investment in a competitor's company (without an employer's permission).

Not all "conflicting interests," however, constitute conflicts of interest.[2] For example, a parent who is torn between wanting a divorce and wanting to remain with her spouse in order to provide support for her children is caught in an ethical dilemma involving conflicting interests, but she is not in a conflict of interest. However, a parent coaching her daughter's soccer team is often faced with a conflict of interest because of her desire to keep her child playing as much as possible while needing to keep her child on the bench for the well-being of the team. The difference is that, in the coaching case, the interest as parent threatens (or might threaten) her role responsibilities as coach.

Finally, our definition distinguishes between individuals and **typical persons.** Consider a judge of such exceptional integrity that she would be fair in adjudicating a dispute involving a family member. The judge is still considered to be in a conflict of interest because a *typical* judge in that situation would be at risk of failing to fulfill her role responsibilities. Indeed, the judge is obligated to avoid even the *appearance* of a conflict of interest. Similarly, the American Physical Therapy Association (APTA) *House of Delegate Standards, Policies, Positions and Guidelines* (HODY06-02-28-50) declares that members of the board or the board-appointed body should not participate in discussions of a case if there is a relationship that would prevent them from acting impartially "or that reasonably would tend to cast doubt on the member's ability to act impartially."

In Case 8.1, Brenda is confronted with conflicts of interests *and* conflicting interests. Kelly's attempts to increase the revenue stream is blatantly illegal and unethical. At the same time, it produces a temptation to look aside, not only because of the revenue but also because of the conflicting interests of the Patrick/Kelly relationship. In retrospect, Brenda might well appreciate the nepotism policies many private companies have in place to avoid such entangled conflicting interests and conflicts of interests. Moreover, if Brenda attempts a cover-up, she might place her clinic at risk. Patrick also has a profound dilemma to confront as he considers the future of his relationship with his unborn child and the likely outcomes if Brenda notifies law enforcement.

## EPISODIC AND SYSTEMIC CONFLICTS OF INTEREST

In what follows we concentrate on routine and recurring types of conflicts of interest. Recurrence takes two forms. **Episodic** conflicts of interest arise from choices made voluntarily—for example, giving and accepting personal gifts on the job. In contrast, **systemic** conflicts of interest arise from the very structure of professions and other social practices. For example, there is an ongoing temptation in all professions with a fee-for-service reimbursement system to provide unnecessary services to clients in order to increase profits. Conversely, there is the ongoing temptation to limit services in a capitated reimbursement system. The following case study centers on episodic conflicts of interest against the background of systemic conflicts of interest.

## CASE 8.2 Physicians' Duplicity

Joseph Caldwell is the CEO of a hospital located in a rural area of northern California. The hospital is one of eight owned by a nonprofit corporation based in Sacramento. Joseph's hospital has a long history in the community, and it expresses its commitment to the community in its mission and vision statements. Over the years, the hospital's excellence has resulted in a virtual monopoly, with little competition in the geographical area. Joseph is aware of the temptations for institutions in similar circumstances to exploit clients, but he has been vigilant in keeping costs within reason while providing excellent care, including to its large and growing geriatric population.

The corporation has approved a $175 million expansion with the stipulation that profit from Joseph's hospital has to improve. Joseph does a close audit with the chief financial officer and discovers that the orthopedic department, unlike the other departments, consistently loses money. He also finds that a major source of lost revenue is through the medical appliances used. The markup for the appliances is extremely high, but because of the relatively low volume that the hospital chain commands, they are not in a position to reduce their cost significantly. The bottom line is that most payers reimburse at a rate lower than that which the hospital uses to purchase the appliances.

On closer investigation Joseph discovers that one surgeon orders his appliances from only one vendor, who tends to be nearly 30% more expensive that the nearest comparable bid. Another surgeon orders from another company that has an even higher percentage deviation from the lowest bid. There is no evidence that either company provides superior products. When Joseph asked his assistant what she thought was going on, she responded that in the one case the physician ordered appliances only from his son, who was a sales representative. In the other case, the physician was the owner of the company whose products he purchased. Joseph set up an interview with each surgeon. The one said up front that his loyalty was to his son who was struggling to support his family. The other said that the reason he owned the company was because of his dissatisfaction with the low quality of products offered by other companies. He went on to recite his company's stringent quality control methods and affirmed that he believed his products were in the best interest of the patients.

In many states, Joseph could fire both surgeons for conflicts of interests that put the new facility in jeopardy. But in California and a few other states, the law embraces a "corporation practice of medicine doctrine" intended to prevent the conflicts that occur between the physician-patient relationship and the business model. Physicians cannot be hired by corporations that are not physician-run unless they have a health plan license. Rather, the physicians are hired by medical groups that contract with hospitals. At least in theory, physicians can work for multiple hospitals under the group contracts or operate a private practice. Thus, the chief executive officer (CEO) could at the end of the contract refuse to sign the group on again, but in this rural area that would mean he would have virtually no orthopedists. The CEO did the next best thing. He gave Purchasing a directive that removed both companies as approved vendors for the hospital. Both surgeons tried to incite a work stoppage, but neither succeeded and neither left their group or the hospital.

Some systemic conflicts of interest are inescapable and morally tolerable—short of overthrowing or radically modifying social practices and economic systems (which can generate new systemic conflicts). To be sure, some ethicists do stipulate that the expression "conflict of interest" refers only to morally objectionable situations, which explains why the expression typically carries unsavory connotations. Notice that ordinary usage allows one to say that parents who (permissibly) coach their children's teams are in a conflict of interest. As another example, the Federal Aviation Administration (FAA) permits designated engineers working for airline companies to serve as FAA inspectors on the airplanes the engineers help build.[3] This is a clear conflict of interest, in that the engineers' loyalty to their companies could threaten their duties to be impartial inspectors. Yet the conflict of interest is acceptable because the complexity of airplanes and the limited resources of the FAA make this the most workable arrangement for inspection. Similarly, the Commission on Accreditation in Physical Therapy Education includes physical therapy faculty from already accredited programs on its on-site review teams when a school is being considered for accreditation. The reason for this is similar to that in the FAA case: it takes someone fully informed about educational theory and the discipline of physical therapy to judge accreditation worthiness. It is expected that the faculty on the review team will disregard the fact that all other accredited programs are potential competitors for students.

In general, conflicts of interest are **tolerable** when the relevant systems (institutions, economic structures, etc.) are morally permissible, when effective procedures for overseeing abuses are in place (laws, self-regulation within professions, consumer-group publications), and when the relevant parties voluntarily accept the arrangement. For example, consider the economic systems of Western democracies that combine, in varying degrees, capitalism (free enterprise), government regulation, and professional self-regulation.

Calling a conflict of interest tolerable, we should add, does not banish moral concern about threats to responsibilities. Parents who coach their children remain open to criticism for making biased judgments. Similarly, inescapable conflicts of interest call for conscientiousness by committed professionals and vigilance by disciplinary structures. In short, defining a situation as a conflict of interest raises a red flag, but it does not indicate how the flag is to be waved.

Nevertheless, there is a strong presumption against preventable conflicts of interest in the professions. Why is that? One reason is clear from the definition: conflicts of interest threaten responsibilities, potentially undermining professional integrity. Another reason is that even the appearance of conflicts of interest can endanger the trust of patients and the public. And yet another reason is that most conflicts of interest involve deception and other failures of truthfulness. All these values—integrity, trustworthiness, and truthfulness—are aspects of honesty, which we therefore adopt as the central guiding value in thinking about conflicts of interest.

Regarding episodic conflicts of interest, alternative moral responses include the following options:

1. "Escape from them, typically by relinquishing the conflicting interest that threatens the role responsibility;
2. Avoid them in the first place;
3. Disclose them to appropriate parties (such as employers, clients);
4. Take other steps, as appropriate, even if it is only exercising special caution to ensure role responsibilities are properly met."[4]

Health care exists because individuals are vulnerable and need help. Furthermore, harm caused by mistakes frequently cannot be undone, unlike mistakes made in financial or legal matters. As a result, disclosure of conflicts of interest is generally not enough. To undermine the trust on which care is built is to diminish the care itself, regardless of whether professionals profit financially or not. Unlike law or banking, in which it is desirable for all parties to be vigilant and in which full disclosure helps assure that vigilance, the primary concern and focus in health care is for the patient to achieve better health or function. This concern is often in response to a sudden illness that finds the patient uninformed about the best course of treatment and hence needing to trust the judgment of providers. Thus, to minimize threats to patient trust, there is a strong presumption that therapists and other health-care professionals should do everything possible to avoid conflicts of interest related to patient care. The avoidance is not only a provider responsibility, but also one of management. "It is a true mark of professionalism to avoid situations that might inappropriately influence professional judgment. It is a true mark of institutional respect for professionalism to implement policies to protect professionals from inappropriate pressures or influences."[5]

## SYSTEMIC CONFLICTS WITHIN MANAGED CARE

### CASE 8.3 **Wall Street Medicine**[6]

Magnum HMO is one of the largest chain of hospitals in the United States. Its CEO explained to shareholders at a recent conference that the company's strategy is to be "Wall Street medicine." The goal is to be the largest hospital chain in the U.S. and to reward its stockholders accordingly. Magnum HMO aggressively recruited top talent and managed each hospital in its chain like a separate entity in order to maximize profit through easily defined lines of authority and accountability.

Fielding Community Hospital had been through seven CEOs in 6 years, and under the current CEO it had started to show a significant profit for the first time. Father Whitmore was in Fielding visiting his sister and her family on his annual vacation. After dinner at the newest restaurant in town, Father Whitmore complained of stomach pain and nausea. His sister, fearing any number of possibilities, insisted that he go to the emergency room at Fielding. Once there, he was referred to the on-call cardiologist. He was rushed to the catheterization laboratory and in less than 30 minutes was notified that he had multiple blockages and needed emergency bypass surgery. The surgeon told him his condition was grave. Father Whitmore listened but told the cardiologist he would go back to his home and check in with his personal cardiologist immediately. The surgeon became visibly upset and stormed out of the room.

Father Whitmore flew out that night and called his cardiologist, Dr. Klein, the next morning. They met at the hospital where a workup was done but discovered no blockages or any other sign of cardiac disease. Dr. Klein contacted Fielding Community Hospital and requested electronic transmission of their findings. He identified nothing that would justify the diagnosis or

**the $47,000 bill. Because of Father Whitmore's extensive network through the church, two other people came forward with nearly an identical experience at Fielding Community with the same cardiologist and one other. Together they did a Web-based search and found that the Fielding Community cardiology team produced the lowest mortality rate in the country. It was a mere 1.75%. The volume was not surpassed by any medical center in the country, yet Fielding was a relatively small town. The next highest volume in the state was a mere 20% of their volume. With time and persistence it was discovered that Magnum HMO had given the two physicians the right to be reviewed only by themselves. As a result of this practice, they received enormous salaries and bonuses unmatched anywhere in the state. The volume and extremely low mortality rate were due to unneeded surgeries done on relatively healthy individuals. The settlement to Medicare alone topped one billion dollars, and Father Whitmore and the two other patients who blew the whistle were given nearly 10 million dollars under the False Claims Act.**

**Adapted from United States District Court for the Southern District of Florida, Case No. 07-61329, filed on September 18, 2007, U.S. v. Christi R. Sulzbach, defendant, and was retrieved through the OCEG Web site.[6]**

The most basic systemic conflicts of interest center on the primary good served by the profession. Described in general terms, this good is shared by all health fields: to promote health while respecting patient rights. Described more specifically, the good served by physical therapy treatment is to restore persons to more functional, pain-free, and independent lives as well as to help prevent injuries and pain in the first place. Three interwoven questions arise immediately.

1. When is health-care intervention warranted and at what level?
2. Who defines acceptable outcomes—the patient, the provider, or the reimbursement organization?
3. What is the cost, and who pays?

Most people—healthy and functional with respect to the expectations of others, age, and level of activity—could profit from physical therapy services in preventing problems such as poor body mechanics and improving such areas as balance and gait. Who defines the threshold for such services? If left to patients, all will draw a different line in the sand. Even where there is obvious disability, some patients are quickly resigned to a life of needless dysfunction; others want athletic skills rather than mere average abilities. Needs for physical therapy can be highly specialized, even within the specialties recognized by the national organization and achieved through extensive training and monitored clinical experience. For example, within sports medicine, some PTs specialize in treating only professional dancers and the unique injuries and risks associated with that profession.

As with physicians, therapists' primary conflict of interest is centered in the entrepreneurial method of reimbursement and the acquisition of medical services. All health-care providers affirm an ethic of beneficence and equality (serving all patients to the best of one's ability) and an ethic of equity (service according to a patient's ability to pay or a plan's prenegotiated equity format). Yet, equality and equity can conflict in nuanced ways. In addition, each of the methods of reimbursement carries with it potential conflicts of interest between whatever service is provided (or denied) and the financial well-being of the provider.

Like most professions, physical therapy generates systemic conflicts of interest centered on the therapist's dual roles of adviser and provider.[7-12] Thus, most professionals advise clients about options, help decide the best course of action, and then provide the services. The implications of adviser-provider conflicts differ according to the payment systems within which health professionals function, and those systems are presently in turmoil. Historically, the two main categories are fee-for-service and managed care.

In traditional fee-for-service systems, the provider has a systematic incentive to advise for unnecessary services, thereby raising costs dramatically. Fee-for-service tends to bring higher costs for patients, unnecessary tests, and unnecessary procedures. The provider's self-interest leads to setting goals and timetables to harvest the maximum payment, even as patients and insurance companies desire to restrict cost as much as possible. In the fee-for-service system, it is not uncommon for therapists in private practice to earn yearly incomes that are multiples of the national average. The goals, objectives, frequency, and duration of treatment are largely at the discretion of the therapist, expressed to and endorsed by the referring physician. Yet, in most cases, the therapist's discretion works in the interest of the patient.

Joan Gibson defines managed care as any delivery and reimbursement system that attempts to control the following: (1) the clients served, (2) the range of benefits and services offered, and (3) costs.[13]

Managed care has evolved as a significant health-care system since the congressional passage of the Health Maintenance Organizations Act of 1973, but its earliest roots were in the early 1900s.[14] In theory, it is organizationally configured as a composite of the most productive elements of business theories. In truth, managed-care systems' cost structure for providing services constitutes a systematic incentive to *not* advise patients of all needed services and thus minimize usage of services. Capitation is based on paying according to numbers of members in the health plan rather than on usage of services. In a managed-care environment, the conflict of interest is between the duration of treatment in the best interest of the client and what is permissible (reimbursable) under the managed-care plan. The move to managed care generates many conflicts for PTs in their role as advisers. Should the therapist counsel the client about the true potential and risk in the minimal care that is being reimbursed? Should the therapist inform patients of options that might produce beneficial results but at extra cost for the provider? Should the therapist limit client expectations and thus meet standardized pathways and time frames?

At its core, then, the primary conflict of interest in a managed-care situation is between business standards and professional standards.[15] The following table provides a brief look at some of the common values characteristic of a profession and those of business **(Table 8–1)**.

Therapists might be employees of managed-care organizations or provide a contracted service for the organization. The contracted-service arrangement relieves the managed-care organization from having to provide fringe employee benefits as well as from having to meet requirements governing the employer-employee relationship. Within this contractual arrangement, the business model is coercive when it "deselects" health professionals, including physicians and PTs, because of their so-called "excessive" resource utilization.[16] Under this arrangement, services can be limited contractually, both directly through gag orders and indirectly by providing incentives to limit care, such as those inherent in capitated plans or even by replacing trained professionals with less costly and less-trained employees.[12(p131-138), 14(p139-152)] Most contracted services can be discontinued for any reason, by either side, and are not subject to the due process review or the same laws governing an employer-employee relationship. Hence, contentious or resource-demanding providers are likely to find themselves without a job and without means to appeal.

Legally, providers are caught between judicial rulings and a managed-care corporation's right to end contracts at any time and for unspecified reasons. In *Wickline v. California,* 1986, the court made it clear that if the provider did not try to negotiate against an adverse limitation in coverage that would adversely affect the patient, the provider would be held accountable for an unfavorable outcome.[16(p144)] In effect, the court demanded that professionals make decisions by way of advocacy for the patient, even if business policy points in the opposite direction.

**TABLE 8–1. Professional and Business Values**

| CHARACTERISTICS OF A PROFESSIONAL | BUSINESS VALUES |
|---|---|
| 1. Makes decisions by means of general principles and theory | 1. Select clinical pathways to reduce variability and increase efficiency |
| 2. Has unique knowledge | 2. Shared knowledge is versatile, therefore more efficient |
| 3. Status is awarded by accomplishments | 3. Competition enhances profit and acquisition of power |
| 4. Decisions made on behalf of the client/patient | 4. Actions should yield reasonable or maximal profit |
| 5. Authority is accepted only from colleagues | 5. Managers should be trained in business theory |

## CASE 8.4 Profits Versus Patients

John is a therapist with a contract to provide services to the patients of Sheraton Managed Care. Sheraton is very clear in its contract that John is to follow the critical pathways. He can treat patients fewer times if warranted, but he cannot extend additional care without approval. He is not free to refer patients to outside therapists, nor is he in any way to "undermine" the credibility of the care offered by Sheraton Managed Care.

In the course of treating a 42-year-old man for injuries resulting from multiple gunshot wounds, John realizes that his patient should have the care of a PT with expertise in treating the hand. He also realizes that he will not be able to help his patient reach his potential within the number of visits approved by Sheraton Managed Care.

Sheraton has never honored any of his requests for extensions. If John does not petition for an extension and the patient is harmed—for example, he cannot return to employment—then John may well be liable for the harm. But another petition from him might reduce the likelihood that his contract will be renewed and even put him at risk for dismissal. If he informs the patient that he needs a therapist with an expertise in hand therapy, and if the patient then demands from Sheraton the expertise John recommends, John will most certainly be dismissed. However, if John uses his social skills and

**convinces the patient that he is getting the very best care, it is unlikely there will be any negative repercussions for John. Integrity, trustworthiness, and truthfulness are all at risk in this environment.**

The contracted service model is coercive to the provider, and it is deceptive to the patient because it encourages the provider to withhold important information. These contracts often embed many items of information typically not available to the public—for example, economic incentives and disincentives to PTs and physicians, treatment options under the plan, and gag orders (forbidding providers to tell patients) on expensive procedures.

Most managed-care structures have six features that create a mixture of benefits and potential problems.[17]

1. Managed-care corporations frequently use teams, often preferring transdisciplinary teams. Although therapists have long worked in teams, the teams are most often multidisciplinary or interdisciplinary. In the multidisciplinary team, representatives from different disciplines share common general goals for the patient, even though each discipline supplies only its own specialized skills. In the interdisciplinary team, the disciplines share common goals but the activities are synergistic and overlapping. For example, the PT might request that the occupational therapist and speech therapist position the child in a particular way to maximize stretch on the hamstrings. In turn, the speech therapists might request that all disciplines use words with three or fewer syllables when addressing the patient. Team meetings are occasions where requests are conveyed, goals are decided, and everyone is updated on the patient's status.

   In the transdisciplinary team model, more highly integrated care is provided, and activities and techniques are taught across disciplinary lines. If the patient is primarily cared for by an occupational therapist, that therapist might receive instruction from physical and speech therapists to implement their respective professional programs. This model has been encouraged in many institutions as a means of cost containment. Yet professional objections have been voiced concerning occasions when unexpected patient responses occur and the caregiver does not have the theory base to respond appropriately. Some therapists reject this model because they believe it sacrifices quality care and because it might violate the state-defined scope of practice for each participating licensed profession. In the APTA *House of Delegate Standards, Policies, Positions and Guidelines*, it is stated in HOD P06-99-12-05 that "The American Physical Therapy Association (APTA) opposes the concept of the cross-trained professional practitioner, defined as 'a health care practitioner who is cross-trained in area(s) of practice in which the individual is neither educated nor licensed.'" Therapists who have had success using this model caution that the standards of practice must be reviewed and discussed well in advance of implementing them to determine their appropriate scope.
2. Managed-care structures combine administrative and clinical duties. Although this combination creates variety in the workday of some, for many others it displaces the care they would prefer to give to patients.
3. Managed-care companies train people only in what they need to know and standardize treatment for greatest efficiency, such as through critical pathways. This practice tends to limit the understanding of the clinician relative to the overall distribution of resources within the organization, thereby lessening fully informed advocacy for patients. The uniqueness of individual patients is not always best served by a singular approach that minimizes professional judgment.
4. A managed-care environment maximizes team efforts at problem solving. This is a positive feature when it is understood to be consultative problem solving, with professionals still in charge of the decisions relative to their expertise. If, however, the group decisions override individual professional decisions, the therapist must spend significant time building power and influence within the group to ensure effective advocacy for the patient.
5. A managed-care environment rewards team effort rather than individual skill development. Rewarding team productivity treats all contributions within the group equally, even though typically the value of contributions varies considerably—especially in a rehabilitation setting.
6. Managed care links all evaluations ultimately to customer (patient) satisfaction. Its retail approach to health care can displace the most important element in medicine—professional standards of practice. Patients may be pleased if they are attended to and treated with respect in attractive settings, as with retail sales, and the telephone calls made by the receptionist or nurse to inquire about how the patient feels after hospitalization might be influential in surveys of satisfaction, but such calls or décor do relatively little to ensure competent care. The patient typically does not know what care, procedures, and medications would provide maximal health benefits, so the patient's expressed satisfaction is uninformed, particularly in the elements of care that are most critical.

Regardless of the employment relationships within the managed-care environment, the primary responsibility of PTs is to their patients: to provide quality services and products at reasonable costs within the constraints of respect for autonomy. In addition to issues of cost, quality, and control, there are related considerations about honesty and maintaining the public trust, which require avoiding even the appearance of objectionable conflicts of interest. There are also responsibilities to employers, to coworkers, and to the general public. Exactly when these responsibilities are threatened requires close attention to context, enlightened by a broad understanding of human propensities.

Overall, in our judgment, the managed-care system of recent decades encourages providers to offer a minimum level of care, not an optimal level. Although economic realities cannot be ignored, concern for the patient must remain paramount. When patients would probably profit from additional treatment, they should be so informed. Defending the adequacy of a managed-care pathway that is not appropriate for a given patient is dishonest. Therapists should not sign contracts that restrict expression of professional opinions or gag orders, any more than physicians should.

The APTA *Code of Ethics* offers guidance, although it leaves specifics to the judgment of individual practitioners. For example, principle 3D states that "Physical therapists shall not engage in conflicts of interest that interfere with professional judgment."

## PHYSICIAN REFERRAL

### CASE 8.5 **Physician Kickbacks**

Troy is a licensed PT who graduated 4 years ago. He has worked as a full-time employee at the local hospital and has done home health physical therapy on the weekends. In addition to paying off half his student loans, he has saved enough to consider buying a private practice near his home that has just come up for sale. The owner of the practice has been in the same location for a decade and has a professional staff of six PTs, two PTAs, and two PT aides. The staff has grown slowly over the years, but the financial records show a steady income stream. Troy decides to take the big step and buy the practice.

The first few months go so smoothly that he wonders why he did not make this move sooner. But he has also noticed that about 20% of the revenue consists of large payments that pay off liens (generated by lawsuits) under the former owner, all managed by an attorney, Andrew Son. In addition, all the medical referrals involved had been placed by Dr. Harold Simmons, who also forwards nearly 40% of the current patient load. Late one Friday afternoon, the attorney, Andrew Son, called and asked Troy if he would forgive a lien on a lawsuit that had not paid out as much as expected. The lien was for nearly $12,000 in patient services to Harvey Cone. Troy was unfamiliar with the particular case but explained that when he bought the practice he expected to get the unpaid revenue as part of the practice revenue. Troy said he would not forgive the lien.

Mr. Son was clearly annoyed and asked if Troy would at least lower the lien to half. Again, Troy refused. When Mr. Son asked if Troy was going to send his client to collection for the debt, Troy said "yes." The conversation ended abruptly. Barely 30 minutes passed until Dr. Simmons called Troy and explained that Mr. Son was furious and that Troy needed to call Mr. Son and apologize and to drop the lien. Dr. Simmons explained that Mr. Son was a large referral resource for him and that he needed a PT who would provide services. Dr. Simmons told Troy that because medical insurance was usually not involved in the cases, Troy could charge whatever he wanted, within reason, but to be sure to use as many modalities and other lucrative venues as possible. Troy could hardly believe what he was hearing. But he also felt trapped. After much consideration and several long talks with his partner, he severed all ties with Dr. Simmons. The business dropped quickly in revenue, so Troy set out to market his services directly to physicians in the area. One surgeon told him that unless Troy could purge the practice of its reputation established by the prior owner, the surgeon would have nothing to do with the practice. The surgeon also explained that most physicians knew about the referrals and the thinly disguised kickbacks and that it was unlikely any of them would want their names associated with Troy's business. Business continued to decline rapidly, so Troy changed the name of the practice. But by this time he was associated with the previous owner and the practice failed.

Historically, physician referral has been one of the most discussed conflicts of interest in physical therapy. At one time, PTs worked most often directly under physicians' supervision. As physical therapy became increasingly professionalized, and therapists' required skills were greatly augmented in both diagnosis and treatment, there was a strong move toward private practice therapy. As a result, problematic physician referral arrangements were established that allowed physicians and PTs to profit, particularly when physicians were paid simply for making referrals.

The practice had serious potential for abuse, as was widely appreciated by the early 1980s. It often constituted kickbacks that significantly increased costs to patients, adversely affected judgments about quality of services, and threatened public trust. A consensus developed that referral was not a service from which physicians should be allowed to profit. In 1983, the APTA forbade PTs from entering into arrangements that allowed physicians or other referring practitioners to profit from simply making a referral.

Tygiel has cited many instances in which patient rights were abused when physicians profited from referrals.[18] The instances included prescribing unnecessary services, on the part of both physicians and PTs; low-quality care as a result of physicians not considering the appropriateness of the specialization of the therapists they used; and denying patients the therapists they preferred. In one case study, an orthopedic surgeon employed a PT who, although well trained in treating spinal conditions, did not have expertise in hand therapy—even though hand surgery was a primary component of the surgeon's practice. Hand therapy and the custom splinting frequently required is a highly specialized area of practice for physical and occupational therapists. The surgeon nevertheless referred his patients to the therapist in his employment, even though patients frequently had to be referred later to one of four qualified hand therapists in the community because the surgeon's favored therapist lacked the special skills needed. The later re-splinting by a qualified therapist was an additional cost to the patient.

The APTA *Code of Ethics* has since been clarified and strengthened to forbid PTs from entering into many problematic referral relationships. However, regardless of how carefully a code is constructed, it is not possible for a single document to anticipate all possible variations on a common theme. For example, consider a case in which the husband is a physician and the wife is a PT. Although legally their practices are separate and therefore withstand the APTA definition of conflict of interest, their joint income is enhanced by referrals from the physician husband to his therapist wife. The physician responds that he wants his patients to receive the best physical therapy care available, and he believes that is provided by his wife. Clearly, there is a possibility for abuse. Disclosure of the relationship to patients by the physician or therapist should be supplemented prior to the first appointment with a listing of other therapists in the area with similar training. Principle 7D of the APTA *Code of Ethics* appears to support the spirit of this recommendation: "Physical therapists shall fully disclose any financial interest they have in products or services that they recommend to patients/clients."

When professional groups are unsuccessful in managing the behavior of their members, state and federal legislatures take action to correct or contain practices that do not comply with the best interests of patients and payers. Two such examples are the Anti-Kickback Legislation (section 1128B of the Social Security Act) initiated in 1972 and amended on multiple occasions and the Stark Laws (I–III), also known as the Federal Physician Self-Referral laws (initiated in 1989 and revised with new refinements published by the Center for Medicare & Medicaid Services with still more revision in process). Briefly, the anti-kickback statute and its revisions are criminal statutes that prohibit any health-care provider or entity from paying or receiving rewards for referral for any federally funded health-care services. The specifics and exceptions are too numerous and complex to explore in full in this text; in general, remuneration in any form for the purpose of procuring or receiving referrals is strictly forbidden. The Stark Laws pertain to physicians' self-referral to any services in which they or a member of their family have a financial interest. Unlike the anti-kickback laws, these are civil statutes that directly target physicians for self-referring and expand the coverage to prevent any provider from billing for those services under federal payment. Intent is not considered because it is a statute of "strict liability." As with the anti-kickback laws, there are numerous exceptions. Many PTs hope that physician-owned physical therapy services will cease to be an exception to the law. One current exception has to do with rural practices where no other competing service exists within 25 miles of the patient's home. For updates on these and other relevant laws, consult the documents available through the home page of the APTA. Both the anti-kickback and physician self-referral issues have been additionally addressed by many states, and those state restrictions may be considerably more stringent.

Referral issues have become somewhat more convoluted in managed-care situations in which the senior physicians in a health maintenance organization (HMO) are also its owners. Profit is still the concern, but this time underuse (rather than overuse) of physical therapy poses the more serious offense. The dilemma is compounded by the dependent role of the PT. In some states, such as California, the PT can evaluate and, in some states, they can treat a patient without a physician's referral, but in most states, insurance carriers will not reimburse the patient or therapist without the referral. As a result, therapists are financially wedded to physicians even though they themselves are increasingly skilled and professional enough to be capable of making independent physical therapy diagnoses and treatments. This financial tether has the potential to bind the professional judgment of the therapists to a menu of physician-acceptable options.

## EQUIPMENT AND SUPPLIES

PTs frequently make equipment for patients, such as splints and seating inserts. Therapists who work with patients know their specific needs and have the specialized knowledge to order equipment. In private practice it is not usual for the therapist to charge patients for materials and the time used to construct the equipment. These therapists often supply equipment at a lesser cost than do specialized vendors, but not always.

Therapists who fabricate equipment for patients often cite patient benefit as the primary motivation. Because equipment, especially splints, needs to be custom-made, therapists argue that when they do the fabrications it is more time-efficient and ultimately contributes to a better product. They do not have to take the time to communicate in detail the patient's needs to a fabricator. They also point out that fabricating a piece of equipment enables them to respond to unanticipated variables, to change the specifications of the equipment, and to implement those changes immediately.

Many therapists charge only for the cost of the materials, plus their customary practice rate, to generate the equipment. There are companies dedicated to the creation of these appliances, however, and these companies are quick to point out that this practice robs them of needed income for tasks they are specifically trained to perform. But perhaps the greater problem is the appearance of a conflict of interest. Therapists can easily fill any downtime with equipment fabrication, thereby securing a steady income in private practice. Hence, there is the temptation to create a market for equipment within the therapist's patient population, which could not possibly get the exact appliance without going to another therapist who also manufactures equipment. The appliances are so uniquely a blend of the patient's need and the therapist's goal of correction that without the therapist's input, an outside vendor would be unable to meet the patient's needs adequately.

Therapists also should not have a major financial interest in the company that supplies them with products they use in practice. Yet there is an interesting dilemma inherent in this advice. Because, in general, people are advised to invest in companies or markets with which they are familiar, it would seem to be good business practice for therapists intent on securing extra financial security to invest in companies whose products they know to be better than those of the competition. Even though therapists may own stock in those companies from which they make purchases, they are driven by the commitment to provide the best supplies. As a result, stock ownership is inherently objectionable only if it becomes excessive or if the company supplies inferior products or offers direct kickbacks—as defined by reasonable guidelines within organizations and the profession.

## GIFTS

The importance of conflict of interest, as well as of context, enters centrally into a discussion about gifts. Principle 7C of the APTA *Code of Ethics* states, "Physical therapists shall not accept gifts or other considerations that influence or give an appearance of influencing their professional judgment."

Precisely what does this mean? The intent is not to forbid all gifts, even though such a prohibition might be necessary in some settings, such as the defense industry, in which gifts from contractors to government officials are essentially banned altogether. In physical therapy, like many other professions, hard-and-fast rules on gifts can cause unexpected negative consequences. For example, many gifts from suppliers, or vendors, are "reminder items" that have negligible monetary value. But as a tool to enhance a relationship, their value cannot accurately be measured in dollars. Instead, their value must be considered relative to the subtle influence on the relationship and related decisions. The American Medical Association allows small gifts, and anyone who has attended a health profession conference in the United States has experienced how widespread this practice has become. At APTA and other health-related conferences, the trend has been to move away from promotional gifts that can be used with patients and instead toward gifts specifically for the therapists, often without any relationship to the products the vendors sell.

Other gifts raise different concerns, both in their acceptance and rejection. In most physical therapy settings, the therapist is engaged with the patient over significant periods, and the quality of that time is enhanced by collaborative goal setting and assessment—tasks that frequently build a social as well as professional relationship. Patients often see the therapist as their primary advocate and their primary hope for restoration of function. As a result, gifts from patients to therapists are common, especially in pediatric settings, and often insignificant in their cost—for example, drawings, homemade cards, or a box of chocolates. Whereas with vendors such small gifts might be objectionable because they may be intended to influence therapists in the products they purchase, gifts from patient to therapist could actually strengthen a component of care.

It is also true that in some cultures gifts are given to health-care providers out of custom and appreciation, without any intent to acquire more or better services. To refuse such a gift is considered an insult. Refusal says symbolically the gift and the giver are unappreciated, and thereby the patient-therapist relationship is disrupted. Because the type of work that therapists perform requires maximum effort and cooperation from the patient, any action that diminishes the trust with the patient potentially diminishes the effectiveness of the intervention.

At the same time, no therapist is immune to attempts by patients to influence them to provide more services as appreciation for a gift. Patients sometimes try to influence therapists to continue treatment past the point at which, in the therapists' judgment, the patient has the capability of benefiting from treatment. Many patients believe that as long as the therapist continues treatment, hope for significant recovery or restoration of function exists. Certainly no one wants patients to abandon realistic hope, but patients should not cling to false hope when doing so undermines efficient use of services or equipment. In these ways, gift giving and receiving are caught in a subtle interplay of hope and honesty in ways that call for good judgment rather than fixed rules.

The cost of a gift is one guide to its intent, albeit a fallible one. For example, gifts must be assessed in relation to the economic situation of patients rather than to its value to the therapist. What appears to be a large gift to a therapist may be an inexpensive expression of appreciation by a patient, whereas for another patient the same gift would be a considerable sacrifice. In all these cases, one must assess the intent based on the history of the relationship and what is known of the patient. Thus, gifts from patients are governed by internal policy and decisions made considering content and intent.

Gifts to physicians and patients do, however, have legally defined limits intended to prevent undue influence on acquiring referrals from physician or services from patient self-referral. The Stark Laws do not allow gifts of a greater sum value than $300 in 1 year (adjusted each year for changes in the cost of living) to physicians.[19,20] Gifts to patients cannot exceed $10 per gift or more than $50 in sum to any one patient in a year.[21,22] Whereas discounts can be given to patients if they are reported accurately, Medicare and Medicaid coinsurance and deductibles cannot be waived unless one is in compliance with a series of conditions that include but are not limited to patient need or failure to collect even after reasonable collection efforts. For more specifics, consult the National Health Service Web site or the APTA Web site for updates.

Despite such moral subtleties of gift giving and receiving, in practice the difficulties are not insurmountable. Finley offers several criteria that cover most cases.[23] Gifts should be expressions of gratitude, not manipulation or coercion; they should have minimal monetary value; they should not significantly shape relationships with vendors; they are best when they benefit people in need; their cost should not be passed on to patients; and, most important, one should be willing to disclose the gift to interested parties.

## TEACHING AND RESEARCH

PTs who are also professors have new roles and hence new potential conflicts. Professors of physical therapy experience enormous demands from research and consulting requirements that can threaten teaching responsibilities. Exactly how much time, effort, and skill professors are morally obligated to devote to the teaching role is contestable, thereby inviting a temptation to give more attention to prestige-promoting activities such as writing and research for publication, at a considerable cost to students. But there are threats to research as well, and in general the temptation to enhance personal income, job security, and prestige presents threats to role responsibilities in academia as well as to patient treatment.

### CASE 8.6 Research Credits

Sharron and Emily had decided on a topic for their student research project and contacted two faculty members, Dr. Black and Dr. Leonard, to see if they would agree to be their mentors as called for in the research syllabi. Dr. Leonard agreed to be the chair because she knew Dr. Black was working under several deadlines over the next year and could provide little more than some insights and editorial revisions. Most often, Sharron and Emily met with Dr. Leonard, who then updated Dr. Black through e-mails that copied Sharron and Emily. At most, Dr. Black gave editorial comments about drafts but did not review the data or data analysis and had only an overview knowledge of the methods. The research project was complex but beautifully executed. Unlike many other student projects, this one would easily be published in a second- or even first-tier journal.

Sharron and Emily were more concerned about graduation than publications, so once they had their sign-offs, they let matters coast until they were licensed. At that point, Dr. Leonard contacted them and urged them to polish the draft and submit it to a journal. Sharron took the lead in finishing the project for publication. She relied heavily on Dr. Leonard, who introduced the topic of authorship and rankings. He pointed out the standard for authorship in physical therapy and suggested that he appear last to designate his senior researcher status. Emily volunteered to be second author and Sharron would be first. Dr. Leonard asked the group if they thought Dr. Black was entitled to an authorship credit or would an acknowledgment be more appropriate. The three reviewed the standards, and Sharron and Emily voted for an acknowledgment. The article was submitted to a prestigious journal and accepted, contingent on revisions. Over the following 6 weeks, the revisions were made and the article was put in cue for publication.

Sharron e-mailed Dr. Black and told her that she would appear in the acknowledgment if it was all right with her. Dr. Black did not respond. In fact, no one knew that Dr. Black was angry until the editor of the journal called Sharron, with follow-up e-mails to Emily and Dr. Leonard, stating that Dr. Black had contested the publication on the basis that she had been denied the right to both review the final draft and to authorship. As a consequence, the editor said he had two choices. One was to initiate an investigation and the other was to drop the article from the cue. Sharron presented him with a statement outlining what Dr. Black had done on the project and compared that with the standards for authorship published by the journal. An investigation was undertaken and, after a year's delay, the article was published with an acknowledgement of Dr. Black but without listing her as an author.

In addition to such systemic conflicts of interest, there are episodic conflicts of interest in the teaching arena. One area of concern, for example, is sexual affairs between teacher and student. Do such affairs threaten professors' ability to grade fairly—threatening it sufficiently to call for a university policy forbidding affairs with current students? In our view, the answer is yes, and that applies not only to the university environment but also to clinical instructors in the clinic setting who teach students as a part of the university program. Others disagree, and many schools do not have policies forbidding such affairs. Values of freedom, sexual and otherwise, are invoked to prevent anything stronger than legally mandated sexual harassment policies. At the very least, however, it is important for universities to give careful attention to this issue and to develop policies after full discussion.

Additional conflicts of interest arise in accepting, rejecting, and supervising student internships. Curricula in programs accredited by the Commission on Accreditation in Physical Therapy Education are required, in "Definitions Related to Curriculum" of the "Evaluative Criteria for Accreditation of Educational Programs for the Preparation of Physical Therapists," to provide clinical education experiences that "comprise all of the formal and practical 'real-life' life learning experiences provided for students to apply classroom knowledge, skills, and professional behaviors in the clinical environment."(2p159) An emerging problem, however, especially in a managed-care environment, is that many therapists are simply refusing to take students because of productivity standards that leave little or no time to supervise the student, thereby adding to universities' difficulties in finding appropriate internship experiences.

To further complicate matters, government regulations are constantly in revision. When administrators of Medicare–Part B determined that covered services could not be rendered by students, including physical therapy and medical students, clinicians had to either find new patient experiences for interns or withdraw as student clinical supervisors. At the other end of the spectrum, students in some facilities were sometimes treated as revenue-generating personnel with little, if any, supervision. Because the latter is the only situation over which the educational facility has governance, many schools regularly interview students and conduct on-site clinic visits to ensure that students receive supervision and are not used solely to increase revenue at the expense of the safety of patients. However, as clinical sites continue to diminish, temptations increasingly arise for educational institutions to rationalize inadequate supervision as preferable to creating expensive new university-sponsored clinics to supply needed clinical experiences. At the same time, students sometimes find themselves in situations where there are conflicts of interest of significance to their progression in the clinic affiliation.

## CASE 8.7 Inadequate Supervision

Megan is on the last of her clinical affiliations, and this one looked like the most promising. The clinic had a department chair who had graduated from a prestigious physical therapy program and would act as the clinical coordinator. The patient load was varied and complex, and Megan was up to the challenge. The day Megan started her affiliation, the chair and clinical coordinator, Pamela, was overwhelmed with a report due to the Joint Commission on Hospital Accreditation. As a consequence, she apologized but put Megan in charge of five patients with uncomplicated diagnoses. There was no supervision, but Megan thought that as some of the administrative duties were fulfilled, Pamela would be there to offer her some instruction and oversight.

By the end of the first week, all that had changed. Megan now had a full patient load, varied and complex. She began to notice that PTAs and sometimes PT aides treated patients without the oversight and at times without consultation with the PT as called for in her state statutes. Clearly, she realized the lack of oversight was not a single event but seemed to be systemic. There were simply not enough PTs to cover the daily load. She talked with Serena, another PT, and expressed her concern. Serena said she shared Megan's concern, but the financial climate in that area had brought financial pressure on the organization and that Pamela's request for more help had been rejected each time she had submitted it. There was just no other way to meet the demand and if they did it "by the book," some patients would go without any care.

Just prior to Megan's mid-rotation review, Megan talked with her director of clinical education (DCE) at the school as required. She told the DCE only that she did not believe she was getting adequate supervision because Pamela was so busy with the administrative tasks in her job. The DCE did the site visit and asked Pamela if Megan was being adequately supervised. Pamela responded that she and her other therapists were observing Megan closely but that Megan was such an accomplished student that all she really needed was more practice. When the DCE relayed this to Megan, Megan was conflicted about whether to tell the DCE the entire story. By academic department policy, it would be highly likely that Megan would be pulled from the site and would have to wait for another site to open and then start the affiliation all over. At a minimum, it would mean delaying her completion by 6 to 8 weeks, and those were weeks she needed to work. As well, she reasoned, she did not want to put Pamela on the defensive or start her career with any enemies. Pamela was in the leadership of the state chapter of the APTA.

Another set of issues concerns the selection of candidates for educational programs. Periodically, the number of applicants to schools of physical therapy decreases, in particular when managed care institutes cost-saving measures that directly impact the employment opportunities for and salaries of therapists. Meanwhile, the number of accredited physical therapy programs in the United States has increased, rendering some schools unable to fill their class quotas. Like most businesses, university departments are staffed and funded on the basis of anticipated enrollment and accompanying tuition revenue.

Taken together, these pressures intensify schools' dual need to select competent students who, on graduation, will be able to pass licensure examinations while at the same time keeping enrollment levels adequate to ensure the survival of the department. These educational institutions serve as the gatekeepers to the profession and have a duty to populate it with competent professionals. Although some schools have responded to these financial threats by increasing their recruitment programs, it is feared that as competition increases for a diminished pool of applicants, compromises in admission standards are inevitable.

Even the method of selecting candidates is controversial. Basic academic abilities and skills needed to complete the academic program are obviously needed, but what additional qualifications are required? Should the educational institutions focus only on recruiting future clinicians when there are other areas of the profession, such as research, that are seriously deficient? Given the extremely diverse areas of specialization within clinical applications—combined with the employment opportunities in teaching, supervision, and case management—the task of defining valid admission criteria is daunting. Restricting the student population too narrowly does a disservice to the profession, but to apply no standards invites inappropriate academic recruitment to fill revenue needs.

In all university teaching, research responsibilities are important in their own right in addition to their general contribution to education. The profession of physical therapy is criticized for failing to provide documentation that treatment methods pass accepted standards of scientific inquiry for efficacy, and professors share a responsibility to help remedy that. Practitioners also have this duty, but the conflicts are significant. Especially in a managed-care environment, therapists' first obligation is to provide the best care to the patients who depend on them. Patient loads and allotted time typically eliminate any hope of conducting valid scientific enquiry in the true experimental model. Even quasi-experimental models require more time and planning than most therapists in clinical practice can be expected to accommodate.

In conclusion, the study of conflicts of interest provides a prism for exploring both the core commitments of, and differences between, individual professions, and nowhere is that more true than in physical therapy. Although we have commented on possible solutions, often the primary challenge is to identify and keep salient key areas in which conflicts of interest recur and are especially likely to cause harm. In the next chapter we comment further on understanding wrongdoing in conflicts of interest and elsewhere.

## DISCUSSION QUESTIONS

1. In Case 8.1, identify the conflicts of interest and the conflicting interests for Brenda and Patrick. Are all the conflicts morally objectionable, or would they be tolerable under certain conditions?

2. In an advertisement for a new profitable leg brace, a PT endorses the equipment and discusses how it has helped hundreds of her patients. In truth, however, the therapist has had little direct involvement with the braces, apart from being allowed to purchase stock, at a substantially discounted rate, in the company producing the braces. After consulting the APTA *Code of Ethics,* discuss under what conditions this endorsement and ad would constitute an objectionable conflict of interest. Under what conditions would it be a tolerable conflict of interest?

3. Bill is a hospital administrator in a location that still has a substantial number of patients who pay independently (fee-for-service) for treatment, and he oversees a physical therapy clinic whose revenue has steadily eroded.[24] He calls the clinic director, Mark, and suggests that he

expand the number of procedures used per patient visit and thus increase the reimbursement or else be prepared for decreased staffing in the future. Reluctantly, but loyal to his staff, Mark encourages his staff to increase overall modality (procedure) utilization. Identify the conflict of interest involved in this case, and present and defend your view about whether Mark acted ethically or unethically. If you cannot determine an answer, what further information would you need to know?

4. Marsha has maintained a profitable and expansive private practice since the early 1980s. Despite an excellent reputation, she has not been successful in negotiating a rate with the largest local managed-care company that would be an amount adequate to cover her costs and generate a reasonable profit. The last time she spoke with the company's representatives, they suggested that, to be awarded a contract that would allow her to make a reasonable profit, she should decrease patients' length of stay and be more willing to rely on patient self-administered home treatment programs when their functional abilities improved. Marsha believes her therapists are at their ideal performance level now, but she knows that fiscally the company's recommendations make sense. What conflicts of interest, if any, do you see in the company's proposals?

5. Trevor is a PTA at a private practice named Care Unlimited. He is also the owner of the practice and employs 12 PTs and 5 PTAs. Partly because of reduced revenues and partly because of personal beliefs, he instructs the PTs to work "smarter" by using the PTAs as much as possible to free the PTs to evaluate and establish the treatment programs for more new patients. During an especially busy day, Trevor is in the clinic when one of the assistants, Shannon, comes to him and says that she will have to dismiss a patient for the day because a change in the patient's status warrants a different course of treatment. However, the patient's PT is busy with a new patient and will not be available to consult on the issue in a time frame that will work for the patient. Trevor reviews the patient's chart, he and Shannon agree on an alternate treatment program, and he instructs her to change the program and to treat the patient. What conflicts of interest are apparent in this situation? What arguments and documents should the PTs offer? What arguments and documents should Shannon offer?

6. Considering the inherent conflicts of interest that arise in both fee-for-service and capitated reimbursement plans, what type of reimbursement plan would most diminish the conflicts related to method of reimbursement? Explain your answer.

7. If you were given the opportunity to speak with a congressional leader on matters related to health care, what policies and laws would you recommend to regulate managed care in the area of conflict of interest? Keep in mind that in the current political environment, managed-care corporations, just like any other business, must be allowed to satisfy shareholders by generating a profit.

8. Is direct access to physical therapy a realistic alternative to physician referral? Why are the insurance companies resistant to direct access to physical therapy? What needs to occur within the profession for current students and practitioners to engage in direct access?

9. Through on-line searches, discover and discuss the measures your state has taken to reduce the conflicts of interests on patient referrals by physicians to PTs.

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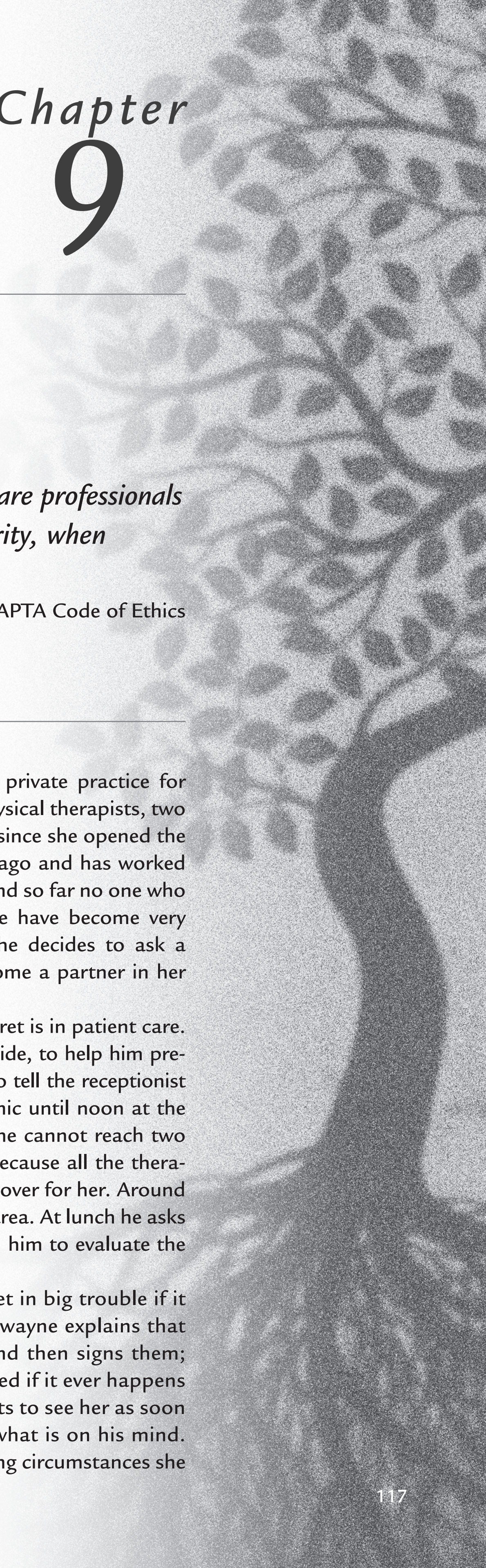

# Chapter 9

# Integrity and Wrongdoing

*Physical therapists shall discourage misconduct by health care professionals and report illegal or unethical acts to the relevant authority, when appropriate.*

Principle 4C, APTA Code of Ethics

## CASE 9.1 Misassigning an Aide

Margaret has been a physical therapist since 1982 and has been in private practice for 12 years. Her practice has flourished, and she currently employs two physical therapists, two aides, and a receptionist. One of her aides, Dwayne, has been with her since she opened the practice. He enrolled in a doctor of physical therapy program 2 years ago and has worked part-time while in school. The practice functions on a “family” model, and so far no one who has joined the practice has left. The business aspects of the practice have become very time-consuming, and Margaret would much rather treat patients. She decides to ask a friend, Mark, who is also a physical therapist, if he would like to become a partner in her practice. He immediately says yes.

The transition goes well, and Mark is amazed at how efficient Margaret is in patient care. In turn, he picks up his productivity partly by using Daphne, the other aide, to help him prepare for and clean up after patients. Margaret calls in one Wednesday to tell the receptionist that she has a plumbing emergency at home and will not be in the clinic until noon at the earliest. The receptionist tries to reach all the morning patients, but she cannot reach two returning patients and one new patient scheduled for an evaluation. Because all the therapists are booked, Margaret tells the receptionist to ask Dwayne to take over for her. Around 11 a.m., Mark sees Dwayne talking with a new patient in the treatment area. At lunch he asks Dwayne what was going on, and Dwayne explains that Margaret asked him to evaluate the new patient, which he did.

Mark becomes agitated and tells Dwayne that all of them could get in big trouble if it were discovered that an aide was evaluating and treating patients. Dwayne explains that will not happen because Margaret recopies his notes in the chart and then signs them; they have done it many times before. Mark tells him that he will be fired if it ever happens again. He then tells the receptionist to let Margaret know that he wants to see her as soon as she gets in. Shortly after 2 p.m. Margaret arrives and asks Mark what is on his mind. He explains what happened, and Margaret acknowledges that in pressing circumstances she has used Dwayne to help her. She states that Dwayne has worked for her 10 years, is excellent, and now he has most of his basic training behind him. Mark tells her that is irrelevant and that she cannot use an aide to treat and evaluate. She agrees not to let it happen again.

Four months later, Mark takes time off to go to the American Physical Therapy Association (APTA) meetings and returns to find two new patients in addition to his continuing patients. While going over Margaret's evaluation with one of the new patients, the patient explains that Mark must be mistaken because the patient was evaluated by the therapist who introduced himself as Dwayne.

This chapter explores compliance issues; that is, moral issues that arise when individuals—including professionals, patients, and family members—make wrong decisions, even though it is reasonably clear what is required of them. We begin with sexual harassment, including harassment of patients by therapists, harassment of therapists by other employees, and inappropriate sexual behavior by patients toward therapists. Then we turn to problems of drug abuse by professionals, followed by problems of fraud in the health-care industry. Next we look at whistle-blowing as a response to wrongdoing within corporations. We conclude by discussing three areas of mandatory reporting of injuries caused by the wrongdoing of others: family violence, child abuse, and elder abuse.

## SEXUAL HARASSMENT

Sexual harassment is an abuse of power involving sex. It is objectionable primarily because it violates individuals' autonomy—their right to pursue their interests without harmful interference by others.[1] Typically, it inflicts harm on people at a time when they are especially vulnerable in their roles as either patients or employees. In many instances coercion is present; for example, when employees think their jobs are at risk or when patients perceive that the quality of care is dependent on their compliance with inappropriate requests. Beyond coercion, harassment violates patients' trust that professionals will provide them with optimal care. When the media make the general public aware of abuses, an organization or an entire profession may be adversely affected. For all these reasons, the APTA's *House of Delegate Standards, Policies, Positions and Guidelines* states clearly in HOD P06-99-17-06 that "Environments in which physical therapy services are provided, or in which the work of the American Physical Therapy Association and its components is carried out, should be completely free of sexual harassment."

### Harassment Among Employees

### CASE 9.2 Sexual Banter in the Workplace

Advanced Care is a private physical therapy practice that has been in operation since 1989 and is owned by Paul Sanford. The practice has been highly successful by adapting to the multiple changes that have occurred since the practice started. There are 14 full-time therapists, 4 physical therapist assistants, and 3 physical therapy aides. The staff has always been predominantly male, and currently only one female therapist is employed. Sandra started 3 months ago but is already considering leaving the practice, even though she likes the pay, the hours, and the patient load.

She tells a close friend that her office, which is actually a cubicle, provides no protection from the constant bantering of the other therapists. The men have never treated her unfairly nor disparaged her, but their conversations constantly reference their sexual adventures and fantasies. She has never considered herself a prude, but she finds their comments both distracting and offensive to women in general. When she expressed her concerns to the owner, he advised her to not listen to the discussions, that "men will be men," and that there was nothing he could do. Her friend suggests she might be dealing with sexual harassment.

Legal protection against sexual harassment is founded on the federal Civil Rights Act of 1964.[2] The first regulations, however, explicitly classifying sexual harassment as a form of sexual discrimination appeared in 1980 and were ruled as such by the U.S. Supreme Court in *Meritor Sav. Bank v. Vinson* (1986). The issue garnered national attention in 1991 when, during the Senate confirmation hearing for Supreme Court nominee Clarence Thomas, attorney Anita Hill charged that Thomas had sexually harassed her when she worked for him at the Justice Department. Thomas won confirmation, but sexual harassment became a topic indelibly etched on the public's consciousness.

The Equal Employment Opportunity Commission (EEOC) defines sexual harassment in the workplace as follows: "Unwelcome sexual advances, requests for sexual favors, and other verbal or physical conduct of a sexual nature constitute sexual harassment when submission to such conduct is made either explicitly or implicitly a term or condition of an individual's employment, submission to or rejection of such conduct by an individual is used as the basis for employment decisions affecting such individual, or such conduct has the purpose or effect of unreasonably interfering with an individual's work performance or creating an intimidating, hostile or offensive working environment."[3]

Subsequent court rulings distinguished two main categories[1(p441)]:

**Quid pro quo** ["this for that"]: Unwelcome sexual advances, requests, or other sexual conduct that is made a condition of employment, promotion, pay raise, or other job benefit.

**Hostile work environment:** Unwelcome sexual advances, requests, or other conduct that may unreasonably interfere with work performance or create an intimidating or offensive work environment.

The courts have interpreted these two categories very broadly. Thus, quid pro quo sexual harassment includes all unwelcome sexual offers, even if they occur only once. Hostile environment harassment includes any feature of the workplace that could lead employees to believe their ability to work or to compete fairly is in jeopardy. For example, suppose a supervisor or coworker makes inappropriately explicit sexual comments. It is not necessary that anyone be the target of the comments. The EEOC has stated that "the victim does not have to be the person harassed but could be anyone affected by the offensive conduct."[2(p1,19)] This conduct includes language and jokes that make for a "sexually poisoned workplace" (as in Case 9.2), posting pornographic or sexually oriented pictures, solicitations for sexual favors, or name calling focused on a person's gender.[2(p2,3),4] Interpretation of exactly what counts as sexual harassment is made from the perspective of a "reasonable person," a "reasonable woman," or a "reasonable victim," depending on the court.[5,6]

Sexual harassment can be between persons of the same sex, as the Supreme Court made clear in *Oncale v. Sundowner Offshore Services, Inc.* (1996). This ruling also clarified that harassment need not involve sexual desire: "Harassing conduct need not be motivated by sexual desire in order to be actionable, and the standards in same-sex cases will be the same as in opposite-sex cases: whether the sex-based conduct is sufficiently severe and pervasive to create an objectively hostile or abuse work environment."[7]

What if managers claim to be unaware of the problem and hence are not responsible for the actions of their employees? In the eyes of the court, corporations are still responsible because the managers' job is to know what goes on in the workplace, and negligence does not absolve managers of that responsibility—they "knew or should have known." To avoid liability, employers must prove they used reasonable care to prevent and correct harassing behavior and also show that the victim unreasonably failed to take advantage of preventive and corrective action.[8] If for any reason managers retaliate against an employee who has alleged sexual harassing behaviors, then they have committed a second offense under Title VII of the Civil Rights Act of 1964.

In all cases pursued through the EEOC, the victim must exhaust administrative remedies before the EEOC will give its permission for a lawsuit. Of course, one can skip the EEOC altogether, depending on the state, and file for compensatory and punitive damages through civil court. In all states, the victim can sue through civil court for damages due to defamation or emotional distress.

Clearly, at the very least, every employer should:

1. "Publish a written policy forbidding sexual harassment;
2. Implement a complaint procedure with clear prohibition on retaliation;
3. Set up programs to train all current and future employees about the policy and complaint procedures."[9]

## Harassment of Patients

Sexual harassment of patients by therapists is categorically forbidden. It violates the autonomy of patients, who have chosen to seek therapy—and who have decidedly not chosen to serve as objects of someone's sexual gratification. Patients trust that professionals will set aside their self-serving motivations in order to provide quality health care. The rare therapist who violates that trust is harming patients at a time of great emotional and physical vulnerability. The trust of colleagues, within each organization and the profession as a whole, is also violated, because when abuse comes to light, negative publicity harms both the health-care organization and the profession.

What about situations in which sexual attraction is mutual and appreciated? In such instances it might seem there is no victim and hence no harm. One troublesome issue, however, concerns the genuineness of the relationship. Formal roles (therapist, patient) can eclipse important values that support lasting committed relationships often desired by one or both parties. Furthermore, even if there is no interest in protecting the duration of the relationship, the organization might be harmed. A health-care service environment is tightly focused on the services and equipment linked to the delivery of care; it has nothing to gain by allowing behaviors contrary to its mission, and problems arise all too often as relationships go awry. Thus, failed romantic relationships in the employment setting are a frequent cause of charges of sexual harassment, as one party keeps pursuing a relationship unwanted by the other. Failed relationships are also a source of violence in the workplace.[10]

Taken together, these considerations support a complete ban on any kind of sexual relationship between professional and patient. Yet, would such a ban violate the autonomy and the sexual freedom of consenting adults? After struggling with this question, the APTA adopted an approach that forbids all sexual relationships with current patients while allowing consenting adults to pursue a relationship after formally ending the professional-client relationship. Principle 4E of the APTA *Code of Ethics* states: "Physical therapists shall not engage in any sexual relationship with any of their patients/clients, supervisees, or students." It leaves open, however, situations where patients or students are transferred to other therapists or when supervisors transfer. But we caution that patients', students' and subordinates' vulnerabilities can extend beyond the time the therapist provides professional services.

### Harassment by Patients

A far more common problem is inappropriate sexual behavior by patients toward physical therapists. Therapists, male and female alike, are especially at risk for these behaviors because of the close physical contact and prolonged private communication with patients. In addition, because of their physical disabilities and complex psychological states that may be altered by medications, feelings of isolation, and damaged self-esteem, patients frequently experience a need for reassurance that they are desirable and worthy of love.

The statistics are dramatic. According to a study conducted in Canada, 92.9% of surveyed practicing physical therapists experienced some level of inappropriate patient sexual behavior in the work environment.[11] Of those, 32.8% of female physical therapists and 37.5% of male physical therapists experienced severe inappropriate sexual behavior by patients. More than 66% of students in physical therapy, by the end of their training, encountered inappropriate sexual behavior by patients. In the United States, a national study published in 1997 found that 86% of physical therapists experienced some form of inappropriate sexual behavior by patients, and 63% reported at least one incident of sexual harassment by patients.[12]

Patient harassment of therapists occurs at several levels.[12] Mildly inappropriate sexual behavior by patients, characterized as suggestive stories or solicitations for dates, is frequently best handled by ignoring or being nonresponsive to the behavior, thus escaping from the conflict. Moderate (deliberate touching, direct propositions) and severe (forceful fondling and attempts to secure sexual intercourse) inappropriate sexual behavior presents the therapist with much more difficulty—and sometimes temptation.

In these cases, disclosure to appropriate parties and notations on the patient's chart usually secure a just outcome. In difficult cases, patients can be reassigned to a new therapist. However, many therapists fear that administrative efforts will downplay the offense or even blame the therapist for contributing to the situation. This may be because administrators are often preoccupied with patient satisfaction to keep the market share necessary for survival and profit. Portrayal of the organization or individual therapist to the public as repressive, lacking a sense of humor, or being plain "hard-nosed" does not increase subscription rates or ensure continuing contracts. To counter these perceptions, many therapists ignore patients' inappropriate behavior and fail to report it to supervisors, fearing that their own integrity might be brought into question. Indeed, therapists who complain about patient behavior to supervisors are frequently regarded as "whistle-blowers," those who reveal an institutional secret. As a result, some therapists believe they have no realistic means of protecting themselves or achieving fairness.

If a patient sexually harasses a therapist, the supervisor is responsible for taking immediate action to prevent recurrence, even if the employee does not complain. Attorney and physical therapist Ron Scott suggests that responsible steps include the following:

1. "Investigating the victim's complaint;
2. Counseling the offender to cease and desist from further sexual harassment of the victim;
3. Transferring the patient to the care of another therapist;
4. Consulting with other health professionals, the referring physician, human resources management, or an EEOC official, as appropriate, for advice;
5. Removing from the clinic the patient who continues to harass staff sexually."[13]

## DRUG ABUSE BY PROFESSIONALS

### CASE 9.3 Taking a Patient's Drugs

Stuart is a physical therapist at Saint Joseph's and works almost exclusively with patients who have undergone hip surgery. He has developed a rigorous approach that has gotten excellent results. He has learned that patients overmedicated with pain relievers are extremely difficult to work with because their feedback is unreliable and can err on the side of therapy that is too aggressive and possibly injurious. A proper regimen allows the patients to make functional gains more readily. All this requires teamwork with the nursing staff. Over the past 3 months Stuart received a series of complaints from patients about pain prior to and following therapy. When he asked if they had received pain medications, they responded negatively. He pulled the chart on three of the patients who had complained, and they all had standing orders for pain medication. The charts indicated they had received the medications when requested. Knowing the anxiety that patients experience in the hospital, he temporarily assumed that they were mistaken.

The next time it happened, he pulled the chart and saw the same standing order and the same notes that they were administered as requested. He also noticed that Betty was the attending nurse in all four cases. He reported his suspicion to his supervisor, Kim. Kim contacted the nursing supervisor, Joan. Joan stated it could all be a coincidence but she would arrange a meeting with Betty and requested Kim to be present. At the meeting, Joan calmly presented the observations and asked Betty if she was using the patient's drugs. Betty broke down and admitted everything and explained that she had migraines and her primary care provider wanted to try everything except drugs. She stated that her care had actually improved because of the pain relief but admitted that she could not foresee how she could function without the medications. Joan advised her of the employee assistant program at the hospital that required a leave of absence without pay and drug monitoring for 6 months after completion of the program. Betty immediately said that she would like to enter the program. Joan thought the whole matter was over until contacted by the Chief of Rehabilitation and the head of Human Resources. Kim was not satisfied with the assistance program as a solution and believed Betty should simply and swiftly be fired and reported to the authorities for theft, among other charges. The hospital policy manual listed the employee assistant program as one option but did not eliminate firing as another option.

Substance abuse and substance dependency are special concerns in the health professions.[14] Given the nature of their work, health professionals often have knowledge of and easier access to drugs than do most citizens, although drugs permeate society. Moreover, the work of professionals often involves a high stress level, if only because of continual striving for excellence in performing complex tasks. Abuse of drugs by professionals is easy to ignore, cover up, or rationalize, given the image of "druggies" as entirely unlike highly educated and socially contributing individuals.

Do employees have a privacy right to use or abuse drugs without penalty from their employer or interference by colleagues as long as they do their jobs? If so, random drug testing—and the penalties it imposes—is presumably unjustified, even though it is widely practiced. Or is substance abuse utterly irresponsible and something that should be reported to authorities?

Defenders of a strong right to privacy in drug use argue that adults should be allowed to pursue their freedom unless they harm others. These defenders consider many current drug laws excessively punitive, and they object to allowing employers to invade their employees' privacy via mandatory drug tests. Often they defend their view by appealing to the "harm principle" articulated by John Stuart Mill in *On Liberty*: "That principle is that the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant."[15]

Mill argued that each individual is best able to make decisions about happiness and self-fulfillment. Often people make mistakes, but those mistakes can strengthen the capacities for choice, insight, and emotional development. Accordingly, Mill strongly opposed nearly all forms of paternalism regarding competent adults, including government control of alcohol and other drugs, although he allowed government the right to tax and provide other disincentives to drug use. Most critics of drug testing allow some exceptions. Consistent with the harm principle, they acknowledge that testing is justified when workers who use drugs, such as airline pilots and train engineers, impose a clear and present danger to others. This exception would seem to apply to many health professionals, who could do great damage to patients if their judgment becomes drug-impaired.

Defenders of strict laws governing drug abuse and drug testing in the workplace go further in emphasizing these dangers to patients and to others. Serious addictions, whether to cocaine or to alcohol, are a "bomb waiting to explode." Certainly in the long run, worker productivity is threatened, but in the health-care environment much more than absenteeism and decreased energy are at stake. There are dangers to patients.

Even if the extent of privacy rights regarding drugs was clear, the entire debate over drug use is complicated by many questions.[16] One important question is whether drug abuse and addictions should be considered as forms of sickness to which medical approaches apply or as acts of immorality. The **therapeutic trend in ethics** is the tendency to adopt health-oriented attitudes and approaches to problems earlier viewed in moral terms.[17] This trend unfolded on many fronts throughout the 20th century, but nowhere was the trend more dramatic than in the perception of addictions. The official view, first endorsed in the 1930s by Alcoholics Anonymous, is that alcoholics have a disease, and this view has been adopted toward many other addictions, from drugs to pathological gambling. Psychiatrists now label substance dependency a mental disorder—a form of impairment or distress occurring when three or more of the following criteria are met during a 12-month period:

1. "Increasing tolerance (the need for greater amounts of the drug to achieve the desired effect);
2. Withdrawal effects;
3. Taking more of the drug than intended;
4. Unsuccessful efforts to cut down or control use of the drug;
5. Spending much time obtaining, using, and recovering from the drug;
6. Giving up important activities in using the drug;
7. Continuing use of the drug despite knowing the harm it is causing."[18]

Critics of the therapeutic trend in ethics argue that this specification of substance abuse is nothing more than a description of the loss of control involved when individuals fail to meet their responsibilities to maintain rational supervision of their lives. Harmful addictions, according to critics, are bad habits for which individuals remain morally accountable. They are habits that can take on a life of their own, becoming central activities that powerfully shape the lives of individuals and lead to cognitive distortion and adverse physiological effects.[19,20] Nevertheless, the law holds addicts accountable for the damage they cause, even though at the time they might not be fully in control of their actions. Thus, by the time intoxicated persons get into a car, they might be literally out of control but they are fully accountable before the law for drunk driving and any injuries caused. Moreover, therapeutic perspectives necessarily regard individuals as responsible for seeking and cooperating with available help.

Probably a dual moral and therapeutic view of addictions is needed, but society is only beginning to work out such a nuanced view.[21] As just one of many examples of society's confusion about this question, consider two recent California laws. The "three strikes law," implemented in 1994, made lengthy prison terms mandatory for commission of a third felony, and since drug abuse is a common felony, California prisons were immediately loaded beyond capacity with drug offenders. Then, in 2000, the public passed Proposition 36, sending nonviolent drug abusers into mandatory therapy instead of prison. Considering substance abuse and dependency as sicknesses, Proposition 36 can be seen as a form of paternalism that forces sick people to get help. Alternatively, it can be viewed as affirming that use of illegal substances is a crime for which individuals are brought before the law even though those individuals are not morally blameworthy, but rather sick and in need of therapy.

The clash of moral and therapeutic views enters into one of the most difficult decisions professionals sometimes make: what to do when a colleague is abusing drugs. Is the colleague a wrongdoer who should be reported to an employer or other authorities before causing serious damage to patients, or a victim of a sickness and in need of sympathetic help? Often the answer seems to be a combination: the professional is doing something wrong but also needs help, at least until a point is reached at which the professional refuses help and pursues a destructive course that requires forcible intervention.

Purtilo considers the following case.

"Suppose that during the past few months you have seen a drastic change in your colleague AB, who lately has a disheveled appearance and is unable to remember even simple things. Every time you approach AB about this, he says he is okay; however, several incidents in the last week have convinced you that he is putting patients at risk. One patient took you aside and suggested that AB was 'acting kind of strange,' but the patient would not elaborate. You strongly suspect AB has a substance abuse problem."[22]

What should you do? Purtilo argues that usually a combination of compassion and firmness toward the colleague is needed. She recommends the following steps: First, gather information discreetly, trying to balance the need to confirm and document your concerns with the protection of AB's privacy. Talk with and seek advice from trusted colleagues, again while trying to maintain confidentiality. Second, identify and weigh the conflicting duties that invariably create an ethical dilemma in such situations, including duties to protect patients, duties to AB and other colleagues, and duties to one's organization. In the situation, which is most important? Third, consider all reasonable options, including morally creative ways to resolve the dilemma. Fourth, proceed with courage, and attempt to minimize harm to all involved.

Scott believes that licensure regulations or state or federal law should mandate that peers must report providers who are impaired because of the potential risk to patients.[23] This position is supported by Principle 5E of the APTA *Code of Ethics,* which states "Physical therapists who have knowledge that a colleague is unable to perform their professional responsibilities with reasonable skill and safety shall report this information to the appropriate authority." However, at what point is the provider incompetent, and just how much impairment is cause for action?

In some situations, group interventions prove effective. Coombs states, "A caring group of family, friends, and other associates, all carefully rehearsed, surprise the addict in a meeting in which they tell him or her how the addictive behavior adversely affects them."[14(p168)] Other times, having a trusted friend, perhaps oneself or another colleague, speak with the drug-impaired professional is enough. In extreme situations, the best route might be to blow the whistle on the individual by filing a formal complaint with one's employer or other authority. All these choices carry risk, but there can also be serious risks in doing nothing.

## FRAUD

### CASE 9.4 Fraudulent Billing

Frank has been with Buena Vista Rehabilitation for 3 years, and during that time his patient load grew to the point where he had few appointment times available for new patients. Administrators are pleased with his work, particularly with the profit ratio of his department. Administration has maintained a freeze on hiring because of the marginal profit of the institution as a whole. Rather than have patients go without care, Frank initiated several group activities, one of which was a knee therapy group. The group consisted of eight patients who were at the same approximate stage in their rehabilitation. The patients did exercises together at Frank's instruction while providing encouragement to each other. At each session the patients reviewed their home programs, asked questions, and expressed any concerns.

The group was a success in several ways. Patients liked working together, for the effective therapy the social benefits, and the information they gathered from other patients. Frank was pleased because the patients did well, and the one class opened up seven appointment times for him. Even though he knew that Buena Vista was in marginal financial trouble, Frank did not want to lose the revenue from these patients that would have been gained had they been seen individually. He therefore billed Medicare for each patient under the CPT code for individual therapy. Because an appreciable amount of time was spent on the home program reviews, he also billed this activity under CPT 99071, a code for educational materials (there is no reimbursement code for oral review of home programs).

Prior to its implementation, Frank had reviewed the group idea with the department chair, who instructed him in the Medicare codes and billing format. From Frank's perspective, the patients received necessary treatment, and the department was rewarded at a rate that made financial survival more likely.

In 2008 the estimated national paid claims error rate was 3.8% for Medicare alone. Improper payments in 2007 were $10.8 billion for a paid error claim rate of 3.9%. The rate in recent years has been dropping from a high in 1996 of 14.2%, largely because of increased enforcement efforts.[24] The improper payments frequently occurred when care was billed but never delivered, when noncovered services were coded as covered services, or when charges were "upcoded" to represent a higher level of service than was actually performed. In general, such activity constitutes *fraud*—the intentional misrepresentation of eligibility of the services or goods delivered. *Abuse* occurs when reimbursement is sought for treatments or goods that are medically unnecessary, excessive, or inappropriate.[25] Abuse calls into question the moral integrity of the practitioner, and even of the profession when it occurs frequently. Because financial resources are limited, any effort to claim payment unfairly suggests that unless taxpayers bear the responsibility of payment, patients in need of services will have to be denied.

The APTA *Code of Ethics* strictly forbids fraud and abuse under Principles 3, 4, 5, and 7. Depending on whether it is with private or public insurance, fraud also violates federal or state laws in addition to accreditation standards and licensure regulations.[23(pp127-129)] For example, in Case 9.4 Frank is probably guilty of Medicare fraud, and, because he mailed the requests for reimbursement, he is also probably guilty of mail fraud. Because mail fraud is a category of most state and the federal offenses under the Racketeer Influenced and Corrupt Organizations (RICO) Act, especially if there is a pattern of abuse, mail fraud may well bring civil and criminal charges.[26] If Frank were to submit claims electronically, there is a separate federal law that covers the use of telephone lines for fraudulent purposes.[27] Were he to lie about his actions or make false statements, he would commit a separate felony under the False Claims Act. Even though he was given bad advice by his superior, he remains personally culpable—ignorance is no excuse.

Frank's supervisor is probably guilty of conspiracy, both because he facilitated the fraud and because he failed to report Frank's illegal activity. Any peer who has knowledge of fraud and fails to report it is also guilty of conspiracy. Even if his supervisor had not advised Frank and had not been told what had occurred, the supervisor would still have been charged with conspiracy under the "knew or should have known" standard.

Health-care reimbursement systems are becoming increasingly protected from abuses other than fraud. For example, kickbacks for goods, services, or referrals—either receiving them or giving them—is prohibited under the federal Health Insurance Portability and Accountability Act of 1996. Physical therapists have paid fines, and some have served prison sentences as well as expulsion from the APTA and the loss of their licensure.

Although deliberate fraud might appear to be easily detected, institutional and covert forms are not always apparent. For example, some facilities maintain patients regardless of their ability to profit from therapy until the third-party payments are exhausted.[28] As another example, some providers exhaust the coverage under one diagnosis and then assign a new, false, diagnosis to receive extended reimbursed treatment.

Some fraud has systemic features between organizations. For example, in California three hospitals contracted with a center to recruit homeless patients with valid Medicare/Medicaid cards. The homeless were given cash to undergo sometimes days of tests and treatments, symptoms they had been coached to present. They were admitted without physician screenings and diagnosed by unqualified staff.[29] In New York State, seven hospitals participated in a similar scheme through bribes of alcohol/cigarettes/money for false diagnoses, resulting in Medicare and Medicaid billings in excess of $50 million.[30] Similarly, but in reverse, many other hospitals have been charged in cases involving discharging patients prematurely and dumping them on Skid Row with only a hospital gown and intravenous devices still attached. In these cases the aim was to avoid administering care that would not be compensated.[31]

More recently, under the Fair and Accurate Credit Transactions Act of 2003, physical therapists who bill for services delivered and meet other criteria must comply with "red flag rules."[32] The purpose of these rules is to prevent patients from stealing the identities of insurance-covered individuals for the purpose of acquiring health service illegally. This is currently an evolving set of regulations that the reader can follow through the APTA Web site.

Not all misrepresentation clearly rewards the provider. In some publicly funded therapy, such as children's services, continued therapy is contingent on continued documented progress. When therapists exaggerate or even create improvements for the sake of continuing therapy, they might be acting on what they perceive to be the best interest of the patient. In some cases, patients do level out, only to improve later. Therapists sometimes express the fear that unless they continue seeing the patient, they will not know if the patient has just reached a plateau or reached maximum potential. Sadly, the cost of futile treatment, regardless of whether it is intermittent or continuous, is passed on to the children who are on the waiting lists. The longer they wait, many believe, the more narrow the window of opportunity for treatment to be maximally effective. The better approach would be to regularly audit the child who has ceased to make genuine progress and re-intervene if lack of progress is indeed just a temporary phase of development.

## WHISTLE-BLOWING

In discussing sexual harassment, drug abuse, and fraudulent billing, we commented on some of the appropriate or even obligatory responses to wrongdoing. We now consider a controversial response by professionals: whistle-blowing. In recent decades, whistle-blowing has received considerable attention in ethics discussions, and for good reason. Professionals are often aware of, or have grounds to suspect, instances of malpractice, negligence, and other forms of wrongdoing. Professionals are charged with serving the good of their clients and the wider good of the public as it bears on their professional roles. At what point are professionals morally required or permitted to "blow the whistle" by reporting the problems to appropriate officials? And because there are typically severe penalties for whistle-blowing, do whistle-blowers deserve support and legal protection by government, professional societies, and others?

We adopt this definition of whistle-blowing: "[Whistle-blowing is] the actions of employees (or former employees) who identify what they believe to be a significant moral problem concerning their company (or other corporations they deal with), who convey information about the problem outside approved organizational channels or against strong pressure from supervisors or colleagues not to do so, with the intention of notifying persons in a position to take action to remedy the problem (regardless of whatever further motives they may have beyond this intention)."[33(p139)]

Whistle-blowing might be **internal**—information is conveyed to higher authorities within the organization, **external**—information is conveyed outside the organization, perhaps to a journalist or a government official, **open**—in which one identifies oneself as the source of the information, or **anonymous**, whereby one withholds one's identity. A mixed case occurs when one reveals one's identity to a journalist on the condition that one's name will not be revealed to the public.

Whistle-blowing decisions typically center on the ethical dilemmas created by conflicting professional obligations, namely:

1. Loyalty to one's employer and colleagues, including specific duties of confidentiality and team play, versus
2. Duties to protect one's patients, one's future patients, and the wider public; given the harsh repercussions for whistle-blowing, the dilemmas also involve weighing
3. Rights to pursue one's career and responsibilities to oneself and to one's family.

What guidance concerning whistle-blowing can be found in the APTA *Code of Ethics*? Principle 4C states: "Physical therapists shall discourage misconduct by healthcare professionals and report illegal or unethical acts to the relevant authority, when appropriate." This principle is vague, but it seems to convey a spirit of support for responsible whistle-blowing aimed at protecting the public and the profession. Principle 9.1(c) apparently supports that interpretation: "A physical therapist shall report any conduct that appears to be unethical, incompetent, or illegal." Physical therapists are not, however, told to whom to report—to one's boss, to an appropriate government official, to a journalist, or to someone else? Critics opposed to whistle-blowing might interpret these statements as requiring only internal reporting—that is, reporting within the organization's approved channels. Perhaps it is fair to say that currently the APTA *Code of Ethics* does not provide explicit and strong support for whistle-blowing based on responsible professional judgment.

James offers a list of proposals in making whistle-blowing decisions[33]:

- "Make sure the situation is sufficiently serious to involve great harm, specifically in the form of violating important rights;
- Examine your motives to make sure your judgment is not being distorted, as often it is in such situations;
- Verify and document information about the problem;
- In informing relevant authorities, state the facts clearly, effectively, and without making personal attacks;
- Determine who is the best individual or group to alert to the problem;
- Determine whether internal, external, open, or anonymous whistle-blowing is likely to be most effective while causing the least amount of adverse side effect;
- Consult an attorney to ascertain that you are not violating the law and to protect against retaliation;
- Expect retaliation."

The personal consequences for "taking on" the organization are usually serious. Studies find that up to 90% of whistle-blowers experience some form of retaliation from their employers.[35] These retaliations take the form of harassment, social ostracism, unsatisfactory job ratings, suspension, outright dismissal, and blacklisting by other similar organizations. Sometimes phone calls and mail are monitored, and not infrequently whistle-blowers are transferred to jobs they are not qualified to do, making them likely to fail so that employers can dismiss them for incompetence. In most cases, whistle-blowers face a drastic social and financial change for the worse, even when they make a valuable social contribution.

In recognition of the benefits to society and the costs to the whistle-blower, the federal False Claims Act rewards whistle-blowers with 10% to 30% of triple damages and fines for fraud uncovered in federally funded programs. Government employees are protected by the First and Fourteenth Amendments to the Constitution, the Civil Service Reform Act of 1978, the Whistle-Blower Protection Act of 1989, and the 1994 amendments, along with over 28 other whistle-blower protection policies. In the private sector, however, there is no comprehensive federal law that offers this protection. At present, 42 states and the District of Columbia offer redress through civil action, which entitles whistle-blowers to a jury trial in an effort to collect compensatory and punitive damages for employer acts of retaliation.[35]

### CASE 9.5 **Whistle-Blowing at UCI**

An example of whistle-blowing in the health-care environment occurred at the University of California, Irvine (UCI). Marilyn Killane, the office manager at the Center for Reproductive Health, and Debra Krahel, the senior administrator, were forced from their jobs "because they believed in the most basic of moral precepts—honesty and integrity in the workplace."[35] Killane blew the whistle on physicians in the unit who were prescribing drugs that were not FDA-approved as well as for their billing irregularities. Earlier, when she refused to participate in the cover-up of wrongdoing, she immediately started receiving negative evaluations from her boss. (Later her boss and two others were sued by UCI for failing to report nearly $1 million in diverted patient cash fees, some placed in envelopes and taken home by the physicians.) Killane had reported her findings to Krahel, who then refused her boss's demand that she dismiss Killane. Soon afterward, Krahel discovered what later the university would acknowledge: "Human eggs were harvested from about 40 patients, fertilized, and, without consent of the donors, transferred as embryos to other patients. At least four children were born."[35] Krahel and Killane were quickly targeted by UCI for retaliation that took the form of questioning their integrity, humiliating them in public, isolating them from their peers, and ultimately firing them.

At the time Krahel had reported the improprieties to internal auditors, she requested protection under state and federal whistle-blower laws, which would impose a $10,000 fine and up to a year in jail for retaliating offenders, in addition to civil awards of punitive damages. Ultimately Killane received $325,436 and Krahel $495,000, which, after attorney fees, were reduced to $90,000 and $220,000, respectively. Because of their court appearances and the reluctance of other employers to hire whistle-blowers, both women remained unemployed for an extended time, imposing severe hardship on their personal lives and professional careers. Often, whistle-blowers must change fields of work and location and, even then, regaining their lives and jobs "can take a half-dozen years."[36(p4)]

If there is any consensus on whistle-blowing, it is that responsible steps should be taken to prevent the need for it. Within organizations, that means maintaining an ethical climate in which the highest professional standards are institutionalized and in which workers are free to express responsible professional judgment without threats of retaliation. It also means maintaining open-door policies in good faith and, at least within larger organizations, offering the availability of an ombudsperson to whom one can talk in confidence about a problem. Within professional societies, hotlines can be established to enable professionals to seek advice confidentially. As for the government sector, virtually all federal agencies have hotlines to which employees can report wrongdoing. Government hotlines do not always provide safety for whistle-blowers, however, and even among the best hotlines, only 20% of calls are investigated within a year.[35]

Finally, in trying to provide an honest portrayal of the risks to whistle-blowers, we do not want to leave the impression that we are against responsible whistle-blowing. On the contrary, we express our personal admiration and gratitude for whistle-blowers like Krahel and Killane, who act at great personal sacrifice on behalf of the public and the clients they serve. In our view, they are exemplars of moral integrity. Our concern is to emphasize the need for professional societies and the wider society—everyone—to meet their obligation to protect responsible whistle-blowers.

## FAMILY VIOLENCE

We turn now to legally mandatory reporting of injuries to patients caused by the wrongdoing of family and others. We briefly discuss family violence in general and child abuse and elder abuse in particular. Family violence takes many forms, including emotional abuse, but we focus on physical violence. Moreover, although all members of families can be at risk of domestic violence, including adult males, we focus on the groups that are most vulnerable and hence most at risk: children, women, the elderly, and the disabled.

Violence against members of these groups is all too common, and most physical therapists will encounter it. It is the APTA's position that physical therapists and physical therapist assistants should routinely screen all patients for domestic violence.[37,38] To facilitate this, the APTA published its *Guidelines for Recognizing and Providing Care for Victims of Domestic Violence, Guidelines for Recognizing and Providing Care for Victims of Elder Abuse, and Guidelines for Recognizing and Providing Care for Victims of Child Abuse*. The reasons supporting routine screening is in part based on the fiduciary responsibility to patients. Pragmatically, a physical therapist is usually the health-care professional most consistently involved with the family and hence is uniquely positioned to identify family violence. In a show of strong support, the 2010 revised APTA *Code of Ethics* states in Principle 4D that "Physical therapists shall report suspected cases of abuse involving children or vulnerable adults to the appropriate authority, subject to law."

In a study published in1996, 43% of physical therapists surveyed said they had treated a patient who they knew or suspected had been physically abused by their spouse or partner, and 71% of these therapists said they had treated at least one battered patient during the past year.[39] The number of battered women encountered by therapists might be higher; only 5% of the therapists surveyed make routine inquiries about patients' relationships with their partners, 1% asked routinely about patients being battered, and 58% had never asked patients whether they were battered.

The study, however, also suggested that many physical therapists are not well-informed about physical abuse. For example, fewer than half the therapists were aware that the most common battery injuries occur in a central pattern around the head, neck, chest, and abdomen. When therapists did identify battered patients, they rarely informed the police or even documented the injuries properly by taking a photo or gathering other evidence, a step that is especially important when cases enter the legal system.

### CASE 9.6 An Abused Spouse

Tammy is a 43-year-old female who was referred to physical therapy for an evaluation for vestibular, balance, and equilibrium functions, as well as gait training with crutches. When her therapist, Ted, reviewed the emergency room chart, he noticed that the referring physician had cast her broken femur and treated her for lacerations and multiple bruises. The physician reported that Tammy traced her injuries to a fall down a flight of steps in the home she shared with her husband and 4-month-old daughter. Everything seemed routine to Ted except for the requested evaluations. Upon further examination of the chart, he realized that Tammy had been admitted on several occasions for various injuries resulting from accidents. The previous occasion was only 6 months ago while she was pregnant with her daughter. In that accident, which she attributed to falling on a spill on the kitchen floor, she sustained a concussion and multiple bruises, many of which were documented to be on the dorsal surface of her hands and arms.

When Ted met Tammy, she pointed to her bruised face and laughed about how clumsy she was. She was charming and tried with diligence to learn crutch walking. Ted suggested she go home and try out her new skills and return in 3 days to start the testing. At that time, any problems Tammy was having could be remedied with the crutches. At Tammy's next appointment, she had some problems with the crutches, but the problems were minor and quickly solved, allowing Ted to start the testing. Her balance reflexes, equilibrium, and vestibular functions were normal in every way. In reporting the results to her, Ted stated he did not understand how someone could have so many accidents and have such good reflexes. Tammy confided that she had, in fact, not fallen; her husband had lost his temper and hit her. She quickly clarified the situation by saying that it was her fault because she knew what things set him off; she had done something "stupid that deserved to be punished." Ted asked her what had caused this last episode. She replied that she had overcooked the meat for dinner and knew how much her husband hated a ruined meal after he had worked hard all day. Tammy looked Ted straight in the eyes and said "This is between you and me; if you ever tell anyone, I will deny it."

After lengthy agonizing, he reported his suspicions and the conversation to the authorities. Tammy denied ever having had the conversation with Frank. She called him at the office to plead with him to tell the police that he had made a terrible mistake. When Ted refused, Tammy told him how hurt she was that he had breached the confidentiality she expected. Besides, her husband was now so angry that she was afraid that he would kill her. Ted began to wonder if he had indeed made a mistake.

This case raises several general ethical conflicts for therapists. Exactly when does concern for patients' safety, as well as respect for reporting laws, override respect for patient autonomy and confidentiality? Why does the law intervene even when the victim might lie to protect the attacker and frequently reunites with the abuser? Ethically, therapists are justified in intervening because the victim is generally considered to be psychologically dependent on the aggressor and therefore cannot act autonomously. How to proceed can be a difficult matter requiring good moral judgment.

Domestic violence is a complex and not yet fully explained pattern of behaviors used to oppress and exploit, all too often resulting in death.[40,41] Generally, the victim progressively loses self-governance through a series of stereotypic behaviors by the aggressor, which reduce the victim's self-esteem. Typically the family unit is isolated, with few if any social connections, thereby enabling the aggressor to go undetected by outsiders, with isolation limiting the resources to help the victim. In an effort to save the relationship, the victim may temporarily separate an average four to five times before actually dissolving the relationship.[42] Fears of retaliation are well founded. Women are more at risk of being killed by a male partner than by anyone else in or out of the family.[43] To compound matters, domestic violence does not begin and end with a single family unit. Scholars refer to the "social heredity of family violence" to remind us that these patterns of behavior are passed from parents to children.[44] To help break this intergenerational cycle, some cities, such as Los Angeles, provide a witness protection plan to women who will testify, so that they can be relocated secretly and given a new identity that will make it impossible for their husband to find them.

## REPORTING CHILD ABUSE

### CASE 9.7 An Abused Child

Trevor, a 3-year-old child, presented himself as compliant and willing to follow requests, but for some reason he appeared to be very sad. He rarely spoke of happy events and was always worried about meeting expectations. His mother and father seemed devoted to him. A speech therapist involved in his care suspected child abuse, but she had little evidence. She also feared that a less-than-convincing report to authorities would only result in the parents pulling him out of the center and keeping him at home, precluding outsiders from knowing what was going on. The physical therapist noticed some bruises that might be consistent with falls, which are common in patients who, like this child, wore bilateral long leg braces. When the therapist asked the mother about the child's facial bruises, she replied that he had fallen.

As time went on, Trevor became more comfortable with the therapist and, in one session, cried when he could not perform a requested exercise. The therapist reassured him that they would do another activity instead, but the child kept weeping. When asked what was wrong, the child explained that his mother would "whip him when he did not do good." The pieces began to fit together and were confirmed the following week when the therapist saw the mother pull her son from the car by one hand with a force that nearly dislocated his arm.

What should the therapist have done? If the setting were a hospital, a committee would be available to take over the case, once abuse was reported. In this case, the therapist worked in a small private clinic where no such committee existed. The therapist doubted whether there was sufficient evidence to make a convincing case to the police, and he knew the parents could easily explain the bruises as due to the child's coordination and balance problems. The therapist also feared that the child would be severely beaten when he returned home and would not be brought to therapy again, anywhere. Even asking too many questions of the parents might alert them and lead them to cancel appointments. The health-care team decided to suggest to the mother that she join a "mothers' group" to try to provide some support and perhaps some better parenting skills. The speech therapist, however, became afraid about her own and the clinic's legal liability and reported the family to the authorities. Within 12 hours the child was removed from the home by the sheriff at the direction of the Child Protection Services. The clinicians never heard from the family again.

Reporting abuse of children and the elderly is now a matter extensively required by law, both state and federal.[45] In addition, public interest groups have developed explicit definitions of these abuses. We discuss these matters in this and the next section. We also comment on the responsibilities of supervisors within organizations. Although reporting child abuse is the direct responsibility of the person who witnesses the actual signs and symptoms, the supervising therapist is often consulted because the symptoms and the laws are often ambiguous. The state and federal laws are generally very clear that supervisors may not inhibit or obstruct the reporting of abuse by therapists they supervise.

Child abuse is so prevalent that it is unlikely that any center treating children will not at some point be faced with contacting child protective services. The prevalence is somewhat attested to by the number of journals dedicated to this subject. For 2007 the rate of victimization was 10.6 per 1000 children (794,000 children), which was evenly split between male and female. In 80.1% of cases the perpetrator was a mother or father.[46] In 2004 it was reported that children classified as disabled had a 68% greater chance of being maltreated than nondisabled children.[46]

Federal legislation provides the minimum standards for child abuse, neglect, and sexual abuse through the Child Abuse Prevention and Treatment Act (CAPTA), as amended by the Keeping Children and Families Safe Act of 2003.[47] Each state enhances these definitions as it considers necessary, thus yielding variations among the states in coverage and definitions. CAPTA stipulates that a child, in the case of abuse and neglect, is any youth younger than 18 years, but that in cases of suspected sexual abuse the states must specify the age for their state. At a minimum, child abuse and neglect is "any recent act or failure to act on the part of a parent or caretaker which results in death, serious physical or emotional harm, sexual abuse or exploitation." Construed more broadly, it is "an act or failure to act which presents an imminent risk of serious harm."[48]

The National Clearinghouse on Child Abuse and Neglect Information, along with the American Prosecutors Research Institute, has summarized nearly 40 state statutes, both civil and criminal, to provide the following descriptions.[48]

- **Physical abuse** is characterized by the infliction of physical injury as a result of punching, beating, kicking, biting, burning, shaking, or otherwise harming a child. The parent or caretaker may not have intended to hurt the child; rather, the injury may have resulted from overdiscipline or physical punishment.
- **Child neglect** is characterized by failure to provide for the child's basic needs. Neglect can be physical, educational, or emotional.
- **Physical neglect** includes refusal of or delay in seeking health care, abandonment, expulsion from the home or refusal to allow a runaway to return home, and inadequate supervision.
- **Educational neglect** includes the allowance of chronic truancy, failure to enroll a child of mandatory school age, and failure to attend to a special educational need.
- **Emotional neglect** includes such actions as marked inattention to the child's needs for affection, refusal of or failure to provide needed psychological care, spousal abuse in the child's presence, and permission of drug or alcohol use by the child. The assessment of child neglect requires the consideration of cultural values and standards of care as well as recognition that the failure to provide the necessities of life may be related to poverty.
- **Sexual abuse** includes fondling a child's genitals, intercourse, incest, rape, sodomy, exhibitionism, and commercial exploitation through prostitution or the production of pornographic materials. Many experts believe that sexual abuse is the most underreported of child maltreatment's because of the secrecy or "conspiracy of silence" that so often characterizes these cases.
- **Emotional abuse** (psychological/verbal abuse, mental injury) includes acts or omissions by the parents or other caregivers that have caused, or could cause, serious behavioral, cognitive, emotional, or mental disorders. In some cases of emotional abuse, the acts of parents or other caregivers alone, without any harm evident in the child's behavior or condition, are sufficient to warrant intervention by child protective services. For example, the parents/caregivers may use extreme or bizarre forms of punishment, such as confinement of a child in a dark closet. Less severe acts, such as habitual scapegoating, belittling, or rejecting treatment, are often difficult to prove and, therefore, protective services may not be able to intervene without evidence of harm to the child.

This brief summary cannot pinpoint all instances that may be relevant to therapists. For example, Texas includes in its definition of child abuse any child born addicted to alcohol or illegally acquired controlled substances.[49] Texas law describes signs and symptoms of abuse as well as the presence of any of the substances in the child's bodily fluids. In several states, the laws provide permission for parents to reject nonemergency and non–life-threatening health care if such care is against their religious beliefs, thus not qualifying as physical neglect.

The standard for reporting child abuse is reasonable suspicion, not certainty. Because all states allow anyone to report child abuse, the system is geared to screen out cases that are not likely child abuse and to investigate the balance to determine if child abuse has taken place. California's definition of reasonable suspicion is: "it is objectively reasonable for a person to entertain a suspicion, based upon facts that could cause a reasonable person in a like position, drawing when appropriate, on his or her training and experience, to suspect child abuse."[50] Kalichman states that "professionals who have reached a level of reasonable suspicion but not reported because they have not backed up their suspicion with evidence are in noncompliance with reporting laws. Thus, gathering evidence of abuse is not among the expected roles of mental health professionals.... Because most practitioners have not acquired adequate skills to investigate the occurrence of abuse, they may be overstepping their boundaries by doing so."[51(p55)]

Because there are no validated assessment tools to detect abuse, therapists must rely on their professional judgment. In the case of suspected physical abuse, there may be symptoms that promote a low level of suspicion, such as emotional distress. Suspicions may be greater if the therapist sees a patient with unexplained bruises, welts, imprints of ropes, and burn impressions.[51(p67)] In cases of suspected sexual abuse, the continuum may run from emotional distress (low suspicion) to verbal disclosures (high suspicion). Somewhere between the extremes, the therapist has to determine a reasonable level of suspicion.

When it is determined that a suspicion is reasonable, state laws are in general agreement that an oral report must be made, immediately followed by a written report. The time frames for the written report have great variability among states. In each state, the child protective agency instructs the caller on the content of the written report. The oral report requires the name of the child, the child's current location, the parent or caretaker's address and telephone number, the child's age, and the extent of the injuries. The person reporting must request instructions whether to tell the caretaker, whether to retain the child to await the child protective agency to take custody, and whether to pursue other options depending on state law. Although the report is usually made with the child protective agency in the state, in some states the report may also be made to the local police. In either event, agencies typically report the incident to all other relevant agencies and departments.[52]

## REPORTING ELDER ABUSE

The National Elder Abuse Incidence Study was requested by Congress and released in 1998.[53] The study used a stratified, multistage sample composed of 20 counties in the nation that were believed to be representative of the country. Researchers found that an estimated 449,924 elders older than 60 years had been subjected to abuse or neglect by others. Only 236,322 cases had been reported to adult protective services, and of those only 48.7% were substantiated. The balance either did not reach their state's level of proof or were still under investigation at the end of the study.

Among those cases that were substantiated, 75% of elders who were abused were physically frail, most were women, and most were clustered in the yearly income range of $5000–$9,999. Cultural patterns also emerged, with extremely low percentages among all minorities except African Americans. White adults generally committed 79% to 86% of offenses in the categories of abuse and 41.3% of cases of abandonment. For African Americans, figures ranged from 9% to 17% for the categories of abuse, with a 57.3% rate of abandonment. Of all abusers, nearly two thirds were either a spouse or an adult child. Hickey and Douglass stated that 62% of professionals who deal with the elderly had seen indications of physical abuse.[54] In nursing homes, researchers found that within the last year of the report, 36% of workers had seen at least one act of physical abuse, and 81% had seen psychological abuse. Among the workers, 10% admitted that they had committed physical abuse, and 40% of workers admitted to committing psychological abuse.[55]

Compared with child abuse, however, elder abuse receives significantly less attention. In a review of the literature in *Index Medicus*, only 26 articles on elder abuse appeared in a 5-year period, compared with 248 on child abuse.[56] Although there has been some improvement, elder abuse remains largely unrecognized and underreported. A 2004 Michigan study reported that of the 25% of physical therapists who suspected abuse, over half failed to report it.[57] In 1975 the Older Americans Act created an ombudsperson program in all states to investigate and resolve nursing home complaints.[58] There are also adult protective services in most states to investigate reported cases, and some provide the victims and families with protective services or treatment. Even where there are few, if any, laws specifically targeted for elder abuse, local and state laws exist to cover theft, assault, and other common forms of elder abuse. Amendments to the Older Americans Act passed in 1987 did provide relevant definitions to help states identify the problems, but they were not for enforcement purposes. As a consequence, states vary greatly in how they define elder abuse. Even with differing definitions, the National Center on Elder Abuse stated that Adult Protective Services in

2004 received 565,747 reports of elder abuse, representing a 19.7% increase over the 2000 survey. The substantiated reports increased 15.6% over the same time.[59]

In general, elder abuse is often described as follows.[60]

- **Domestic elder abuse** generally refers to any of several forms of maltreatment of an older person by someone who has a special relationship with the elder (e.g., spouse, sibling, child, friend, or a caregiver in the older person's own home or in the home of the caregiver).
- **Institutional abuse** generally refers to any of the preceding forms of abuse that occur in residential facilities for older persons (e.g., nursing homes, foster homes, group homes, board and care facilities). Perpetrators of institutional abuse usually are persons who have a legal or contractual obligation (e.g., paid caregivers, staff, professionals) to provide the elderly with care and protection.
- **Physical abuse** is defined as the use of physical force that may result in bodily injury, physical pain, or impairment. Physical abuse may include but is not limited to such acts of violence as striking (with or without an object), hitting, beating, pushing, shoving, shaking, slapping, kicking, pinching, and burning. Such abuse includes the inappropriate use of drugs and physical restraints, force-feeding, and physical punishment of any kind.
- **Sexual abuse** is defined as non-consensual sexual contact of any kind with an elderly person. Sexual contact with any person incapable of giving consent is also considered sexual abuse. It includes but is not limited to unwanted touching; all types of sexual assault or battery, such as rape and sodomy; coerced nudity; and sexually explicit photographing.
- **Emotional or psychological abuse** is defined as the infliction of anguish, pain, or distress through verbal or nonverbal acts. Emotional/psychological abuse includes but is not limited to verbal assaults, insults, threats, intimidation, humiliation, harassment, treating an older person like an infant; isolating an elderly person from his/her family, friends, or regular activities; giving an older person the "silent treatment," and enforced social isolation.
- **Neglect** is defined as the refusal or failure to fulfill any part of a person's obligations or duties to an elder. Neglect may also include failure of a person who has a fiduciary responsibility to provide care for an elder (e.g., pay for necessary home care services) or the failure of an in-home service provider to provide necessary care. Neglect typically means the refusal or failure to provide an elderly person with such life necessities as food, water, clothing, shelter, personal hygiene, medicine, comfort, personal safety, and other essentials.
- **Abandonment** is defined as the desertion of an elderly person by an individual who has assumed responsibility for providing care or physical custody.
- **Financial or material exploitation** is defined as the illegal or improper use of an elder's funds, property, or assets. Examples include cashing an elderly person's checks without authorization; forging an older person's signature; misusing or stealing an older person's money or possessions; coercing or deceiving an older person into signing any document (e.g., contracts or will); and the improper use of conservatorship, guardianship, or power of attorney.
- **Self-neglect** is characterized as the behavior of an elderly person that threatens his/her own health or safety. Self-neglect generally manifests itself in an older person as a refusal or failure to provide self with adequate food, water, clothing, shelter, personal hygiene, medications (when indicated), and safety precautions. The definition of self-neglect excludes a situation in which a mentally competent older person, who understands the consequences of his/her decisions, makes a conscious and voluntary decision to engage in acts that threaten his/her health or safety as a matter of personal choice.

Because many of the states that have elder abuse laws modeled them on child abuse laws, there are mandatory reporting requirements that generally include all health-care workers, with the same protections for reporting that exist with child abuse laws.

In many ways, detecting elder abuse is even more difficult than detecting child abuse. Unlike children, many elderly live alone and might rarely venture into settings where abuse could be detected. Elders may even protect the abuser for fear that any alternative would be worse than their current status. In some states, if victims say they do not want corrective action, the state will abide by that decision as long as the victim is competent. However, in those states with mandatory reporting requirements that honor the elder's request, health-care providers are not relieved of their responsibility to file a report.[61]

At first glance, the threshold for reporting seems lower for adults than for children. That would certainly be true if the adult were competent and physically able to summon help. Yet many adult victims are as helpless as a child in protecting themselves, especially when they have low incomes, are physically fragile, have cognitive impairments, and experience depression—if only from knowing they are being mistreated by children or a spouse whom they helped and supported when they themselves were healthy.[62] Moreover, retaliatory battering is a genuine danger, because adult protective services are so underfunded that they often are not able to provide the resources necessary to rescue elders without institutionalization. In fact, 30% of batterers inflict further assaults during prosecution.[63]

## DISCUSSION QUESTIONS

1. In reflecting on Case 9.1, what has been your experience thus far, either as an aide, assistant, volunteer, or student intern, with the way clinicians use physical therapist aides? Would you be willing to report inappropriate use to your director of clinical education? If not, what are the barriers?

2. Brent has been a therapist with professional sports medicine for approximately 3 years. He was assigned 4 weeks ago to provide therapy to Emily, a 23-year-old sports enthusiast who had injured her anterior cruciate ligament while skiing. Her surgery had been performed by one of the leading orthopedists in the state, and because she had been in excellent physical health at the time of the accident and was highly motivated, she did extremely well in physical therapy. Even this early in her rehabilitation, she was functional, without pain, and eager to start preparing herself for the next season on the slopes. Brent proposed a step-down therapy schedule, giving the home program the major emphasis, with weekly and then semiweekly checkups at the clinic. Because Emily was paying privately, Brent was certain this would be a welcome accommodation. Instead, Emily seemed hurt when Brent proposed the change in schedule. She explained that the money was not a problem and that she would prefer a more rigorous schedule at the clinic. Somewhat conservative in his care, Brent suggested that she take some extra time to allow maximal healing before pushing on to the next level. At this point Emily stated that what she really wanted was to see more of him, whether in or out of the clinic. She told him that over the past month she had developed a strong emotional attachment to him and wanted to explore what the relationship might mean. Brent admitted to himself that he found her attractive also. What should he say next and why? (Brent and Emily are single.)

3. Drawing on your education, personal experience, and research, discuss whether alcoholism and drug abuse are best approached in therapeutic terms (as sicknesses), in moral terms (as wrongdoing for which individuals are morally responsible), or some combination. In doing so, indicate how you will respond to substance abuse and substance dependence by colleagues and by patients. Use a specific example, such as Stuart in Case 9.3.

4. Have you witnessed any suspected fraud in the health-care environment and, if it was excused or explained, how was it justified or rationalized?

5. Present and defend your view about when, if ever, whistle-blowing by physical therapists and other health professionals is morally permissible and morally obligatory. When it is obligatory, should whistle-blowers be given legal protection? Would you favor revising the APTA *Code of Ethics* to include support for responsible forms of whistle-blowing? What other forms of support might the APTA provide? Discuss several types of examples, including Case 9.5, and cases of disgruntled employees seeking revenge against their bosses.

6. Identify the barriers you believe exist in reporting child abuse, and then analyze those barriers against existing laws, state and federal, to determine if they are realistic barriers.

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## Chapter 10

# Leadership and Administration

***Physical therapists shall promote organizational behaviors and business practices that benefit patients/clients and society.***

Principle 7, APTA Code of Ethics

### CASE 10.1 **Moving into Management**

Sara responded to an advertisement placed by Northeastern Health Care for the position of chief physical therapist at a local hospital. She had decided to make the change from practicing physical therapist to supervising therapist because she hoped to improve outcomes in health-care delivery. Northeastern offered only a slightly higher salary than she had received as a practitioner, and the hours were going to be longer. Nevertheless, she saw the new job as a genuine opportunity.

At first, the job of supervising eight therapists and eight aides was overwhelming. In the first month, she called a department meeting and asked the therapists and staff what they would like to see improved. To her surprise, their only concerns were to reduce the patient load and to increase the flexibility of work hours. She had fully expected to hear complaints about overdelegation of patient care to aides, lack of continuing education leaves, and the absence of certified specialists on staff. After the meeting, she set up an appointment with her boss, John, director of the rehabilitation division. She expressed to John her surprise that the staff did not appear to be worried about the quality of care the patients were receiving or the absence of a dynamic professional exchange of ideas and expertise. She wondered about the feasibility of her plan to require weekly case conferences at which therapists could present difficult cases for input from other therapists. In fact, she was beginning to wonder whether any of her ideas for professional development would work.

John told her the hospital was happy with the way things were now. The department was producing a good profit, the employees performed their jobs, and few patients complained. He said anything she could do to increase productivity and profit would be welcomed, but any efforts that might detract from the current level of productivity would need to meet with his approval before they could be introduced to the staff. Sara began to realize that she was essentially being asked to function as an efficient manager, whereas she had changed jobs hoping to expand into more of a leadership role in the health-care environment.

## LEADERSHIP IN PROMOTING AN ETHICAL CLIMATE

Throughout their careers, physical therapists must work collegially with supervisors, managers, coworkers, and support staff. In doing so, therapists need to understand ethical issues from the point of view of people in positions of authority because therapists often oversee the activities of a variety of support personnel, thereby functioning as supervisors in the delivery of care, and many therapists move into supervisory and management positions at some point during their careers. As stated in "Guidelines: Physical Therapy Claims Review" (G08-03-03-07), effective practice includes the ability to "interact and practice in collaboration with a variety of professionals" and to "direct and supervise physical therapy services, including support personnel." For these reasons, this chapter discusses some of the ethical challenges of leadership in several contexts: decision making within different kinds of organizations, patient-related duties, personnel duties (including worker safety), and organizational duties.

In one sense, "leadership" is a descriptive term referring to the organizational roles of supervisors and managers. In another sense, the one explored here, **leadership** is a value—the virtue of influencing people in morally desirable ways. Leadership is different from "headship." **Headship** is being appointed to be in charge of a section, division, or larger unit within an organization or group. But becoming a leader requires something more. Even some high-level managers who head an office are not leaders, and indeed some leaders do not hold official positions within organizations. What, then, is the difference between efficient managing and effective leadership?

The answer depends on one's value perspective and the specific values one builds into the concept of leadership. One view is that leadership is simply successful managing, influencing people to get things done. Although both leadership and successful managing certainly involve influencing people to achieve desired ends, what if those ends are immoral? This is sometimes called "the Hitler problem": Did Hitler exhibit leadership? He was enormously influential, but he is the epitome of an evil tyrant. Many theorists insist that leadership suggests the opposite of tyrannical control.

A large amount of literature is devoted to defining leadership and to developing generic models for leadership as a value. As Ciulla argues, debates over models of leadership are invariably debates about moral values—specifically, about what it means to be a morally admirable leader, director, supervisor, or manager.[1] Such discussions focus on what moral values should guide the procedures of leaders (how they lead), their aims (purposes), and their effectiveness (morally desirable results). Thus, leadership means influencing people in morally desirable or at least morally permissible ways and directions.

For example, in his famous "transforming model" of leadership, Burns suggests that good leaders, "transforming leaders," seek to engage the full person, including the "higher needs."[2] Burns presents his view in contrast to the traditional concept of leaders as setting forth incentives in the form of self-interested gains, which include salary, medical insurance, and a pleasant work environment. Moral values enter this concept, primarily as procedural constraints on the relationship between the leader and follower. These procedural values, such as fairness, trust, and honesty, are enormously important, but transforming leadership involves more. It is focused on end-result values, such as liberty and equality (especially in the political arena that Burns studied) and patient values (such as healing and respect for autonomy) in health-care professions. Clearly, Burns is not simply describing; he is prescribing. He is attempting to portray a desirable form of leadership. In general, to present a model of good leadership is to present one's view of ethically desirable forms of leading.

Exactly what it means to show leadership needs to be determined contextually, although there are several tasks that leaders generally undertake. Gardner summarizes those tasks as follows: "[E]nvisioning goals, affirming values, motivating, managing, achieving a workable level of unity [within groups], explaining, serving as a symbol, representing the group externally [to other groups], and renewing [organizations]."[3] We emphasize the role of leaders in promoting an ethical climate within organizations.

An ethical climate has at least three dimensions: moral responsibility, trust and trustworthiness, and effective conflict resolution. In the morally responsible organization, moral values in their full complexity are discussed and affirmed. Moral language, such as set forth in the APTA *Code of Ethics,* is accepted as a legitimate part of the corporate dialogue. The moral dimensions of the organization are not allowed to be forgotten amidst a concern for profits or personal power. The moral goals embedded in the enterprise are promoted rather than eclipsed.

A second feature of an ethical climate is its strong sense of mutual trust, based in turn on a conviction of the trustworthiness of professionals. In such an environment, employees are allowed, invited, and encouraged to participate in the organization beyond their narrowly assigned duties. In particular, they have a role in developing the policies and procedures of the organization. Leadership, in order to achieve envisioned goals, must generate a shared commitment to those goals.

A third feature of an ethical organizational climate is effective and fair conflict resolution. Conflicts arise in all organizations, and they take many forms, such as disagreements over schedules, prioritizing projects, making resources available, technical issues about appropriate therapies, administrative procedures, cost and billing procedures, and personality clashes. Often, several types of conflicts combine. For example, it can be difficult to see whether personality conflicts or professional judgments are involved in how best to help a particular patient.

### CASE 10.2 A Staff Conflict

**John and Tim often debated the merits of proprioceptive neuromuscular facilitation and neuro-develomental treatment for patients undergoing rehabilitation after a stroke. At a staff meeting, a heated argument broke out between them about which approach would best fit a new patient. In desperation, the chair of the meeting assigned the patient to another therapist, with the instruction that she should use whatever techniques she believed were appropriate. In fact, the chair knew that the two men often disagreed and, to some extent, their personal conflicts affected the willingness of the staff to address difficult subjects. The chair set up an appointment with both men to start a program of conflict management whose ultimate goal was to help Tim and John develop cordial and professional work behaviors and skills.**

Leadership is a widely applicable value rather than the sole province of managers. Ruth Purtilo, a leader in the study of physical therapy ethics, argues for the need to go beyond two familiar models of leadership: captains and shepherds. The captain model, used in the military and in sports, places the focus on one key individual who has primary responsibility and authority. The shepherd model emphasizes the leader as a benevolent nurturer of employees. Both models capture elements of truth about what is needed, but both models are limited by their focus on encouraging leadership in only a few individuals. Instead, Purtilo calls for development of leadership as a quality in all individuals: "Each member of APTA must assume a central role in advancing the moral life of the profession: Each member must nourish a seed of self-governance, assume ultimate responsibility for his or her own actions, and be sensitive and responsive to those committed to his or her care."[4]

Some health-care organizations establish structures inviting leadership in solving organizational ethical problems. For example, institutional review boards are responsible for protecting both human and animal subjects in research and are discussed in Chapter 4. A second type of organizational ethical monitoring system is the institutional ethics committee. There might be two committees, one to address administrative ethical decisions, including resource allocation and cost control, and a second to govern patient concerns, such as decision making when a patient is incompetent and has no identified surrogate decision maker. Within hospitals, these committees are typically interdisciplinary and consist of physicians, attorneys, nurses, therapists, clergy, and community members. There might be additional committees, such as the infant care review committee, which is encouraged by the U.S. Department of Health and Human Services to attend to the specialized ethical concerns originating in neonatal care units. Some large hospitals employ ethicists for consultation either individually or through a team of ethicists and trained clinicians who work as a unit.

By having formal structures to respond to ethical concerns, organizations enforce expectations that ethical behavior will permeate the entire cultural climate. In an ethical cultural climate, it is far easier for division and department chairs to engage staff in decision-making strategies that emphasize "the right thing to do" instead of what is most expedient or what is solely in the best interest of the department.

## DECISION MAKING AND ORGANIZATIONAL MODELS

Everyone has experienced the frustration caused by organizational barriers that prevent the achievement of a fair and desirable outcome. Many organizations have pioneered value-based changes. To better understand the capacity of organizational values to influence employees, we review three types of hierarchies in organizations:

1. Formal
2. Informal
3. Professional

### Formal Hierarchies

The formal chain of command in a typical business acknowledges the tasks and duties of key players and outlines the distribution of decision-making authority in each position. Organizational theorists propose multiple structural models, which Morgan clusters into four models, using the metaphors of machine, organism, brain, and culture.[5] Each model has the potential to influence the quality of the ethical decisions made by employees.

1. **Machine model.** This organization has bureaucratic structures with numerous strata of highly specialized staff, each with clear demarcations in authority. These structures work well in protected environments, such as surgical suites and mailrooms, in which the "market" (customers, clients) is reasonably secure, the "product"

(service) standardized, and efficiency is most important. To achieve this efficiency, priority is placed on obedience to rules and uniform ways of performing tasks. This ensures equal and impartial treatment to the consumers. However, machine models can also emphasize dominance and control that translate into an oppressive work environment devoid of creativity, one in which decisions follow the rules even when the rules do not offer the best solution in a particular situation. When corruption is uncovered, it is not uncommon for the participants to excuse their behavior with "I was just following orders."[6]

2. **Organism model.** This organization stresses participative decision making, a reduced hierarchy, and psychological incentives achieved largely through "family" groups. This model works well in organizations integrating multiple professions, but these organizations tend to be self-insulating, leading to consensus at the cost of innovation and tolerance of dissent. Where organizations put groups in competition for resources without oversight, the common excuse for corruption is the belief that "everyone does it."[7]
3. **Brain model.** This organization blends elements from the machine and organism models. This model is best exemplified by the stratum theory, which divides an organization into six strata based on the attention span needed for a task completion. These attention spans range from up to 3 months in stratum one to 30 years and beyond in stratum six. In the top stratum—the outer cortex of the brain—the chief executive officer is expected to make decisions based on a vision that projects up to or even beyond 30 years into the future. At the bottom stratum, the tasks are essentially maintenance, much like the workings of the brainstem. Without the addition of collaborative decision making and excellent communication between strata, short-term goals and long-term goals do not match, and ethical decisions tend to be uninformed by a cross-strata perspective. These decisions are thus inadequate to address the plurality of concerns that exist in every organization.
4. **Culture model.** Each organization is like a separate culture with its own set of beliefs and values. Within the organization, there are mini-cultures that define themselves. As an example, for many years the U.S. Atomic Energy Commission consciously created shields to protect its internal culture of secrecy and expansiveness. One of these shields, used to protect the agency from public criticism and political accountability, was a diversification program in which the commission was decentralized, with contracts given to outside companies to perform research and development. Although the agency was well aware of the environmental hazards secondary to the research and aware of the public's concern about those hazards, it made no effort to hold the outside contractors responsible for the contamination. When criticism was expressed about the increased environmental hazards being generated, the Commission stated that each diversified location was separately responsible. As a result, the commission avoided holding itself or its contractors accountable for wrongdoing.[7(p177)]

Although organizational structures can greatly damage the quality of ethical decisions, they can also be revised so as to enhance them. Cooper distinguishes between two important avenues for improving formal hierarchies to enhance ethical conduct: external and internal controls.[8]

*External controls* include any attempt to shape or prescribe the conduct of the individuals in the organization. Codes of ethics for the organization and for departments are examples of external controls. Ford and Richardson report that the research shows that "[t]he existence of corporate codes of conduct will positively increase an individual's ethical beliefs and decision behavior."[6(p216)] It appears that organizational, including departmental-specific, statements are of even greater value to employees than professional codes of ethics. The likely reason is that they are more personalized to the particular environment and directly linked to organizational expectations, thereby potentially affecting promotion and pay.

*Internal controls* consist of the internalized values of employees that guide the individual, especially in the absence of external controls. An example of a way these internal values are expressed and nurtured is the regular effort by employees and employers to identify and discuss ethical concerns. The identification process might involve creating ways for employees to report suspicious behavior or wrongdoing while offering protection and confidentiality to the informant.[9,10] The discussion of ethical concerns is probably best accomplished when ethics training courses are used. The discussion meetings that follow should be held on a regular basis, focused on the identification and solution of current problems and conducted using a Socratic method of dialogue.

There are at least three additional strategies that, when added to a hierarchical organization, further promote ethical conduct but that neatly fit neither the internal nor external control definition. The first is the publication of clear lines of accountability at each level of the organization that specify the limits of authority. The second is the creation of a "constitutional bureaucracy" in which each level of the organization has an advisory board comprising elected employee representatives who participate in policy formation and conflict resolution.[9(pp178-183)] The third is the use of ad hoc committees. Such committees can resolve an immediate problem and then be dissolved, thus avoiding the power struggles that often occur in fixed committees. They carry the added flexibility that managers can quickly alter the blend of personnel composing them.

## Informal Hierarchies

Although the formal hierarchy can have a profound influence on the ethical decision making in an organization, the informal hierarchy is also very influential. The informal hierarchy encompasses the politics of the organization and access to key decision makers. For example, the formal organizational chart will probably not list administrative assistants and secretaries prominently, but in the informal structure they are the ones who have crucial access to key decision makers and to classified information and who often control the timing of disclosure of information. Informal groups are also in this invisible hierarchy and have much to do with defining the values of the organization.

The informal hierarchy exists within the larger context of the organizational culture. As Morgan states, "Organizations are mini-societies that have their own distinctive patterns of culture and subculture. Such patterns of belief or shared meaning, fragmented or integrated, and supported by various operating norms and rituals, can exert a decisive influence on the overall ability of the organization to deal with the challenges that it faces."[5(p121)]

Formal and informal structures of organizations constantly influence each other. As an example, the actions of a metropolitan university president in refusing to approve an underqualified candidate for tenure sent an important message of fairness to the rest of the university community. The university had recently experienced financial cutbacks, and many of the faculty believed that one of the professors up for tenure would be welcomed, despite a less than impressive academic performance, because of strong ties with a wealthy foundation. There were rumors that the chairman of the foundation had recently given the university an unsolicited award and that the implicit message was more support would come if the candidate received tenure. The president of the university vetoed the tenure application. There was a renewed sense of the importance of fairness based on merit and an increase in the respect for the president.

## Professional Hierarchies

The professional hierarchy, operating as a distinct structure that also overlaps other structures, is usually built on the traditional roles of domination in health-care decision making: physicians at the top, followed by nursing, physical therapy, occupational therapy, respiratory therapy, and so on. The historical dominance of physicians within the domains of nursing and physical therapy is linked in part to the role of the physician as the case manager. It is also historically linked to sexism, given the predominance of physicians, who are male, and physical therapists and nurses, who are female. Decker states that, within health care, "formally, administrators are in charge. But informally, clinical expertise holds much of the power. For many physicians, that power often does not require accountability to administration or to other staff."[11] In a study of purchases of high-technology equipment, most of which was already available at other private or shared locations, it was discovered that physicians, not hospital administrators, were primarily responsible for the purchases, in part to maintain status among other physicians.[12]

Sometimes, especially in health care, all three hierarchies overlap, and the desired checks and balances are lost. Business values uninformed by provider-patient values can be devastating. Likewise, provider-patient values uninformed by rightful business concerns can also have catastrophic consequences.

## Power and Authority

All three internal hierarchies—formal, informal, and professional—are concerned with power. Having power means having the ability to cause change, directly or indirectly, and thus power is a necessary component of leadership. However, unlike leadership, which is a virtue, power can be used for evil as well as good. Typically, people acquire power by being perceived as having special knowledge or skills, access to information, and control over resources affecting the actions of the group. The powerful could not, however, maintain their influence without the conformity of others. Several major research projects have studied the power of conformity within groups. The best known is the Milgram study.[13]

In this experiment, the subjects were told they were part of a study to understand the effect of punishment on memory. However, the true purpose of the study was to examine obedience and conformity to authority within the study group. They were told that a person just out of their view, but whom they could hear, was the "learner" and that whenever the learner made a mistake, they were to administer an electrical shock. There were 30 lever switches labeled as ranging from 15 volts to 450 volts, with adjacent labels ranging from "Slight Shock" to "Danger: Severe Shock." As the shocks became stronger, the learner (who was not in fact receiving shocks) would exclaim that he had a weak heart, and at 300 volts he would kick the wall. After 300 volts he made no noise at all. Nearly 65% of the subjects continued to deliver the shocks at the instruction of the researcher all the way to the 450-volt level.

Many other studies support these findings, while augmenting them with attention to "group-think." For example, Asch conducted a series of experiments in which groups were assembled and asked questions whose answers were obvious. However, all members of each group except one, who was the subject of the experiment, had been coached to give the same incorrect answer. Over 74% of the experimental subjects conformed to their group, even though their conformed answers were incorrect.[14]

## PATIENT-RELATED DUTIES

Having discussed general theory and related overarching problems, we now turn to the responsibilities of a generic physical therapy department manager (chair, supervisor) who is given opportunities for moral leadership as well as risks of failed leadership. These responsibilities are multiple and include duties to the patients seen in the department, to professional and staff employees, to the organization, and to the manager personally to find solutions that do not compromise moral integrity.

It would be a mistake to think that the role of managers, such as department chairs, is to deal primarily with staff rather than patients. Department chairs are commonly asked to make decisions that have rather profound effects on patients, as illustrated in the following case adapted from Gervais and colleagues.[15]

### CASE 10.3 **In Over One's Head**

Complete Care Health Systems is an integrated nonprofit health-care delivery system whose slogan is "Quality health-care services across the continuum of care." Because of severe financial losses in the prior year, all divisions were directed to cut costs. Marcia Lewis is a physical therapist who manages the division called Peerless Home Therapy Care, which delivers physical therapy to the patients covered by Complete Health Care Systems.

One of the subdivisions is a program called the Pediatric High-Intensity Home Care Program, which provides therapy in home care to medically compromised children with complex health-care needs. It differs from other subdivisions in its increased frequency and duration of treatments. Nearly all its patients are funded by Medicaid, which has failed to increase its payments proportionally to the increase in the costs of the services. The costs include continuous in-service training needed by therapists to interact with the high-tech equipment and special needs of these children. As a consequence, each year the program has operated at an escalating loss of profit. In the past, the losses had seemed justified because the unit saved other divisions the cost of providing for these children at rates that would have been even higher. Yet, when costs were analyzed, each unit was segregated from the whole. Unless the subdivision could stand on its own, something had to change.

Other providers in the area had already withdrawn from this type of service because of the cost, and so it seemed apparent to Marcia that this program would have to close or change drastically. It could be closed by not taking on any new patients. Another option was to limit access to the program, and yet another was to take on new patients but do so in a time-limited contractual manner. Marcia thought that the best solution, consistent with the "continuum of care" commitment, was to provide services for only 6 months and in that time help families find other services or make other arrangements. Marcia requested the help of Peerless Home Care's ethics committee, which, along with her staff, developed a respectful way to announce this new policy to the current patients.

The committee called the patients' parents the day that certified letters were sent out to give them advance notice. The letters contained an announcement that service would be discontinued in 6 months, a list of home-care providers, the name of a staff person at Peerless who would assist the parents in the transition, and the name of a management person they could contact with questions. Physicians, social workers, and departments that would be affected were also notified. Despite these efforts, one parent contacted a reporter who, following an investigation, made it a high-profile story. The story generated so much bad publicity that ultimately a high-level administrator reversed Marcia's decision and made the public announcement that Complete Care Health System would not abandon its patients.

The primary difficulty in this case was that Marcia Lewis accepted, or was forced to accept, a level of decision making that was beyond the scope of her job description and training. In doing so, she squandered an opportunity to provide leadership within the organization that would have maintained the trust of the public and perhaps even improved the care given. Anytime a course of action is in opposition to the mission statement of an organization or requires balancing the business interests of the organization with its responsibility to deliver care, the decision should be made at the high end of the organizational hierarchy, ultimately by the board of directors. Had Marcia recognized the limits of her authority and presented the problem to the board, the board could have notified all patients of their concerns with the program and asked for a joint meeting to gather information and share possible solutions. The board would retain the formal decision-making powers, but the texture and depth of information that board members would then possess would make a just decision more likely. The decision would also be more satisfying to the public if the board informed them of how they weighted the relevant variables. Regardless of the decision, trust would not have been eroded so seriously.

We now highlight some managerial duties, beginning with patient-related responsibilities. Productivity and efficiency of staff should be key expectations of department chairs, in the eyes of the organization and patients alike. Managers are responsible for the fair allocation of the primary assets of the profession—in particular, treatment time and effectiveness. Organizations see this as a supervisory function to ensure revenue, and patients regard it as an accountability issue for their treatment expectations. Staff therapists, however, do not always see it from either perspective; rather, they view it from a position of how it affects their jobs.

As part of their duty to patients, supervisors must be diligent in detecting bias in treatment by staff because it affects treatment time and efficacy. In the past, bias has on occasion been expressed as a refusal to treat, but more frequently it disguises itself as the "professional judgment" that some patients will not benefit from an intervention. Such patterns of professional judgment need to be tracked by a supervisor to detect either a conscious or an unconscious bias influencing the allocation of care. Consider the following example.

### CASE 10.4 Unintentional Sexism?

**Renee, a supervisor, noticed that Sue consistently focused on ambulation for the elderly male patients who were being rehabilitated after a stroke and on activities of daily living for the female patients with the same diagnosis. When Renee questioned this pattern, Sue was obviously embarrassed and admitted that she just assumed, without asking, that these would be the patients' priorities. Sue volunteered that her selections of goals could easily be considered sexist and promised to document the patient priorities for treatment goals.**

While efficiency of the staff is a manager's duty to patients, effectiveness is an equally important duty. A department supervisor is morally responsible for ensuring that the therapists hired are effective and competent. Thus, during the hiring process, the supervisor confirms graduation from an accredited program, checks licensure to ensure it is current, seeks recommendations from prior employers, and makes inquiries about criminal behavior. The duty is to hire people who will not harm patients or staff or be so disruptive that the department is damaged. There are limits, however, to diligence in making inquiries about prospective employees. For example, a supervisor is not permitted to make any inquiry into conduct outside the employment setting, because doing so violates privacy laws and does not demonstrate respect for the autonomy of the applicant. The fact that a therapist is a staunch environmental activist, for example, is irrelevant to whether that therapist is fit to practice. Because no one person can judge with certainty the competence of another in a single interview, potential employees should be interviewed by other therapists in the unit. Interviewers can use case studies to evaluate the candidate's proposed treatment strategies and then meet with the chair to synthesize their impressions and arrive at a recommendation.

After a new therapist is employed, the supervisor can help ensure efficiency and efficacy in patient care by providing opportunities for continuing education, including reviewing issues of cultural sensitivity. Many health-care organizations working within managed-care limitations do not provide funds or time for formal continuing education, but a supervisor can provide the leadership to initiate a group effort to critically review current research through a journal club held after work or on weekends. At the very least, the manager should not be an obstacle to efforts to ensure current competency. When therapists wish to attend conferences relevant to enhancing their skills, managers should work with them to provide a flexible workweek or other strategy so that time missed can be accrued through additional patient treatment time.

Assigning patients, often tedious and time-consuming, brings with it a host of considerations. The patient expects to receive the best care available. Therapists expect to be treated fairly and equally. However, all therapists are not equally skilled in all areas of practice. The profession is simply too expansive for everyone to hold equal expertise in pediatrics, geriatrics, sports medicine, acute care, and other specialized areas. Even within any one of these areas, it is doubtful that all will be equally skilled in all facets of that specialty. It is the responsibility of the manager to know the staff's skills, strengths, and weaknesses and assign patients appropriately. If a therapist has a problem that causes patient assignment to be unequal (either in complexity of care or in number of patients), the manager has the responsibility of providing opportunities for the therapist to develop the essential skills. If the therapist refuses or is unable to acquire the needed competencies, and the deficiencies are significant, the manager must dismiss that therapist and find a replacement.

## PERSONNEL DUTIES

### CASE 10.5 Cut Salaries or Staff?

Ron has been practicing clinically for 14 years. He returned to school 6 years ago and earned a master's degree in health-care administration. He accepted the position of chair of the physical therapy department at Mercy Hospital 2 years ago. Immediately he made needed changes in the methods used to assign patients to therapists, instituted flexible work schedules, and established weekly case review sessions that were more like continuing education than peer review. He is generally perceived as a strong leader by the therapy staff, which consists of 12 full-time therapists and 3 physical therapist assistants.

Mercy Hospital had been on the brink of bankruptcy for years. It has managed to survive through the efforts of a highly competent chief executive officer who could generate donations and assistance when times were difficult. Nevertheless, the board of directors sold the hospital to Partners in Health Care, Inc., one of the larger publicly traded national managed–health-care organizations. Ron met with his new supervisor, Harold, the vice president of rehabilitation, who alerted him that the therapy department was losing money. The losses were not great and certainly did not constitute a threat to the organization as a whole, but the problem had to be solved so that the department would make at least a 10% profit. This was the margin of profit essential to support other services, such as the prevention and immunization programs, that could not be expected to be self-supporting. If this profit goal could not be reached, the organization would abolish the physical therapy department as it was currently structured but retain Ron as chair to manage per diem therapists. Harold explained that the savings of such a change would be significant because per diem therapists were paid only for their hours of patient contact and received no benefits, which totaled over 35% of the salaries of the current staff. Harold said that he would give Ron 1 week to develop and implement a plan that was equal, or nearly equal, to the per diem strategy.

Based on his experience, Ron reasoned that a full per diem staff was simply not acceptable. Patients would lose the continuity that was essential to good care, and there was no way he could ensure competency in specialized areas for complex patient needs. His solution was a proposal that left the current team intact but imposed a 10% reduction in pay across the board. The proposal would also end overtime pay, and it would impose unpaid "voluntary" time for the case reviews that had proved professionally valuable. In addition, he requested that each therapist donate 1 weekend day every 6 weeks without pay.

According to Ron's calculations, which were confirmed by the accounting staff, this proposed solution would slightly improve the return that a per diem staff would generate for the organization. He called a department meeting and explained his reasoning for the proposal. At first, the staff seemed accepting. He felt confident that, after giving them a couple of days to think it over, they would rally behind his ideas.

At the end of the second day, Ron called another department meeting. Sharon, one of the therapists, said that the staff had met without Ron to assess their options and the group had asked her to speak for them. She expressed her thanks to him for proposing what he clearly believed was the best alternative. The group had decided, however, to take another course of action, which was also currently being considered by the nursing staff in response to cuts in their area. They had contacted the labor union to ask it to represent them in their dealings with management.

The therapists had in theory endorsed a job action that would leave patients without any therapy, and they believed that management would quickly realize that they could not afford such an action, in terms of either patient liability or bad publicity. The group saw no reason why they should lose salary or personal time. They were all prepared to take this job action for a duration of up to 3 weeks, and some would continue even longer.

Ron thought he provided responsible leadership when he made his proposal to the staff. Did he? He could probably have reached a much better decision about "the right thing to do" if he had had more information. For example, he might have tried to hear from the therapists on an individual basis how they weighed such issues as patient abandonment, future long-term good versus short-term harm, or perhaps their perspective on how good a leader they perceived him to be. Because more information tends to generate better decisions, a "thick" rather than a "thin" case description is preferable. Nevertheless, whether in textbook cases or in real life, there is always a limit on what can be known before having to make a decision.

One of the most important findings about organizational life is that administrative units make decisions in what is called a "bounded rationality."[16,17] That is, organizations typically come up with decisions that are good enough (satisfactory) but usually not ideal because of very real constraints on time and information. The time constraints exist especially in businesses operating in volatile markets where agile, quick responses are needed to survive. In turn, the time constraints limit the information managers can gather and analyze. The time and information deficits force decisions that will suffice—that is, solve problems—even though better solutions could be found under less constrained conditions.

Personnel duties are particularly sensitive to issues of justice and fair dealing and are also usually performed under tight time constraints. Given such constraints, there is a tendency to treat everyone equally. But is that fair, and does that mean that the support staff (secretaries, administrative assistants, aides) should be managed in the same way as the professional staff? Probably not, because of one major difference: the professional's job is defined primarily by the profession. The manager of a professional team monitors for incompetence but does not define or teach competency; this is handled through the professionals' education. Support staff, on the other hand, must be given specific expectations about what their jobs entail and taught the process by which to achieve those expectations. That does not mean that their autonomy is not just as worthy of respect as that of the professionals, but in work behaviors they do have fewer opportunities for making autonomous decisions.

The key to fair treatment of personnel starts with an honest, detailed job description that includes both the skills and values that are required from the organizational point of view. The job description, in essence, defines the contractual agreement between the employee and the employer. Obviously, the skills possessed by the employee must match the needs of the organization. Less obviously, the basic organizational values must also match those of, or at least be acceptable to, the employee.

For example, Hospital Z has an interdisciplinary team approach to patient care, a corporate culture that values diversity, and a commitment to putting quality of care on equal footing with profitability. A potential employee who prefers to work autonomously with a homogeneous population and who feels that only quality of care should be addressed in the professional setting is clearly a poor risk. Thus, the best time to address a match in values is during the employment interview. Employers must be honest about the values of the organization and stress that if there is not a match the candidate would be better served by employment elsewhere.

As stated earlier, the job description is the single most important element in hiring. The description must reflect the job content accurately, and it must be posted in a public area accessible to all potential candidates. The candidate's résumé must be validated, but the extent to which this can be accomplished is affected by state laws concerning the right to privacy, which should be consulted prior to inquiry. If possible, it is best to state on the job application form itself that the information will be verified. Those verifications may involve contacts with the following: former employers, licensure boards, universities, Office of the Inspector General in the U.S. Department of Health and Human Services (fraud), law enforcement agencies (criminal), the National Terrorism Database, the National Sex Offenders Public Registry, and national and state malpractice databases.

In some cases these inquiries can be consolidated through fee-for-service sites on the Web, using key words such as "background checks." Steingold recommends having the applicant sign a consent form to authorize this investigation and thereby reduce the risk for the employer.[18] This procedure also fairly informs potential employees that truthfulness is of value in the organization. Employers must then verify the dates and responsibilities provided by the applicant, as well as any written communication former employers are willing to share concerning past job performance. These steps are critical; unfortunately, more than a few individuals have inflated and even lied about job responsibilities in previous employment. Truthfulness is an essential component in employment; if it is lacking, the manager will either have to check the accuracy of any statement made by that employee or disregard that person's input. Neither is a reasonable option.

Once the applicant pool is defined, the format and content of the application and interview process must treat all candidates equally. The initial application process will probably be managed by human resource personnel, who usually have the assistance of legal advisors, but the department chair usually conducts the interview and may request other staff members to interview candidates also. Each interviewer should have a written list of questions so that all candidates are treated equally. Since the landmark case of *Griggs v. Duke Power Company* in 1971, only items proved to be reasonably relevant to the job task(s) can be asked in the process of selecting employees. In that case, heard before the U.S. Supreme Court, Mr. Griggs was refused employment as a manual laborer because Duke Power Company required that employees in that job function have a high school diploma. Because the company could show no relevancy of a high school diploma to laying telephone lines (the job for which Mr. Griggs had applied), it lost the court case.

Because managers purchase the skills and talents that fit a specific job description, there is no need to ask irrelevant questions, such as "Are you married?" or "Where were you born?" or "When did you graduate high school?"—all of which imply a selection bias that is irrelevant and may be illegal.[18] Questions that reveal an applicant's age (especially older than 40), such as the question about high school graduation, or that pertain to race, religious beliefs, physical disability, financial status, birthplace, or ethnicity are illegal, in addition to many others; the questions vary by state and often involve references to marital status and sexual orientation.[18]

A manager must be honest with prospective employees and be especially careful not to promise or imply a job security that is unrealistic. The 1877 U.S. document "Horace Wood's Treatise on Master and Servant" officially endorsed the tradition of "at-will" employment in the United States, which means that an employee can leave a job at any time, and an employer can dismiss an employee at any time for any reason, and even for no reason.[19] Since that time, the courts and Congress have limited the employer's legal reasons for dismissal, but the employee remains free to come and go at will.

In truth, there is no job security unless a contract employment is created. This can happen when an administrator informs a prospective employee that "if you do a good job, you need not worry about your employment."[20] Statements such as this create a contract that is additional to the "at will" employment tradition and leaves the organization subject to charges of wrongful termination if employment is terminated. In fact, the three most common bases for lawsuits include wrongful termination based on stated or implied conditions of work, discrimination based on legally protected classifications, and retaliation that violates rights granted under state or federal law.[19(p205)]

## WORKERS' SAFETY

One category of an organization's personnel duties warrants mention: maintaining a safe workplace. Employees have the expectation that their employer will act in their behalf to make their work environment as safe as possible. That expectation became a legal right under the Occupational Safety and Health Act passed by Congress in 1970.

The intent of the act was to reduce workplace hazards by requiring employers to meet specified health and safety standards. The act contained a provision for a new agency, called the Occupational Safety and Health Administration (OSHA), to be housed in the U. S. Department of Labor for the purpose of establishing additional health and safety standards. In Section 18 of the Act, states were encouraged to set up their own job safety and health programs, which OSHA would approve and monitor. Presently, 24 states have their own programs, many of which are more stringent than the federal OSHA standards.[21]

State and federal programs cover all health service organizations, with the exception of self-employed professionals with no employees. Organizations are also required to keep records of accidents requiring more than simple first aid and to provide safety training.

Workers were given two basic legal rights by OSHA. First, workers have a right to register a complaint with OSHA, and they cannot be harmed by the employer for doing so. Second, if workers sincerely believe that a serious injury or death might occur because the work area is unsafe, they can refuse to work, and employers may not retaliate. OSHA has the right to issue citations and can enforce fines and even prison sentences, although these harsher consequences usually occur only in extreme cases and after repeated warnings. Because each state program has unique properties, only the broad categories of recommendations outlined by OSHA for health-care settings are discussed here.

Hospital and other health-care settings are particularly vulnerable to hazards because of the complex nature of the services delivered and the speed at which they must often be administered. Unlike employees in most businesses, hospital employees are often near explosive gases and liquids, do heavy lifting, and often encounter wet floors. Examples of the types of common hazards and injuries that OSHA addresses are hernias, back injuries, fires (patient rooms, storage areas, and equipment are most frequently involved), compressed gases, flammable/combustible liquids/vapors/gases, and electrical equipment. In 1991 OSHA issued its Blood-Borne Pathogens Standards, which provides essential protection for health-care workers who might be at risk for blood-borne diseases such as hepatitis and HIV infection. This was revised in 2001; detailed recommendations can be referenced at OSHA's Web site.[21]

The two risks of greatest concern to physical therapists are addressed in OSHA's long-standing recommendations for preventing back injuries and the more recent OSHA standards for preventing violence in the health-care setting. Proper lifting techniques and strategies for managing the physical demands of health care are provided in the preparatory educational programs, but violence is overlooked, even though therapists are specifically mentioned among those health-care workers who are covered by the guidelines. Assaults are more frequent in settings common to the health-care and social services than in any other setting, according to the Bureau of Labor Statistics in 2006.[22] The incidence is probably seriously underreported because for too long many have believed that the risk of assault and violence came with the territory.[23]

Many factors contribute to violent responses in the health-care workplace, not the least of which is the level of violence in the nation itself and the general population's easy access to handguns.[24] In addition, there are increasing numbers of mentally ill patients released from hospitals with no follow-up care who carry guns.[25] The more salient reason, however, for the prevalence of assault probably has to do with the stress of patients' life-altering injuries, including loss of income and disruption of social and emotional support.

In response to violence in health-care settings, OSHA has recommended the use of metal detectors, close-circuit video recordings, and bullet-resistant and shatterproof glass in reception, admitting, and client service rooms. OSHA recommends that alarm systems not be dependent on telephone lines, installed throughout the facility, and include panic buttons in hallways and stairwells supplemented with handheld alarm devices and hardwired reporting devices in the admissions area, nursing stations, and emergency rooms. Furniture should be affixed to the floor, and other items that could be used as weapons, such as vases and pictures, should be properly secured.

## ORGANIZATIONAL DUTIES

Managers have a cluster of duties concerning the general well-being of the organization. These duties include risk management, fair allocation of resources, sustaining teamwork within the organization, and a host of additional duties at the level of upper management.

### Risk Management

Managers typically function as departmental risk managers. Most large hospitals have full-time risk managers, whose job includes monitoring compliance with local, state, and accrediting agency regulations. These managers create systems to monitor all departments for safety and patient violations, and they are required to respond immediately to any patient who has been injured by hospital personnel. At the departmental level, the manager is expected to ensure compliance with the following five directions, among others.

1. All employees in the department are expected to adhere to hospital/organizational policies. A good manager, and certainly an effective leader, knows that managing is far more than compliance to the letter of each rule. It is rare that a general rule will correctly fit each situation. As a consequence, the manager is constantly deciding how much compliance with selected policies is needed and when policies need revision to better fit the current work environment. In order to maintain the trust of the staff, management must avoid even the appearance of wrongdoing or favoritism by communicating the rationale for different standards of productivity where it will not break a rule of confidentiality such as an illness that the employee does not want revealed. In general, the manager should take care in open communications to respect the confidentiality and personal information of all employees.
2. All equipment should be maintained according to manufacturer instructions and inspected on a regular basis to ensure it is safe for patient treatments. When new equipment is purchased, it should be tested prior to patient use to ensure it is properly calibrated and safe.
3. In the event of a patient or employee injury in the department, there must be an immediate and medically appropriate response that is professional, sympathetic, and followed by a written incident report. Most departments have well-established policies and procedures that prescribe the format of this response.
4. Staff must understand that it is essential to respect patients' informed consent and that it is important to inform patients about treatment and the methods that will be used, where and why touching of the patient is required, and expected outcomes. Any procedure, including evaluations, that involves touching the patient in areas that might be interpreted as sexual should be explained in advance and must be documented.[25]
5. Supervision must be available for all staff while patients are treated in the department. Managers are the organization's representatives, as well as representatives of the staff; hence, they are expected to be available as needed. They must keep the receptionist or some other staff member informed about their daily activities and how they can be reached.

### Fair Allocation of Resources

One of the most important functions of any manager is the fair allocation of resources to employees. Traditionally, the higher the manager is in the hierarchy, the greater the resources at hand to distribute. Because of the perceived power that goes with allocation of resources, managers must be aware that even the appearance of wrongdoing or unfairness, no matter how unfounded, will damage the trust employees have in them.

Because managers work in a fiduciary role when it comes to allocation, it is usually best if all concerned parties are involved in the decision making about resource allocation. Often, staff members are involved as advisors, with final decision resting with the manager. This is because, although employees have a vested interest in their own rewards and maintenance, the manager has the responsibility of managing present and future goals for the entire department. Thus, rather than distribute resources to individuals, the manager might make better use of those resources by investing them in long-term department development. In that event, managers should explain to their staffs the principles that guided their thinking and the potential trade-offs between benefits and burdens.

There are times when information cannot be shared with staff, perhaps because it is proprietary or because it violates the privacy rights of another employee. For example, if managers are aware of confidential negotiations for a merger with another company, they are not free to reveal that information, even if it is the reason for a sudden staffing freeze. Funds might have to be spent to secure a 30-inch computer monitor to give reasonable accommodation as a part of Americans With Disabilities Act compliance to a new receptionist with a vision disability. Although it would be clear that a disability is involved, that information cannot be released to the staff without the employee's permission.

Managers are best advised to indicate to employees there are reasons they cannot divulge information at a given time, but that as soon as possible they will explain their reasoning.

## Maintaining Teamwork

The manager's responsibility to promote and ensure teamwork is an organizational duty that overlaps with personnel duties and affects patient-related duties. There are three basic types of teams in health-care rehabilitation: multidisciplinary, interdisciplinary, and transdisciplinary (defined in Chapter 8).

All teamwork raises ethical concerns. Teamwork creates the obvious gain of peer interaction through participation in team decision making, but teamwork also brings the equally obvious loss of professional autonomy in making requisite compromises. Individuals are no longer completely free to intervene as they see fit, because decisions are now joint ventures, and interventions are tailored and scheduled around the team's resources. Moreover, it seems that in all groups there is the somewhat troublesome problem of "free riders"—those who produce just enough to get by and who do not contribute as equal members. Fairness is a powerful force in the workplace. When it is perceived as absent, morale in the entire group is affected. Peer pressure might be effective in changing the unproductive behavior if that person values the opinions and wishes of the other team members. However, as long as the person is meeting minimum expectations, the manager might lack the leverage to implement change.

The more troublesome aspect of team membership is its fracturing of the individual provider's sense of responsibility for the patient. When the team is the accountable unit, sometimes, in spite of ethical responsibilities, none of the members feel individually accountable for the outcomes. This reality is akin to the bystander effect that psychologists discovered in studying the Kitty Genovese tragedy (Chapter 2): the natural tendency to assume that someone else will respond to a problem.

## Upper Management Duties

The further up the hierarchy, the increasingly complex the decision making. The number of variables needing consideration increases. Decisions that have a global effect on the organizational culture or fiscal stability of the organization are typically made by the top managers along with the chief executive officer (CEO) and the board of trustees. A decision that might be made at this level, for example, is whether to establish a voluntary affirmative action program.

Top managers must juggle and integrate numerous competing interests. The CEO of a hospital is typically responsible to the board of directors or trustees not only for the decisions the CEO makes but also for all the decisions made by the vice presidents and their managers. The CEO must communicate with the Joint Commission and other accrediting agencies as well as negotiate with labor unions that represent employees of the hospital. The CEO must ensure that the hospital complies with city, county, and state laws as they relate to patient care, building codes, and various other regulations. Fund-raising in the form of attracting charitable donations and submitting grant applications is part of the CEO's responsibilities as well as developing long-range strategic plans for the hospital. At each successive move up the hierarchy, the manager has greater contact with the external environment of the organization. Most of these responsibilities involve making fair distribution of existing and future resources. While the primary focus of the hospital should be the patients it serves, the hospital also has a role as an employer with broader social and legal obligations. To that end, there are leaders who are effective and demonstrate courage and moral authority, as in the following case.

## CASE 10.6 Removing Corruption

Clara was the new CEO at a small hospital in a rural area of North Carolina. In the first month, she realized that more than half the patients were there because of referrals from two surgeons on staff. For any hospital, this places the institution in a vulnerable position. One of her first objectives was to increase referrals from other physicians in the area to help balance the referral load. During the fourth month of her tenure, she was reviewing charges and discovered a series of charges from the two referring surgeons for seminars that did not appear on the hospital schedule and for grand rounds on days that ground rounds were not conducted. She immediately called the two surgeons into her office and confronted them with what she believed to be false billings for services.

They made no effort to deny, justify, or explain the charges but instead asserted that they were the main revenue stream for the hospital and expected to be rewarded appropriately. At first she was startled at their assumptions and bravado. She mentioned the Stark Laws, anti-kickback statutes, and the Racketeer Influenced and Corrupt Organizations Ace, but neither of them responded. She said she would meet with them later, at which point they notified her they would like to be paid within the next 5 working days. Angered and frustrated at their insubordination, she decided to dig deeper. Much to her amazement, she found this arrangement had a long standing under the former CEO and, from what she uncovered, it looked like he had allowed them to bill for procedure they did not perform. It had been a very lucrative deal for the surgeons, but now the False Claims Act was also in effect. This was a major decision with the very real repercussion of closing the hospital. The wrongdoing was so pervasive and had such long historical roots that sorting it out with payers and accreditations would consume the balance of resources needed to run the hospital. After thinking about it over the weekend and consulting with another CEO at another location, she set up a meeting with the board of directors. At that meeting, she announced that she intended to launch a full investigation and take the appropriate legal steps to remedy the situation. Much to her surprise, several board members said they were thankful someone would take this on because the situation had been developing for years, and they had not been able to acquire enough information to take action. Clara stated that with their support, she intended to be honest with the press and the patients; she believed transparency was their only real course of action. Reluctantly, the board agreed.

In the following year, there was less shock in the medical community than anticipated. The referral base steadily increased. Clara made it a point to personally thank each physician who referred to the hospital. In several of these conversations, she discovered that others had stayed away from her hospital, unwilling to be immersed in what they suspected was a culture of wrongdoing and a potentially embarrassing employment/referral situation.

True leadership teamed with good business strategies to minimize the vulnerability of the institution succeeded in this case to stabilize the institution and position it for future growth.

## DISCUSSION QUESTIONS

1. Outline what you consider the key ethical values, both procedural and result-oriented, that define leadership. Then apply your concept of leadership to Sara's situation in Case 10.1. What avenues for effective leadership might she have available in her situation?

2. In Case 10.5, what variables do you hope Ron's staff considered before deciding to join the union and embark on a job action? How would you weigh the variables and options, and what course of action would you have taken if you had been a therapist in Ron's unit?

3. As a cost-saving measure, a managed-care organization announced that it would do away with the chairpersons of each department and ask each department to run itself. Members of the physical therapy department were to leave any unmanageable problems to the division chief, who would handle performance appraisals and strategic planning for the division and thus for each department. What are some strategies you could use to keep the operations of the department fair for the department employees? Address patient scheduling, conflict management, and resource allocation for continuing education and patient supplies.

4. The CEO of a health-care organization announces, through the division chief, that staff therapists will have to reduce the time spent with patients so the organization can meet the time allowance that third-party payers are willing to fund. In the past, therapists were scheduled in 30-minute blocks of time, for ease of scheduling and because most therapists needed that amount of time to prepare for, assess, treat, and educate each patient. Now, some cases will receive only 20 minutes. The reason seems clear: the hospital is trying to make more money. You are concerned that the patients will receive less care than is desirable. What options might you pursue?

5. You are the chief physical therapist at a small private hospital, in a department with four additional therapists. The chief occupational therapist at the hospital has quit after a long dispute with management, and the vice president in charge of rehabilitation announces that the two departments will be combined under your leadership. How will you assuage the fears of the occupational therapists concerning your ability to fairly and credibly evaluate their patient care?

6. The therapist in charge of the whirlpool area reports to you that the Hubbard tub sample sent for a bacteria reading has come back positive for *Escherichia coli.* Because the unit has a full roster of patients from the burn unit to be treated each day, either a new Hubbard tank will have to be purchased or rented, or the patients will have to be sent to another hospital. New admissions will also have to be rerouted until the tank is sterilized, and key components are disassembled and sterilized. Even with a crew working around the clock, it will be days before a tank will be ready for patient use. You take the matter to the division chair. Instead of authorizing

transfers for treatment, the chair says to fill the old tank with as much disinfectant as available, add alcohol and anything else that might kill the bacteria, run it, rinse it, and readmit patients. What should you do?

7. As chief therapist in the rehabilitation unit, you are initially impressed with Susan's efficiency. Although a new graduate, she treated more patients in her first month than some of the senior therapists on staff. Early in the third month, Steve, one of the physical therapist assistants, approaches you. Steve has been in the department for 15 years and is generally considered the best assistant on staff. He is concerned that Susan has instructed him to do full patient evaluations parallel to her while she evaluates other patients. In addition, she has asked him to propose treatment plans, which up until now she has approved without question. Steve adds that he considers himself competent to do what is requested, but he questions if this is entirely permissible. What would be your response, and what would be your course of action?

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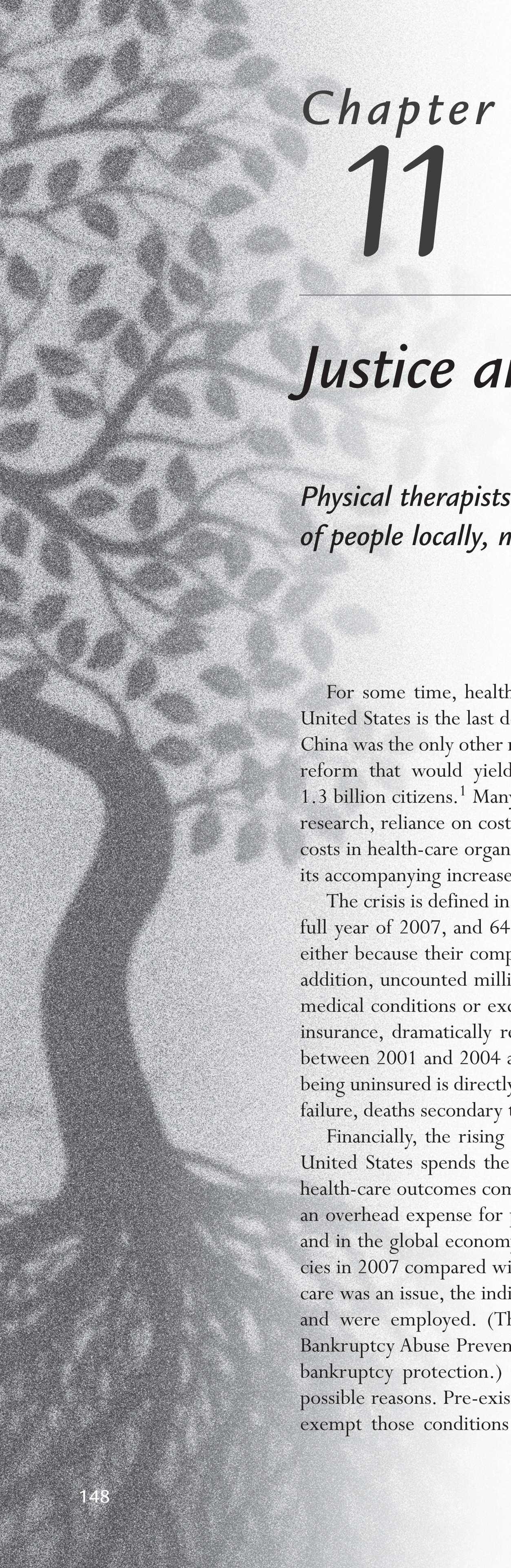

# Chapter 11

# Justice and Access to Health Care

***Physical therapists shall participate in efforts to meet the health needs of people locally, nationally, or globally.***

Principle 8, APTA Code of Ethics

For some time, health care in the United States has been in crisis, financially and morally. The United States is the last developed country without an effective health-care system for all its citizens. China was the only other major country without universal coverage until it announced in 2008 a major reform that would yield 90% coverage by 2011 and universal coverage by 2020 to its nearly 1.3 billion citizens.[1] Many factors created the U.S. crisis, including expensive advances in health-care research, reliance on costly technology, public demand for the best care possible, high administrative costs in health-care organizations, and the dramatic extension of the average American life span, with its accompanying increase in medical intervention.

The crisis is defined in multiple ways. Over 45 million Americans had no medical insurance for the full year of 2007, and 64.5 million people were uninsured for at least 6 months in 2007 and 2008, either because their companies did not provide it or because they could not afford to pay for it.[2] In addition, uncounted millions of people have only partial health-care coverage because of preexisting medical conditions or exclusion clauses in their policies. Not having insurance, or having inadequate insurance, dramatically reduces health-care outcomes. The Institute of Medicine issued six reports between 2001 and 2004 and again in 2009 reviewing health outcomes research. Each concluded that being uninsured is directly related to poor health outcomes, such as increased risk for congestive heart failure, deaths secondary to heart attacks, and higher mortality rates following severe auto accidents.[3]

Financially, the rising cost of health care has had dramatic macro-level effects. Even though the United States spends the most of any industrialized country—between 50% and 100% more—its health-care outcomes compare poorly in almost all areas. Employer-based insurance premiums create an overhead expense for products and services that put citizens at an economic disadvantage, locally and in the global economy. At the micro level, medical costs were a factor in 62.1% of all bankruptcies in 2007 compared with 46.2% in 2001.[4] In the nearly 75% of the bankruptcies in which medical care was an issue, the individuals had health insurance; most were well educated, owned their homes, and were employed. (These data are prior to the recession that started in 2008 and after the Bankruptcy Abuse Prevention and Consumer Protection Act, which made it more difficult to file for bankruptcy protection.) Being insured did not protect families from financial disaster for several possible reasons. Pre-existing condition clauses in insurance policies can temporarily or permanently exempt those conditions for which a person has a likelihood of an occurrence. High deductibles and low caps can also limit protection. One of the more devastating acts on the part of insurance companies is the practice of rescission.

In many rescission cases, an individual pays premiums for years, and when a claim is placed, especially for a diagnosis such as cancer that will result in significant payouts, the original application is reviewed for any error of omission or commission. Even the slightest oversight is used as justification to claim that the policy was issued on fraudulent grounds and is therefore not to be honored. In one case, an insurance company refused to pay for treatment for an aggressive form of breast cancer because the nurse who was the policy holder had failed to notify them of a visit to a dermatologist for acne. In 2009 the House Subcommittee on Oversight and Investigations conducted an investigation and found that among three insurers, over 20,000 people had their coverage canceled to avoid more than $300 million in claims over a 5-year period. The three CEOs testified before lawmakers that they would not agree to limit rescission to policy holders who intentionally lied or in other ways committed fraud to acquire health insurance. These rescission practices were initially uncovered by the investigative reporting of the *Los Angeles Times;* later investigations found the practice to be widespread.[5]

The health-care crisis also presents a moral issue because of the enormous suffering caused when individuals lack proper medical coverage. This moral issue relates to distributive justice; in other words, given scarce (limited) resources, what is a just and fair way to make health-care services available? This question is germane to both microallocation—or determining what, for individuals and organizations, is the just or fair way to balance the competing claims of individuals for limited resources—and macroallocation, which is a determination of which resource allocation system for health care within a society is most in tune with principles of justice. Although a major health-care reform has recently been enacted (the Patient Protection and Affordable Care Act), there are continuing challenges and revisions as this book goes to publication, and it is unlikely that all problems will be erased. Health-care reform will be an ongoing process of matching needs with resources based on compromises made within a democratic system of government. In this chapter, we explore some options and introduce some of the principles of justice used to evaluate those options. (A fuller discussion of ethical theories appears in Chapter 12.) We conclude with a discussion of the important, but often neglected, topic of *pro bono* services that will still be relevant even if universal coverage is adopted. There are always populations without insurance, including tourists, residents without citizenship, and people who elect to not participate in any health insurance plan, among others.

## MICROALLOCATION: BALANCING PATIENTS' NEEDS

**Microallocation** deals with issues concerning justice in distributing resources to individuals and within health-care organizations. It involves balancing conflicting claims of patients and sometimes third parties, allocating the time spent by health professionals, and distributing other limited resources. For example, one type of conflict involves scheduling problems. When a clinical staff is overloaded on a given day because a therapist calls in sick, what is a fair way to allocate the time of other staff physical therapists? Suppose a patient arrives late for an important therapy session because of traffic delays beyond the patient's control, necessitating postponement of the regularly scheduled care of a patient in less need? Does greater need override scheduled appointments? Another frequent problem concerns when to decrease or terminate treatment of a patient whose insurance coverage has ended.

We consider several cases in some detail.

### CASE 11.1 Unequal Care

Helen had been the chief physical therapist in Buena Vista Rehabilitation's physical therapy department for 4 years. She had made tremendous progress in raising the standard of care in the department by acquiring the funds from administration to hire the best available therapists. In doing so, she made a conscious effort to hire people educated at a variety of universities to enrich the professional peer interactions concerning patient care. Ironically, the resulting diversity of viewpoints was integral to the following dilemma.

Karen and Corey, two of Helen's staff therapists, expressed their frustration about the differential care of two patients. Each patient had the same diagnosis and was the same age, but each had different health insurance policies. Karen's patient was entitled to only 6 visits, exactly half of the 12 visits Corey's patient was allotted. Karen called the insurance company to explain the complexity of the diagnosis and her treatment proposal, but her request was refused. Karen and Corey were convinced there was an injustice, and Karen decided to give her patient six more sessions without reimbursement.

However, Helen had long ago implemented a policy of no courtesy treatments, because the department could not afford to lose the revenue that free treatments entailed. Helen told Karen that if she wanted to come back on her own time, she could use the department. But Helen would not change the policy because doing so would be unfair to the other therapists, who would also be damaged by any cuts in the revenue. Karen responded that it did not seem fair that she should have to give up her family time to solve the organization's problem.

Karen's desire to provide adequate treatment for her patient is compelling, but is it the duty of the department to administer justice between unequal plans? Helen is caught in a dilemma between her responsibilities to provide quality care to each patient, to be loyal to her staff, to be fiscally responsible by working within the restrictions of different insurance plans, and to maintain overall standards of excellence. She is aware that the American Physical Therapy Association (APTA) *Code of Ethics* states in Principle 8A: "Physical therapists shall provide *pro bono* physical therapy services or support organizations that meet the health needs of people who are economically disadvantaged, uninsured, and underinsured." However, it also states in Principle 7B, "Physical therapists shall seek remuneration as is deserved and reasonable for physical therapy services." In Helen's department, "deserved and reasonable" means staying on budget or losing staff or equipment or both.

Given such obstacles, how is the fair distribution of resources to be determined? A starting point is the formal principle of distributive justice, which says similar cases should be treated similarly. This purely logical principle provides important guidance by requiring consistency, but it says nothing about what makes cases "similar" in moral terms. That is, it says nothing about the substantive features of cases that should be taken into account, let alone about which features are most important in particular situations. Is medical need the only relevant feature, or is the difference in health-care plans of most relevance?

Substantive considerations can be formulated as material principles of justice. Beauchamp and Childress identify six principles:

1. "To each person an equal share;
2. To each person according to need;
3. To each person according to effort;
4. To each person according to contribution;
5. To each person according to merit;
6. To each person according to free-market exchanges."[6]

All six principles could be applied in Helen's case, but which should have priority? For example, should considerations of need lead Helen to modify her firm policy? Because the insurance for fewer visits cannot be adjusted upward, should the patient with 12 authorized visits be cut to 6 so that patients with similar diseases are treated similarly? Considerations of justice also enter into how staff therapists are evaluated—a matter that bears on fair and effective allocation of care to patients. If Karen or Corey decided to engage in pro bono work on their own time, how should Helen acknowledge each of their efforts when it is time for staff evaluations? We leave further examination of these issues to the discussion questions at the end of this chapter.

### CASE 11.2 **Fairness to Staff**

Helen negotiated with management for money to cover the tuition costs and time with pay for the staff to take continuing education courses. The vice president in charge of the division explained that there was a precedent in another area to allow up to 3 days per year with pay for verified continuing education. The vice president could not, however, create a new budget line item to pay for the courses without offering that same opportunity to nursing and all other health-care professionals, and there simply were not enough uncommitted funds to do that. Helen requested use of the conference room and one treatment room for one night per week after 7 p.m. so that the department could provide continuing education courses and raise funds at the same time by charging a registration and attendance fee. The staff would teach the courses over a given period. The funds raised could then be used for education courses for her therapists. The vice president agreed.

When Helen announced the plan, she stated that as all the therapists were professionals, they should all be treated as equals, and therefore they would share equally in the funds generated by the classes and would all have 3 paid days per year to use the money. Stuart, one of the senior therapists, objected, noting that not everyone on staff was capable of conducting a class. Even if they all could present programs of equal length, they would certainly not all have equal appeal and would therefore not deliver equal money to the general fund. As an example, he suggested that there would probably be high interest in his own area of joint mobilization, but he doubted that many would attend Mary's course, which would focus on her specialty of pediatric burn assessment, even though it was of equal value to the department. He questioned whether all rewards should be equal if contributions were going to be unequal.

Helen wanted the staff to be treated as equals in terms of the money because she wanted to maintain cohesion and unity in the department. But Stuart was correct in that the contributions, at least financially, would be different. After much discussion, Helen stated that market demands, while very real, should not be the basis for unequal treatment, because different expertise was needed in the department for it to remain a comprehensive physical therapy department. Unequal effort, however, was the greater difficulty, because some of the new therapists were recent graduates and could not be expected to produce an advanced program. In fact, they were in greater need of attending the continuing education courses than others. The compromise she proposed was that the newer therapists would not offer programs, but rather they would team up with the more experienced therapists who were presenting and be responsible for all handouts, announcements, and all other associated duties, leaving the presenters with only the preparation of the course content. She then stated that she wanted all the staff to attend all the presentations.

Which of the principles did Helen use, and which ones did she abandon? How would you have done it differently? These questions are examined further in the Discussion Questions after we explore other related topics in this chapter.

## CASE 11.3 **Fairness to Children**

Pacific Hospital was one of several long-term care facilities supported by the California. Pacific was unique in that it was dedicated solely to pediatric care. For the most part, the patient census was composed of children who were either too fragile medically to remain at home or who had too many complex problems to be cared for by their parents. The parents had either voluntarily relinquished custody to the state or the courts had placed the children at the hospital after assuming custody because of either abuse or neglect. The hospital had a large campus and was efficiently managed by trained administrators and by a professional staff of physicians, nurses, physical therapists, occupational therapists, and other health professionals. Medical care was supplemented by a staff of volunteers from the community who played with the children, took them on walks, and in general were surrogate parents or grandparents to them.

Jeff had specialized in pediatric physical therapy early in his career and saw Pacific Hospital as an opportunity to help a segment of the pediatric population often overlooked. On his first day at the hospital, he was given his patient roster by the chief therapist, Rafael. The roster contained nearly 200 names. Jeff explained to Rafael that it was impossible to deliver care to all 200. Rafael agreed and said that it was not the expectation that he would, unless he wanted to use the "shotgun" approach and give a little care to each child, asking nurses and aides to assist him in carrying out assigned programs. Usually, Rafael explained, therapists selected approximately about 30 patients for more intensive therapy.

Later that day, during orientation, Jeff learned that Pacific Hospital was conducting a pilot program that would take the highest functioning children and place them in group homes in the community and managed by paid custodial help. The children would return to the hospital for medical emergencies and physician appointments, but therapies would no longer be provided to them on an ongoing basis. The aim of this program was to place as many of the children as possible in a more normal community environment, making use of local community resources such as schools and clinics. Fiscally, the commitment was to reduce the census as much as possible to meet the demands of new admissions without having to expand the physical or professional resources of the hospital.

Over the next week, Jeff reviewed his charts and visited each of his 200 patients. They fell into two major groups. The first group, representing about one-third of his roster, was composed of patients who would probably be able to move into community homes. To do so, they would need to acquire better skills in the activities of daily living and ambulate safely with or without assistive devices. Some children in this group needed to improve gross motor skills, such as throwing or kicking, so they could engage in play with other children. The second group, including patients with the most severe problems, would probably stay in the hospital. This group would benefit from therapy to relieve and prevent pain, specifically through better positioning, range of motion, and varied postural activities. They could also acquire basic gross motor skills that would provide them with some control over themselves in their environment, such as rolling over to prevent skin breakdown. Others could benefit from activities to improve head control, allowing safer caretaker handling.

Jeff asked Rafael for advice about selecting patients for care, because nearly all could benefit. Rafael remarked that, as he was the professional, he would need to take responsibility for those choices. The other staff used varied criteria to make such choices, and he encouraged them to work out the triage system that made them feel comfortable with delivering care.

Who, then, should Jeff schedule for therapy? Applying the six principles of distributive justice, all the children have a need, but the principles of effort, contribution, merit, or free-market exchange do not seem to fit the situation. Adopting a "shotgun" approach by "giving to each person an equal share" would be a dubious way to help patients make a significant transition to other settings. Should Jeff spend more time and effort with the children in the first group so that they can move from the hospital to a community living environment, or should he focus on the others, who might acquire minimal motor milestones or benefit from help in the prevention of pain?

Many would argue that significant gains will require more intense therapy than the fewer than 10 minutes per week (in a 40-hour workweek) that equal distribution of time would allow for all 200 patients. As a consequence, we have to sort through the variables to see which are most compelling. Is it fair to assume, for example, that community placement is in all cases such a highly desirable goal that it displaces consideration for those who must stay in the hospital? A child in the second group, who most likely will stay in the hospital, might argue that she should not be blamed for her disabilities. She might even argue that the severity of her disabilities entitles her to more, not less, care.

On the other hand, perhaps it is the groupings themselves that distract from a truly relevant variable. Perhaps, rather than determining whether community placement or increased control over the hospital environment is most important for any given child, one should try to judge which children are most likely to transition to a higher level of functioning with intervention. Similarly, should the administration's desire to move as many children out of the hospital be the deciding variable, or should such additional variables as age, degree and type of abnormal motor tone, ability to appreciate acquired goals, and motivation, which are but a few of the relevant issues at the micro level of patient care, be considered?

## CASE 11.4 Justice in Payments

When Possibilities Unlimited, a private physical therapy practice, was purchased by Hartford Care, the staffing was left intact as were the profitable methods for patient care delivery. The success of Possibilities Unlimited rested in part on patients who paid for their own therapy and whose programs were supervised by physical therapists but implemented by a staff of highly trained physical therapist assistants. Hartford Care brought with it a blend of patients financed by point-of-service care, health maintenance organizations (HMOs), and Medicare insurance, which by sheer volume reduced the clinic's ability to admit private-paying patients. The high volume of care necessitated that most of the care be delivered by assistants supervised by the physical therapists.

Mark had been with Possibilities Unlimited for 3 years before it was purchased, and he was confident in the quality of care delivered by the assistants. With Hartford's knowledge and consent, Mark, like all other therapists in the unit, signed notes written by the assistants whenever third-party reimbursement honored only direct service by a therapist. Therapists cosigned all other care delivered by the assistants. The volume of patient care become so large that there were many patients for whom he signed who were known to him only through their initial evaluation. The increase in patient volume also brought a decrease in the time available for the therapists and assistants to case-conference, and the reviews became hurried and often incomplete.

When Elizabeth, a therapist, was hired, she immediately began to question the way in which care was delivered by the assistants. She refused to sign for the assistants and co-signed only when she had closely supervised the delivery of care. At the first staff meeting, she charged that the current policy of signing and co-signing was unethical and perhaps illegal. It had to be changed or she would be forced to report it to the relevant insurance companies.

How do the material principles of justice apply in this case? The third-party payers have clearly defined the type of service, its amount, and by whom the services should be provided through their contracts and agreements. The free-market exchange principle entails compliance with a number of conditions, and to violate portions of an agreement without the consent of the contractor is to possibly commit fraud, as when the service is delivered by an assistant but signed (not co-signed) by the therapist to represent it as the therapist's care. When patients selected their third-party payers, they were sometimes given the conditions and terms of the negotiated contracts; therefore, both the third-party payer and the patient have been deceived.

## CASE 11.5 Medicare Justice

Lynn, in her mid-30s, had entered the physical therapy program at a respected university. Prior to entering the program she had been a paralegal with her father's law firm, but she decided she would rather help people in a more "hands on" profession. After graduating from the program, she focused her continuing education and work experience in geriatrics. For the past 2 years she had been working at a skilled nursing facility in a retirement community. Her reputation as a therapist was unquestioned, and she had become best known for her patient advocacy. She almost always won her appeals with Medicare and the HMO when she believed a patient needed additional therapy, thanks in part to her paralegal background.

Cora Hopkins was an 82-year-old widow with mild dementia who had recently fallen and broken her hip. Lynn was particularly fond of Cora and had worked intensely with her. The results, however, were less than expected. Cora, although clearly appreciating the attention and effort, was simply too weak and frail to carry out the traditional course of treatment to prepare her for ambulating. Cora's sedentary lifestyle prior to the accident had in many ways contributed to her minimal muscle strength, range, and balance. Lynn decided that she would advocate a full rehabilitation program, 5 days per week, that would maximize Cora's potential for ambulating once the fracture healed.

Although the course of treatment she proposed was virtually unheard of, Lynn felt confident that her understanding of the appeals process, with help from her father's firm, would result in the outcome she wanted for Cora. Two weeks after she submitted her written petition for additional treatment, which referenced her father's law firm, a representative from Medicare called to set up an appointment. At this meeting, the representative cited the history of extensions and additions granted to Lynn but did not grant the full program requested for Cora. When Lynn protested, the Medicare representative looked at her and said, "I am trying to decide if you are crossing the line between advocating for the patient's good and abusing the system. Because the resources are limited, someone else receives less each time we give your patients more."

* * *

Certainly Lynn has done nothing illegal, but are her actions ethical? She seems to be applying the principle of justice: "To each person according to need." One could argue that no one is harmed by Lynn's zealous advocacy for her patients, and some are indeed helped. Yet a closer investigation reveals hidden costs to the clinic beyond the therapist's time, such as administrative cost to review her numerous appeals. Has Lynn crossed the line?

## MACROALLOCATION: PRIORITIES IN PUBLIC POLICY

**Macroallocation** addresses public policy issues related to distributing resources for health care within a society, whether at the federal, state, or local level. It might seem that macroallocation issues have little relevance to physical therapists in their daily work, but, increasingly, physical therapists are being called on to be involved in public debates, in keeping with Principle 8B of the APTA *Code of Ethics*: "Physical therapists shall advocate to reduce health disparities and health care inequities, improve access to health care services, and address the health, wellness, and preventive health care needs of people." The extent to which physical therapy is a part of future standard care in the United States will largely depend on on how well the profession justifies its interventions, mainly by documenting patient improvements scientifically, and on how convincingly the profession marshals persuasive arguments and presents them to the public and lawmakers. At some level, whether in the national forum of the APTA, at the state level through local APTA chapters, or in one-on-one campaigns for the profession with individual citizens, all physical therapists have a vested interest in seeing that decisions made about the inclusion of physical therapy in overall treatment are informed and fair.

Macroallocation issues may be sorted into three categories. The first concerns prioritizing health-care services and asks the question: Given limited funding for health care, which medical treatments should have priority? The second category concerns prioritizing health care among other societal "goods": Within the current system of health care, how should overall quantities of health-care resources be balanced against other social goods, such as education, environmental protection, and promotion of the arts? The third category focuses on establishing a viable system of health care within a society: Which system of health-care delivery best meets the requirements of justice? These are all large and complex issues, but we can briefly illustrate each.

### Priorities Among Medical Treatments

No system of managed health care delivery attempts to deliver all possible treatments to all people in all circumstances. Hence, there must be some method of establishing priorities. As an example of prioritizing limited health-care services, consider Oregon's experiment since 1988 in allocating health care for the poor. In its earliest version of the allocation process, Oregon developed a complex ranking of hundreds of medical procedures.[7] For example, it gave reproductive services—prenatal services, genetic counseling, amniocentesis, and others, but not including infertility counseling or treatment—the highest priority: 10 on a scale of 10. It set rehabilitation for improved function at level 7 and organ transplantation at 3. The specific rankings proved controversial, and Oregon revised them based on opinion polls, interviews with residents, and commissioner votes. The list now includes a total of 688 medical services and procedures, with Oregon Medicaid paying for the top 568. Throughout the ongoing debate, the views of health professionals as well as of the general public are regularly solicited.

Individual physical therapists living in Oregon, as well as both the Oregon branch of the APTA and the national APTA, have had the opportunity to provide input. In this connection, Coy considered the actions of a therapist who provided services for many patients with tendinitis, which was not covered under the original Oregon plan. The therapist was indignant and lobbied for a change in the policy, arguing that the therapy enabled patients to work and to function normally. Coy pointed out that, given the fixed allocation of medical resources under the plan, the single-minded lobbying for one service necessarily implied cutting back services in other areas. Hence, she argued, therapists need to adopt a community perspective in addition to their focus on the good of individual patients: "Justice may require some patient or professional interests to be less well-served to secure larger societal interests. It would be morally irresponsible to lobby for narrow patient or professional interests that are contrary to the interests of the commonwealth."[8]

Coy provides a valuable caution against using a blinkered approach when participating in public policy debates, acknowledging how one's own economic interests might distort judgment. At the same time, her conclusion leaves several questions unanswered: Is it inherently wrong to promote funding for a type of therapy that one sincerely believes is underfunded? It is, after all, standard practice for such one-issue advocacy to take place in funding programs. Should lobbying at this level be thought of as partly a political act in which competing and partisan convictions are allowed to clash, with an outcome decided by legislators who are the ones most required to take a balanced view? Is Coy correct in urging that professionals involved in the dispute constantly seek to integrate their personal commitments with a vision of the wider public good? We tend to favor Coy's position, but we acknowledge that the commitments of advocates for specific causes also play an important role, and those commitments are not always easily contained within an impartial perspective of the full good of the community.

## Health Care Versus Other Goods

The need to prioritize direct health-care services among other social goods routinely arises in debates about health-care funding at the national level. For example, should the federal government fund prescription drugs? The issue is an important one as prescription drug costs continue to increase rapidly, and many retired persons living on fixed incomes are adversely affected even if covered by Medicare. If the federal government assumes funding at a time when the public will not accept increased taxation, some other government programs have to be downsized. Remember that health is affected by far more than the direct delivery of care. Safe working and living environments, adequate nutrition, education, pollution-free environments, and safe food are just a few of the factors directly related to health-care outcomes that are not under the health-care delivery system. It is estimated that medical services contribute only 10% to 15% to the reduction of premature deaths.[9]

## Systems of Health-Care Delivery

Which system of delivering health care within a society best satisfies the requirements of justice as well as the requirements of benevolence (compassion, decency)? There is no general answer; health-care systems must be constructed in part to reflect the varied traditions of particular societies.

For example, when the Canadian medical system was being debated, the citizens were clear that they wanted health care to be provided equally to all. The British system, however, has evolved into a two-tiered system in which the health care provided to all citizens can be supplemented at will with treatment by private practitioners, through use of either supplemental insurance or direct private payment. In each case, the system of delivery fits the predominant value of fairness in distribution in those countries. For Canadians, only the principle of justice that states "to each person an equal share" was acceptable. The British system combined equal share with "free-market exchange" to allow those with the resources to acquire additional or different services. In each case, most of the population in each country is satisfied, on average, with the system in place. But all health-care systems are constantly in revision in order to best meet the changing needs of the population and the resources available to meet those needs.

In contrast, most U.S. citizens are displeased with their current health-care system, which combines several traditions that pull in different directions: a strong sense of individualism and self-reliance that places responsibility for health on individuals; a free-market system that is open to profit-seeking in virtually all areas of health care; and, since the 1930s, a commitment to providing basic "goods," when they are available within the community, to individuals unable to secure them (welfare). Possibly as a result of powerful lobbying by physicians, the insurance industry, and pharmaceutical companies to preserve the entrepreneurial system of health-care delivery, health care in the United States has not been recognized as a right for the majority of citizens younger than 65 years. Certainly it has not been recognized as a right backed by the obligatory duty of government to provide it, at least in the way police protection, fire protection, and public education are provided through local, state, and federal tax revenues. Notable exceptions are Medicare and Medicaid and numerous other entitlement programs, including emergency care mandated since 1989 by the Emergency Treatment and Labor Act.

In 1983 the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research argued that the federal government had a moral obligation to ensure that everyone has access to an adequate level of health care.[10] Acknowledging that the meaning of "adequate" is inevitably open to dispute, the commission used the term to indicate a medical and political middle ground between the ideal maximum health service for everyone and minimal emergency care. The commission also underscored that maintaining health at some basic level should have a high social priority, given its centrality to people's ability to pursue all other human activities.

The commission stopped short, however, of saying there is a human right to health care. Moreover, the commission drew a sharp distinction between placing responsibility with the federal government for ensuring *access* to basic health care (which was the commission's preference) and making the federal government the primary provider of health care (what is often called "socialized medicine"). The commission stipulated that the federal government must create a just health-care system, not that it should directly deliver health care. Critics found this conclusion unsatisfactory. They viewed it as a failure in the effort to ground the government's health-care obligation in the U.S. tradition of human rights, and it provided little guidance on how to implement the obligation it did ascribe to the government.

Clearly, Americans have had extreme difficulty reaching consensus on a fair and just health-care system. At present, the United States has a mixed system, combining for-profit managed-care corporations, nonprofit organizations, selected federal government programs, and various forms of oversight by state governments. These fundamental components are unlikely to change in the foreseeable future, although access may change in significant ways.

For its part, the APTA has outlined a "Position on Priorities in the Health Care System" in its *House of Delegate Standards, Policies, Positions and Guidelines* in HOD 06-97-07-20 (Program 19) that endorses universal coverage, exemption from restrictions based on preexisting conditions, and direct patient access to physical therapists.[11] The APTA document, "Principles for Delivering Physical Therapy Within the Health Care System," states that "Patients or clients should have the option of selecting a physical therapist as their practitioner of choice [and] as their entry point into the health care system relative to the prevention, evaluation, and treatment of physical impairment, functional limitations, and disability due to musculoskeletal or neuromusculoskeletal disorders."[12] In its concise but comprehensive statement, APTA's "Position on Priorities in the Health Care System" addresses access-to-care issues and parameters of concern under "Quality of Care," "Prevention," "Benefits," "Cost Containment," and "State Autonomy."

While much of the impetus for change in the current U.S. system is argued from the justice point of view, there are additional concerns—humanitarian, practical, and national pride—that make change imperative. At one time, the common perception—fueled by nationalism and success in technology and research—was that the United States supplied the best health care in the world. Although that may be true in some regions of the country, high-quality care is generally accessible only to those with the financial resources to select among the best providers with access to the best facilities. At the current rates, only those in the highest-income categories can afford unrestricted access to superlative care. When one reviews health outcomes for the aggregate of the U.S. population compared with those from other countries, the statistics are grim. Although the World Health Organization, in its "World Health Report 2000," ranked the United States first in per capita government health-care expenditure, the country is number 37th in health-care performance. In the health-care performance category, based on disability-adjusted life expectancy, the United States was ranked number 72.[13]

If we look specifically at health outcomes rather than system delivery, the results are also unsatisfactory. In 1999, the National Institutes of Health ranked the United States last of the G-7 industrialized nations in life expectancy, placing it below France, Japan, the United Kingdom, Italy, Canada, and Germany, in that order.[14] Similarly, in other markers of health, such as infant mortality rates, the United States has not earned favorable averages.[15]

None of this would be quite so disquieting if the United States did not have the highest gross national product in the world.[16] Obviously, when comparing the United States with those countries having universal coverage, even minimal universal coverage will generate better averages. Nonetheless, the comparisons do speak to the health of the nation as a whole.

If health-care reform is imperative, what options exist? We outline four proposals for alternative systems.

1. Free-market system
2. Single-payer federal government plan
3. State-based managed competition[7(pp510-540)]
4. Universal insurance

In all likelihood, free-market, state-based managed competition and universal insurance can work together, all active at the same time depending on the context (employment-based insurance, severity of illness, etc.).

### Free Market

A free-market (a market operating by free competition), primarily managed-care, system would place full responsibility on individuals for the acquisition of their health care. People would have to acquire private insurance, enroll in the health coverage plan at their place of employment as part of a benefit package, or pay privately. As is currently done, most employers would negotiate annual contracts with HMOs that utilize a managed-care approach to control costs. (Essentially, managed care means reducing costs through a screening process that limits access to medical specialists and expensive technology and sets caps on costs for certain services. Beyond that, HMOs take various forms, including preferred provider operations that allow patients, for an added fee, to select their personal physician within an HMO.)

Alarm over escalating medical costs has also favored this free-market direction during the past 2 decades. Defenders highlight the benefits of flexible options within HMOs, the emphasis on competition among health-care providers in the spirit of for-profit capitalism, the reduced costs to employers, and a minimum of government interference. In addition, individuals are encouraged to accept greater responsibility for their health, and HMOs have an incentive to provide better preventive care in order to minimize the onset of diseases and illnesses that require expensive treatment and intervention.

Critics of managed care argue that these systems give health-care professionals an incentive *not* to provide optimum care, primarily because of their profit motive and their short-term financial perspective. Critics also argue that the extensive profits once enjoyed by managed-care organizations have decreased over time, and lower profit margins often translate into decreased services. In addition, corporations with large numbers of employees who are disabled or who have special medical conditions have difficulty finding HMOs willing to negotiate fees for their services. Because of the high costs, small companies are often unable to offer health-care coverage as part of their benefit package, leaving many workers (often low-paid ones) without health-care insurance.

Critics also argue that preventive care coverage has been neglected by HMOs because subscribers (employees) often change jobs and/or insurance plans before the HMO profits from its prevention efforts by avoiding the more expensive treatment a major illness would require. Because contracts are usually negotiated yearly, the new contract can reflect any increase in the number of medically at-risk employees working at a corporation.

### Single-Payer Federal Government Plan

In contrast to the current U.S. system, a single-payer federal plan would have the strong advantage of ensuring automatic coverage to everyone, or almost everyone, at some level of adequate care. The drawbacks of the program would likely include higher taxes to fund the medical care and increased government involvement in the health-care environment at a time of concern about "big government." The actual cost and the amount of savings are difficult to project, but fiscal benefits could be realized from a reduction in administrative charges. Canada administers its national plan for less than half what the United States spends on its fragmented approach. Critics who object to "socialized medicine" believe it leads to long waiting lists for specialty care and low salaries for physicians; advocates believe that some of its problems could be solved by allowing individuals to pay for supplemental coverage. Advocates also point out that under the current system, many still wait for care or are denied some care altogether and that those without insurance may never receive care. In any case, many doubt that Americans will ever embrace heavy federal government involvement in health-care delivery beyond the selective programs for the elderly (Medicare), for the poor (Medicaid), and for children (the 1997 Children's Health Insurance Program).

### State-Based Managed Competition

To some, state government involvement is preferable to that of "big" (federal) government. State-based managed competition would organize the pool of health-care recipients as citizens of individual states (although, in one variation, small states might opt for more regional pools). The individual states would then negotiate each year (or so) with health-care providers to seek a combination of high-quality and low-cost care while making sure that the poor, the disabled, and other disadvantaged groups are included. The benefits of such a program are its universal coverage and the cost savings of managed care. The disadvantages, according to critics, combine the drawbacks of both of the previous systems: heavy government involvement (single-payer system) and pressures to withhold expensive treatments (managed-care system). When President Clinton proposed a version of state-based managed care in the mid-1990s, Congress rejected it. However, some states, most notably Oregon and Hawaii, are currently experimenting with various forms of state involvement.

### Universal Insurance

On March 23, 2010, President Obama signed into law landmark health-care reform legislation entitled the Patient Protection and Affordable Care Act (PPACA) (Public Law No: 111-149). The legislation, along with the Health Care and Education Reconciliation Act of 2010 (Public Law No: 111-152) signed into effect March 30, 2010, will extend health-care coverage to approximately 94% of U.S. citizens. The cost of implementing the legislation is estimated to be under $900 billion over the next decade, but the Congressional Budget Office estimates that the cost will be fully paid by fees and taxes built into the bill and its companion reconciliation amendments and would reduce the national deficit by $143 billion over the same 10 year time.[17]

The PPACA as amended requires that all citizens, with few exceptions, will be required to carry health-care insurance, much like car insurance is required to operate a motor vehicle. The amended PPACA contains provisions to be enacted in a stepwise progression starting in 2010, with others starting as late as 2018. Among those provisions starting in 2010 are the elimination of lifetime limits on health benefits, required coverage for preventive services and, where dependents are covered, it increases the age up to 26 years. Initiating in 2012 will be a program to incentivize quality outcomes in acute care. In 2014 preexisting conditions will not be allowed as a consideration for coverage, and premiums can only be influenced by age, geography, tobacco use, and family size. By 2018 excise taxes of 40% will be charged to insurance companies which charge premiums above set thresholds for individual and family plans.[18]

Most will receive coverage through their employer. Employees of small companies and the self-employed will have to purchase insurance from a commercial insurance company. For this to occur, the government will regulate insurance companies in ways never before attempted. There are two methods proposed to help ensure more manageable rates. First, American Health Benefit Exchanges will be established by 2014 in each state. The plans that companies propose in the exchanges will be accredited for quality and will require benefit options to be presented in a standardized way to allow easy comparisons. In addition, federal support will be available for new nonprofit insurance cooperatives to develop. These new exchanges and cooperatives should provide enough competition to reduce premiums. For those citizens who do not have the resources to purchase insurance, there will be expansions of Medicare/Medicaid as well as tax credits to assist in the purchase of a plan.

One controversial participant in American Health Benefit Exchanges would have been a government-initiated nonprofit insurance company that would have been self-sustaining on member premiums. This proposal was not included in the amended PPACA but has advocates as a future amendment. In theory, this nonprofit entity would best be able to offer decent low-premium insurance, thus forcing the for-profit companies to tailor competitive programs.

We caution that health-care reform in a democracy is not just a meeting of minds on best health-care outcomes; it is also a political process. There will be steady revisions and refinements as long as there is a system. In reality, this is simply the first step in developing the first true health-care "system" in the United States. In the future, citizens need to advocate for best health practices. One way they can make informed decisions on their providers is to have access to data, already collected on infection rates in hospitals, malpractice settlements, and disciplinary actions taken and pending on providers. To keep the industry efficient, many have proposed that fiscal payment by all payers be based on outcomes rather than procedures, thus necessitating a coordinated team approach. This in turn would be facilitated by full electronic medical records for efficient access and review. A single medical file would reduce the risk of drug interactions because one physician happened to be unaware of another's prescription.[19]

## RAWLS'S THEORY OF ECONOMIC JUSTICE

All the preceding issues, especially the alternative proposals for health-care delivery systems, can be approached within broader ethical theories of the sort presented in Chapter 12. As just one example, here we introduce just one ethical theory that has been at the center of recent debates about justice in health care: John Rawls's theory of "justice as fairness," set forth in *A Theory of Justice*, a book widely regarded as the single most important work in 20th-century social and political philosophy. Rawls believes that two principles should govern economic systems, at least those of Western political democracies:

1. "Each person is to have an equal right to the most extensive scheme of equal basic liberties compatible with a similar scheme of liberties for others.
2. Social and economic inequalities are to be arranged so that they are both (a) reasonably expected to be to everyone's advantage, and (b) attached to positions and offices open to all."[20]

In brief, the first principle prescribes maximum equal liberty for individuals. The second principle endorses differences in wealth and power if those differences benefit everyone, especially (as Rawls adds) the most disadvantaged members of society. Rawls also adds that the first principle has priority. It specifies that before differences in money and authority are discussed, the most liberty possible be made equally available to all members of society. This means establishing respect for basic political and legal rights, such as the right to vote, to assemble in voluntary groups, to exercise religious faith, and to be given due process in an effective system of law. After these basic liberties are ensured, the second principle then endorses the pursuit of wealth and power within a free market (capitalism), so long as this pursuit results in helping the least advantaged members of society. There are several ways this help can occur—for example, free markets create jobs, provide goods and services, and create wealth that sometimes is distributed through philanthropy. However, a graduated tax system (taxing the rich at a higher rate) is also considered to be essential in redistributing wealth with an intent to help the least advantaged.

Rawls's way of arguing for his two principles is as famous as the principles themselves. He asks, essentially, which moral principles would people, as rational and fair beings, agree to as governing the basic institutions and procedures in society? This could be stated as which principles would people agree to in order to form a hypothetical agreement (social contract) with one another within a fair negotiating context in which no one had a special negotiating advantage? As a heuristic device to ensure such fairness, Rawls wants everyone to imagine being in "an original [contracting] position" behind a "veil of ignorance" in which people do not know any specific details about themselves that could bias their judgment.

To experience this scenario, right now imagine that we, as individuals, do not know if we are rich or poor, a member of any particular ethnic group or nation, living in this century or the last century, or even male or female—each of these factors could bias the principles of justice we select. However, we do have general knowledge about psychology, economics, ethical theories, and so on. As rational beings, we are motivated to get as many "primary goods" as possible for ourselves and the people we care deeply about. Rational goods are desirable things that every reasonable person would want, such as liberty, opportunities, and self-respect. (Note: In saying we seek primary goods for ourselves, Rawls is not embracing ethical egoism, which says we should only care about ourselves. An ethical egoist would not be willing to get behind the veil of ignorance in the first place.)

In this fair-contracting situation, behind the veil of ignorance, Rawls argues that we would select his two principles to govern our society. We would select Principle 1 because it assures that whatever our position in society turns out to be, we will have basic political and legal rights ensuring opportunities to participate in society and improve it—for example, by voting. We would select Principle 2 because it would ensure that even if we were to become disadvantaged, the differences in wealth and power within society would benefit us.

Rawls's principles are attractive because they seem to articulate many of the fundamentals of the American social, political, and legal system. That system is founded, first and foremost, on ensuring basic political rights (Principle 1). In addition, most Americans also endorse allowing individuals to keep large amounts of wealth and power when doing so tends to contribute to the well-being of the disadvantaged members of society (Principle 2). Moreover, Rawls's two principles combine some appealing aspects of both rights and duty ethics (Principle 1) and utilitarianism (partly reflected in Principle 2).

It might seem that Rawls's principles are too abstract to require any one health-care system. Nevertheless, Principle 2, which would steadily raise the well-being of the least advantaged members of society, clearly supports concern for people who lack health-care insurance, or at least those who lack any realistic opportunity to afford it.

Although Rawls calls his approach "egalitarian," it is in fact a particular version of equality called "maximin," which means resources should be maximized (constantly increased) for people at the minimum level of well-being, even when doing so does not maximize the total good.

This emphasis would be even more dramatic if health care were considered to be a primary good—a good that all rational beings would want—in developing the argument for the two principles. Rawls does not list health care as a primary good, but others have plausibly done so.[21] Without health, and hence health care, none of the other primary goods are possible, including the continued existence of life and the pursuit of all liberties. Indeed, some might view the opportunity to have affordable health care at some basic level as a basic liberty of the sort listed in Principle 1.

Nevertheless, despite Rawls's enormous influence, there is no consensus that he is correct. Critics challenge the plausibility of his veil of ignorance argument. Are people genuinely capable of imagining themselves behind a veil of ignorance, not knowing their individual plans and interests, the circumstances in which they live, the communities in which they participate? But the difficulty is not only with the extent of imagination. Morality seems to begin with one's particular situation and identity in ways that require greater recognition in thinking about the principles by which one should live. Also, Principle 2 requires constant attention to increasing benefits to the least advantaged, whereas some critics think it suffices to provide a basic safety that meets essential needs.

Where does this disagreement about justice leave us? As we concluded in Chapter 2, it is extremely unlikely that any ethical theory will ever prove convincing to all reasonable persons. Moreover, there is as much internal disagreement about the important details of a given type of ethical theory (say, libertarian versus other forms of rights ethics) as there is among defenders of different types of theories (say, rights ethics versus utilitarianism). Yet these results need not be a cause for despair. There remain large and dramatic areas of overlapping agreement among the ethical theories when applied to specific situations. Jennings addresses the subject of liberty as a core American value that should be recognized in two distinctly different ways. He defines "negative liberty" as freedom of choice, autonomy, and being free from obstacles. With little dissent, most recognize this is a primary value. "Positive liberty," however, is what he describes as the freedom that is secondary to shared privileges, such as public financed education. Just as society would not prosper if the population were illiterate, society cannot prosper unless everyone has similar advantages of some basic decent minimum of health care. Negative liberty is about letting individuals flourish, and positive liberty is about equipping them with the opportunities they need in their social context in order to flourish individually.[22]

Above all, any sound ethical perspective will emphasize tolerance and reasonable compromise among different perspectives in working out shared health-care programs within democratic and pluralistic societies.[23]

## PRO BONO SERVICE

### CASE 11.6 **Pro Bono**

Cora has operated her private practice near Myrtle Beach for approximately 12 years. It has slowly grown to include three additional physical therapists, two aides, a receptionist, and a part-time bookkeeper. The practice has its seasonal ups and downs. When the tourist season is in full swing, they can barely keep up. But in the winter months, the pace is much more relaxed. Claudia was having her breakfast at home, reading the paper as usual before going to the office. On the third page she read about a terrible accident that had occurred just outside town in which a 32-year-old man, with his mother (age 58) and his son (age 6) as passengers, crossed the divide and ran head into a semi truck. The 6-year-old child was killed instantly, and the mother and her son were severely injured. Two days later, Claudia was again reading the paper, which reported that a surgeon, Dr. Smithe, had donated his services and performed bilateral hip replacements on the mother and did open reduction internal fixation on both femurs of the 32-year-old man as well as some other less radical procedures. The article reported that the family was without insurance and that the 32-year-old was a landscaper and that his mother worked as a housekeeper. Claudia was moved by the generosity of the surgeon. As soon as she arrived at her office, she wrote a letter to Dr. Smithe offering to do the follow-up physical therapy pro bono if he chose to make the referral. Three days passed, and Dr. Smithe called her and expressed his deep appreciation for her offer and that he would refer them to her within the week. The two patients were grateful, cooperative, and fully engaged in their rehabilitation. Claudia saw them during her lunch hour so as to not adversely affect the profit of the clinic. Although she was the sole owner, she had a very generous agreement with the therapist who worked for her in that they had a base salary but shared in the profits of the firm. Within 6 weeks, the patients had met their goals and were discharged. Dr. Smithe called Claudia and told her how very pleased he was with their progress and thanked her again for helping out. Soon, there were a number of insured referrals from Dr. Smithe, and Claudia was pleased with this new referral resource. About a month later, Dr. Smithe sent a patient that he asked Claudia to see on a pro bono basis. Given the number of referrals he had sent, Claudia felt she really had little choice. But soon the referrals from the surgeon and then a second surgeon for pro bono care began having an effect on the bottom line. Claudia did not know how to manage the uncompensated need for care, the surgeon's expectations, and her staff's expectations.

The APTA *Code of Ethics* states in Principle 8A: "Physical therapists shall provide pro bono physical therapy services or support organizations that meet the health needs of people who are economically disadvantaged, uninsured, and underinsured." It is noteworthy that "shall" replaces the "should," which was used in an earlier version of the code. As it is typically used in codes, "shall" is a weaker term used to suggest "desirable, but not mandatory." "Should" is a stronger term used to suggest a duty. Of course, "or support organizations that meet health needs of people who are economically disadvantaged, uninsured, and underinsured" seems to allow considerable latitude in interpreting the pro bono duty. Cynics would argue that it allows profit-driven organizations to essentially ignore any serious pro bono contributions by making a small donation to some other group that does provide services for those in need.

Do physical therapists have a substantial responsibility to provide pro bono services, and what does that responsibility entail? Historically, medicine began with a strong tradition of pro bono service. In the 5th century BC, Hippocrates urged physicians to offer such services: "Sometimes give your services for nothing, calling to mind a previous benefaction or present satisfaction. And if there be an opportunity of serving one who is a stranger in financial straits, give full assistance to all such. For where there is love of man, there is also love of the art. For some patients, though conscious that their condition is perilous, recover their health simply through their contentment with the goodness of the physician. And it is well to superintend the sick to make them well, to care for the healthy to keep them well, also to care for one's own self, so as to observe what is seemly."[24]

In this passage, Hippocrates offers several reasons for what is now called pro bono service. He suggests that such services should be done in a spirit of gratitude, as a way to express thanks for one's good fortune—perhaps connected to the privilege of being able to work as a professional—as well as for having society's support in gaining an education to be a professional. He also suggests that a habit of providing pro bono service helps keep alive motives of caring ("goodness"). These motives promote the profession of physical therapy directly, by strengthening commitments to help, and indirectly, by contributing to a character that inspires trust and hope in patients.

Like other members of classical Greek society, Hippocrates thought in terms of virtues and moral ideals, such as caring (or goodness) and self-respect (or honor). He did not draw a sharp distinction, as is done today, between a mandatory duty and supererogatory acts—that is, acts that are morally desirable but also morally optional (beyond the call of duty). Debates concerning pro bono service often center on precisely this distinction. Is pro bono service a basic duty of each therapist, and if so, how much is required by that duty? Alternatively, is pro bono service a collective duty incumbent on the profession as a whole but not necessarily a requirement for each therapist? Is pro bono service a moral *ideal* that is desirable to promulgate within a profession, in particular among physical therapists, but not a matter of basic duty at all?

These questions are critical because so many patients and members of the public are currently not receiving adequate services. The principle of benevolence straightforwardly seems to require filling this gap in access to services by widespread provision of pro bono service. In reply, some critics state that mandatory pro bono service violates the rights of professionals, essentially functioning as an unfair tax on their labor and income. They say it also leads to shoddy work from individuals who feel resentment at being pressured to work without compensation. Other critics contend that society should provide funding through taxation, rather than place a special burden on professionals, a burden that results in sporadic help for individuals in need. These critics say it is unfair for society to allow a general health crisis to exist by failing to ensure adequate health insurance programs and then to expect professionals struggling to earn a living to assume this responsibility.[25] Mandatory service also defeats the very spirit of voluntarism that is morally rewarding to professionals precisely because of the element of voluntary choice.

Defenders of a strong pro bono requirement argue that the public reasonably expects professions to help establish institutions and practices that foster public access to their services.[26] The public grants special recognition to a profession, essentially giving it a monopoly or quasi-monopoly in delivering a particular set of services. The public also provides financial support to universities and to students (in the form of scholarships, reduced-interest loans, and subsidized tuition) as well as to supportive related institutions, such as licensing, regulation, and law. In return for such benefits and privileges, the public expects the profession to be responsive to the public interest in obtaining services. Some have argued that professions have a collective (shared) responsibility to foster pro bono service to help fill the gap between the rich and poor in obtaining services. Moreover, they argue, each individual should accept a portion of that shared responsibility, because it is unfair for only a few individuals to take on an excessive burden.

The legal profession has tried to strike a balance with a compromise position that states that attorneys "should" provide some pro bono services but that this "should" does not state a mandatory requirement. In addition, the American Bar Association expands pro bono service to include not only services to patients at no fee or reduced fee but also public service, service to charitable groups, service to one's professional organization, and financial donations to organizations that provide pro bono services to clients. Critics view such statements as little more than window dressing—statements that make it sound to the public as if a serious duty exists ("should") while in fact requiring nothing. Defenders argue that this middle ground ("should" but not "ought") is a reasonable position in physical therapy and other professions: Scott states that, "Pro bono service should be an expectation (but never a requirement) of all professionals to whom the state has granted an exclusive license to practice a profession for profit."[27]

We leave resolution of this issue to the discussion questions at the end of the chapter, but we conclude here by restating two issues discussed in this chapter—(1) what needs to be done to improve the current flawed system, and (2) the role of pro bono work within a system that is more just than the present one—and pointing out the benefits of pro bono service in addressing both. Recall that Hippocrates urged that physicians provide pro bono service in a spirit of generosity and gratitude. To help others was an "opportunity" and also a way to enliven the service commitments that drew one into medicine in the first place. The same argument can be made for physical therapists and other health-care professionals, even within systems of health care alone.

In addition to these profession-oriented reasons, some would argue that pro bono work is a desirable ideal, or even a civic duty, for all citizens who are able to engage in some form of philanthropy—that is, voluntary giving for public purposes.[28] Professionals often find pro bono service an especially fulfilling way to participate in philanthropy.

## DISCUSSION QUESTIONS

1. Referring to Cases 11.1 and 11.2, which of the principles of microallocation did Helen use, and which ones did she abandon? What would you have done in her situation? Using which principles? Answer the same questions regarding the therapists in the other cases in the opening section.

2. Brenda, a physical therapist working in the outpatient department of a large medical center, is assigned two patients diagnosed with an anterior cruciate ligament (ACL) tear.[29] She has helped many patients with this knee injury using a treatment program of 16 to 24 visits over 2 months, the exact time varying according to the severity of the injury and individual differences in recovery progress. Patient X has traditional health insurance that reimburses for all warranted treatment. Patient Y has a managed-care plan that pays for only 12 visits for an ACL tear. Does Brenda face an ethical dilemma, or even two dilemmas, concerning (1) what to do for the course of treatment for the patient, and (2) whether to tell Patient Y about the drawbacks of her insurance program? If so, how should she respond to the dilemmas?

   Also, consider the following view expressed by the president of a physical therapy corporation in response to questions about this case requested by the editors of *PT Magazine*. Which view of justice seems to be in the background of the president's comments, and do you agree with his view? "Brenda's dilemma is simple: (a) She is a staff physical therapist employed by (b) a medical center outpatient department. In accepting that employment, she has tacitly approved agreements that her employer may make with third-party payers. In short, as long as she is a staff physical therapist employed by this medical center, and as long as the medical center accepts the two 'very different' health-care plans, she has an ethical obligation to provide the services as dictated by both payer and employer.…Should she tell patient Y about the difference in care? Only if Patient Y questions the care that he or she is receiving."[30]

3. Present and defend your view on whether pro bono service should be (a) mandatory for each therapist—and if so, how much should be required, (b) a collective duty of the profession as a whole, one that the profession is duty-bound to find ways of implementing, but not necessarily a specific requirement of each practitioner, or (c) a desirable but supererogatory ideal for the profession as a whole but not a requirement of any kind for individuals. In presenting your answer, discuss how it would apply in the case of Helen and Karen. Also, discuss whether the current statement on pro bono service in the APTA *Code of Ethics* is satisfactory.

4. Japan has a health-care system that ranks in the top five in the world in health outcomes and delivery. Unlike the British or Canadian systems, Japan's government support is administered through insurance programs. No universal system in the world costs as much as the current system in the United States, either in per capita government expenditure or in percentage of gross national product. In administrative charges alone, list the expenses additional to actual care that you have witnessed (either as a patient or as a volunteer or paid staff in a hospital setting).

5. What elements would you want as a recipient of care in a health-care system if you could move behind Rawls' "veil of ignorance"? What elements would you want as a provider? Do you find Rawls's approach to justice promising, as a way to outline a fair system of health care in the United States? If not, what criticisms of his view would you raise?

6. During the middle and late 1980s, the British National Health Care Service launched a public education program about AIDS. It used prime-time television ads that were explicit and graphic in identifying the transmission routes and methods of protection. The education program also included posters and handouts targeted for bars and entertainment events, using language that was easily understood by the population. The transmission rate of AIDS in the United Kingdom has been approximately one-tenth the transmission rate in the United States. In the United Kingdom, the National Health Care Service is free to use whatever methods it deems necessary to curb epidemics and is immune from political censure or reprisal. AIDS education efforts in the United States, however, have been and continue to be heavily influenced by local, state, and national political mandates. When government funds health care, what areas should be protected from political interference and left solely to the medical community in order to ensure justice and compassion in health care? Should AIDS education be one of them?

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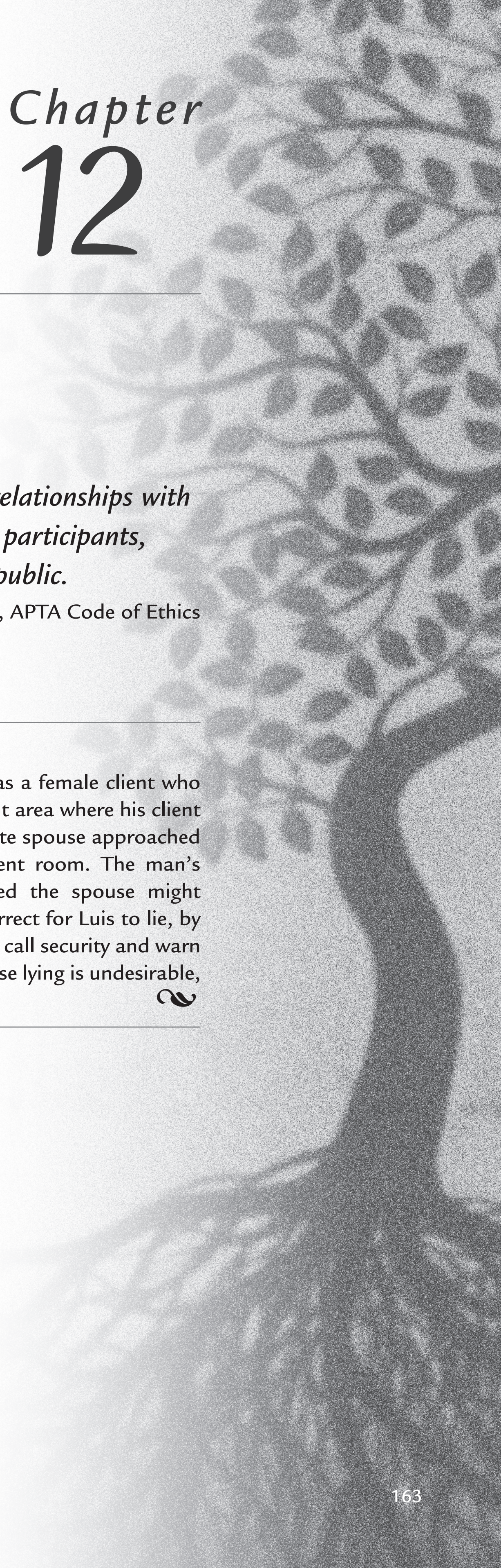

# Chapter 12

# Ethical Theories

> ***Physical therapists shall demonstrate integrity in their relationships with patients/clients, families, colleagues, students, research participants, other healthcare providers, employers, payers, and the public.***
>
> Principle 4, APTA Code of Ethics

### CASE 12.1 **Permissible to Lie?**

Luis Alvarez, a physical therapist working in a rehabilitation clinic, has a female client who was injured in a domestic dispute. Luis was approaching the treatment area where his client was waiting in one of the private treatment areas when the client's irate spouse approached him and asked if his wife was in "there," pointing to the treatment room. The man's demeanor suggested both anger and intoxication, and Luis feared the spouse might complete the battering that led to the admission of the client. Is it correct for Luis to lie, by saying his client has been discharged, thereby allowing himself time to call security and warn the proper authorities? Or should he pursue a different strategy because lying is undesirable, especially in one's role as a professional?

Sound moral judgment must often be exercised promptly, as in the situation faced by Luis Alvarez, with little time to consider an ideal solution. Regardless of its urgency, however, moral judgment is exercised against the background of moral understanding. Ethical theories are attempts to articulate sound moral understanding in a systematic way. They attempt to provide clear, consistent, and comprehensive accounts of morality that are compatible with one's most carefully considered convictions.

Ethical theories have several uses. They cannot, of course, remove moral complexity, and if anything they highlight the moral complexity of even familiar acts, such as lying.[1] They do, however, help clarify and resolve ethical dilemmas by pinpointing and organizing moral reasons. Ethical theories also provide ethical frameworks that can be used to justify general principles in bioethics, such as beneficence and respect for autonomy, as well as more focused rules such as "Do not lie." Ethical theories also can be used for justifying or for critiquing entries in professional codes of ethics as well as general policies and practices in health care and organizations. In this way, ethical theories provide ways of grounding physical therapy ethics in deeper and broader moral perspectives.

Philosophers have developed several influential types of theories.[2] In this chapter we introduce six, each of which has many defenders and each of which has greatly influenced thinking about health-care ethics: rights ethics, duty ethics, utilitarianism, virtue ethics, religious ethics, and pragmatism. There are additional theories that we have touched on earlier, for example care ethics in Chapter 2 and feminist theories discussed in Chapter 5 but the six theories discussed here represent a good sampling of major approaches in health-care ethics. Because each of the theories has several variations, they can also be regarded as moral traditions that remain vibrant today.

As we proceed, we will take note of major variations within each theory **(Table 12–1)**. Doing so reveals that the details of a given theory, as well as its general direction, matter enormously. Often the differences between versions of one type of theory are greater than differences with other types of theories.[3] Also, given the complexity of these theories, it will be helpful to examine them in connection with the more familiar topics of lying (that is, knowingly stating falsehoods with the intent to deceive) and deception (intentionally misleading someone, whether by lying, pretense, or other means). How does each theory explain when and why lying and other means of deception are wrong?

## RIGHTS ETHICS

The language of rights provides one way to formulate Luis Alvarez's dilemma. On the one hand, the battered wife has a right to life as well as a right not to be assaulted by others, including her husband. On the other hand, the husband has a right not to be lied to. The dilemma consists of the clash of these rights, and the question is which right has priority in the situation. The dilemma is properly resolved by exercising good judgment in weighing these conflicting rights. It seems clear that the right to life is more important in this situation, as in nearly all situations, and hence one judges reasonably that the wife's right to life outweighs the husband's right not to be deceived.

But perhaps a lie is not the best solution. Another form of deception might be preferable, or perhaps the ideal solution is to avoid deception altogether, trying instead to calm the irate husband while withholding information. Sometimes the ideal is impracticable. If Luis's choice is between lying and protecting his client, then lying is justified. An ethical theory cannot

**TABLE 12–1. Types of Ethical Theories**

| TYPE OF THEORY | BASIC CONCEPTS | VERSIONS | KEY THINKERS |
|---|---|---|---|
| Rights ethics | Human rights | Libertarianism;<br>community-centered | Locke |
| Duty ethics | Duty to respect autonomy;<br>universalize | Absolutism;<br>Prima facie duties | Kant<br>Ross |
| Utilitarianism | Most good for most people;<br>intrinsic good | Act- vs. rule-;<br>views of good | Bentham, Mill |
| Virtue ethics | Virtues, character, ideals | Classical, modern | Plato, Aristotle, MacIntyre |
| Religious ethics | Sacred, God's commands | World religions;<br>divine command ethics | Religious exemplars, theologians |
| Pragmatism | Context, pluralism | classical; casuistry | James, Dewey |

be expected to make this particular judgment more certain, but it can place it within a broader moral framework.

**Rights ethics** is the ethical theory that regards human rights morally paramount and fundamental. Whereas most ethical theories leave some room for employing the language of rights, only rights ethics views human rights as foundational—the moral bottom line. Accordingly, conduct is morally right (obligatory) when and because it respects human rights. The power of this approach to morality is manifested in important social movements: civil rights, women's rights, workers rights, gay rights, and animal rights. Most important for health-care ethics, the patients' rights movement has for several decades shifted moral decision making in health care away from physicians to patients.

Rights ethics is probably the most familiar ethical theory, at least in the United States; it is the theory on which the American political and legal system is founded. In the Declaration of Independence, Jefferson wrote, "We hold these truths to be self-evident; that all men are . . . endowed . . . with certain unalienable rights, that among these are Life, Liberty, and the pursuit of Happiness." Notice that Jefferson appealed to human rights as self-evident, that is, as intuitively obvious to reasonable persons. Ascribing human rights to each person is one way to express the dignity and the authority of individuals to be counted as moral equals with other individuals.

What are human rights? They are morally valid entitlements or claims on other persons, recognizing that others make similar claims on us. Mature and competent adults have the ability, as well as the moral authority, to assert these claims, but infants and incapacitated adults need to rely on others to assert the claims on their behalf. Human rights, also called natural rights, are unalienable in that they cannot be abolished or taken away (made "alien").

Although human rights cannot be taken away, they are of course sometimes violated. For example, the rights of enslaved persons are violated completely, but they still possess those rights. To complicate matters, people can voluntarily wave or exchange some rights in particular situations, as when someone agrees to undertake certain risks at the workplace in exchange for more desired benefits. People can also authorize others to exercise rights on their behalf, as when they sign a durable power of attorney document, stipulating who has the right to make health-care decisions should they be rendered unable.

## Additional Types of Rights

Human rights are distinct from legal rights, even though they overlap. Legal rights are the areas of freedom and benefits recognized in a particular legal system. In contrast, human rights are possessed by human beings regardless whether the laws of their societies recognize them. Apartheid in South Africa and slavery in the United States were systems of legal rights that violated human rights, and human rights are still violated by some legal systems around the world. In the Declaration of Independence, are the rights to life, liberty, and the pursuit of happiness listed as legal rights or as human rights? The answer is: both. They are human rights insofar as they are possessed by all humans, and they are legal rights insofar as that document, together with the U.S. Constitution and other laws, embeds human rights in the law.

Rights ethicists regard human rights as morally fundamental, but which are the most basic human rights? Different rights ethicists give different answers to this question. For example, a century before Thomas Jefferson drafted the Declaration of Independence, English philosopher John Locke formulated the first systematic rights ethic, listing the most basic rights as life, liberty, and property.[4] Jefferson changed Locke's British emphasis on property to the American emphasis on the pursuit of happiness. Other ethicists attempt to shorten the list of basic rights even further, to one: the right to pursue one's legitimate interests, essentially the right to liberty.[5] Rights to property and the pursuit of happiness, then, are seen as implied by the right to pursue one's interests and that even the right to life is implied by the right not to have one's liberty brought to an end.

Another disagreement among rights ethicists concerns whether only liberty rights exist, or whether liberty rights also imply welfare rights. **Liberty rights** are rights not to be interfered with; for example, the rights not to be killed, not to be kidnapped, and not to have one's property stolen. (The "not" explains why they are also called "negative rights.") **Welfare rights** (also called "positive rights") are rights to receive essential goods when one is unable to earn those goods on one's own and when the community has the resources to provide them. An infant's right to receive care from its parents is an example. Other examples, recognized in American society beginning in the 1930s, include a disabled person's right to medical care, a fired worker's right to unemployment compensation, and the rights of senior citizens to social security.

### Versions of Rights Ethics: Libertarian Versus Community-Oriented

**Libertarians** are rights ethicists who believe that only liberty rights exist. They object to taxing people to support government welfare programs such as Medicare and unemployment compensation. Libertarian views have had increasing political influence in recent years, not only in dismantling parts of the welfare system but in pushing for greater individual responsibility for financial matters. Yet, these views remain a minority position among the general public, which continues to support Medicare, Medicaid, Social Security, and government support for education. Libertarians also constitute a minority among rights ethicists, most of whom believe that human rights include both liberty and welfare rights.

Community-oriented rights ethicists, who believe in welfare as well as liberty rights, are more community-oriented than libertarians. They emphasize that rights must be understood within moral communities based on mutual respect and goodwill; otherwise, they easily degenerate into narrow self-seeking. For them, liberty rights imply at least minimal welfare rights. What point would there be in ascribing liberty rights to severely handicapped children unless doing so placed a duty on communities to make available essential resources for enabling those children to develop their capacities for liberty? Thus, most rights ethicists require the allocation of public funds to support physical and occupational therapy services to all disabled children. These services are provided regardless of the family's ability to pay through children's services in each state supported by local, state and federal money.

### Rights and Deception; Human and Special Rights

It might seem that a wide gap separates respect for fundamental human rights and the mundane presumption against deception. In fact, however, the connection is straightforward. The right to pursue liberty (freedom, autonomy) is violated when others deceive one, thereby undermining the pursuit of one's legitimate interests. Thus, lying to clients about matters related to their therapy undermines their exercise of liberty as they pursue the especially valuable goal of improving their health. The presumption against deception is frequently lessened when the interests being pursued are not legitimate, as in the case of the irate husband threatening violence. The presumption is also overridden by other competing rights that are more pressing, as with the wife's right not to be put at risk. The wife has this human right in general, but the right is bolstered by her special right to safety while under the care of the therapist.

This last point introduces a distinction between two types of moral rights: human and special. **Special moral rights** arise from contracts, promises, legislation, school membership, and relationships with professionals. Because special rights make reference to particular relationships and memberships, they are not human rights possessed by every person. Nevertheless, human rights enter into understanding special rights. For example, the special rights created by contracts should be respected because doing so respects the fundamental human right to liberty. Luis Alvarez's client acquired special rights when she was accepted as a patient, under the care of Alvarez and his clinic. Yet those special rights are undergirded by her human rights to liberty and to not being assaulted.

In general, for rights ethicists, good moral judgment consists in identifying the full array of rights relevant to situations and finding the most reasonable way of balancing those rights. All rights have limits, and most have some permissible exceptions when they conflict with other rights. Balancing rights against each other can be complicated, and exactly what is required depends on how the theory is unfolded as well as on how rights apply to particular circumstances.

To sum up, the fundamental idea in rights ethics is a human right—a valid moral entitlement or claim on other persons because all humans have equal moral worth. Human rights are distinct from legal rights, which are entitlements or claims specified in a society's laws. Most rights ethicists believe there are two kinds of human rights: liberty rights not to be interfered with, and welfare rights to receive certain benefits from the community (when one cannot earn them and the community has them available). But libertarians deny that welfare rights exist as human rights, and they seek to dismantle legal welfare rights (welfare rights embedded in the law). There are also special moral rights, for example those created by promises or contracts, which are justified by reference to human rights to liberty. Taken together, these distinctions suggest how a major moral theory and tradition seek to express the complexity of the moral life.

## DUTY ETHICS

The next theory, duty ethics, is in many ways the mirror image of rights ethics. Rights ethics makes human rights fundamental and regards duties as derivative: because you have a right to life, I have a duty not to kill you. Duty ethics inverts this approach. It begins with the idea of duties to respect persons and then regards rights as correlated with these duties.

A second way to formulate the ethical dilemma faced by Luis Alvarez is in terms of duties. Luis has a general duty to prevent harm to an innocent person as well as specific duties to prevent harm to his client while under his care. He also has a general duty not to lie. These duties clash, thereby creating an ethical dilemma. The dilemma is resolved by understanding which duties have priority in the situation, presumably the duty to prevent harm to the client.

Notice that this way of structuring the dilemma mirrors the earlier approach in terms of rights. Indeed, most rights and duties are correlated with each other: if you have a duty not to kill me, then I have a right not to be killed. Yet, whereas rights ethicists take human rights to be morally ultimate, duty ethicists regard duties as fundamental.

### Kant: Respect for Persons

Duty ethics is the view that actions are right when, and because, they are required by principles of duty that specify mandatory types of conduct.[6] Immanuel Kant, who lived from 1724 to 1804, was the most influential duty ethicist. He attempted to articulate high-level principles that could identify specific duties. One of these principles, respect for persons, is among the most famous in the history of ethics: "Act so that you treat humanity, whether in your own person or in that of another, always as an end and never as a means only."[7] Roughly paraphrased, this means one should always show moral respect toward yourself and others—appreciating how persons place limits ("ends") on your actions rather than being mere means to gaining benefits for yourself. Paraphrased another way: always respect persons as having legitimate purposes ("ends") of their own, which place limits on your own purposes, and respect your own rational purposes as limiting how you act toward yourself.

Kant believed that all specific moral duties, including duties not to deceive, cheat, steal, and murder, are entailed by this principle, as the varied dimensions of what it means to respect persons. In addition to duties to others, people have duties to themselves, to respect their individual rational nature as autonomous beings. Abusing drugs and alcohol, not developing one's talents, and committing suicide are some of Kant's examples of damaging or destroying autonomy. Kant calls these the duties of self-respect. This idea has been enormously influential in ethics.[8,9]

What does it mean to treat humans as ends in themselves? It means respecting them as rational, autonomous beings who have their own rational purposes, their own "ends." If the word *autonomy* is omnipresent in medical ethics, it is because Kant made the word central to his moral perspective. Today, the word is often taken to mean self-determination. Insofar as Kant intended this meaning, his emphasis on respect for autonomy parallels the emphasis in rights ethics on respect for liberty. But Kant also built into his conception of autonomy the idea of rationality: having the capacity and disposition to act according to universally valid principles of action and on rational desires.

Precisely what Kant meant by rational principles and desires was revealed in a piecemeal fashion from his examples. Thus, in four famous examples, he assumes that rational beings desire:

1. To continue living;
2. To desire to develop their talents and aptitudes;
3. To not have others make insincere promises to them; and
4. To receive necessary help when in severe hardship.

As a result, committing suicide or neglecting one's talents violates the duties of self-respect, and when one makes false promises or fails to help others in severe hardship, one violates the duty to respect others.

Notice that Kant's respect for persons is formulated as a command: "Act always…." Kant called this general principle of respect the categorical imperative to suggest that it commands unconditionally. He also called specific duties, such as "Tell the truth" and "Keep your promises," categorical imperatives. By "categorical" he meant that there are no conditions or special goals attached, unlike the imperative "If you want to be happy, be honest," or "If you want people to like you, keep your promises." These "if" commands are hypothetical imperatives—imperatives with a condition (or "hypothesis") attached.

Kant insisted that morality requires people to do certain things *because* those things are duties, not because those things contribute to personal gain or self-interest. In this way, he made motives and intentions especially important in thinking about morality. People are to do their duty because it is their duty; people are to do what is right because it is right. Kant called this conscientious devotion to doing what is right the "good will," and he located moral dignity in the capacity to exercise this moral good will. People have worth as moral agents because they are capable of caring about moral values as binding on themselves, as rational moral agents, rather than acting solely out of ulterior motives of self-interest.

## Kant: Universal Principles

Kant set forth a second version of the categorical imperative: "Act only according to that maxim [i.e., motivating principle] by which you can at the same time will that it should become a universal law."[7(p340)] This idea of *universalizing* is familiar from the golden rule: Do unto others as you would have them do unto you. For Kant, the "others" are rational beings. He argued that moral duties are universal in that they apply to all persons who find themselves in morally similar situations. Thus, valid principles of duty are those that people can, without self-contradiction or conflict in rational will, conceive of and desire that every rational person act on.

For example, if one tries to universalize—imagine everyone acting on—the rule "Lie when you can gain an advantage from doing so" or the rule "Make false promises when it benefits you," one becomes caught in a contradiction or conflict with one's rational will. As rational beings, people desire not to be deceived and in general to live in a world of trust in which truthful communication is the norm. Hence the desire to deceive or to make a false promise conflicts with one's rational nature, preventing one from endorsing these principles as universal principles. We can, however, conceive of all rational beings not lying and not making false promises, and so these are sound principles of duty.

Kant's universalization test expresses an important logical truth: consistency requires that a moral judgment about a specific action extend to all relevantly similar actions. However, logical consistency is only a formal test; it is not a substantive way of telling what duty is. Stated in another way, it is a necessary but not a sufficient condition for telling what duties are. Thus, it is not a helpful guide in determining what duties are unless one makes a large number of assumptions about what all "rational beings" desire.

Despite Kant's enormous influence, nearly all ethicists agree that he made one monumental mistake. He believed that everyday moral principles, such as "Tell the truth" and "Keep your promises," are absolute, with no permissible exceptions. Yet, such an absolute view fails to help when duties come into conflict and create ethical dilemmas. It provides no guidance when the duty not to lie conflicts with the duty to protect innocent life. Resolving an ethical dilemma often requires making an exception, a permissible exception, to a general principle of duty that clashes with another duty.

Conflicting duties are commonplace, and it is a puzzle why a thinker of Kant's stature could have failed to appreciate this familiar occurrence. Perhaps he confused the ideas of absolute duties (duties having no permissible exceptions) and universal duties (duties applying to everyone placed in similar situations). Clearly, a rule could be universal while permitting some exceptions, for example, "Tell the truth except when doing so threatens a human life." Or perhaps Kant was misled by failing to distinguish the idea of absolute duties from his notion of categorical imperatives (that moral duties must be heeded simply because they are duties), a notion that carries a firm tone of "Do not deceive—period!" Or, as his harshest critics suggest, perhaps he was prone to moralizing, in the pejorative sense of being inflexible, dogmatic, parochial, lacking nuanced sensitivity to context, and being excessively judgmental.[10]

## Ross: Prima Facie Duties

Kant's ethics need to be revised in order to be viable. David Ross (1877–1971), made the needed revision by saying that everyday rules are **prima facie duties:** genuine duties that sometimes have exceptions when they conflict with other duties having greater importance in a given situations. Thus, there is a prima facie duty not to lie, but there is also a prima facie duty to protect innocent life and a further duty to protect a client under one's care. Lying to a criminal in order to protect one's family can be fully justified, not only permissible but even obligatory. One's **actual duty** or "duty proper" in a situation—that is, one's duty in the particular circumstances—is to tell a lie in order to save a life. (The expression "prima facie" is now a standard term in ethics, and it is frequently applied beyond duty ethics. For example, rights ethicists speak of prima facie rights, meaning rights that have permissible exceptions when they conflict with other rights.)

How does one know that the duty to protect innocent life generally overrides the duty not to lie? Ross believed people can know general, prima facie duties with certainty—that these duties are as self-evident as mathematical truths and people know this through immediate intuition (at least once they reach moral maturity). In contrast, actual duty in specific situations is frequently less certain. One must simply think hard and sensitively: "When I am in a situation, as perhaps I always am, in which more than one of these prima facie duties is incumbent on me, what I have to do is to study the situation as fully as I can until I form the considered opinion (it is never more) that in the circumstances one of them is more incumbent than any other; then I am bound to think that to do this prima facie duty is my duty sans phrase in the situation [i.e., my actual duty, all things considered]."[11]

In emphasizing the need to reflect in this contextualized manner, Ross went beyond Kant, who thought actual duties could be understood in the abstract, without attending to the complexities and nuances of specific situations. However, Ross relied heavily on intuition in identifying prima facie duties. More recent duty ethicists have tried to go beyond intuition and to formulate more general tests for identifying duties.

Using Ross's version of duty ethics, good moral judgment consists in identifying the full range of duties relevant to a situation and reflecting carefully on how to balance those duties in light of the relevant facts about the situation. Doing all this can be complicated, and it gets more complicated as the duty ethics are fleshed out. In particular, just as rights ethicists disagree in their lists of the most basic rights, duty ethicists differ in their lists of basic duties. For his part, David Ross organized the most basic duties into six categories:

1. "Duties deriving from one's own actions, either in making commitments (duties of fidelity) or in causing harm to others (duties of reparation);
2. Duties deriving from other people's acts of service toward oneself (duties of gratitude and reciprocity);
3. Duties to maintain fair distributions of benefits and burdens (duties of justice);
4. Duties based on the sheer opportunity to help others (duties of beneficence);
5. Duties linked to opportunities to develop one's talents (duties of self-improvement);
6. Duties of not injuring others (duties of nonmaleficence)."[11(p21)]

In *Principles of Biomedical Ethics*, Tom L. Beauchamp and James F. Childress set forth a primarily duty-ethics approach inspired by David Ross, centered around the four basic principles mentioned in Chapter 2:

1. "Respect for autonomy;
2. Nonmaleficence (do not harm);
3. Beneficence (promote good);
4. Justice."[12]

In turn, these four principles imply more specific "rules," such as professionals' obligation to maintain confidentiality and to obtain informed consent with patients.

### Summary: Rights Ethics Versus Duty Ethics

In summary, whereas rights ethics holds that duties are derived from human rights, duty ethicists make duties fundamental: your rights to liberty are correlated with my duty to respect your liberty. Kant thought that all specific duties are implied by a general duty to respect the autonomy (self-determination) of rational agents—agents who are capable of acting on universal principles and who possess rational desires such as to respect themselves and to be respected by others. He also thought that moral duties are universal principles that one can envision all rational beings acting on, without contradiction or conflict in one's own rational will. Kant was an absolutist who believed that duties have no permissible exceptions. In contrast, most duty ethicists follow David Ross in acknowledging that duties are usually prima facie: they can have some legitimate exceptions when they are overridden by other duties. Determining priorities among duties requires exercising good judgment, although ethicists attempt to establish some general priorities among duties.

Both rights ethics and duty ethics hold that actions are right or wrong because of their inherent nature—for example, as acts of respecting liberty or being truthful—rather than solely because of their consequences. Stated in another way, actions are right when they are required by principles of duty or rights. The overall consequences of actions are downplayed: rights are to be respected, and duties are to be met, even when doing so does not always promote the general good.

Because of this similarity, duty ethics and rights ethics are often lumped together and dubbed deontological ethical theories. As such, they are contrasted with consequentialist (or "teleological") ethical theories that determine right and wrong solely in terms of consequences. Ethical egoism, discussed in Chapter 2, is a consequentialist theory in that it says people should maximize good consequences for themselves. The most influential consequentialist theory is utilitariarianism, which says people should maximize good consequences overall, taking into account everyone affected by their actions.

## UTILITARIANISM

**Utilitarianism** compresses all moral principles into one: produce the most good for the most people, considering equally the interests of each person affected by one's actions. This compression makes utilitarianism seem like a simple theory. Examine the facts, exercise best judgment about the effects of alternative choices, and make the choice that maximizes the good consequences overall. For example, lying is right when it promotes the most good, and it is wrong when it promotes more bad than good.

This appearance of simplicity quickly dissolves, however, as utilitarians unfold their theories in different directions. One difference concerns whether one should focus on the consequences of individual actions (act-utilitarianism) or on general rules (rule-utilitarianism). A second difference concerns how to understand good consequences.

### Act-Utilitarianism Versus Rule-Utilitarianism

Utilitarians disagree about whether good consequences should be measured with respect to each action or instead with respect to rules. **Act-utilitarianism** focuses on each action: An act is right when it maximizes good effects, more than (or at least as well as) any other options available in a situation. According to act-utilitarianism, moral decision making requires one to identify all the feasible options in each situation, to weigh the likely good and bad consequences for each option, and then to select the option that maximizes good overall. In the case of Luis Alvarez, look at the specific alternative actions available to him, and select the one that maximizes the good in his situation.

Act-utilitarians are generally critical of rights ethics and duty ethics because they view those theories as supporting dogmatism and rigid obeisance to rules. Yet, precisely because of their neglect of rules, act-utilitarians often get into difficulties by allowing too many problematic loopholes that run counter to the most carefully considered moral convictions. For example, act-utilitarianism would seem to justify dishonesty, such as cheating, lying, and stealing, in situations where no one learns about the dishonesty and where the benefit to the dishonest person is greater than the damage to others.

Consider this example. John, a physical therapist in the acute ward of a local hospital, neglects to deliver prescribed services to client A in order to spend extra and non-reimbursed time with client B who is about to be discharged early and who desperately needs extra treatment. John, in order to account for his time, charted care for client A. Subsequently, because of factors unrelated to physical therapy care, client A dies, and there was in fact virtually no way for John to get caught. According to the act-utilitarian approach, John made the right decision because the measurable goods outweighed any negative outcomes. But because such conclusions seem mistaken, perhaps most contemporary utilitarians now focus on the consequences of rules rather than those of individual actions.

**Rule-utilitarianism** is the view that people should follow a particular set of rules that, were they adopted in a society, would maximize overall good (or at least promote as much good as any competing set of rules).[13] Here the task is to compare sets of rules against other sets of rules to determine which would be maximally beneficial to a society.

In particular, most lying to obtain benefits for oneself is wrong because, if society adopted such a rule, havoc would ensue. People would be unable to trust one another and hence would be reticent to make agreements and form lasting personal relationships.

Of course, rules need to take into account general settings, but the benefits of avoiding lying would preclude far fewer objectionable loopholes than act-utilitarianism permits. Moreover, because rules interact with rules, rule-utilitarians usually think in terms of a code of ethics, a set of interrelated rules. They also allow that special sets of rules will have importance in some settings—specifically, professional codes of conduct that apply to particular professions.

## Theories of (Intrinsic) Good

What is the good that is to be maximized, whether with regard to individual actions or general rules? It must be specified and tallied up without mentioning rights, duties, or other types of moral considerations—otherwise the theory would bring in additional elements beyond good consequences. In particular, one must avoid assuming additional principles of justice about how goods are distributed. Utilitarians, then, set forth a theory of **intrinsic goods** (things worth seeking for their own sake) and **intrinsic bads** (things to be avoided, given their very nature) in nonmoral terms, without making additional moral assumptions.

Jeremy Bentham, writing in the late 18th century, held that the only intrinsic good is pleasure and the only intrinsically bad thing is pain (a view sometimes called **hedonism**).[14] Moreover, only the quantities of pleasures matter, so that equal amounts of the pleasures of love and wisdom are on a par with the pleasures of eating and sex. Bentham thought this approach would allow mathematical calculations of good, creating what he called a "hedonic calculus." Most utilitarians find this approach too simple. How does one measure the quantities of pleasures and pains—in love, friendship, or even sex—so as to be able to compare them in tallying up pleasures and pains? Are all pleasures intrinsically good, including the pleasures of the rapist and sadistic murderer?

Most tellingly, are pleasures the only good things? Robert Nozick proposes an "experience machine," something like a virtual reality machine. "Suppose there were an experience machine that would give you any experience you desired. Superduper neuropsychologists could stimulate your brain so that you would think and feel you were writing a great novel, or making a friend, or reading an interesting book. All the time you would be floating in a tank, with electrodes attached to your brain. Should you plug into this machine for life, preprogramming your life's experiences?"[15]

Few would plug into the machine for life (although perhaps for short periods). That is because people find intrinsic value in things beyond pleasures, and even beyond having experiences.

John Stuart Mill, the greatest of the utilitarians, illustrates the complexity that emerges as a theory of intrinsic good is refined. Mill argued that the quality of pleasures as well as their quantity must be taken into account in understanding happiness, which he thought was the sole intrinsic good. Some pleasures are inherently better in kind than others. This sounds plausible. The pleasures of love can be counted more heavily than the pleasures of violence. Yet, how in general are people to tell which pleasures are of higher quality? Mill suggested this test: "Of two pleasures, if there be one to which all or almost all who have experience of both give a decided preference, irrespective of a feeling of moral obligation to prefer it, that is the more desirable pleasure."[16] Restated, the relative quality of two pleasures is determined by a large majority vote of those who have experienced both.

However, can't a majority, even a large majority, be mistaken? Appealing to the widespread views of his time, Mill argued that the pleasures of love, friendship, intellectual endeavors, and in general those of the "higher faculties" are inherently superior to the pleasures of the body. But Mill lived in the Victorian Era, and today it is unlikely that most people would say that the pleasures of good sex or of athletic competition are of lower quality than the pleasures of poetry.

Both Bentham and Mill confused pleasure with happiness, thinking that the injunctions "produce the most pleasure" and "produce the most happiness" were synonymous. In fact, pleasure is a relatively short-term conscious emotion or feeling, whereas happiness is a longer-term way of living that embodies many pleasures, some pains, and some unconsciousness—one can be happy for an entire summer, during which one is asleep one-third of the time—in a pattern that one can affirm overall as enjoyable. Notice, too, that not all pleasures contribute to happiness: cocaine use might be pleasurable, but it can also destroy happiness.

Overall, Mill is best interpreted as saying that the intrinsic good is happiness or a happy life, not pleasure per se. He defined happiness as "not a life of rapture; but moments of such, in an existence made up of few and transitory pains, many and various pleasures, with a decided predominance of the active over the passive, and having as the foundation of the whole not to expect more from life than it is capable of bestowing."[16(p13)] Such a definition makes it clear that we have moved a long way from the initial simplicity surrounding the utilitarian view. If grasping what happiness is involves such complexity, the same is even more true in judging how happiness is to be promoted.

In *On Liberty*, Mill argued that each individual is best able to chart a path to happiness and that individuals are helped in doing so by being allowed maximum personal freedom. To that end, he would favor removing bans on illegal drugs, polygamy, and a host of other restrictions on how individuals shape their lives. Specifically, he argued for what is called the **harm principle:** "That the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."[17] In developing his thesis, Mill invoked rights language. Unlike rights ethicists, he understood rights in terms of utility: rights are those areas of liberty that tend to have especially beneficial consequences and hence deserve protection by laws and other social sanctions.

In both his language and his emphasis in *On Liberty*, Mill defended views very close to those of libertarians, and certainly his emphasis on respect for autonomy was as profound as that of Kant. This overlap suggests an important truth: the details of an ethical theory matter enormously. Indeed, the details with which a type of ethical theory is developed can matter more than the general contrasts between different types of theories (such as utilitarianism versus rights ethics).

In the 20th century, utilitarians developed alternative theories of intrinsic good. Troubled by the difficulties in quantifying pleasures and objectively measuring happiness, economists adopted a theory of goodness as **preference satisfaction:** intrinsic good consists in satisfying human preferences, as manifested in how individuals spend their money. Other utilitarians regard the economist's approach as too crude and not only because satisfying preferences does not always contribute to pleasure or happiness. These more "ideal"-oriented utilitarians developed pluralistic theories that list many intrinsic goods, such as happiness, (most) pleasures, love, friendship, virtues, and appreciation of beauty.

### Summary

Utilitarianism says that right and wrong are exclusively a matter of maximizing good consequences (and minimizing bad consequences) overall, taking all persons affected into account equally. It has two major forms, depending on whether the consequences are measured with regard to each action (act-utilitarianism) or with regard to sets of rules (rule-utilitarianism). This distinction between act- and rule-utilitarianism was drawn in the 20th century, and scholars see elements of both forms of utilitarianism in the 19$^{th}$-century writings of Bentham and Mill. There are also scholarly disputes about how far act- and rule-utilitarianism differ in practice. There is no doubt, however, that alternative theories of what is intrinsically good matter greatly. Most theories of intrinsic goodness fall into four categories: pleasure (hedonism), happiness, preference satisfaction, and a list of varied goods (pluralistic theory).

## VIRTUE ETHICS

From the 18th-entury Enlightenment until recently, ethical theories have emphasized right and wrong action (and rules about right and wrong acts). Certainly, that is true of utilitarianism, duty ethics, and rights ethics. In contrast, the ethics of classical Greece and Rome emphasized what it means to be a good or bad person, together with related concerns about good lives, good relationships, and good communities. **Virtue ethics**, also called **character ethics**, shifts the focus to these latter concerns, especially to the kinds of person one should aspire to be.[18-20] Virtue ethics has evoked renewed attention in recent decades, and it now plays a major role in health-care ethics.

Within the framework of virtue ethics, lying is objectionable when it manifests vices. Specifically, lying is wrong when it manifests the vice of dishonesty—both untruthfulness and untrustworthiness. Many lies are objectionable for additional reasons, such as when they enter into cruelty, corruption, and selfishness. Nevertheless, some lies are permissible and even admirable—for example, when they are necessary to protect legitimate privacy (lies of self-respect) or to protect innocent lives (beneficent lies), as in the situation of Luis Alvarez. Because there are many virtues, resolving ethical dilemmas often requires balancing conflicting virtues within particular situations.

Virtues and vices have direct implications for conduct, although they highlight *habits* of conduct rather than individual actions or even rules of action. Equally important, virtues bear on all aspects of character: virtues are desirable patterns of desires, intentions, emotions, attitudes, and reasoning, as well as conduct. Vices are undesirable patterns of these things. A central challenge for virtue ethics is to establish the precise connection between conduct and virtues (and vices).

### Classical Versions

Plato left this connection between conduct and virtues as something of a mystery. In attempting to argue that morality is in one's self-interest, he tried to show that the virtues provide an inner harmony that makes for mental health and well-being: "Virtue is as it were the health and comeliness and well-being of the soul, as wickedness is disease, deformity, and weakness."[21] This intriguing suggestion connects with modern emphases on holistic health, indeed with the World Health Organization's definition of health as complete physical, mental and social well-being. Yet, it led Plato to portray ethics (or justice, as he called it) as a matter of the inward self rather than of external behavior. More fully, Plato divided the soul or mind into three parts—Reason, Spirited Element (something like a sense of honor), and Appetites. Each part has its distinctive virtue—wisdom, courage, and moderation, respectively—that enabled it to perform its distinctive function with excellence. Thus, moral persons will have wisdom in guiding their reason, courage in exercising their spirited element, and moderation in governing the appetites, such as desires for food, sex, and earning money. Plato does not explain, however, how these virtues are identified in outward conduct. In practice, how does one define what wisdom, courage, and moderation are?

Aristotle tried to answer this question by suggesting that proper conduct consists of exercising practical wisdom, instilled through years of proper training in reasoning, perception, and emotion.[22] Given the complexity of the world, it is impossible to formulate the nuanced skills comprising good judgment in the form of simple rules. In practical situations, good judgment locates the "mean," or "golden mean," as it has since been called, between two extremes. The mean is the appropriate middle ground between two vices, deficiency (too little) and excess (too much). Aristotle thought that most virtues govern specific areas of life.

For example, temperance is the virtue governing the appetites, enabling one to locate the mean between hurtful self-denial (defect) and overindulgence (excess). Courage is the virtue in confronting danger by locating the mean between cowardice (defect) and foolhardiness (excess). Generosity is the virtue in giving, whose mean lies between stinginess (defect) and wastefulness (excess). Truthfulness is the virtue in truth telling, which resides in the mean between lacking candor (defect) and revealing everything, even when it violates confidentiality or causes great harm to others (excess).

Aristotle's doctrine of the mean is interesting, but it does not provide sufficient guidance about what the virtues imply. Contemporary virtue ethicists are developing a variety of new approaches in clarifying the virtues. The concern about specific guidance remains. Some virtue ethicists accept that a virtue ethics can provide only rough guidance in the form of highlighting key ideals of character and community. They see this not as a failing of their theory, but rather the nature of morality, which allows far less precision than mathematics. Perhaps most ethicists believe that virtue ethics needs to be supplemented by some moral rules or principles that specify what comprises right action. Insofar as their theory warrants the label of virtue ethics, they continue to see the virtues as primary. Still other ethicists have come to believe that a complete ethical theory must integrate the virtues with moral rules of some kind.[23]

## Modern Versions

Paralleling debates within other theories, virtue ethicists debate which virtues are most fundamental. Aristotle, Plato, and classical Greek civilization in general accented four cardinal virtues: wisdom (most important), courage, temperance, and justice. Alasdair MacIntyre in *After Virtue*, an influential book that renewed interest in virtue ethics, reaffirmed these virtues and added honesty and integrity as especially important in contemporary society.[24] In the context of medical ethics, Edmund D. Pellegrino and David C. Thomasma's *The Virtues in Medical Practice* examines a longer list of virtues: practical wisdom, fidelity, justice, fortitude, temperance, integrity, and altruism.[25]

Virtue ethicists also disagree about whether the virtues must be all or nothing. Aristotle insisted that a virtue is a settled habit shown consistently. He even endorsed a doctrine of the unity of the virtues: to have one of the cardinal virtues—wisdom, courage, temperance, and justice—is to have them all. More recent virtue ethicists, however, understand the virtues to be more independent of each other, and sometimes at odds.[26] For example, to be fully honest may threaten being fully loving, and in making decisions about lying one might have to balance honesty against the virtue of friendship (which had great importance to Aristotle). Contemporary virtue ethicists also insist that persons can manifest a virtue to a certain extent but not fully, or within some contexts but not others. For example, a professional might maintain standards of integrity at work but in private life engage in spouse abuse.

In general, the resurgence of virtue ethics has broadly influenced thinking about morality in four directions. First, virtue ethics focuses greater attention on moral motivation and moral psychology—the psychology of the moral life. Kant highlighted motives, but he did so with a narrow emphasis on doing what is right because it is one's duty. Virtue ethicists, with their interest in how virtuous habits are taught, have led to a wide exploration of emotions, attitudes, and other areas of inner life.

Second, virtue ethicists spur greater attention to personal relationships. Modern philosophy—especially rights ethics, duty ethics, and rule-utilitarianism—has a distinctive bias in favoring abstract rules that requires one to be impartial. Virtue ethics turns people toward communities and personal relationships that significantly define who they are as individuals. These ties make special moral demands that need to be balanced against general duties of justice. This theme resonates with the call for health-care ethicists to pay greater personal attention to their clients.

Third, virtue ethics highlights ideals of moral aspiration. Most virtues are connected with corresponding ideals—for example, compassion with ideals of compassionate devotion to others and justice with ideals of a just society. Those ideals admit of degrees, ranging from a mandatory minimum to levels far beyond that minimum. Professionals bring to their careers an array of ideals of caring for their clients, their profession, for society in general. In addition, virtue ethics highlights the importance of pro bono service, of sometimes providing services to patients who are unable to pay the full cost.

Fourth, virtue ethics renews attention to communities, including how communities instill values in children and in citizens. Virtues specify desirable ways of relating to other people, to organizations, and to communities. Hence, virtue ethics can be developed in alternative directions using different social-political perspectives. The views of the ancient Greeks were aristocratic in emphasis, although an aristocracy based on talent rather than inheritance. Modern theories are democratic in spirit, although often critical of excessive individualism. In particular, MacIntyre's work is often interpreted as a version of communitarianism, the political theory that emphasizes the common good as being as important as individual rights.[27]

## RELIGIOUS ETHICS

**Religious ethics** links moral virtues, ideals, and principles to religious beliefs and ideals.[28] Thus, within religious ethics, lying might be condemned as betraying a religious covenant and as violating a divine commandment not to bear false witness against one's neighbor. At the same time, many religions promulgate the commandment to love one's fellow human beings, and that commandment seems to justify lying in order to protect them from serious harm. Once again, good moral judgment comes into play in determining when lies are permissible, but this time good judgment is understood and unfolded within a religion. We focus our discussion around three possible ways of linking morality with religious belief: moral motivation, moral guidance, and moral justification.

What is a religion? In *The Varieties of Religious Experience*, William James suggested there is no essence to religion, in the form of a set of defining features that must be present ("necessary conditions") and suffice to specify it ("sufficient conditions"). Instead, in examining paradigms of religions, "we may very likely find no one essence, but many characters [i.e., features] which may alternatively be equally important to religion."[29]

For example, one needs to be skeptical of the familiar idea that religion, by definition, requires belief in God. It is true that belief in a single deity (monotheism) is central in most world religions; for example, Judaism, Christianity, and Islam. But other religions believe in many gods (polytheism), most notably Hinduism, classical Greek religions, and the religions of some African tribes. Still other religions, like Zen Buddhism, do not believe in a supernatural deity at all or, like Confucianism, downplay the importance of belief in God.

### Motivation and Guidance

Typically, a religion has two general features connected with **moral motivation**, both in reinforcing moral motivation in everyday life and in teaching morality and stimulating moral development.

Religions typically provide a worldview—some general perspective about the universe and the cosmic origins of humans—that they connect with morality. For example, theistic religions usually make central a deity (or deities) who created the universe with some plan for humanity. That plan includes rewarding moral conduct and discouraging immorality. The aim is to inspire emulation of the ideal moral goodness of God (or gods), as well as the goodness found in moral paragons within the religious tradition.

As a second example, consider the doctrine of karma, prominent in Hinduism and Buddhism. It asserts that good deeds beget good fortune, and bad deeds bring bad consequences to the agent. The doctrine is not a social claim about reciprocity ("what goes around comes around") nor a psychological claim about the effects of guilt feelings on future conduct. Instead, it is a metaphysical claim that morality is built into the very structure of the universe—a powerful source of moral motivation.

Another typical feature of religions is that they are embedded in communities structured by shared beliefs, practices, rituals, scripture, and narratives. The rituals might be social, such as attending a church, synagogue, or mosque. They might be more private, such as prayer, meditation, and fasting. Either way, they provide a way to encourage moral accountability among believers and in relation to key authorities within the religion. They also seek to foster self-discipline and involvement in helping others.

In addition to strengthening moral motivation, religions typically seek to provide moral guidance. One way they do this is through promulgating specific principles. For example, the Golden Rule is found in all major world religions, either in its positive version (Do unto others as you would have them do unto you) or negative version, such as Confucius formulated in the 6th century B.C.E.: "Do not impose on others what you yourself do not desire."[30] Another way is to highlight selected virtues as especially central.

For example, Christianity makes the virtue of love paramount; Buddhism emphasizes compassion; Judaism emphasizes righteousness and justice; Islam emphasizes piety and pursuit of excellence; and Navaho ethics emphasizes harmony, peace of mind, health, well-being, and beauty. Religions often provide guidance in the form of parables and stories (narratives), such as the parable of the good Samaritan.[31] Whether through principles, virtues, or parables, most religions seek a higher standard of conduct or virtue than is common in society. To be sure, they can also have a lower standard, for example the Aztec's practice of human sacrifice and some contemporary religion's endorsement of female circumcision.

### Justification and Divine Command Ethics

Distinct from moral motivation and moral guidance, religions make claims about **moral justification**, specifically that moral values are justified by appeal to commandments of a deity. This view is called **divine command ethics**: moral judgments are justified solely because they conform to God's commandments. This is a troubling view, and it is rejected by many theologians as well as most philosophers. Not only does it imply that if there were no God there could be no morality, but it also makes nonsense of the idea of God being morally perfect. It suggests that moral reasons are created by God's commandments rather than being the basis for making those commandments in the first place. A morally perfect deity would command what is morally right, on the basis of sound moral reasons. Those reasons provide a justification for those commandments, just as they provide a justification for human actions of right and wrong. Divine command ethics essentially says that the commands create morality, literally by creating what counts as moral reasons. Hence, the reasons do not exist until after the commands are issued, thereby rendering God's commands arbitrary and lacking in any justification.

For example, rape is neither right nor wrong until after God issues some command concerning it. Yet most religious people believe that God would forbid rape for good reasons, perhaps for the same moral reasons people condemn it: violation of autonomy, infliction of suffering, and so on. Rather than rape becoming wrong only after God condemns it, God sees that rape is wrong and for that reason condemns it.[32]

### Religion and Health-Care Ethics

This brief discussion of religious ethics prompts the question: what relevance does religious ethics have with health-care ethics? For one thing, religious ethics enters into the reflection of professionals in professional ethics, whether in the classroom or at work.[33] Catholic thinking has played a major role in the development of bioethics, and today health-care ethics has advanced to the point where entire books are written within the traditions of major world religions.[34] Ideally, religious and secular ethics can interact through mutually enriching dialogue in the same ecumenical spirit in which different religious traditions interact.

Patients' religious views frequently enter significantly into how they respond to their illnesses and the decisions they make about the direction of their health care. As we discussed in chapters 5 and 6, health professionals need to develop sensitivity to different cultural and religious traditions in order to properly care for clients from those traditions. In addition, respect for patients' autonomy, and more generally functioning as a professional, requires learning to maintain professional distance, an idea discussed in Chapter 4, by not imposing one's own religious outlook on patients.

Finally, we note that secular medical ethics arose out of a need to solve dilemmas for which most religious ethics offered little guidance. The rapid increase in technology during the past 50 years brought with it situations never before faced by humans in the delivery of care. An example is the proper determination of death when machines properly attached can create the semblance of life, long after a cognitive or spiritual presence has been lost. Especially in the United States, it is essential to search for common, or at least overlapping, values in a pluralistic society. Such values make possible meaningful dialogue across multiple religions and diverse value systems.

## PRAGMATISM

**Pragmatism** explores how responsible moral judgment can be exercised without resorting to a comprehensive theory such as rights ethics, duty ethics, utilitarianism, virtue ethics, or religious ethics. It elucidates how good moral judgment balances conflicting moral reasons and creatively extends them into new situations. These means include rights, responsibilities, and ideals of character, even though they cannot be encapsulated in comprehensive and systematic theories. Pragmatism, as an ethical outlook, does not reduce morality to expediency. Instead, it means paying close attention to the full range of moral values that enter into particular situations and trying to find the best way to give each its due—for example when making decisions about whether to lie in Luis Alvarez's situation.

Broadly understood, pragmatism refers to a cluster of approaches to ethics that are wary of abstract rules and elaborate systems of principles. Pragmatists heavily emphasize the importance of context—of looking closely at the facts and values pertinent to particular situations. They also emphasize paradigms—clear-cut cases—as helpful guides in decision making, both in identifying routine cases and in understanding why moral dilemmas depart from routine cases so as to generate moral vagueness (unclarity about how to apply moral concepts and principles), moral ambiguity (more than one plausible moral interpretation of a situation), moral conflict (principles pointing in different directions), and moral disagreement (differing viewpoints among involved persons).

### Classical Versions

If an ethical theory must be a search for systematization of the sort illustrated in utilitarianism, duty ethics, rights ethics, and virtue ethics, then pragmatism may seem to be an "anti-theory" approach to moral reasoning, and indeed some of its defenders and critics portray it that way. In our view, however, pragmatism is an ethical theory, a theory about morality, because of the sophisticated development it received in the so-called classical era of American philosophy, represented especially by William James (1842–1910) and John Dewey (1859–1952), and because of its refinements by contemporary pragmatists such as Richard Rorty, Hilary Putnam, and thinkers who adopt pragmatic approaches to health-care ethics.[35]

Both James and Dewey developed theories about moral decision making as an attempt to integrate the rich multitude of responsibilities, goods, social policies, and ideals of character that apply to particular situations. Dewey was especially concerned with making policy decisions, especially about approaches to public education, within democracies that embody an array of conflicting traditions and moral perspectives. In education, as elsewhere, morality calls for "creative intelligence" to find a practical solution that "coordinates, organizes and functions each factor of the situation which gave rise to conflict, suspense and deliberation."[36] More broadly, Dewey expanded Aristotle's emphasis on the importance of habits in shaping character and conduct. Habits acquire a power ("dynamic quality") of their own that propels actions, in good or bad directions—a fruitful idea in thinking about habits that maintain or harm health.[36(p37)]

That is not to say that moral principles are useless. Instead, it is to view principles more as general guides than as recipes for specific action. According to Dewey, "A moral principle, such as that of chastity, of justice, of the Golden Rule, gives the agent a basis for looking at and examining a particular question that comes up. It holds before him certain possible aspects of the act; it warns him against taking a short or partial view of the act. It economizes his thinking by supplying him with the main heads by reference to which to consider the bearings of his desires and purposes; it guides him in his thinking by suggesting to him the important considerations for which he should be on the lookout."[37]

### Casuistry

A recent variation of pragmatism can be found in Albert Jonsen and Stephen Toulmin's revival of casuistic thinking. In the relevant sense, casuistry is not sophistry—that is, hair-splitting rationalization—but instead careful attention to paradigm cases, models, analogies, and refined intuition. Jonsen and Toulmin were led to their approach during their participation in the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, from 1975 to 1978, whose charge was to develop national guidelines for protecting research subjects in experiments on humans. The commission was composed of people of widely differing cultural, religious, and political orientations, and as a result they failed to agree on many general ethical principles and priorities. Nevertheless, the group was able to reach substantial agreement at the level of specific cases: "So long as the debate stayed on the level of particular judgments, the eleven commissioners saw things in much the same way. The moment it soared to the level of 'principles,' they went their separate ways. Instead of securely established universal principles, in which they had unqualified confidence, giving them intellectual grounding for particular judgments about specific kinds of cases, it was the other way around."[38]

## WHICH THEORY IS BEST?

How are ethical theories assessed so as to determine which one is best? Showing that an action or rule is morally justified might involve appealing to an ethical theory, but how does one decide which ethical theory is most insightful and helpful?

The answer turns on what one seeks from an ethical theory. One seeks a moral perspective that is clear, consistent, and comprehensive that applies to all moral issues of interest. The theory must be sufficiently simple and practical to provide useful guidance. Most important, it must be compatible with one's most carefully considered moral convictions; that is, with the moral beliefs one has thought most insightfully about and of which one is certain. To take an extreme example, if an ethical theory justified rape or torturing babies for fun, we would know the theory was false—and perverse. Again, if act-utilitarianism justified rampant cheating, then it should be rejected.

In this way, just as theories are used to justify actions and rules, personal judgments about actions and rules provide a crucial touchstone for testing the adequacy of theories. To borrow an expression from John Rawls, this back-and-forth procedure seeks a "reflective equilibrium" between the ethical theory and a host of particular judgments. Rather than rely on isolated self-evident moral intuitions, as David Ross had us do, one regards the justification of both the theory and specific judgments as "a matter of the mutual support of many considerations, of everything fitting together into one coherent view."[39]

We believe the general type of ethical theory (utilitarianism, rights ethics, etc.) is not by itself crucial in deciding the usefulness of a theory. What matters is the detailed working out of the theory in a specific version. In the general sketches we have provided, rule-utilitarianism, duty ethics, and rights ethics are all promising ethical theories. If they were not, they would not be as widely discussed as they have been for centuries, nor would they continue to have many defenders. Notice that each of the ethical theories identifies the same basic moral principles, even though they provide different moral languages in stating the principles and different ways of justifying them. For example, all of them agree there are prima facie obligations not to lie, steal, or cheat—whether because such principles have generally good consequences (rule-utilitarianism), respect persons' autonomy (duty ethics), or respect persons' rights (rights ethics).

Virtue ethics is equally important and can be interpreted as complementing the rule-oriented theories. Essentially it sets forth a view of the kind of person one should aspire to be as well as of the kinds of relationships and societies people should live in. Such views complement rather than compete with theories of right action. In this spirit, the key values used to organize the chapters in this book have dual dimensions, as responsibilities and as virtues. Good judgment, emphasized in this chapter, can itself be viewed as a virtue, when it becomes a habitual tendency, or as an ability in meeting responsibilities, and the same is true of professionalism, the value highlighted in Chapter 1.

Religious ethics, as already noted, will enter into understanding patients' view of their own well-being as well as into the moral ideals that many individual professionals bring to their work. Given a pluralistic democracy, and especially the need for professional distance, religious discourse need not be prominent in public discourse about professional ethics.

Pragmatism has importance in responding to the many unprecedented situations that contemporary societies present. It has special relevance to contexts of shared decision making, in the professions and elsewhere, in which individuals need to accommodate their moral convictions within groups they participate in—without abandoning their most carefully considered principles. In our view, it is not an anti-theory so much as a theory that can be developed with different emphases, linking it with rights ethics or virtue ethics and so on. If it is understood as an explicit rejection of systematic theories, it nevertheless remains an illuminating account of how most people engage in serious moral deliberation in practical situations.

In any case, all the theories seem to us worthy of consideration as ways of organizing moral reflection, stating and resolving ethical dilemmas, justifying principles of professional duty, and highlighting key moral ideas such as autonomy and respect for persons. Certainly all of them play prominent roles in contemporary health-care ethics. They are useful tools and illuminating perspectives for reflecting on all the issues raised in this book.

## DISCUSSION QUESTIONS

1. Monica Reid was angry and confused. After studying hard for the midterm in her neurophysiology course, hoping to get an A or at least a high B, she received a B-. She knew the professor graded on a scale and was one of toughest graders in the physical therapy program in which she was enrolled as a second-semester student. She also knew that at least three students who received higher grades had cheated on the examination. They had access to several pirated exams kept in fraternity and sorority files, and one of them offered her access, which she refused. That student also informed her that the group was preparing crib sheets as backups and, if necessary, would excuse themselves to go to the restroom during the exam to consult notes in their pockets. Reid was in a quandary about whether to report the students to the professor. Was there any responsibility to report the cheaters, or would reporting them merely be a self-interested act of "ratting"? In answering this question, apply each of the ethical theories. What does each theory say about (a) what is wrong with cheating in general, and (b) whether Monica Read should report the cheating?

   Also, in deciding whether she should report the cheating, is it relevant how many students are cheating? What similarities and differences do you see between this issue and questions about whether physical therapists ought to report health professionals who engage in wrongdoing (discussed in Chapter 9)?

2. Ethics includes moral inquiry into policies and laws, as well as individual conduct, and sometimes moral dilemmas can be resolved only by shifting attention to questions of policy. Which university policies concerning plagiarism and other forms of cheating are morally justified? Is there a universal answer to this question, or does the answer depend in part on the nature of the university?

3. One objection to act-utilitarianism is that it seems to justify some clear injustices.[40] For example, suppose a drunkard who is a nuisance in the local community were kidnapped and his organs transplanted to save 10 other individuals who contribute greatly to the community but who are seriously ill. The act-utilitarian theory seems to permit or even require doing so. What would a duty ethicist and a rights ethicist say about such actions? Do you see any way for utilitarians to revise their theory, perhaps by shifting to rule-utilitarianism, so as forbid such injustices?

4. Write down a list of absolute duties; that is, duties that never have a permissible exception, under any circumstances. Is the list very long? Would you expect every reasonable person to agree with your list?

5. We said that, for the most part, rights and duties are correlated, so that if you have right to life, then I have a duty not to take your life. (There are some exceptions, for example, a newborn has rights, but it is too young to have duties.) This suggests, as we also noted, that rights ethics and duty ethics can be viewed as mirror images of each other. Yet, critics argue that rights talk tends to reinforce patterns of self-centeredness by leading to a preoccupation with one's own rights. In this connection, suppose that Thomas Jefferson had written, "We hold these truths to be self-evident; that all people are created equal; that they owe duties of respect to all other rational beings, and are owed these duties in return." How might this difference in emphasis have affected Americans' view of community? For example, might it have helped create an atmosphere in which there would already be a system of national health coverage?

6. Plato believed that moral virtue and mental health substantially overlap. Assess this belief in light of one of what has been called the therapeutic trend: the tendency to approach moral matters using health-oriented perspectives.[41] In particular, consider the prevalent view that alcohol and drug dependency are diseases, either physical or mental, as listed in *Diagnostic and Statistical Manual of Mental Disorders*.[42] Is such a view compatible with holding individuals morally responsible for their conduct? In this connection, discuss the recent laws in Arizona and California to send nonviolent first-time drug offenders into therapy rather than to jail. Does responsibility for one's own health have any implications concerning how physical therapists respond to noncompliant patients, for example, those who fail to cooperate with the prescribed exercises?

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# Appendix

# 1

# *Code of Ethics*

**HOD S06-09-07-12** [Amended HOD S06-00-12-23; HOD 06-91-05-05; HOD 06-87-11-17; HOD 06-81-06-18; HOD 06-78-06-08; HOD 06-78-06-07; HOD 06-77-18-30; HOD 06-77-17-27; Initial HOD 06-73-13-24] [Standard]

## PREAMBLE

The Code of Ethics for the Physical Therapist (Code of Ethics) delineates the ethical obligations of all physical therapists as determined by the House of Delegates of the American Physical Therapy Association (APTA). The purposes of this Code of Ethics are to:

1. Define the ethical principles that form the foundation of physical therapist practice in patient/client management, consultation, education, research, and administration.
2. Provide standards of behavior and performance that form the basis of professional accountability to the public.
3. Provide guidance for physical therapists facing ethical challenges, regardless of their professional roles and responsibilities.
4. Educate physical therapists, students, other healthcare professionals, regulators, and the public regarding the core values, ethical principles, and standards that guide the professional conduct of the physical therapist.
5. Establish the standards by which the American Physical Therapy Association can determine if a physical therapist has engaged in unethical conduct.

No code of ethics is exhaustive nor can it address every situation. Physical therapists are encouraged to seek additional advice or consultation in instances where the guidance of the Code of Ethics may not be definitive.

This Code of Ethics is built upon the five roles of the physical therapist (management of patients/clients, consultation, education, research, and administration), the core values of the profession, and the multiple realms of ethical action (individual, organizational, and societal). Physical therapist practice is guided by a set of seven core values: accountability, altruism, compassion/caring, excellence, integrity, professional duty, and social responsibility. Throughout the document the primary core values that support specific principles are indicated in parentheses. Unless a specific role is indicated in the principle, the duties and obligations being delineated pertain to the five roles of the physical therapist. Fundamental to the Code of Ethics is the special obligation of physical therapists to empower, educate, and enable those with impairments, activity limitations, participation restrictions, and disabilities to facilitate greater independence, health, wellness, and enhanced quality of life.

## PRINCIPLES:

### Principle #1

Physical therapists shall respect the inherent dignity and rights of all individuals. *(Core Values: Compassion, Integrity)*

1A. Physical therapists shall act in a respectful manner toward each person regardless of age, gender, gender, race, nationality, religion, ethnicity, social or economic status, sexual orientation, health condition, or disability.

1B. Physical therapists shall recognize their personal biases and shall not discriminate against others in physical therapist practice, consultation, education, research, and administration.

### Principle #2

Physical therapists shall be trustworthy and compassionate in addressing the rights and needs of patients/clients. *(Core Values: Altruism, Compassion, Professional Duty)*

2A. Physical therapists shall adhere to the core values of the profession and shall act in the best interests of patients/clients over the interests of the physical therapist.

2B. Physical therapists shall provide physical therapy services with compassionate and caring behaviors that incorporate the individual and cultural differences of patients/clients.

2C. Physical therapists shall provide the information necessary to allow patients or their surrogates to make informed decisions about physical therapy care or participation in clinical research.
2D. Physical therapists shall collaborate with patients/clients to empower them in decisions about their healthcare.
2E. Physical therapists shall protect confidential patient/client information and may disclose confidential information to appropriate authorities only when allowed or as required by law.

### Principle #3

Physical therapists shall be accountable for making sound professional judgments. *(Core Values: Excellence, Integrity)*

3A. Physical therapists shall demonstrate independent and objective professional judgment in the patient's/client's best interest in all practice settings.
3B. Physical therapists shall demonstrate professional judgment informed by professional standards, evidence (including current literature and established best practice), practitioner experience, and patient/client values.
3C. Physical therapists shall make judgments within their scope of practice and level of expertise and shall communicate with, collaborate with, or refer to peers or other healthcare professionals when necessary.
3D. Physical therapists shall not engage in conflicts of interest that interfere with professional judgment.
3E. Physical therapists shall provide appropriate direction of and communication with physical therapist assistants and support personnel.

### Principle #4

Physical therapists shall demonstrate integrity in their relationships with patients/clients, families, colleagues, students, research participants, other healthcare providers, employers, payers, and the public. *(Core Value: Integrity)*

4A. Physical therapists shall provide truthful, accurate, and relevant information and shall not make misleading representations.
4B. Physical therapists shall not exploit persons over whom they have supervisory, evaluative, or other authority (e.g., patients/clients, students, supervisees, research participants, or employees).
4C. Physical therapists shall discourage misconduct by healthcare professionals and report illegal or unethical acts to the relevant authority, when appropriate.
4D. Physical therapists shall report suspected cases of abuse involving children or vulnerable adults to the appropriate authority, subject to law.
4E. Physical therapists shall not engage in any sexual relationship with any of their patients/clients, supervisees, or students.
4F. Physical therapists shall not harass anyone verbally, physically, emotionally, or sexually.

### Principle #5

Physical therapists shall fulfill their legal and professional obligations. *(Core Values: Professional Duty, Accountability)*

5A. Physical therapists shall comply with applicable local, state, and federal laws and regulations.
5B. Physical therapists shall have primary responsibility for supervision of physical therapist assistants and support personnel.
5C. Physical therapists involved in research shall abide by accepted standards governing protection of research participants.
5D. Physical therapists shall encourage colleagues with physical, psychological, or substance-related impairments that may adversely impact their professional responsibilities to seek assistance or counsel.
5E. Physical therapists who have knowledge that a colleague is unable to perform their professional responsibilities with reasonable skill and safety shall report this information to the appropriate authority.
5F. Physical therapists shall provide notice and information about alternatives for obtaining care in the event the physical therapist terminates the provider relationship while the patient/client continues to need physical therapy services.

### Principle #6

Physical therapists shall enhance their expertise through the lifelong acquisition and refinement of knowledge, skills, abilities, and professional behaviors. *(Core Value: Excellence)*

6A. Physical therapists shall achieve and maintain professional competence.
6B. Physical therapists shall take responsibility for their professional development based on critical self-assessment and reflection on changes in physical therapist practice, education, healthcare delivery, and technology.
6C. Physical therapists shall evaluate the strength of evidence and applicability of content presented during professional development activities before integrating the content or techniques into practice.

6D. Physical therapists shall cultivate practice environments that support professional development, lifelong learning, and excellence.

## Principle #7

Physical therapists shall promote organizational behaviors and business practices that benefit patients/clients and society. *(Core Values: Integrity, Accountability)*

7A. Physical therapists shall promote practice environments that support autonomous and accountable professional judgments.
7B. Physical therapists shall seek remuneration as is deserved and reasonable for physical therapist services.
7C. Physical therapists shall not accept gifts or other considerations that influence or give an appearance of influencing their professional judgment.
7D. Physical therapists shall fully disclose any financial interest they have in products or services that they recommend to patients/clients.
7E. Physical therapists shall be aware of charges and shall ensure that documentation and coding for physical therapy services accurately reflect the nature and extent of the services provided.
7F. Physical therapists shall refrain from employment arrangements, or other arrangements, that prevent physical therapists from fulfilling professional obligations to patients/clients.

## Principle #8

Physical therapists shall participate in efforts to meet the health needs of people locally, nationally, or globally. *(Core Value: Social Responsibility)*

8A. Physical therapists shall provide *pro bono* physical therapy services or support organizations that meet the health needs of people who are economically disadvantaged, uninsured, and underinsured.
8B. Physical therapists shall advocate to reduce health disparities and healthcare inequities, improve access to healthcare services, and address the health, wellness, and preventive healthcare needs of people.
8C. Physical therapists shall be responsible stewards of healthcare resources and shall avoid over-utilization or under-utilization of physical therapy services.
8D. Physical therapists shall educate members of the public about the benefits of physical therapy and the unique role of the physical therapist.

Proviso: The Code of Ethics as substituted will take effect July 1, 2010, to allow for education of APTA members and non-members. For more information go to www. apt. org/ethics

# Standards of Ethical Conduct for the Physical Therapist Assistant

# Appendix 2

**EFFECTIVE JULY 1, 2010.** For more information, go to www.apta.org/ethics

**HOD S06-09-20-18** [Amended HOD S06-00-13-24; HOD 06-91-06-07; Initial HOD 06-82-04-08] [Standard]

## PREAMBLE

The Standards of Ethical Conduct for the Physical Therapist Assistant (Standards of Ethical Conduct) delineate the ethical obligations of all physical therapist assistants as determined by the House of Delegates of the American Physical Therapy Association (APTA). The Standards of Ethical Conduct provide a foundation for conduct to which all physical therapist assistants shall adhere. Fundamental to the Standards of Ethical Conduct is the special obligation of physical therapist assistants to enable patients/clients to achieve greater independence, health and wellness, and enhanced quality of life.

No document that delineates ethical standards can address every situation. Physical therapist assistants are encouraged to seek additional advice or consultation in instances where the guidance of the Standards of Ethical Conduct may not be definitive.

## Standards:

Standard #1: Physical therapist assistants shall respect the inherent dignity, and rights, of all individuals.

1A. Physical therapist assistants shall act in a respectful manner toward each person regardless of age, gender, race, nationality, religion, ethnicity, social or economic status, sexual orientation, health condition, or disability.

1B. Physical therapist assistants shall recognize their personal biases and shall not discriminate against others in the provision of physical therapy services.

Standard #2: Physical therapist assistants shall be trustworthy and compassionate in addressing the rights and needs of patients/clients.

2A. Physical therapist assistants shall act in the best interests of patients/clients over the interests of the physical therapist assistant.

2B. Physical therapist assistants shall provide physical therapy interventions with compassionate and caring behaviors that incorporate the individual and cultural differences of patients/clients.

2C. Physical therapist assistants shall provide patients/clients with information regarding the interventions they provide.

2D. Physical therapist assistants shall protect confidential patient/client information and, in collaboration with the physical therapist, may disclose confidential information to appropriate authorities only when allowed or as required by law.

Standard #3: Physical therapist assistants shall make sound decisions in collaboration with the physical therapist and within the boundaries established by laws and regulations.

3A. Physical therapist assistants shall make objective decisions in the patient's/client's best interest in all practice settings.

3B. Physical therapist assistants shall be guided by information about best practice regarding physical therapy interventions.

3C. Physical therapist assistants shall make decisions based upon their level of competence and consistent with patient/client values.

3D. Physical therapist assistants shall not engage in conflicts of interest that interfere with making sound decisions.

3E. Physical therapist assistants shall provide physical therapy services under the direction and supervision of a physical therapist and shall communicate with the physical therapist when patient/client status requires modifications to the established plan of care.

Standard #4: Physical therapist assistants shall demonstrate integrity in their relationships with patients/clients, families, colleagues, students, other healthcare providers, employers, payers, and the public.

4A. Physical therapist assistants shall provide truthful, accurate, and relevant information and shall not make misleading representations.
4B. Physical therapist assistants shall not exploit persons over whom they have supervisory, evaluative, or other authority (e.g., patients/clients, students, supervisees, research participants, or employees).
4C. Physical therapist assistants shall discourage misconduct by healthcare professionals and report illegal or unethical acts to the relevant authority, when appropriate.
4D. Physical therapist assistants shall report suspected cases of abuse involving children or vulnerable adults to the supervising physical therapist and the appropriate authority, subject to law.
4E. Physical therapist assistants shall not engage in any sexual relationship with any of their patients/clients, supervisees, or students.
4F. Physical therapist assistants shall not harass anyone verbally, physically, emotionally, or sexually.

Standard #5: Physical therapist assistants shall fulfill their legal and ethical obligations.

5A. Physical therapist assistants shall comply with applicable local, state, and federal laws and regulations.
5B. Physical therapist assistants shall support the supervisory role of the physical therapist to ensure quality care and promote patient/client safety.
5C. Physical therapist assistants involved in research shall abide by accepted standards governing protection of research participants.
5D. Physical therapist assistants shall encourage colleagues with physical, psychological, or substance-related impairments that may adversely impact their professional responsibilities to seek assistance or counsel.
5E. Physical therapist assistants who have knowledge that a colleague is unable to perform their professional responsibilities with reasonable skill and safety shall report this information to the appropriate authority.

Standard #6: Physical therapist assistants shall enhance their competence through the lifelong acquisition and refinement of knowledge, skills, and abilities.

6A. Physical therapist assistants shall achieve and maintain clinical competence.
6B. Physical therapist assistants shall engage in lifelong learning consistent with changes in their roles and responsibilities and advances in the practice of physical therapy.
6C. Physical therapist assistants shall support practice environments that support career development and lifelong learning.

Standard #7: Physical therapist assistants shall support organizational behaviors and business practices that benefit patients/clients and society.

7A. Physical therapist assistants shall promote work environments that support ethical and accountable decision-making.
7B. Physical therapist assistants shall not accept gifts or other considerations that influence or give an appearance of influencing their decisions.
7C. Physical therapist assistants shall fully disclose any financial interest they have in products or services that they recommend to patients/clients.
7D. Physical therapist assistants shall ensure that documentation for their interventions accurately reflects the nature and extent of the services provided.
7E. Physical therapist assistants shall refrain from employment arrangements, or other arrangements, that prevent physical therapist assistants from fulfilling ethical obligations to patients/clients.

Standard #8: Physical therapist assistants shall participate in efforts to meet the health needs of people locally, nationally, or globally.

8A. Physical therapist assistants shall support organizations that meet the health needs of people who are economically disadvantaged, uninsured, and underinsured.
8B. Physical therapist assistants shall advocate for people with impairments, activity limitations, participation restrictions, and disabilities in order to promote their participation in community and society.
8C. Physical therapist assistants shall be responsible stewards of healthcare resources by collaborating with physical therapists in order to avoid over-utilization or under-utilization of physical therapy services.
8D. Physical therapist assistants shall educate members of the public about the benefits of physical therapy.

Proviso: The Standards of Ethical Conduct for the Physical Therapist Assistant as substituted will take effect July 1, 2010, to allow for education of APTA members and non-members.

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