Ethical Dilemmas in Genetics and Genetic Counseling

Principles through Case Scenarios

EDITED BY JANICE L. BERLINER

OXFORD

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About the Editor

Janice L. Berliner, MS, CGC, has 25 years of experience in genetic counseling, primarily in cancer risk assessment. She provides education to health professionals and the community and also participates in research projects of the Clinical Genetics Service at Memorial Sloan Kettering Cancer Center. She has served on numerous committees as well as the Board of Directors of the National Society of Genetic Counselors and the American Board of Genetic Counseling.

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1

Introduction to Clinical Ethics

REBECCA R. ANDERSON

The field of human genetics grows more complex and more vexing with each passing day. Scientists, clinicians, and patients struggle to understand floods of information, tantalizing and incomplete. They wrestle with ethical dilemmas posed by evolving technologies whose sequelae cannot be predicted. Meanwhile, policymakers are buffeted by constituencies clamoring for or against restrictions in research and practice.

Our guides through these thickets will be the members of the fictitious *Jones/Smith family*, depicted in Figure 1.1. With each chapter, we will examine some portion of their story in relation to an ethical issue posed by genetics in medical practice or research. Although the narrative builds from chapter to chapter, it is not necessary to read the book from beginning to end because each chapter stands on its own.

Chapter One offers an overview of medical ethics as it relates to human genetics. First, some basic definitions are in order.

The terms *moral* and *ethical* are used interchangeably in many contexts. Both terms refer to our sense of the good or the right, but not merely as matters of etiquette or social propriety. Rather, they are concerned with the most basic rules and commitments of human relationships and the management of divergent viewpoints and interests. Some people use the word *ethics* to denote the systematic analysis of what constitutes good or right behavior and *morals* to denote the underlying general principles.[1] Others advance different definitions.

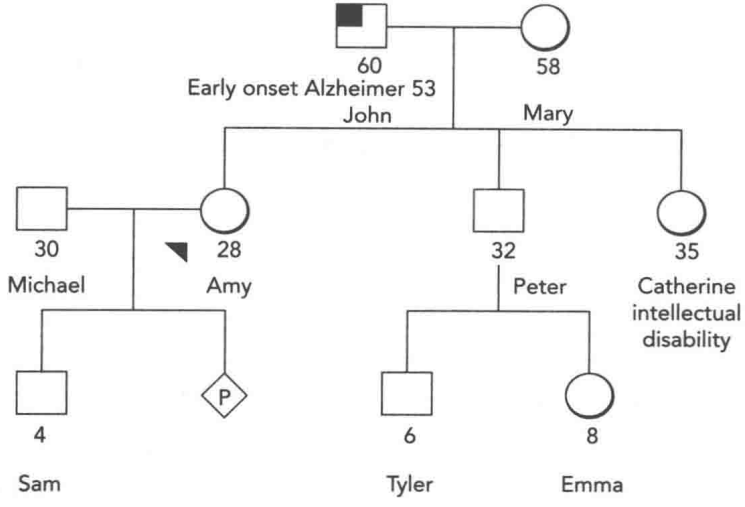

FIGURE 1.1 Amy, age 28, is the youngest daughter of John and Mary Jones. Amy is an accountant married to Michael Smith, a patent attorney. They have a healthy son, Sam, age 4, and Amy is pregnant. Amy's brother, Peter, is 32 and has two healthy children: Tyler, age 6 and Emma, age 8. Peter is an engineer and his wife, Joy, is a potter. Amy's oldest sibling, Catherine, is 35 and single. She has moderate intellectual disabilities secondary to complications of chicken pox. Since the age of 28 Catherine has lived in a group home and Amy has served as her legal guardian. Catherine's move from her parents' home was precipitated by early-onset Alzheimer in her father, John. A former banker, John began behaving erratically in his late 40s and was diagnosed with Alzheimer at 53. He tests positive for a dominant mutation in a presenilin gene, conferring a dramatically increased risk for early-onset dementia. Mary Jones continues to care for her husband at home but is finding this increasingly challenging as John's agitation and combativeness increase.

In this book we will use *moral* to refer to the convictions, conventions, and decisional processes guiding the good and the right in our nonprofessional lives. Moral convictions evolve from religious, philosophical, and cultural foundations (and possibly from genetic influences, but that's not a discussion for this text). Our legal system

reflects widely shared moral convictions in both civil law (honoring one's promises in a contract, for example) and criminal law (punishing deliberate harm to another's person or property). Personal moral codes and principles often encompass thoughts, motives, and feelings as well as behaviors. Importantly, individuals choose their own sources of moral authority, and an authority persuasive to one person (e.g., a sacred text) may not be persuasive to another.

We will use *ethical* to refer to the convictions, conventions, and decisional processes guiding right behavior in professional life and in public policy. Although these definitions are somewhat arbitrary and carry significant overlap, the distinctions are useful, particularly when personal convictions of providers are in tension with professional expectations.[ii]

Although evolved from the same foundations as personal codes, professional codes of ethics, whether written or unwritten, tend to be more circumscribed. They reflect the custom and practice of skilled specialists who are pledged to use their training in the service of others. Ethical behavior for a professional may be defined by precedent as much as by adherence to principles and, as a rule, ethical precepts focus on behavior rather than on the internal processes of the actor.[iii]

In written form, professional codes, position statements, policies, guidelines, and practice parameters reflect peer consensus on appropriate behavior at the time of their adoption. Many such statements carry disclaimers, allowing individual providers to exercise their own judgment when departure from the norm is indicated. But professional behavior is not immune from outside influence. State licensure often governs entry into professional practice. Increasingly, state and federal statutes control key elements of the provider–patient relationship.[iv] Unless professional behavior meets a minimum *standard of care*, the professional may be civilly or criminally liable for failure to practice in a responsible manner.

The *standard of care* in the medical context typically measures the provider's acts (or failure to act) against those of a *reasonable and*

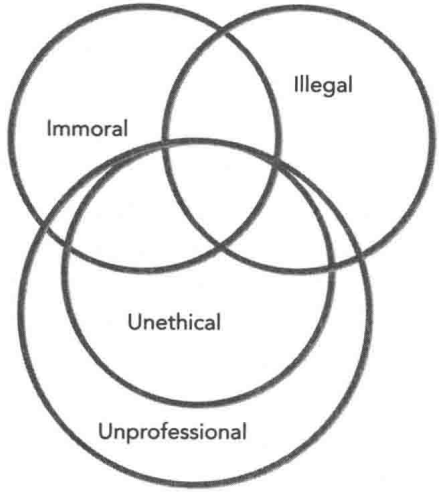

FIGURE 1.2 A single act may run afoul of only one of these categories, or may violate all four. If one has a consensual sexual relationship with someone to whom one is not married, one's behavior may be considered immoral but typically not unethical, unprofessional, or illegal. If one's intimate partner is a patient, one's behavior is both unethical and immoral. Such behavior violates regulatory but usually not criminal law: although one could lose one's license, one is not likely to go to jail. However, if that patient is 12 years of age, one has planted oneself in the middle of all four circles and can expect to do time.

prudent practitioner exercising *ordinary care and skill* under the *same or similar circumstances* in the *same or similar locality*.[v] State legislatures have adopted statutes defining the medical standard of care for their jurisdictions, and the courts apply those definitions when determining whether a provider has met the standard when the events in question took place (Figure 1.2).

Another ancient and central feature of professional practice (at least in law and medicine) is *fiduciary duty*. Because professionals possess knowledge and skills not commonly shared by lay people, their clients essentially are at their mercy. Clients may not even know the right questions to ask when they consult a professional and rarely