CHAPTER 1

COST, QUALITY, ACCESS, AND CHOICE

I. INTRODUCTION

Cost, quality, access, and choice are the chief concerns of the health care system and the central themes of these materials. Concerns over justice and equity run through concepts of cost, quality, access, and choice, and are increasingly reflected in health care law and policy. Each captures a broad interest related to the health and well-being of both individuals and populations.

“Cost” encompasses actual health-related expenses, such as amounts individuals pay out of pocket for medical services and products, and—for those who are insured—premiums paid for health insurance. Such expenses also include the cost to employers and taxpayers of providing tax-advantaged health insurance to employees and the cost to taxpayers of funding and operating public insurance programs, Veterans Administration hospitals and clinics, state hospitals, and other public health care programs and providers. Additionally, they include the systematic cost of uncompensated care, which leads directly to higher health care prices and indirectly—through consumer bankruptcies—to higher prices generally, especially higher consumer credit interest rates. Finally, there is the cost of unnecessary care, which increases utilization, drives up the cost of insurance, and increases the incidence of iatrogenic injuries that generate still more costs.

On the other hand, the concept of “cost” goes much further than actual expenses, encompassing the cost of health care that is not received when needed. Sick or injured individuals who forgo needed care incur personal cost when, for example, they lose income from missed work days, and their lost productivity imposes costs on their employers and co-workers. Contagious disease when untreated will spread to others, costing additional missed days of work or school. Injuries or illnesses that are not treated thoroughly and in a timely manner also impose non-financial costs. The ability of individuals to participate in family life, social life, and political life is diminished by under-treated illnesses and injuries and, when the incidence of under-treated ill-health becomes significant at a population level, these become significant societal costs as well. Sickness, injury, and impairments also impose costs not typically categorized as ‘health care costs,” including: uncompensated caregiving by family or
friends; equipment, supports and services necessary to maintain function and independent living when possible; residential supports such as assisted living; and transportation to and from health care offices and facilities. In short, the concept of cost as used here recognizes that, as a matter of personal and public well-being, there are monetary and non-monetary costs for ill-health and for health care. The issue of cost is discussed throughout the book, and in more detail in Chapters 9, 10, and 11.

“Quality” is implicated by efforts to preserve health and, when illness or injury occurs, to restore health safely and effectively through the work of health care professionals, institutions, and integrated delivery systems. So, for example, the quality of care a patient receives is determined not only by the professionalism of her physician or other medical professional, but also the ability of the payer network and the clinic or hospital through which her physician practices to organize all aspects of the delivery of that patient’s care. Increasingly, physicians and hospitals are parts of ever-larger delivery systems that provide thousands of individuals with all of the care they might need, and many include health plans that provide the coverage for care received through such an integrated delivery system. As those systems exert more control over their affiliated health care professionals and institutions, quality of care turns more often on the quality of integration and management of these systems. For these reasons, quality is increasingly important as a measurable outcome that can be used by patients, policymakers, and payers to evaluate providers, institutions, and systems. These aspects of quality are explored in particular in Chapters 5 and 6.

The concept of “quality” also has a regulatory dimension. Preventing ill-health and, when necessary, restoring health depend not only on private health care providers, but also on public systems. For example, state licensing systems and conditions imposed by Medicare and Medicaid on participating providers assure levels of provider quality. Licensure is addressed in Chapter 2, and “conditions of participation” in public insurance programs as quality levers are explored in Chapter 3. Similarly, the Food and Drug Administration assures that privately marketed drugs and devices are safe, effective, and unadulterated. State and federal public health systems that track infectious diseases, require certain food labels, inspect grocery stores and restaurants, and monitor drinking water all promote quality by preventing illness and injury and responding to health problems at a population level. The tools of public health are presented in Chapter 22.

“Access” addresses inequity related to health and health care. It describes the problem that many Americans experience obtaining health care because they cannot afford to pay for care or because they cannot find qualified providers willing and able to provide care. Access is most clearly
implicated by the 27.3 million Americans who remained uninsured at the end of 2016. Those without private insurance and who are not eligible for Medicare or Medicaid lack a reliable means to pay for health care services should they experience a significant injury or illness. This, in turn, leads to poorer health because the uninsured are less likely to obtain preventive care or care for chronic conditions. Moreover, the concept encompasses an inequitable pattern associated with a lack of health insurance. The uninsured are significantly more likely to have low incomes, which means that any medical services they receive are likely to result in bills that create a financial crisis. For a thorough description of insurance and access, among other things, see Chapter 9.

The concept of “access” casts a wide net across health law and policy and addresses obstacles to care beyond ability to pay. Concerns over access include issues as disparate as the absence of accessible medical and diagnostic equipment for treating patients with physical disabilities; the lack of providers in rural areas; and conscience-based refusal by providers regarding particular health care services when those providers dominate available services. Along with “quality”, access draws attention to patterns of unequal access and treatment experienced by disadvantaged groups, and discrimination on the basis of race, gender, disability, and other characteristics across the health care system, which are examined in Chapter 7. Similarly, it accounts for inequities in the social conditions that affect population health, including the fact that those in poverty are significantly less likely to enjoy clean air and drinking water, safe outdoor spaces for exercise, and reasonable proximity to a health care provider or to a source for purchasing healthy food.

“Choice” acknowledges that respect for persons is uniquely important in relation to health and health care. Individuals can experience profound vulnerability as a result of ill-health and as a result of paying for medical care to restore and maintain health. Respect for that experience is a common theme throughout health law, bioethics, and policy. Most typically, “choice” is associated with respect for patients by health care providers, and it is reflected in the laws of informed consent and confidentiality among others. See Chapter 4. The concept, however, has a broader reach. As discussed in Chapter 22, it encompasses public health measures that—in the midst of an emergency—require the cooperation of individuals within the population at risk. Additionally, laws affecting provider networks can expand or limit a patient’s choice of physician. An individual’s choice of health plan is implicated by subsidies and exchanges created by federal law and coverages mandated by state law. These laws and the regulation of insurance plans and managed care more generally are examined in Chapter 10. A patient’s treatment choices are also restricted by regulations that prohibit unproven drugs from entering the
market or by insurance contracts that exclude coverage for alternative therapies.

These four concerns operate in a dynamic and complex relationship. See Figure 1. It is easy, for example, to assume that increasing quality or access must naturally increase costs. One might assume that increasing the required staff-to-patient ratio in health care facilities increases the costs of care. The same assumption may be made about the impact on health care costs caused by increasing the number of individuals eligible for or the range of services covered by Medicaid or Medicare, our public programs for covering the elderly, disabled, and poor. In each of these examples, however, it is possible that total cost actually is lowered by avoiding facility-generated injuries or infections or by providing timely care that avoids extraordinary costs incurred as a medical condition or disease moves to later stages untreated. In other situations, however, enhancing one value truly may diminish another. Preserving individual choice through maintaining the private health insurance system, for example, most likely increases costs overall, but perhaps the increase in cost is justified.

Figure 1:

![Diagram of Cost, Quality, Access, and Choice]

Of course, the analysis of the impact of particular legal and policy decisions on cost, quality, access, and choice is not entirely a dispassionate, rational, empirically-based calculation. Political strength, economic power, and culture and tradition all influence how we view the relative advantages and disadvantages of particular proposals and how we ultimately design our systems. In addition, gains and losses are not shared equally, so advocates may represent particular interests.

Ongoing health reform debates put a powerful spotlight on concerns over access, cost, quality, and choice. Public understanding of the Patient
Protection and Affordable Care Act (ACA) centers on the tentative adoption of the principle that providing access to some form of basic medical care is important to the health and flourishing of society as a whole. Access to adequate care is the banner headline for the ACA, even as that principle faces continued opposition. The vehicles chosen for achieving this goal rest on a second principle so embedded in our culture that forward progress was probably impossible without honoring it. That value is individual choice, and it is reflected in the oft-stated mantra expressed in the campaign to gain public support for the ACA: “No one will make you change your coverage; if you like it, you can keep it.” In addition, the question of individual choice, and its apparent conflict with increasing access, took center stage in the battles over the constitutionality of the ACA.

The ACA certainly responded to concerns about access and choice, but it is attempting to do much more in refashioning health care delivery and payment systems. The goal is to develop a system that provides higher quality health care to more people at lower cost. It is ambitious.

In the end, cost, quality, access, and choice are derived from a defining reality that health is a fundamental human need. Without it, economies stall, social and democratic structures are strained, and the lives of at least some individuals are up-ended. The 2014 U.S. Ebola scare, for example, disrupted international and interstate travel, pushed thousands of health care workers and soldiers into quarantine and out of the workforce as they returned from Ebola-ravaged West African countries, and resulted in scores of discriminatory incidents by employers, schools, retailers, and others. Similarly, the 2009 H1N1 pandemic closed schools and businesses, threatened trade and diplomatic relationships between U.S. and Mexico, and undercut the international market for pork.

Consequently, systems designed to maintain and restore both individual and population health are essential, as are laws designed to assure those systems are competent, affordable, accessible, and fair to all who rely on them. While these laws have roots in a wide range of other fields of law—such as administrative law, antitrust, business associations, civil rights law, constitutional law, insurance regulation, taxation, torts, and others—they take on new meaning when applied to promote individual and population health. Wendy K. Mariner identifies this phenomenon in her article Toward an Architecture of Health Law, 35 Am. J. L. & Med. 67 (2009), as she explains how health law pursues justice in the context of health:

Most fundamentally, health law adopts and adapts principles from other legal domains to protect the value of health within a framework of justice and the rule of law. Thus, it is not simply the rote application of contract doctrine to an agreement between entities that happen to be in the health field, but an interpretation of whether and
how that doctrine ought to be modified both to achieve the goal of contract law and to recognize the value of health. In this very broad sense, health law has dual normative goals: justice and protection of health.

This adopt-and-adapt phenomenon is evident throughout these materials. Later in this chapter, for example, a court in Katskee v. Blue Cross/Blue Shield of Nebraska notes the interpretive principle in contract law “that an ambiguous [insurance] policy will be construed in favor of the insured,” and it does so in the context of determining that an individual’s health coverage includes coverage for a latent genetic condition. In short, health law involves more than public and private health systems to which all fields of law are merely applied; rather, law applied in this arena is reinterpreted because health and health care are fundamental needs, which is how health and justice uniquely combine as “Health Law.”

Section II of this chapter highlights concerns over justice and equity that run through concepts of cost, quality, access, and choice, and are increasingly reflected in health care law and policy. It introduces the concepts of just allocation of health care resources and costs, discrimination and inequities in the health care system, and health equity.

Section III of this chapter provides brief exposure to the legal and ethical principles of equitably distributing health risks through insurance and compares pre-ACA and post-ACA concepts of health insurance. It also includes a discussion of what counts as a health care “cost” and issues that arise in distributing the cost of illness and the cost of care.

Section IV presents a case considering the definition of illness in the context of a dispute over what counts as illness and what counts as health care. Studying that case will launch you into consideration of a number of fundamental questions. How do we equitably balance goals relating to cost, quality, access, and choice in individual cases or as a matter of designing what will be covered under insurance? How do we know whether a treatment is useful or not? Who should decide?

**II. JUSTICE AND EQUITY**

As you have seen in the preceding section, concerns over justice and equity run through concepts of cost, quality, access, and choice, and are increasingly reflected in health care law and policy. Three themes merit special attention.

First, the vigorous discussion and debate around the ACA put a powerful spotlight on the values and principles underlying the allocation of health care resources and costs within the U.S. health care system. Concern for distributive justice, or the just distribution of scarce or restricted health care resources, pre-dates the ACA, of course. For example,
such concern figures prominently in decision making regarding the retrieval and allocation of scarce human organs for transplantation examined in Chapter 18.

Ethical and legal analysis of the distribution of health care typically begins with addressing one question: whether health care is distinguishable from other goods and services that are governed by market transactions. Differing opinions on this question are reflected in the social solidarity and actuarial fairness models of insurance introduced in the next section. A second question is how much of a role, if any, the market should play in allocation of health care resources. Because the private market continues to play a large role in the distribution of health insurance and health care in the U.S., a core focus of debate is whether regulation, competition, or some combination of the two is the best strategy for improving our health care system and moving it toward the ultimate goal of providing quality health care to more people at lower cost. This central debate is highlighted in the next section, and explored in detail in Chapter 9.

Second, concepts of justice demand attention to discrimination in the health care system. Although there are many barriers to equal and adequate care, individual and structural discrimination continue to play a significant role. Discrimination has shaped our health care system. Consider that U.S. hospitals and other health care facilities were segregated by law well into the late 1960s and by custom for some time thereafter. Or that well into the 1990s, individuals with disabilities were subject to unnecessary institutionalization, often under inhumane conditions, as a form of “treatment” for a wide range of physical and mental disabilities. Today, there is a strong and growing literature on the health effects of discrimination on individuals and communities. The importance of equal and non-discriminatory access is reflected in the number of federal laws prohibiting discrimination in health insurance or health care. These laws prohibit discrimination in health insurance, health care, or both on the basis of race, color and national origin, disability, genetic information, and gender. Chapter 7 examines the extent to which physicians, institutions, and systems may be legally obligated to treat patients needing medical care under these and related laws, and how effectively these laws address the individual and structural barriers experienced by patients.

The traditional approach of federal anti-discrimination law is to prohibit discrimination based on specific characteristics of an individual. Those characteristics signify membership in a “protected class” or group that has experienced a history of discrimination and disadvantage. Some have argued for a universal approach that provides uniform protections to all without reference to specific characteristics. Supporters of this approach argue that it avoids counterproductive reliance on group identity and captures forms of unfairness not addressed under traditional anti-
discrimination law. The ACA reflects both approaches, as it builds on and expands existing protections for disadvantaged groups, and provides other protections that apply to all, regardless of membership in a protected class. For example, a law that prohibits insurers from charging higher premiums based on race reflects the traditional approach, whereas a guarantee of affordable coverage for all defined as a percentage of household income reflects the universal approach. These and other reforms to private and public insurance are examined in Chapters 10 and 11.

Third, concepts of equity and justice in health care extend beyond discrimination to reach health disparities. A health disparity is a particular type of population-level health difference that is linked to a history of social, economic, or environmental disadvantage. The term generally refers to differences in health status or health outcomes, such as a higher burden of illness, injury, or mortality. It can also refer to differences in access to health care and differences in the quality of care received. Related terms such as health inequity emphasize that such differences are unfair, unjust and avoidable. Health inequities have been a focus of U.S. public health efforts for over 100 years. However, health inequities across race, gender, and disability persist, even after controlling for factors such as ability to pay and medical need.

Health inequities are an ethical concern, and are seen by many as a form of discrimination and social injustice. Health inequities also present more pragmatic concerns for the health care system because they signal a pattern of lapses in quality of care and create excess cost. The ACA contains multiple provisions aimed at the reduction and elimination of health inequities. For example, provisions promoting broader access to affordable and adequate care, such as authorizing the expansion of Medicaid and the requirement that new plans cover preventive services without deductibles or copayments, contribute to the reduction of health inequities by improving health overall. Other provisions address disparities specifically. They include the prohibition of discrimination under Section 1557 and new tools to collect, analyze, and share standardized data. These provisions are discussed throughout the book, and in more detail in Chapters 7, 10 and 11.

Ultimately, the concepts of justice and equity point to the goal of health equity. Health equity is an ambitious goal, including and going beyond each of the three themes above. Consider this definition of health equity from Paula Braveman et al., What is Health Equity? And What Difference Does a Definition Make? Princeton, NJ: Robert Wood Johnson Foundation, 2017:

Health equity means that everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including
powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care. Equal access to quality care is important to the health of individuals and of communities, but it is not the only factor that influences health. It is well established that social and economic factors also influence health outcomes. These factors, commonly referred to as “social determinants of health,” include conditions of early childhood, education, employment, income, housing, the physical environment, access to food, and discrimination and social problems. Addressing these social determinants of health is important for achieving greater and more equitable health on a population level. See Chapter 22.

III. EQUITABLY SPREADING HEALTH RISKS

A. THE ROLE OF INSURANCE

In most developed countries, it is assumed that everyone has a right to health care. While private health insurance exists in almost all nations, most countries rely on a public health insurance financing system to ensure universal access to health care.

In some nations, such as England, Canada, the Scandinavian Countries, and the Iberian and Mediterranean countries, the government finances health insurance directly through general revenue funds. In many of these countries, hospitals are publicly owned, and specialists are hospital employees. In many, including England, general practitioners are not public employees and contract with the health care system. Other nations, including France, Germany, Austria, Belgium, and Japan, have social insurance systems. In these systems, quasi-public social insurance funds pay for health care under contracts with providers, financed largely by employer and employee contributions. Some hospitals are publicly-owned, but many are nonprofit and some are for-profit private facilities. Specialists tend to work for hospitals, and general practitioners tend to be private practitioners. Finally, Switzerland and the Netherlands finance care through private insurance companies. Everyone is required to be insured, however, and insurance is financed in part through public funds, in Switzerland for lower-income households and in the Netherlands for everyone. Insurance in these countries is heavily regulated (underwriting based on health status is prohibited) and in some respects looks more like the social insurance programs in their neighboring countries than like private insurance in the U.S.

The U.S. is unique in that it does not attempt to make health care universally available. Since the middle of the twentieth century, the U.S. has cobbled together a system of private and public insurance that covers most Americans, but still leaves many without health insurance. In 2016,
about 55 percent of Americans were covered by health insurance they receive through their job. This insurance is heavily subsidized by the public generally through tax exclusions and deductions, and is paid for in varying proportions by employers and employees. Another 41 percent—primarily the elderly, disabled, and poor children—were covered through public programs. About 16 percent were covered by other private insurance—often policies they purchased themselves. About 9 percent of Americans were uninsured. See Jessica C. Barnett & Edward R. Berchick, U.S. BUREAU OF THE CENSUS, Health Insurance Coverage in the United States 2016 (Sept. 2017). Uninsured individuals have a right to obtain emergency care in a hospital, whether or not they can pay for it, but do not have a right to nonemergency care, including continuing care after the emergency condition is treated. See Chapter 7. There is a great deal of evidence that the uninsured get less care and get it later and when it is ineffective, resulting in worse health status and earlier death.

The ACA, analyzed at length in Chapter 10, dramatically expanded access to health care even though it has not been fully implemented. The percentage of uninsured American residents dropped from more than 16 percent to about 10 percent (8 percent of legal residents) since the ACA’s insurance reforms and Medicaid expansion took effect in 2014. The ACA increased access to care by expanding Medicaid for lower-income Americans in those states that chose to do so, and by offering insurance premium tax credits to help middle-income uninsured Americans purchase health insurance. States that expanded their Medicaid programs experienced a decrease in the percentage of their uninsured populations that was about 1 percentage-point greater than in states that did not expand their Medicaid programs. The ACA also requires Americans who can afford health insurance to purchase it or pay a penalty; however, the federal tax overhaul recently passed by Congress eliminates the tax penalty starting in 2019. The ACA also penalizes large employers who do not offer their employees adequate, affordable insurance and whose employees end up receiving public subsidies. Finally, it prohibits insurers from discriminating against applicants or enrollees with medical conditions requiring care.

Although proposals for universal health care have been considered in the U.S. since the 1910s, they have always faced strong opposition from some sectors of the health care industry (in the 40s, 50s, and 60s from physicians, now primarily from insurers). Government-financed universal health care has rarely enjoyed broad political support in the U.S. The political institutions and ideological bent of the U.S. have been quite different from those of Canada and most European countries, especially in the post-World War II era when many of those nations adopted public health insurance systems. See Theodore Marmor, The Politics of Medicare (2d ed. 2000); Carolyn Hughes Tuohy, Accidental Logics (1999); Timothy
Illness and injury do not visit everyone at the same point in their lives. As examined in detail in Chapter 9, insurance exists to spread the financial risk of needing medical care from individuals to all members of a group. This suggests a vision of justice that distributes risk broadly. Indeed, social insurance, based on the principle of social solidarity, distributes risk among the broadest possible group, the entire citizenry. But insurance can also be based on an alternative vision of justice, that of actuarial fairness, under which the price that individuals pay for insurance varies based on an estimate of their individual health risks. This difference in vision is explored in Deborah Stone’s classic article on this topic, The Struggle for the Soul of Health Insurance, 18 J. Health Pol., Pol'y & L. 287 (1993).

Stone asserts that “[m]utual aid among a group of people who see themselves as sharing common interests is the essence of community; a willingness to help each other is the glue that holds people together as a society.” She continues:

While in most societies sickness is widely accepted as a condition that should trigger mutual aid, the American polity has had a weak and wavering commitment to that principle. The politics of health insurance can only be understood as a struggle over the meaning of sickness and whether it should be a condition that automatically generates mutual assistance. . . . The private insurance industry, the first line of defense in the U.S. system of mutual aid for sickness, is organized around a principle profoundly antithetical to the idea of mutual aid, and indeed, the growth and survival of the industry depends on its ability to finance health care by charging the sick and to convince the public that “each person should pay for his own risk.”

Stone concludes:

Actuarial fairness—each person paying for his own risk—is more than an idea about distributive justice. It is a method of organizing mutual aid by fragmenting communities into ever-smaller, more homogeneous groups and a method that leads ultimately to the destruction of mutual aid. This fragmentation must be accomplished by fostering in people a sense of their differences, rather than their commonalities, and their responsibility for themselves only, rather than their interdependence. Moreover, insurance necessarily operates on the logic of actuarial fairness when it, in turn, is organized as a competitive market.

**Notes and Questions**

1. The term “actuarial fairness” implies that fairness requires individuals to pay premiums based on an estimate of the likelihood that they
will need medical care. If the fairness principle can be expressed as “treatment like cases alike,” how is mutual aid fair? Is it fair for an individual in perfect health, for example, to pay the same premium as someone with a chronic illness such as multiple sclerosis? What if a person is not ill but is engaging in behaviors that increase their risk of illness or injury, such as smoking or skiing or working under hazardous conditions? The Affordable Care Act rejects the notion of actuarial fairness in most respects, although it allows premiums to reflect the individual’s age, tobacco use, and geographic area of residence. For example, the ACA allows insurers to impose a premium surcharge of up to 50 percent for tobacco use, which may make health insurance unaffordable for many smokers; for these reasons ten states have further limited tobacco surcharges, and several of those prohibit tobacco rating altogether. What is the basis for the above exceptions? Are they fair? Would you delete any of them? Would you add any others?

2. Although the ACA modifies the practice of health insurance by rejecting health status underwriting and expanding public coverage, it does not embrace a vision of a universal right to health care—of social solidarity and mutual aid. Should we move toward that right, or should we in fact be moving in the other direction? See Brietta Clark, A Moral Mandate & the Meaning of Choice: Conceiving the Affordable Care Act after NFIB, 6 St. Louis U. J. Health L. & Pol’y 267 (2013).

3. Is it possible (or desirable) to define a basic level of health care to which all are entitled but provide health care above that level only for those who can afford it? What would be included in that package? See discussion of the “essential benefits package” under the ACA in Chapter 10 and of distributive justice in allocation of health care resources and particularly organ transplantation in Chapter 18. See also discussion in Section B, below.

4. Ability to pay is not the only determinant of access to health care. Even if an individual has insurance that covers the needed treatment, he or she may not be able to get that treatment or may get a substandard level of treatment. Empirical evidence proves, for example, that persons of color do not get necessary treatment or get a significant lesser quality of care than do other people. In addition, individuals with certain types of disabilities or medical conditions, such as HIV or chronic pain, often have substantial difficulty in finding health care professionals willing to provide care. See Chapter 7 for a discussion of laws addressing these situations.

**B. THE COST AND BENEFIT OF HEALTH CARE SPENDING**

Health care is expensive. The U.S. spends far more on health care than any other nation in the world—whether measured by percentage of the gross domestic product or by dollars spent per capita. We also spend more on health care than we do on anything else, and health care expenditures have been growing much more rapidly than the economy generally for decades. You might expect that such spending would result in our being
the world’s healthiest country. That is not the case, however, as demonstrated by the following report, and this leads to the conclusion that we must pursue a greater return on our health care investment.

**ERIC C. SCHNEIDER ET AL., MIRROR, MIRROR 2017: INTERNATIONAL COMPARISON REFLECTS FLAWS AND OPPORTUNITIES FOR BETTER U.S. HEALTH CARE**


The United States spends far more on health care than other high-income countries, with spending levels that rose continuously over the past three decades [ ]. Yet the U.S. population has poorer health than other countries. Life expectancy, after improving for several decades, worsened in recent years for some populations, aggravated by the opioid crisis. In addition, as the baby boom population ages, more people in the U.S.—and all over the world—are living with age-related disabilities and chronic disease, placing pressure on health care systems to respond.

Timely and accessible health care could mitigate many of these challenges, but the U.S. health care system falls short, failing to deliver indicated services reliably to all who could benefit. In particular, poor access to primary care has contributed to inadequate prevention and management of chronic diseases, delayed diagnoses, incomplete adherence to treatments, wasteful overuse of drugs and technologies, and coordination and safety problems.

This report uses recent data to compare health care system performance in the U.S. with that of 10 other high-income countries [Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, and the United Kingdom] and considers the different approaches to health care organization and delivery that can contribute to top performance. We based our analysis on 72 indicators that measure performance in five domains important to policymakers, providers, patients, and the public: Care Process, Access, Administrative Efficiency, Equity, and Health Care Outcomes.

Our data come from a variety of sources. One is comparative survey research. Since 1998, The Commonwealth Fund, in collaboration with international partners, has supported surveys of patients and primary care physicians in advanced countries, collecting information for a standardized set of metrics on health system performance. Other comparative data are drawn from the most recent reports of the Organization for Economic Cooperation and Development (OECD), the European Observatory on Health Systems and Policies, and the World Health Organization (WHO).

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Based on a broadly inclusive set of performance metrics, we find that U.S. health care system performance ranks last among 11 high-income countries. The country’s performance shortcomings cross several domains of care including Access, Administrative Efficiency, Equity, and Health Care Outcomes. Only within the domain of Care Process is U.S. performance close to the 11-country average. These results are troubling because the U.S. has the highest per capita health expenditures of any country and devotes a larger percentage of its GDP to health care than any other country.

The U.S. health care system is unique in several respects. Most striking: it is the only high-income country lacking universal health insurance coverage. The U.S. has taken an important step to expand coverage through the Affordable Care Act. . . . [T]he ACA has catalyzed widespread and historic gains in access to care across the U.S. More than 20 million Americans gained insurance coverage. Additional actions could extend insurance coverage to those who lack it. Furthermore, Americans with coverage often face far higher deductibles and out-of-pocket costs than citizens of other countries, whose systems offer more financial protection. Incomplete and fragmented insurance coverage may account for the relatively poor performance of the U.S. on health care outcomes, affordability, administrative efficiency, and equity.

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The U.S. could learn important lessons from other high-income countries [. . . For example, the U.S. performs poorly in administrative efficiency mainly because of doctors and patients reporting wasting time on billing and insurance claims. Other countries that rely on private health insurers, like the Netherlands, minimize some of these problems by standardizing basic benefit packages, which can both reduce administrative burden for providers and ensure that patients face predictable copayments.

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NOTES AND QUESTIONS

1. This report illustrates that greater cost doesn’t necessarily buy better health or better health care. In fact, some cost control strategies focus primarily on improving the quality of care in order to reduce the number of iatrogenic injuries; increasing the management of care to reduce duplicative testing and rightsize the level of care; and improving knowledge about the comparative effectiveness of different interventions or pharmaceuticals. Others focus on creating incentives for higher quality and lower cost care, including increasing competition over quality and cost and linking payment to quality and efficiency. See Chapter 9 for an extensive discussion of cost control efforts.
2. One of the challenges in analyzing the costs of care, and targeting cost containment strategies, is that health care costs are so easily shifted among entities within our health care system. Incentives for early discharge from hospitals intended to reduce the costs of hospital care, for example, shifted costs to nursing homes as they experienced increased expense in caring for sicker residents. For the elderly population, the move also shifts costs from Medicare (which pays for most of that population’s hospital care) to Medicaid (which pays for most of that population’s nursing home care). See discussion in Chapter 3. Discharges to home increased costs to families who, for example, may be required to take unpaid family leave to care for the patient at home. Similarly, increasing access to Medicaid or Medicare may increase costs on one side of the ledger, but can reduce costs on another. Expanding Medicaid eligibility, for example, may reduce hospitals’ costs in their emergency departments caring for safety net patients; and expanding the Medicare home health care benefit may reduce Medicaid’s cost for nursing home care.

3. The Commonwealth Fund report found the U.S. ranks last with respect to health outcomes and equity while ranking 5th in “care process,” which is the category that takes into account the safety and coordination of clinical care as well as the degree to which episodes of care are patient-centered. These findings may explain why some individuals in the U.S. are highly satisfied with their care despite our nation’s poor overall outcomes. This highlights the difference between individual health and population health, which is explored in Chapter 22. The report’s equity findings also suggest the quality of care is unevenly distributed across different segments of our population. For an analysis of discrimination and unequal access, see Chapter 7.

4. One challenge in comparing the “return on investment” the U.S. gets on health care relative to other countries is that most analyses focus only on spending within the health care system, as opposed to looking more broadly at other spending that impacts health in even more significant ways. In The American Health Care Paradox: Why Spending More is Getting us Less (2013), Elizabeth Bradley and Lauren Taylor present research that sheds new light on how to understand the problem:

[This research] shows that the central paradox faced by the US health care system—exorbitantly high spending and relatively poor health outcomes—could be explained by examining a broader set of national expenditures. We demonstrate that when both social services and health services were taken into account, the United States was not a high spender. The country had moderate levels of spending and moderate health outcomes. Paradox unraveled. The credo of public health schools everywhere was made manifest: the health of a nation is created by more than the money spent in the health care sector. Investments in larger systems of economic, environmental, and social support produce health and support individuals’ quest for well-being.
Indeed, research demonstrates public health spending results in significant benefits. A recent meta-analysis of published research concluded there is a 4:1 return on investment for all local and national public health spending. That ratio jumps to 27:1 when only national public health spending is considered. Rebecca Masters et al., Return on Investment of Public Health Interventions: A Systematic Review, 71 J. Epidemiol. Community Health 827 (2017). For more on population health, see Chapter 22.

Given the growing pressure to control health care costs, this research has captured the attention of federal and state lawmakers, health plans, and providers. These traditional health system actors now recognize that social and environmental factors, such as food insecurity, housing insecurity, environmental hazards, and poor education, have a greater impact on health than medical care. And they are experimenting with non-traditional ways of improving patients’ health (and thus ultimately reducing health care cost) by addressing their unmet social needs. Specifically, they are incorporating social services and other non-clinical support into health care delivery in order to attack the root causes of poor health. For example, some physicians go beyond simply counseling patients with heart disease or diabetes about the importance of eating healthy food. They can now “prescribe” healthy food that patients can get from the hospital food pantry. Some Medicaid health plans are working with providers to offer an even broader range of nutritional support for patients, including the delivery of medically tailored meals, cooking and shopping classes, and nutritional counseling. Early reviews suggest that such efforts can reduce costs, but more evidence is needed about which kinds of innovations work and why. Lauren A. Taylor et al., Leveraging the Social Determinants of Health: What Works? (2016) (analyzing peer-reviewed literature that examined the impact of investments in social services as part of health care and finding that “several interventions in the areas of housing, income support, nutrition support, and care coordination and community outreach have had positive impact in terms of health improvements or health care spending reduction”).

**PROBLEM: WHERE IS THE COST?**

Imagine that your spouse has been severely and permanently injured, your parent is suffering from dementia, or your child has serious cognitive and emotional disabilities. What kind of care do you and your family member need? Of the care you need, what will be considered “health care?”

If you quit your job to care for your spouse or parent, will health insurance pay you a wage for doing so? Should it pay for the care you provide if it would pay someone else to be there? If your spouse or parent needs help in bathing and eating, is that health care? What if they need supplies for incontinence like bed pads or diapers?

If you need to make some changes to your home to accommodate assistive devices for your spouse to provide some mobility or to allow him or her to
communicate, should this be considered medical care? Should health insurance pay for these devices?

If your child needs to attend a special summer camp to improve his skills in interacting with other children, is this health care? If you have to hire someone with special skills to provide care for your child while you take care of other obligations, is this health care?

Our current health insurance coverage draws some lines. For example, Medicare does not cover long-term care or nursing home care except for that required for a short time for rehabilitation. Medicaid covers long-term nursing home care, for those meeting eligibility standards, but does not contribute toward less restrictive environments like retirement communities or assisted living. Private insurance plans typically have provided very limited, if any, mental health care. The ACA requires that private insurers provide parity in their coverage of mental health care, but there will still be issues in defining that care.

The ACA requires an “essential benefits package” be defined for health insurance plans. The Secretary of Health and Human Services has allowed the states to define the required benefits using the typical employer-provided health plan as a benchmark. See Chapter 10. The typical private health plan, however, excludes categories of services that might be considered “social” or “educational” or services where functioning cannot be restored, or assistive equipment and supplies, and so on. See Sara Rosenbaum, Medicaid’s Next Fifty Years: Aligning an Old Program with the New Normal, 6 St. Louis U. J. Health L. & Pol’y 329 (2013).

Does the additional stress, economic burden, and related illness experienced by family caregivers count as a health care cost associated with the cost-containment effort of early hospital discharge or extremely limited coverage for professional home care or nursing home care? Furthermore, should the concern over the quality of health care focus on health care services and outcomes for the patient, or should it reach more broadly? Is the health of family members ever relevant to whether quality care has been delivered? In the case of health care insurance access, costs associated with higher rates of bankruptcies due to medical costs (with default to other creditors as well); higher rates of more serious illnesses and deaths for lack of preventive care or early interventions; and loss of productivity at work as well as loss of jobs are usually kept on a separate “ledger” and not included in calculations of health care costs.

Finally, third-party payers can reduce their costs significantly by establishing co-pays and high deductibles. These cost reductions are shifted directly to consumers. They may, in fact, encourage consumers to forego health care they would ordinarily have used. High co-pays and deductibles, however, are seen as necessary to induce consumers to make financially responsible decisions in their consumption of health care services. See discussion in Chapter 9.
IV. WHAT IS ILLNESS?

We all have an operational definition of health and sickness. I know when I am depressed, have a broken leg, a headache or a hangover. In these circumstances I consider myself to be in ill health because I am not functioning as well as I usually do, even though I may lack a scientific medical explanation of my malaise. But am I in poor health because my arteries are gradually becoming clogged, a process that probably began when I was a teenager? Am I sick or in poor health if I am obese, or addicted to alcohol or drugs, or becoming very old and enfeebled, or struggling with my sexual identity?

We need some definition of health in order to assess the quality of care needed to promote or restore it. A malpractice suit or medical quality audit depends on an ability to distinguish a bad from a good medical care outcome. An understanding of the nature of sickness and health is required to determine what health care society should provide the poor and how much society ought to spend on health care. Should Medicaid (a federal/state health care program for the poor) or a commercial insurer, for example, cover in vitro fertilization or abortions? If the state of being old becomes a state of sickness, does it mean that sickness must be “cured” at public expense? Finally, the definition of health raises questions of autonomy, responsibility, and personhood. Should health be defined by the doctor as scientist or the patient as person, or both?

The Constitution of the World Health Organization defines health as “[a] state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.” When did you last feel that way? Can health ever be achieved under this definition, or is everyone always in a state of ill health? How much can physicians and hospitals contribute to health under this definition? A further provision of the WHO Constitution provides that “[g]overnments have a responsibility for the health of their peoples which can be fulfilled only by the provision of adequate health and social measures.” What are the political ramifications of these principles?

Health can be viewed in a more limited sense as the performance by each part of the body of its “natural” function. Definitions in terms of biological functioning tend to be more descriptive and less value-laden. As Englehardt writes, “The notion required for an analysis of health is not that of a good man or a good shark, but that of a good specimen of a human being or shark.” H. Tristam Englehardt, “The Concepts of Health and Disease,” in Concepts of Health and Disease 552 (Arthur Caplan, H. Tristam Engelhardt, and James McCartney, eds. 1981) (hereafter Concepts).

Boorse compares health to the mechanical condition of a car, which can be described as good because it conforms to the designer’s specifications, even though the design is flawed. Disease is then a biological
malfuction, a deviation from the biological norm of natural function. Illness can be defined as a subset of disease. Boorse writes:

An illness must be, first, a reasonably serious disease with incapacitating effects that make it undesirable. A shaving cut or mild athlete’s foot cannot be called an illness, nor could one call in sick on the basis of a single dental cavity, though all these conditions are diseases. Secondly, to call a disease an illness is to view its owner as deserving special treatment and diminished moral accountability . . . . Where we do not make the appropriate normative judgments or activate the social institutions, no amount of disease will lead us to use the term “ill.” . . .

There are, then, two senses of “health.” In one sense it is a theoretical notion, the opposite of “disease.” In another sense it is a practical or mixed ethical notion, the opposite of “illness.”


Illness is thus a socially constructed deviance. Something more than a mere biological abnormality is needed. To be ill is to have deviant characteristics for which the sick role is appropriate. The sick role, as Parsons has described it, exempts one from normal social responsibilities and removes individual responsibility. See Talcott Parsons, The Social System (1951). Our choice of words reflects this: an alcoholic is sick; a drunkard is not.

Illness has many ramifications. First, it may relieve the individual of certain responsibility. The sick person need not report for work that day; the post-traumatic stress syndrome or premenstrual syndrome victim may be declared not guilty of an assault. A doctor can thus decide whether a patient is culpable or not, disabled or malingering. Sickness also means loss of control. Mild pain may have disproportionate effects on the individual who sees it as the harbinger of cancer or a brain tumor.

Second, a sick person can be assisted by treatment defined by the medical model. The physician can restore control by providing a rational explanation for the experience of impairment. The sick person becomes a patient, an object of medical attention by a doctor. The doctor has the right and the ability to label someone ill, to determine whether the lump on a patient’s skin is a blister, a wart, or a cancer. Perhaps more importantly, illness enjoins the physician to action to restore the patient to health.

Finally, illness costs money. It may cost the patient money in lost time and in medical expenses. And someone receives that money for trying to treat that patient’s illness. But if the patient has private or public insurance, illness means the patient is entitled to have insurance cover some or all of these costs. Thus, our understanding of illness also affects
society. Defining a condition as an illness to be aggressively treated, rather than as a natural condition of life to be accepted and tolerated, has significant economic effects. Medical care is an object of economic choice, a good that many perceive to be different from other goods, with greater, sometimes immeasurable value. Some people are willing to pay far more for medical care than they would for other goods, or, more typically, to procure insurance that will deliver them from ever having to face the choice of paying for health care and abandoning all else. Society may also feel a special obligation to pay for the medical expenses of those who need treatment but lack resources to pay for it.

**KATSKEE V. BLUE CROSS/BLUE SHIELD OF NEBRASKA**

Supreme Court of Nebraska, 1994.

245 Neb. 808, 515 N.W.2d 645.

WHITE, JUSTICE.

This appeal arises from a summary judgment issued by the Douglas County District Court dismissing appellant Sindie Katskee’s action for breach of contract. This action concerns the determination of what constitutes an illness within the meaning of a health insurance policy issued by appellee, Blue Cross/Blue Shield of Nebraska. We reverse the decision of the district court and remand the cause for further proceedings.

In January 1990, upon the recommendation of her gynecologist, Dr. Larry E. Roffman, appellant consulted with Dr. Henry T. Lynch regarding her family’s history of breast and ovarian cancer, and particularly her health in relation to such a history. After examining appellant and investigating her family’s medical history, Dr. Lynch diagnosed her as suffering from a genetic condition known as breast-ovarian carcinoma syndrome. Dr. Lynch then recommended that appellant have a total abdominal hysterectomy and bilateral salpingo-oophorectomy, which involves the removal of the uterus, the ovaries, and the fallopian tubes. Dr. Roffman concurred in Dr. Lynch’s diagnosis and agreed that the recommended surgery was the most medically appropriate treatment available.

After considering the diagnosis and recommended treatment, appellant decided to have the surgery. In preparation for the surgery, appellant filed a claim with Blue Cross/Blue Shield. Both Drs. Lynch and Roffman wrote to Blue Cross/Blue Shield and explained the diagnosis and their basis for recommending the surgery. Initially, Blue Cross/Blue Shield sent a letter to appellant and indicated that it might pay for the surgery. Two weeks before the surgery, Dr. Roger Mason, the chief medical officer for Blue Cross/Blue Shield, wrote to appellant and stated that Blue Cross/Blue Shield would not cover the cost of the surgery. Nonetheless, appellant had the surgery in November 1990.
Appellant filed this action for breach of contract, seeking to recover $6,022.57 in costs associated with the surgery. Blue Cross/Blue Shield filed a motion for summary judgment. The district court granted the motion. It found that there was no genuine issue of material fact and that the policy did not cover appellant’s surgery. Specifically, the court stated that (1) appellant did not suffer from cancer, and although her high-risk condition warranted the surgery, it was not covered by the policy; (2) appellant did not have a bodily illness or disease which was covered by the policy; and (3) under the terms of the policy, Blue Cross/Blue Shield reserved the right to determine what is medically necessary. Appellant filed a notice of appeal to the Nebraska Court of Appeals, and on our motion, we removed the case to the Nebraska Supreme Court.

Appellant contends that the district court erred in finding that no genuine issue of material fact existed and granting summary judgment in favor of appellee.

***

Blue Cross/Blue Shield contends that appellant’s costs are not covered by the insurance policy. The policy provides coverage for services which are medically necessary. The policy defines “medically necessary” as follows: The services, procedures, drugs, supplies or Durable Medical Equipment provided by the Physician, Hospital or other health care provider, in the diagnosis or treatment of the Covered Person’s Illness, Injury, or Pregnancy, which are: 1. Appropriate for the symptoms and diagnosis of the patient’s Illness, Injury or Pregnancy; and 2. Provided in the most appropriate setting and at the most appropriate level of services; and 3. Consistent with the standards of good medical practice in the medical community of the State of Nebraska; and 4. Not provided primarily for the convenience of any of the following: a. the Covered Person; b. the Physician; c. the Covered Person’s family; d. any other person or health care provider; and 5. Not considered to be unnecessarily repetitive when performed in combination with other diagnoses or treatment procedures. We shall determine whether services provided are Medically Necessary. Services will not automatically be considered Medically Necessary because they have been ordered or provided by a Physician. (Emphasis supplied.) Blue Cross/Blue Shield denied coverage because it concluded that appellant’s condition does not constitute an illness, and thus the treatment she received was not medically necessary. Blue Cross/Blue Shield has not raised any other basis for its denial, and we therefore will limit our consideration to whether appellant’s condition constituted an illness within the meaning of the policy.

The policy broadly defines “illness” as a “bodily disorder or disease.” The policy does not provide definitions for either bodily disorder or disease.
An insurance policy is to be construed as any other contract to give effect to the parties’ intentions at the time the contract was made. When the terms of the contract are clear, a court may not resort to rules of construction, and the terms are to be accorded their plain and ordinary meaning as the ordinary or reasonable person would understand them. In such a case, a court shall seek to ascertain the intention of the parties from the plain language of the policy. []

Whether a policy is ambiguous is a matter of law for the court to determine. If a court finds that the policy is ambiguous, then the court may employ rules of construction and look beyond the language of the policy to ascertain the intention of the parties. A general principle of construction, which we have applied to ambiguous insurance policies, holds that an ambiguous policy will be construed in favor of the insured. However, we will not read an ambiguity into policy language which is plain and unambiguous in order to construe it against the insurer. []

When interpreting the plain meaning of the terms of an insurance policy, we have stated that the “‘natural and obvious meaning of the provisions in a policy is to be adopted in preference to a fanciful, curious, or hidden meaning.’” [] We have further stated that “[w]hile for the purpose of judicial decision dictionary definitions often are not controlling, they are at least persuasive that meanings which they do not embrace are not common.’ ”[]

Applying these principles, our interpretation of the language of the terms employed in the policy is guided by definitions found in dictionaries, and additionally by judicial opinions rendered by other courts which have considered the meaning of these terms. Webster’s Third New International Dictionary, Unabridged 648 (1981), defines disease as an impairment of the normal state of the living animal or plant body or of any of its components that interrupts or modifies the performance of the vital functions, being a response to environmental factors . . . to specific infective agents . . . to inherent defects of the organism (as various genetic anomalies), or to combinations of these factors: Sickness, Illness. The same dictionary defines disorder as “a derangement or abnormal physical or mental condition: Sickness, Ailment, Malady.” []

These lay definitions are consistent with the general definitions provided in Dorland’s Illustrated Medical Dictionary (27th ed. 1988). Dorland’s defines disease as any deviation from or interruption of the normal structure or function of any part, organ, or system . . . of the body that is manifested by a characteristic set of symptoms and signs and whose etiology [theory of origin or cause], pathology [origin or cause], and prognosis may be known or unknown. [] Dorland’s defines disorder as “a derangement or abnormality of function; a morbid physical or mental state.” []
[The court looked at similar definitional disputes in other jurisdictions, noting that hemophilia, aneurysms, and chronic alcoholism had been held to be diseases or illnesses under insurance policies.]

We find that the language used in the policy at issue in the present case is not reasonably susceptible of differing interpretations and thus not ambiguous. The plain and ordinary meaning of the terms “bodily disorder” and “disease,” as they are used in the policy to define illness, encompasses any abnormal condition of the body or its components of such a degree that in its natural progression would be expected to be problematic; a deviation from the healthy or normal state affecting the functions or tissues of the body; an inherent defect of the body; or a morbid physical or mental state which deviates from or interrupts the normal structure or function of any part, organ, or system of the body and which is manifested by a characteristic set of symptoms and signs.

The issue then becomes whether appellant’s condition—breast-ovarian carcinoma syndrome—constitutes an illness.

Blue Cross/Blue Shield argues that appellant did not suffer from an illness because she did not have cancer. Blue Cross/Blue Shield characterizes appellant’s condition only as a “predisposition to an illness (cancer)” and fails to address whether the condition itself constitutes an illness. This failure is traceable to Dr. Mason’s denial of appellant’s claim. Despite acknowledging his inexperience and lack of knowledge about this specialized area of cancer research, Dr. Mason denied appellant’s claim without consulting any medical literature or research regarding breast-ovarian carcinoma syndrome. Moreover, Dr. Mason made the decision without submitting appellant’s claim for consideration to a claim review committee. The only basis for the denial was the claim filed by appellant, the letters sent by Drs. Lynch and Roffman, and the insurance policy. Despite his lack of information regarding the nature and severity of appellant’s condition, Dr. Mason felt qualified to decide that appellant did not suffer from an illness.

Appellant’s condition was diagnosed as breast-ovarian carcinoma syndrome. To adequately determine whether the syndrome constitutes an illness, we must first understand the nature of the syndrome.

The record on summary judgment includes the depositions of Drs. Lynch, Roffman, and Mason. In his deposition, Dr. Lynch provided a thorough discussion of this syndrome. In light of Dr. Lynch’s extensive research and clinical experience in this particular area of medicine, we consider his discussion extremely helpful in our understanding of the syndrome.
According to Dr. Lynch, some forms of cancer occur on a hereditary basis. Breast and ovarian cancer are such forms of cancer which may occur on a hereditary basis. It is our understanding that the hereditary occurrence of this form of cancer is related to the genetic makeup of the woman. In this regard, the genetic deviation has conferred changes which are manifest in the individual’s body and at some time become capable of being diagnosed.

At the time that he gave his deposition, Dr. Lynch explained that the state of medical research was such that detecting and diagnosing the syndrome was achieved by tracing the occurrences of hereditary cancer throughout the patient’s family. Dr. Lynch stated that at the time of appellant’s diagnosis, no conclusive physical test existed which would demonstrate the presence of the condition. However, Dr. Lynch stated that this area of research is progressing toward the development of a more determinative method of identifying and tracing a particular gene throughout a particular family, thus providing a physical method of diagnosing the condition.

Women diagnosed with the syndrome have at least a 50-percent chance of developing breast and/or ovarian cancer, whereas unaffected women have only a 1.4-percent risk of developing breast or ovarian cancer. In addition to the genetic deviation, the family history, and the significant risks associated with this condition, the diagnosis also may encompass symptoms of anxiety and stress, which some women experience because of their knowledge of the substantial likelihood of developing cancer.

The procedures for detecting the onset of ovarian cancer are ineffective. Generally, by the time ovarian cancer is capable of being detected, it has already developed to a very advanced stage, making treatment relatively unsuccessful. Drs. Lynch and Roffman agreed that the standard of care for treating women with breast carcinoma syndrome ordinarily involves surveillance methods. However, for women at an inordinately high risk for ovarian cancer, such as appellant, the standard of care may require radical surgery which involves the removal of the uterus, ovaries, and fallopian tubes.

Dr. Lynch explained that the surgery is labeled “prophylactic” and that the surgery is prophylactic as to the prevention of the onset of cancer. Dr. Lynch also stated that appellant’s condition itself is the result of a genetic deviation from the normal, healthy state and that the recommended surgery treats that condition by eliminating or significantly reducing the presence of the condition and its likely development.

Blue Cross/Blue Shield has not proffered any evidence disputing the premise that the origin of this condition is in the genetic makeup of the individual and that in its natural development it is likely to produce devastating results. Although handicapped by his limited knowledge of the
syndrome, Dr. Mason did not dispute the nature of the syndrome as explained by Dr. Lynch and supported by Dr. Roffman, nor did Dr. Mason dispute the fact that the surgery falls within the standard of care for many women afflicted with this syndrome.

In light of the plain and ordinary meaning of the terms “illness,” “bodily disorder,” and “disease,” we find that appellant's condition constitutes an illness within the meaning of the policy. Appellant’s condition is a deviation from what is considered a normal, healthy physical state or structure. The abnormality or deviation from a normal state arises, in part, from the genetic makeup of the woman. The existence of this unhealthy state results in the woman’s being at substantial risk of developing cancer. The recommended surgery is intended to correct that morbid state by reducing or eliminating that risk.

Although appellant’s condition was not detectable by physical evidence or a physical examination, it does not necessarily follow that appellant does not suffer from an illness. The record establishes that a woman who suffers from breast-ovarian carcinoma syndrome does have a physical state which significantly deviates from the physical state of a normal, healthy woman. Specifically, appellant suffered from a different or abnormal genetic constitution which, when combined with a particular family history of hereditary cancer, significantly increases the risk of a devastating outcome.

We are mindful that not every condition which itself constitutes a predisposition to another illness is necessarily an illness within the meaning of an insurance policy. There exists a fine distinction between such conditions . . .

* * *

The issue raised in Fuglsang [] was whether the disease from which the plaintiff suffered constituted a preexisting condition which was excluded from coverage by the terms of the policy. Blue Cross/Blue Shield relies on the following rule from Fuglsang as a definition of “disease”: A disease, condition, or illness exists within the meaning of a health insurance policy excluding preexisting conditions only at such time as the disease, condition, or illness is manifest or active or when there is a distinct symptom or condition from which one learned in medicine can with reasonable accuracy diagnose the disease. []

This statement concerns when an illness exists, not whether the condition itself is an illness. If the condition is not a disease or illness, it would be unnecessary to apply the above rule to determine whether the condition was a preexisting illness. In the present case, Blue Cross/Blue Shield maintains that the condition is not even an illness.
Even assuming arguendo that the rule announced in Fuglsang is a definition of “disease,” “illness,” and “condition,” the inherent problems with the argument put forth by Blue Cross/Blue Shield undermine its reliance on that rule. Blue Cross/Blue Shield emphasizes the fact that appellant was never diagnosed with cancer and therefore, according to Blue Cross/Blue Shield, appellant did not have an illness because cancer was not active or manifest. Appellant concedes that she did not have cancer prior to her surgery. The issue is whether the condition she did have was an illness. Blue Cross/Blue Shield further argues that “[n]o disease or illness is ‘manifest or active’ and there is no ‘distinct symptom or condition’ from which Dr. Lynch or Dr. Roffman could diagnose a disease.” We stated above that lack of a physical test to detect the presence of an illness does not necessarily indicate that the person does not have an illness.

When the condition at issue—breast-ovarian carcinoma syndrome—is inserted into the formula provided by the Fuglsang rule, the condition would constitute an “illness” as Blue Cross/Blue Shield defines the term. The formula is whether the breast-ovarian carcinoma syndrome was manifest or active, or whether there was a distinct symptom or condition from which one learned in medicine could with reasonable accuracy diagnose the disease. The record establishes that the syndrome was manifest, at least in part, from the genetic deviation, and evident from the family medical history. The condition was such that one learned in medicine, Dr. Lynch, could with a reasonable degree of accuracy diagnose it. Blue Cross/Blue Shield does not dispute the nature of the syndrome, the method of diagnosis, or the accuracy of the diagnosis.

In the present case, the medical evidence regarding the nature of breast-ovarian carcinoma syndrome persuades us that appellant suffered from a bodily disorder or disease and, thus, suffered from an illness as defined by the insurance policy. Blue Cross/Blue Shield, therefore, is not entitled to judgment as a matter of law. Moreover, we find that appellant’s condition did constitute an illness within the meaning of the policy. We reverse the decision of the district court and remand the cause for further proceedings.

NOTES AND QUESTIONS

1. Why did the court hold that Katskee was ill when she had no symptoms and no cancer? Can we have a variable definition of illness? For example, could Katskee be ill for purposes of payment for the surgery but not ill for purposes of pre-existing condition exclusions or excusal from work? What about treatment for high blood pressure or arteriosclerosis? The medications to prevent heart attacks are expensive, and are typically covered by health insurance plans. Why would Blue Cross resist covering this treatment for this problem?
2. Katskee was diagnosed with breast-ovarian carcinoma syndrome, a genetically-based condition. Genes for cystic fibrosis, breast cancer, colon cancer, obesity, various aspects of sexuality, violence, and many other conditions, characteristics, behaviors, and personal identities have been identified, and sometimes de-identified, since the 1990s. The explosion of knowledge in genetics is in large part the result of the Human Genome Project (HGP), a project involving sixteen nations and lasting longer than a decade, through which scientists mapped the human genome and developed technologies that greatly enhance further genetic exploration.

What does it mean to have a genetically-related condition or disease? Some genetically-related diseases are monogenic; that is they are associated with the presence of a mutation of a single gene. Even with monogenic conditions, the presence of the mutated gene may not provide a clue as to whether the individual will be severely or moderately affected or will experience no symptoms of the disease at all. Furthermore, while a single gene may be associated with the disease, there may be hundreds of different mutations of that single gene that can signal quite serious manifestations of the disease or none at all. Most conditions associated with genes are not monogenic or even polygenic (requiring the interaction of more than one gene), but rather are multifactorial. Multifactorial conditions, such as cancer, are those in which there is a genetic influence (often requiring the combined effect of several genes) but in which nongenetic elements, including environmental factors, are also essential.

Many genetic conditions require two copies of the relevant genetic material for disease to be expressed; and an individual who carries only one copy of the required material will not have the disease. Examples of such conditions involving what are called recessive genes include sickle cell and cystic fibrosis. If an individual with this genetic characteristic produces children with another individual with the same characteristic, those children may have one copy of the genetic material (a 50 percent chance for each child conceived) or two copies of the genetic material (a 25 percent chance for each child conceived) or none at all (a 25 percent chance for each child conceived). More than 10 million individuals in the U.S. carry one copy of the mutated CFTR gene responsible for cystic fibrosis, for example, and about 30,000 people have the disease itself.

While many diseases involve mutation in genes, not all mutated genes are associated with or cause disease. A mutated gene may not have any health consequences at all. Also, genetic mutations that can trigger disease may occur at any time of life, for example, from environmental toxins or radiation or a virus or aging. Nor are genes necessarily single-effect. Rather, the same gene that is associated with a particular disease may also increase resistance to another.

The method used to identify a genetic connection to particular conditions may also affect the meaning of a genetic “association” with a disease or condition. Most of the genetic connections established prior to the advances of
the latter part of the last century were based on epidemiological studies of the occurrence of particular characteristics or conditions rather than by direct identification of the gene itself. An association between genetic trait and disease established by epidemiological studies alone cannot predict the presence of the trait in any single individual and cannot conclusively rule out that other factors may be required to trigger the disease. A finding of “association” between the presence of a gene or mutation and a particular disease does not establish causation.

Despite dramatic advances in knowledge as a result of the HGP, our everyday language is often inadequate and imprecise. Does it make a difference if something is called a genetic “trait” as compared to a genetic “condition” or a genetic “disease,” “defect,” or “anomaly”? If Katskee were merely a carrier of a recessive gene associated with a genetically-related disorder, would that qualify her as ill? What is the “normal” human genotype? Which genetic traits should be cured, corrected, removed, or, through pre-implantation screening, avoided? Who decides whether a genetic trait should be remedied? Is this a medical decision, a religious decision, a political decision, a social decision, or something else?

3. The syndrome in Katskee, if it materializes, is a medical problem for which the patient bears no responsibility. A more difficult problem area in defining “disease” involves those conditions or syndromes within some control of the individual. Consider for example alcoholism as a disease. What difference does such a label make? What characteristics of alcohol consumption justify the label “disease”? See The National Center on Addiction and Substance Abuse, Addiction as a Disease (2017), noting that “like diabetes, cancer, and heart disease, addiction is caused by a combination of behavioral, environmental and biological factors,” and that the “consequences of untreated addiction often include other physical and mental health disorders that require medical attention.” See also Nora D. Volkow et al., Neurobiologic Advances from the Brain Disease Model of Addiction, 374 N. Engl. J. Med. 363 (2016) (explaining “research has increasingly supported the view that addiction is a disease of the brain” and “[a]lthough [this] brain disease model of addiction has yielded effective preventive measures, treatment interventions, and public health policies to address substance-use disorders, the underlying concept of substance abuse as a brain disease continues to be questioned.”)

Courts have also had to confront the legal significance of such conditions. See, e.g., Ledezma-Cosino v. Sessions, 857 F.3d 1042 (9th Cir. 2017) (en banc) (holding plaintiff, who was a “habitual drunkard,” did not meet the deportation exception for persons of good moral character). A concurring opinion identified the competing characteristics of alcoholism that can lead to different conclusions about how the law should treat people with such conditions:

** ** In my view, Congress could rationally deem habitual drunkards to be at least partially responsible for having developed their condition. Habitual drunkards are those who have allowed themselves to become so addicted to alcohol that they can no longer control their habit of drinking
to excess. That loss of control does not come about overnight; it is acquired as a result of frequent, repetitive acts of excessive drinking. [This] is conduct that Congress could rationally view as volitional, and therefore the proper subject of moral blame.

None of this is to say that Congress’ decision is a wise one. We know considerably more about alcohol addiction today than we did back in 1952, when Congress enacted [the statute]. Scientists tell us, for example, that some people are much more prone to becoming addicted to substances like alcohol than others, with genetic factors accounting for 40 to 70 percent of individual differences in the risk for addiction. In addition, there is a high correlation between alcohol abuse and post-traumatic stress disorder (PTSD), a condition that virtually no one could be blamed for acquiring. As the Surgeon General’s report notes, “[i]t is estimated that 30–60 percent of patients seeking treatment for alcohol use disorder meet criteria for PTSD, and approximately one third of individuals who have experienced PTSD have also experienced alcohol dependence at some point in their lives.

Obesity is another example of a condition whose disease classification has been contested. The AMA did not officially recognize obesity as a disease until 2013, a move that many hoped would remove the stigma associated with it, encourage health care providers to pay more attention to it, and make insurers more likely to cover treatments for it. This decision was made despite contrary recommendations by the AMA’s Council on Science and Public Health. American Medical Association Resolution 115–A–12 (2013). See also Caroline M. Apovian, 374 N. Eng. J. Med. 177 (2016) (“There is good evidence indicating that although obesity may start as a lifestyle-driven problem, it can rapidly lead to disturbed energy-balance regulation as a result of impaired hypothalamic signaling, which leads to a higher body-weight set point. Thus, obesity may be considered a disease initiated by a complex interaction of genetics and the environment.”).

4. In the case of addiction and obesity, the disease label is generally thought to help reduce stigma and increase the opportunity for appropriate health interventions. In other cases, however, people may resist the disease label based on concerns that it may encourage discrimination and even undermine health and well-being. Such concerns were reflected in challenges to the classification of diagnoses related to transgender identity as part of the section on Mental and Behavioral Disorders in the tenth version of the World Health Organization’s International Classification of Diseases (ICD). The term transgender is used broadly to describe people whose gender identity or expression is different from the sex ascribed to them or assigned at birth. The label and definition for gender identity related diagnoses have shifted over time, from Gender Identity Disorder, to Gender Dysphoria, to most recently, Gender Incongruence. These diagnoses refer generally to clinically significant distress caused by a discrepancy or incongruence between one’s experienced or expressed gender and the sex assigned at birth or ascribed to the person.
The process of considering changes to the classification of transgender related diagnoses for the eleventh revision of the ICD (ICD-11), due to be published in 2018, has highlighted the significant health, social, and legal issues at stake. See Rebekah Thomas et al., Ensuring an Inclusive Global Health Agenda for Transgender People, 95 Bulletin of the World Health Organization 154 (2017) (describing the shifting classification of these disorders over time and proposed revisions to ICD-11). Members of the Working Group on the Classification of Sexual Disorders and Sexual Health for the ICD-11 (“Working Group”) published an article explaining the different concerns raised and approaches proposed by human rights organizations, advocacy groups, and professional organizations. For example, some groups wanted such diagnoses removed completely, based on the concern that this pathologizes gender nonconformity and that such diagnoses have been used to target children for unscientific and unethical interventions intended to make them reject their expressed gender identity in favor of the gender ascribed to them. On the other hand, some groups expressed concern that removal of gender identity diagnoses would make it less likely that insurance would cover transition-related care and would make it more difficult for transgender individuals to challenge such denials in court.

Others focused on the stigmatizing effects that classification as a mental disorder would have. The Working Group rejected the idea that the risk of stigma related to mental health alone could be a legitimate basis for removing a diagnosis from the mental disorder section. But the authors did recognize the unique effects this stigma has on transgender individuals—compounding the discrimination they already experience by virtue of their gender nonconformity and potentially having an adverse impact on their health. For example, the authors explained how the association with mental illness has made it more likely that transgender individuals’ competence is unjustifiably questioned in some legal proceedings, such as custody hearings or requests to change identity documents. The authors also noted this stigma has increased the likelihood that transgender individuals are denied care in general medical settings based on the incorrect perception that they need to be treated by psychiatrists, even for conditions unrelated to their transgender status.

The Working Group ultimately proposed reclassifying gender incongruence, moving it out of the section on mental and behavioral disorders. This move was based on the above concerns as well as several additional factors explained below:

From a historical perspective, the classification of gender identity diagnoses as mental disorders appears to have been based more on prevailing social attitudes at the time than of available scientific evidence. In fact, the aetiology of the condition was unknown when placement decisions were made in the past and remains unknown now. There are no scientifically based criteria to differentiate normal and pathological gender identity, and the manner in which any gender identity develops remains unknown and a matter of theoretical speculation. The extant scientific database cannot empirically answer the question of
whether this diagnosis is purely a mental disorder or a disorder with another physical cause. There are a growing number of studies that posit physical rather than mental causes of transgender presentations ***. Further complicating matters, the criteria of distress and impairment that is often required for mental disorders of unknown aetiology are not universally applicable, as there are individuals who today present for gender reassignment who may be neither distressed nor impaired. This may be particularly true for young adolescents who are aware of the possibility of gender transition, live in an accepting environment, and who can have access to puberty suppressing treatments until they are able to take such a decision. ***

*** [Based on the classification of gender incongruence as a mental disorder, as well as the need to distinguish it from other mental disorders, many countries require psychiatrists and other mental health professionals to act as gatekeepers to transition services for transgender people. In some countries, transgender people wishing to transition must prove to psychiatrists that they are the ‘right’ kind of transgender and that they have been so for a sufficiently long period of time in order to qualify for services. This has created some controversy, as many individuals seeking transition do not otherwise have a mental disorder or desire mental health treatment, and the gatekeeping function may be seen as an unnecessarily burdensome requirement. *** Further, this requirement may strain resources in countries that have few mental health professionals.

The gatekeeping role has also sometimes interfered with the positive contributions that mental health professionals can make to the transition process. Counselling and therapeutic approaches may be very important in helping an individual prepare for and cope with the personal and social effects of transition. In this regard, the role of mental health professionals is not fundamentally different from their participation as a part of assessment and treatment for individuals undergoing other complex, life-changing medical treatments such as organ transplantation.

None of the direct treatments prescribed for the condition today could be construed as conventional mental health treatments given that standard approaches today (hormonal, surgical, voice therapy, depilation) involve changing the body and social role rather than changing the individual’s mind. There is no reason to expect that this approach will change in the foreseeable future. *** While the Working Group believes that mental health professionals can play a constructive role in the assessment and treatment of many transgender people as a part of their transition process, it also believes that their involvement in treatment should be based on standards of care, clinical necessity, and health system policies, rather than artificially sustained by a mental disorders classification.
See Jack Drescher et al., Minding the Body: Situating Gender Identity Diagnoses in the ICD-11, 24 International Review of Psychiatry 568 (2012). In determining whether to classify a particular condition as a disease, or which disease category should apply, should social and legal considerations be permissible, or should only medical and scientific considerations be used? Should the answer depend on the identity of the decision maker, the reasons for the label, or how much we know about the etiology of the condition?

**Problem: The Couple’s Illness**

You represent Thomas and Jill Henderson, a couple embroiled in a dispute with their health insurance plan over coverage of infertility treatments. The Hendersons have been having trouble getting pregnant. Thomas has a low sperm count and motility, while Jill has irregular ovulation. They have undergone infertility treatment successfully in the past and have one child. They sought further treatment in order to have a second child. A simple insemination procedure failed. The health and disability group benefit plan of Thomas’s employer, Clarion, paid their health benefits for this procedure.

They were then advised to try a more complex and expensive procedure, called Protocol I, which involved treating Thomas’ sperm to improve its motility. Drug therapy was prescribed for Jill to induce ovulation. Semen was then taken from Thomas, and put through an albumin gradient to improve its motility. The semen was then reduced to a small pellet size and injected directly into the uterine cavity at the time of ovulation.

The Hendersons underwent Protocol I and submitted a bill to Clarion, which refused to pay it. Clarion cited a provision in its plan, Article VI, section 6.7, which provided:

If a covered individual incurs outpatient expenses relating to injury or illness, those expenses charged, including but not limited to, office calls and for diagnostic services such as laboratory, x-ray, electrocardiography, therapy or injections, are covered expenses under the provisions of [the plan].

Under section 2.24 of the plan, “illness” was defined as “any sickness occurring to a covered individual which does not arise out of or in the course of employment for wage or profit.” Clarion denied the Hendersons’ claim on the grounds that the medical services were not performed because of any illness of Jill or Thomas, as required under section 6.7. No provisions in the plan specifically excluded fertilization treatments like Protocol I.

What arguments can you make on behalf of the Hendersons that their situation is an “illness”? What arguments can you make for the insurance company that it is not?