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LEGAL ISSUES IN MEDICINE

WHEN SHOULD PREVENTIVE TREATMENT BE PAID FOR BY HEALTH INSURANCE?

GEORGE J. ANNAS, J.D., M.P.H.

In the national debate about who should have health insurance, surprisingly little attention has been focused on what medical services health insurance itself should cover. Historically, discussions of this topic have centered on concepts such as basic health care or medically necessary care.¹ When the power of medical diagnosis and treatment was limited, these terms had boundaries as well. As physicians' diagnostic prowess has increased, however, especially in the area of genetics, such terms have become open-ended. To avoid predictable conflicts over benefit coverage, much more precise definitions will be required, so that patients and health care providers can understand what is and is not covered by the patient's health insurance plan.²

Although it did not resolve the problem of defining coverage, a recent dispute brought before the Nebraska Supreme Court illustrates the issues that courts will confront more and more frequently if policy makers, physicians, and health care plans do not do a better job of defining the content of health insurance benefit packages.³

THE DISPUTE

Blue Cross–Blue Shield of Nebraska refused to pay for surgery to remove Sindie Katskee's ovaries and uterus because, in their view, the operation was not medically necessary and thus not covered by her insurance policy. The policy, like most, defined medically necessary services as those used in the diagnosis or treatment of 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.³

In 1990 Katskee, on the recommendation of her gynecologist, consulted with Henry T. Lynch, an expert in hereditary cancer, about her family history of breast and ovarian cancer. Katskee's mother and aunt had both died of ovarian cancer; one was diagnosed at 47

years of age, the other at 48 years. Because of this family history, it was estimated that Katskee (and her two sisters) had a 50 percent probability of eventually having breast or ovarian cancer. In the absence of such a family history, the risk of ovarian cancer was said to be about 1.5 percent. Dr. Lynch believed that a total abdominal hysterectomy and bilateral salpingo-oophorectomy was, under the circumstances, "a prophylactic procedure for a genetically predisposed disease," and he recommended it.⁴ He also described Katskee's condition as "hereditary ovarian cancer-proneness," as a "genetic predisposition to an illness," and as "breast–ovarian carcinoma syndrome."⁴

Blue Cross–Blue Shield denied coverage for the surgery (which was performed by another physician) on the grounds that familial breast–ovarian carcinoma syndrome was not an illness at the time of the surgery and therefore the surgery was not medically necessary. The decision was made by the medical director of Blue Cross–Blue Shield without consultation with medical experts or a review of the medical literature regarding breast–ovarian carcinoma syndrome.³

The trial judge granted Blue Cross–Blue Shield's motion for summary judgment. On the basis of the depositions of the physicians involved and oral arguments by the lawyers, the trial judge decided that Katskee "did not have a bodily illness or disease," and the surgery was therefore not covered by her policy.³ Katskee appealed. The Supreme Court of Nebraska reversed the lower court decision and ruled in her favor.

THE OPINION OF THE NEBRASKA SUPREME COURT

The Supreme Court of Nebraska characterized this as a dispute over the meaning of the language used in an insurance contract. In such disputes, contracts are interpreted so as "to give effect to the parties' intentions at the time the contract was made."³ In determining the meaning of the words used in an insurance policy (or any other contract), courts often refer to dictionary definitions and to other judicial opinions that have construed the meaning of the words.

The Nebraska court found that the words "illness," "sickness," and "disease" are often used interchangeably, and it cited with approval the definition of disease in *Dorland's Illustrated Medical Dictionary* (27th edition, 1988):

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, pathology, and prognosis may be known or unknown.

The court also cited with approval the definition adopted by the Iowa Supreme Court (which found that the terms "illness," "sickness," and "disease" were used as synonyms in the context of an insurance policy): "a morbid condition of the body, a deviation from the healthy or normal condition of any of the functions or tissues of the body."⁵ On the basis of these and other definitions in common use, the court concluded that

the language of the policy was not ambiguous but, rather, that it had adopted the “plain and ordinary meaning” of the word illness to

encompass 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.³

Once the court adopted this definition, the only remaining question was whether breast-ovarian carcinoma syndrome qualified as an illness. The court found that it did. In reaching this decision, it relied heavily on the deposition of Dr. Lynch, especially his statements that such surgery is performed as prophylaxis against the onset of cancer and that the at-risk condition itself is the result of a genetic deviation from the normal, healthy state.^{3,4} In the court’s words, “the recommended surgery treats that condition by eliminating or significantly reducing the presence of the condition and its likely development.”³ The court was also influenced by the fact that Blue Cross-Blue Shield offered no evidence to dispute the genetic origin of the condition, nor did it dispute the likelihood that the syndrome would produce “devastating results” in its “natural development.” The court concluded that the patient did have an illness within the meaning of the policy, because her

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.³

The court went on to conclude that even though there was no “detectable physical evidence” of the illness, Katskee nonetheless did “suffer from a different or abnormal genetic constitution.” On the other hand, the court noted that not every condition that “itself constitutes a predisposition to another illness is necessarily [itself] an illness,” but only one that “in its probable and natural progression may be expected to be a source of mischief.”³

PREVENTIVE INTERVENTIONS

It is easy to understand the court’s sympathy for the patient in this dispute. She feared the development of the type of cancer that had killed two close relatives, her two sisters had undergone prophylactic hysterectomies and oophorectomies, and her physicians estimated her own risk of cancer at 50 percent. Moreover, Blue Cross-Blue Shield made no effort to determine the medical or scientific basis of her claim, but rejected it in a seemingly arbitrary manner. Most important, the language of the insurance policy was general and apparently open-ended, permitting the court to inter-

pret it in the patient’s favor. Nonetheless, although the court’s opinion is understandable, following it to its logical conclusion would lead to undesirable consequences.

Since language limiting coverage to “medically necessary” treatment of “illness” exists in most health insurance policies, the problem of interpreting such language is a nationwide one. “Illness,” “disease,” and “sickness” are used interchangeably in most insurance contracts and are extremely broad terms. That is why the phrases “medically necessary” and “medically necessary or appropriate” have been used to set the boundaries for coverage, both for individual health plans and for national health-coverage proposals. But the term “medically necessary” may have even less specific meaning than the term “illness”; reliance on this term increasingly offers an invitation to physicians and patients to challenge medical insurers over coverage.⁶

In the Nebraska case, the patient and her physicians believed that her treatment was necessary. Although her Blue Cross-Blue Shield policy stated that a treatment is not medically necessary just because a physician says it is, it is difficult to come up with a much better definition of medical necessity. The patient and her physicians, for example, concluded that surgery was necessary to prevent ovarian cancer, but not necessary to prevent breast cancer. Since the risk of these two cancers was said to be equal in this case (about 50 percent), what accounts for the difference? In his deposition, Dr. Lynch testified that the primary distinction was that there was a method for detecting breast cancer early (mammography) that did not exist for ovarian cancer.⁴ Given the existence of this method, he recommended prophylactic bilateral mastectomy only for women at high risk who were “cancer-phobic” to such an extent that the fear seriously disrupted their lives. Since that was not an issue in this case, there was no discussion of whether in those other cases the court would have considered a prophylactic bilateral mastectomy medically necessary, or whether breast implants after such surgery would also have been medically necessary. Nonetheless, its opinion suggests that the court would have found both these procedures covered by the policy had the patient and physician agreed they were necessary.

SHOULD PROPHYLACTIC SURGERY BE COVERED BY HEALTH INSURANCE?

How should we decide which prophylactic medical and surgical treatments should be covered in a national health plan (or a private health insurance plan) in a country that is rapidly developing diagnostic tests for genetic conditions that predispose all of us to serious diseases? These genetic tests will, of course, be much more specific than the family history used in the Nebraska case, and pedigrees based on genetic markers are currently used in genetic-research protocols.⁷

There are many possible approaches, but none that seems inherently superior. The first is for physicians to

decide when treatment of a “genetic predisposition” is medically necessary. This standard is open-ended and somewhat arbitrary, since obviously physicians may disagree. Dr. Lynch, for example, had no hesitation in describing the recommended surgery as a necessary “life-saving potential procedure.”⁴ Others might think it always unnecessary or believe that its necessity would be a function of the patient’s age and wishes regarding childbearing. There have been no studies of the effectiveness of such surgical interventions, and their efficacy must be considered unproved at this time.⁸

Another alternative is to let the patient decide what prophylactic treatments are medically necessary. But this, of course, defeats the purpose of having an insurance contract. The patient must consent to prophylactic treatment. But it would be strange, indeed, if the patient could demand that the insurance company pay for it primarily because of his or her fear of cancer or death or because of his or her desire for the treatment. There should be safer, cheaper, and more effective interventions to deal with these states of mind, and no intervention can ever entirely eliminate the risk of cancer or death.

A more attractive alternative might be based on a cost-effectiveness analysis that includes anxiety and fear (as surrogates for the quality of life) as one factor in the determination of necessity.⁹ In this regard, it might be considered reasonable to perform surgery in any woman with a greater than 50 percent risk of a lethal cancer in early or mid-life, but not with a smaller risk or a likelihood of onset later in life. Any cutoff percentage, age, or combination of the two will be arbitrary, and perhaps ultimately politically unacceptable.¹⁰ But most would agree that it is unreasonable to pay for prophylactic mastectomies for any woman with the usual risk of having breast cancer in her lifetime (12 percent). Similarly, it would be foolish for a national health system to provide everyone with an artificial heart (when and if such devices become safe and effective) on the basis of the general risk of dying of heart disease (50 percent) and the particular patient’s wishes.

The central question is when, if ever, genetic predisposition to cancer or any other disease should itself be considered a “disease” for which treatment is necessary or appropriate. Now that the gene for breast cancer has been identified, for example, it will soon be possible to screen not only women but also fetuses, neonates, children, and adolescents for this gene.⁸ Since prophylactic surgery (or any other medical intervention) would be seen by virtually everyone as medically inappropriate and unnecessary in the latter groups, it seems reasonable that possessing the breast cancer gene alone should not be considered an illness for members of these groups. Nonetheless, the logic of the Nebraska opinion suggests that the court would not make this distinction.

Finally, if we decide that a genetic predisposition to

a disease is itself a disease, at least sometimes, is it a preexisting condition that could be used as a reason for exclusion or disqualification for coverage in an individual health insurance policy? To be consistent, the Nebraska court would have to conclude that a genetic syndrome is a preexisting condition, the treatment of which could be excluded from coverage on this basis. Since we all have a number of genetic predispositions that are likely to manifest themselves if we live long enough, this view would require us to conclude that we are all diseased from the moment of conception. Although this statement seems absurd, we are all genetically “ill,” no matter what our physical condition, if the logic of the Nebraska court is accepted and extended.

SOME APPROACHES TO THE PROBLEM

Although the Nebraska case raises more questions than it answers, it does help to clarify some important issues. First, courts will continue to be called on to decide insurance-coverage disputes in individual cases. Moreover, courts will probably side with the physician and patient whenever the language of the insurance policy permits them to do so.^{11,12} If disputes continue to be rare events, this system is workable. But as the number of diagnostic tests for asymptomatic conditions increases, an increase in such disputes is inevitable and clearer definitions are desirable.^{2,6}

Second, we must come to grips with what we mean by prevention — as opposed, for example, to predictive medicine — and when preventive surgery is appropriate. The use of the term “medical necessity” will no longer help us. As Daniel Callahan has noted, “We want to avoid sickness and death. We require whatever it takes to do so. Those are our needs.”¹³ But since we will all die of something, and since this something will almost always have a genetic component, we all have genetic predispositions to terminal illnesses; we just don’t have the power to diagnose or treat them yet.¹⁴ The new genetics tends to eradicate the distinction between prevention and treatment, and thus may make us refocus our attention — away from the question of what medical interventions should be covered to the much more profound one of why medical interventions should be used in the first place.

Since this question is so difficult, we are likely to continue to take a procedural approach to the problem of coverage in the short term. Insurance companies and health care plans are likely to keep the language of their policies vague. Because insurance companies cannot constrain benefits with contract language alone, they are likely to count on the changing financial incentives facing physicians to limit increases in both volume and intensity of care. The gradual replacement of the fee-for-service system with various forms of capitated managed care is currently seen as the primary way to slow the proliferation of new “diseases” and new interventions to address them, and thus the cost of care. This approach will probably ultimately fail, because it

will be seen as arbitrary and unfair, and we will try still others — such as national coverage requirements with or without the assistance of some type of politically accountable national health board. But even this mechanism will not succeed in the minds of patients, physicians, and judges unless we all come to grips with our fear of death and our desire to avoid it at any cost to our health insurers.

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BOOK REVIEWS

THE SAVAGE CHILD

SECRET OF THE WILD CHILD

VHS videocassette, running time 60 min. Boston, NOVA Star of Science Television/WGBH, 1994. \$19.95. *This video will be broadcast on public television on October 18 at 8 p.m. Eastern time.*

In 1970, a girl who had been literally imprisoned in a 10-ft-by-14-ft room from the age of 2 years to the age of 13 came to the attention of Southern California authorities. The reasons for her cruel treatment are unclear. Her father committed suicide the day after she was found; her mother thought her to be mentally impaired. When she was found her height and weight were at the 10th percentile for her age, she had little speech, she walked in a stooped position, and she had permanent calluses on her buttocks from having been strapped to a potty seat for hours at a time. There was no radio or television in the room, and the only magazines had all the pictures torn out. Given this history, one might have expected the child to be ravingly psychotic. She was not. Rather, she was a lovely, charmingly innocent child, who responded readily to warmth and attention. At the hospital to which she was taken, they called her Genie.

This Nova documentary chronicles Genie's life for the first five years after she left her home prison. Incorporating amateur videos, commentary, and scenes from François Truffaut's movie *The Wild Child*, the documentary tells several interrelated stories that raise many human, ethical, and scientific questions. This unique child elicited a variety of reactions in those about her, and their reactions tell us as much about health professionals and researchers as they do about Genie.

Of the several narratives in this tapestry, Genie's is certainly the most poignant and heart-rending. Despite her thinness, bent-over stance, loping gait, and guttural vocalizations, Genie was a lovely child whose sweetness of expression and eager response to kindness and attention evoked compassion and caring, even in those who met her casually on an outing to the park or to the store. Although she made progress over the five years, her fate was not unlike that of Victor, the "wild child" of Truffaut's film, who was discovered in a French forest over 150 years ago. This child, found at about the same age as Genie and trained for six years by the physician Jean Itard, ended his life in a foster home.

A second story is that of one of Genie's teachers at the Los

Angeles Children's Hospital, where Genie was placed after first being discovered. Genie elicited megalomaniacal fantasies in this woman, who believed she was an extraordinary teacher. She saw herself as a "miracle worker" who would do for Genie what Annie Sullivan had done for Helen Keller. She attempted to adopt the child. Fortunately, the extent of the woman's disturbance was recognized, and she was not awarded custody of Genie.

Shortly after Genie returned to the hospital, an arrangement was made for her to live with the psychologist assigned to the case, David Rigler, and his family. Thus began another story. The Rigers served as surrogate parents, tutors, therapists, and researchers. These mixed roles were not easy, and Genie was not always a passive child. She had fits of temper and often hid food that was not discovered until it had spoiled. Genie made some progress under the Rigers' care and even attended a nursery school for a while. She also began to deal with her past, at least a little, and was able to express some anger about the treatment she had received.

While she was at the Rigers' home, Genie was also the subject of an ongoing program of language training and assessment. This is the scientific story. Genie came on the scene just at the time when Noam Chomsky's work on inborn generative grammars was becoming influential. B.F. Skinner's contrasting description of "verbal behavior" as entirely learned was also gathering attention from researchers, as was Eric H. Lenneberg's theory that brain growth was such that it was difficult, if not impossible, to acquire language after the age of 12 or 13. Language acquisition was thus a very hot field when Genie appeared, and many linguistic researchers saw her as the "forbidden experiment" that would allow them to test their competing theories.

A graduate student in linguistics, Susan Curtiss, was assigned to teach Genie to speak and to assess her progress. There are many moving scenes of Curtiss interacting with Genie and evidence of the child's growing vocabulary. Although Genie did learn many words and could correctly label many objects, she was never able to organize words into meaningful sentences. In this regard, she resembled Itard's pupil Victor, who also had learned words but was never able to assemble them grammatically.

After four years, the National Institute of Mental Health, which had supported Genie's stay at the Rigers' and their efforts to study her progress, withdrew its support. The agency was unhappy with the lack of research direction and the absence of systematic data collection. The Rigers, who had