Perils, Pitfalls, and Possibilities in Talking About Medical Risk

Sidney T. Bogardus, Jr, MD Eric Holmboe, MD James F. Jekel, MD, MPH

OU TELL ME THE CHANCE OF BEcoming incontinent from this surgery is 5%. What does that mean? If I get it, it's 100% for me, right?" (spoken by a patient in a study examining perceptions, risks, and benefits of treatments for localized prostate cancer).

The patient quoted is facing a difficult choice: whether to undergo radical prostatectomy for localized prostate cancer. As he considers his options, he must also consider the potential for unwanted consequences from each choice: the risks. Understanding risk is crucial to appropriate decision making, yet it is also a complex task that mixes objective information (What is the risk? How often does the unwanted outcome occur?) with subjective information (How important is this potential unwanted outcome to me?). This patient's case illustrates the importance of risk to individuals, but risk is also important on a societal and policy level, as illustrated by the ongoing controversy regarding the appropriateness of screening mammography for women in their 40s. Here, we suspect, part of the controversy stems from uncertainty regarding the risks involved (the risks of developing breast cancer in this age range, the risks of falsepositive mammogram results, etc), or from differences in the interpretation of the magnitude of the various risks.

Every course of action or inaction in medical care may be associated with both risks and benefits. In discussing the options for managing diverse conditions, physicians must decide how much and what kind of information to present and Virtually every course of medical action is associated with some adverse risk to the patient. Discussing these risks with patients is a fundamental duty of physicians both to fulfill a role as trusted adviser and to promote the ethical principle of autonomy (particularly as embodied in the doctrine of informed consent). Discussing medical risk is a difficult task to accomplish appropriately. Challenges stem from gaps in the physician's knowledge about pertinent risks, uncertainty about how much and what kind of information to communicate, and difficulties in communicating risk information in a format that is clearly understood by most patients. For example, a discussion of the risk of undergoing a procedure should be accompanied by a discussion of the risk of not undergoing a procedure. This article describes basic characteristics of risk information, outlines major challenges in communicating risk information, and suggests several ways to communicate risk information to patients in an understandable format. Ultimately, a combination of formats (eg, qualitative, quantitative, and graphic) may best accommodate the widely varying needs, preferences, and abilities of patients. Such communication will help the physician accomplish the fundamental duty of teaching the patient the information necessary to make an informed and appropriate decision.

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how to frame the discussion. These discussions are constrained by frequent gaps in the state of medical knowledge, the limited knowledge of individual physicians concerning existing data, and patients' differing abilities and desires to understand the details of their conditions and treatments. Furthermore, advances in medical knowledge, concerns about liability, and the expanding influence of economic concerns in health care create pressures that may influence the medical decision-making process, even at the level of individual decisions.

Despite these pressures, communicating information about illnesses, treatments, and prognoses is a frequent and fundamental duty of the physician. The duty stems in large part from the primacy of the ethical principle of autonomy, particularly as embodied in the doctrine of informed consent.¹ Patients must understand the risks and benefits of the options they face to make informed decisions that are appropriate both medically and personally, and physicians must be able to provide suitable, accurate information about risks and benefits in personal, accessible terms to fulfill their essential roles as trusted advisors. Frequently, however, risk is not mentioned at all in medical encounters^{2,3} perhaps a reflection of our unease with the existence of risks in the first place.

Our goals in this article are to describe basic dimensions of medical risk, the challenges involved in discussing risks, and some of the options for presenting risk in-

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Author Affiliations: Departments of Internal Medicine (Drs Bogardus and Holmboe) and Epidemiology and Public Health (Dr Jekel), Yale University School of Medicine, New Haven, Conn.

Corresponding Author: Sidney T. Bogardus, Jr, MD, Yale University School of Medicine, Yale–New Haven Hospital, 20 York St, TMP 15, New Haven, CT 06504 (e-mail: bogardus@gwpo.ynhh.com).

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TALKING ABOUT MEDICAL RISK

formation. The concept of risk generally embodies at least 2 distinct notions: first, an unwanted outcome, and second, some uncertainty about the occurrence of that outcome.^{1,4} We use the term *risk* in the sense of this common use, but try to use the corresponding terms *unwanted outcome* and *probability* when we discuss those aspects of risk. We focus specifically on the communication of risk information from physician to patient because of the centrality of this relationship in health care decisions.

FUNDAMENTAL CHALLENGES What Are the Risks?

Ascertaining the pertinent risks is the first major challenge the physician faces in considering risk. Discussions of risks in medicine involve not only the chance of death but a myriad other outcomes (eg, vegetative state after cardiopulmonary resuscitation, incontinence following surgery for localized prostate cancer, missed subarachnoid hemorrhage in a patient with a new headache).

Understanding pertinent risks, however, does not mean simply knowing the identity of the risks; the concept of risk has several fundamental dimensions, and explicit consideration of these dimensions may facilitate more appropriate discussions (TABLE 1).

What Are the Pertinent Unwanted Outcomes? Identification of pertinent unwanted outcomes is the first task of the physician in approaching medical risk and requires objective description of the outcome of interest (eg, death, disability, pain). The identity of the outcomes is often determined by the activity that provokes the risks. For example, the chance of dying from playing sports is low, but the risk for certain injuries may be reasonably high, such as knee injuries in football. In medicine, there may be several easily identifiable risks associated with an action, ranging in severity from mild (eg, minor nausea or pain) to moderate (eg, complication requiring further therapy and time lost from work) to severe (eg, death).

Identifying the pertinent unwanted outcomes will be difficult if some or all of the risks are not known or fully understood in a given situation. In some situations, one may even have to decide whether a given outcome represents a risk or benefit. For example, chemotherapy might allow a person to live longer with an otherwise incurable cancer. This added life expectancy might be a benefit to some people but for others, the extra time spent in discomfort would be a risk. Most of the time, however, the benefits and risks will be clear. Living longer and having a better quality of life are benefits whereas dying sooner and developing pain or loss of function are unwanted outcomes.

How Permanent Is the Unwanted Outcome? The permanence or duration of an unwanted outcome is a second dimension of risk—one that may tip the balance in favor of or against a certain course of action. Some unwanted outcomes may be permanent (eg, death) whereas oth-

Table 1. Five Basic Dimensions of Risk	
Dimension	Challenges
Identity	Some risks may not be known (eg, new therapies or technologies) Is it a risk, benefit, or both (eg, chemotherapy for cancer = longer survival but more pain and adverse effects)?
Permanence	Is the risk temporary (eg, infection after surgery) or permanent (eg, incontinence after prostatectomy)? If the risk is temporary, for how long?
Timing	When is the risk likely to occur (eg, restenosis after angioplasty, liver damage from taking troglitazone)? Weighing risks that occur at different times–now vs later (eg, coronary artery bypass grafting vs medical therapy for coronary artery disease)
Probability (quantitative frequency)	How likely is the risk for each individual patient? How should the probability be communicated to patients (eg, relative risk, absolute risk, or number needed to treat)? Is the probability of the risk a 1-time occurrence or cumulative?
Value (subjective "badness")	How does each patient perceive the importance of the risk for him/herself?

ers may be transient (eg, pain). For the appropriate benefit, many patients may be willing to face a high chance of severe impairment as long as it will be transient, but may balk if the impairment will be long lasting or permanent. In the case of surgery for prostate cancer, the possibility of permanent incontinence or impotence may sway some patients to favor watchful waiting.

When Will the Unwanted Outcome Occur? The third dimension of risk is its timing. Outcomes may occur very soon (eg, not surviving an operation, becoming nauseated following administration of medicine), in several months (eg, restenosis of a cardiac vessel following angioplasty), or in several years (eg, developing a blood malignancy from aggressive chemotherapy of a previous cancer). For example, patients with multivessel coronary artery disease are often faced with a difficult decision; surgical therapy results, on average, in improved life expectancy in the long run, but complications may lead to early death or significant short-term morbidity. The patient may be trying to balance present benefit with future risk or, conversely, may be deciding whether to accept significant present risk for possible future benefit. In economically derived models of health care decisions, such as cost-effectiveness models, one of the key assumptions is that time in the present is more valuable than time in the future and, hence, future benefit is "discounted." But the weight given to something that happens now as opposed to in the future is a highly individual function, and models based on the average will not be meaningful to many patients.

How Likely Is the Unwanted Outcome? The fourth dimension of risk is its probability (ie, how likely is the unwanted outcome?). This number is known with varying degrees of certainty for different risks,⁴ and errors in the quantitative assessment of risks may be common.⁵ For physicians, this number may simply be difficult to remember. Additionally, the distinction between risk due to a single exposure and cumulative risk from multiple exposures may have to be considered. Probability may be the most

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difficult element to communicate in an understandable way to many patients.

How Much Does the Unwanted Outcome Matter to the Patient? The fifth and perhaps most important—dimension of risk is its value to the patient; that is, its subjective "badness." Different patients will inevitably rate some adverse outcomes differently. What one person views as catastrophic may be viewed by another as an impediment that does not detract from overall quality of life. The ultimate determination of importance is subjective.

The first 4 fundamental dimensions of risk-identity, permanence, timing, and probability-may help patients determine a personal value for the risk. In general, the value of most risks is closely allied with their identity. For example, death and mutilation are usually considered risks of great importance, whereas transient nausea would usually be considered a risk of relatively low significance. A risk may seem more tangible to a patient if it is serious and has a high chance of occurring in the short term. On the other hand, risks with a low chance of occurrence or those that would happen in the distant future may seem more nebulous or less threatening, even serious risks, such as death. Because the probabilities can often be very small, risks may not be conceptually accessible to patients trying to make decisions.

The value placed on a risk may be partly explained by concepts of risk perception developed by Slovic,⁶ in which risk is arranged along 2 axes relating to dread and uncertainty. Dread risks, such as nuclear reactor accidents, are uncontrollable, catastrophic, and not equitable, whereas risks from things like caffeine or aspirin are controllable, individual, and equitable. Uncertain risks, such as those from nitrogen fertilizers, are not observable, unknown to those exposed or the scientific community, and delayed, in contrast with risks such as automobile crashes, that are observable, known to those exposed and the scientific community, and immediate. Although they are derived from mostly nonmedical technologies, the concepts of dread and uncertainty may help explain why patients fear some medical risks, even

those that are uncommon, more than others that are far more common.

Failure to acknowledge and discuss a patient's perceptions of risk may lead to decisions that both the patient and physician later see as unsatisfactory. For example, a woman without risk factors might choose mammography at age 40 years because of a morbid fear of breast cancer and then regret the trauma of a false-positive mammogram and its attendant stressful evaluation. It is the responsibility of the physician, as the most valued giver of information, to facilitate understanding of risk by addressing potential errors or biases in perception and to help place individual risks within the context of all risks and benefits for all alternatives in a given situation.

Which Risks Should Be Discussed?

Selecting the risks to discuss is the second challenge in risk communication. The physician must judge whether to address all conceivable risks, just the most common risks, or only the most important risks. For example, one can discuss the global level of risk from playing football, including injury, medical cost, and time lost from study or work, or a specific outcome, such as muscle aches, knee injuries, or deaths. The former approach has been called a *thick* conception of risk; that is, a conception that comprises a broad range of harms, including social losses and costs; the latter approach has been called a thin conception of risk, focusing only on physical harm.⁷

Regardless of the viewpoint, different treatments will carry different risks. How should physicians decide which risks to disclose? Various standards have been espoused, including the professional standard, in which the information that would generally be disclosed by a community of medical peers sets the standard, and the increasingly recognized reasonable person standard, in which the information that a reasonable person in the patient's position would want to be told sets the standard.1 Neither standard explains precisely how a physician should decide what a reasonable person would want to be told. Disclosure may vary depending on the unusualness of the procedure and the probability of the outcome, although risks of death, disability, and disfigurement generally should be revealed.¹

How Should a Physician Discuss Risks With a Patient?

The way a discussion is framed may help determine the decision a person reaches,⁸⁻¹¹ and features such as the physician's tone of voice or body language or the choice of what information to present first may influence the patient's perception of risk. Even the language chosen may contain loaded terms that can jeopardize unbiased communication. Risks may be considered avoidable or unavoidable, justifiable or unjustifiable, acceptable or unacceptable, serious or nonserious, or rare or common.12 For example, what seems acceptable to one person may seem unacceptable to another (eg, whether impotence following prostate surgery is serious or not depends on individual perspective).

Qualitative vs Quantitative Probability. While the nature of an unwanted outcome must be described qualitatively, the probability can be described either qualitatively (eg, with terms such as rare or infrequent) or quantitatively (eg, with expressions such as "1 in 100"). Some patients may prefer to hear only qualitative descriptions of numerical probability, whereas others would like to "be given the numbers."^{13,14} Qualitative descriptions of probability have the attraction of using common words that seem to be generally understood.15 However, these words, of which there are many, have no generally accepted anchoring at specific quantitative levels of frequency,¹⁶ despite efforts to promote such an anchoring.12,15 Whether the variability in interpretation of qualitative terms is enough to be clinically important is controversial. A rare outcome may deserve close attention if it is death, but a rare outcome that is minor may require no further quantification.

Quantitative Expressions for Risk. The imprecise nature of qualitative expressions of risks has led some authors to urge that they be avoided and that risk information be imparted with strictly nu-

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merical expressions.^{17,18} There are many options for such expressions, including absolute or relative differences in the proportion of an outcome with 2 treatments, the frequency with which an outcome occurs in a certain cohort size, the average loss of life expectancy from a given exposure,^{19,20} the so-called safetydegree scale (the logarithm of the cohort size in which 1 adverse event would be expected to occur),²¹ and the number needed to treat²²⁻²⁴ (the reciprocal of the absolute difference in proportions of patients with a given outcome from 2 treatments or actions, which states the number of patients who must be treated to generate 1 outcome).

Beyond the question of whether patients will understand the difference between relative and absolute differences or the meaning of average loss of life expectancy, there is the complementary issue of which expression to choose. Simply altering the choice of a numerical format can change preference for one course of action instead of another, even if the 2 courses of action have quantitatively identical outcomes.8,10 For example, outcomes can be framed in terms of survival rates or mortality rates; a death rate of 10% may seem quite different from a survival rate of 90%. As another example, a glass half empty may be perceived differently from a glass half full, and there will usually be a preference for the latter. Fortunately, in this instance there is a neutral description that is often lacking in discussions of medical risks (the 8-oz glass has 4 oz of liquid in it).⁷

The framing of outcomes in terms of absolute and relative differences¹⁰ can be manipulated to make a course of action appear more or less favorable or unfavorable. A relative risk reduction of 50%,

for example, is less impressive when derived from the percentages 0.5% and 1.0% than from the percentages 25% and 50%. Furthermore, many physicians appear not to appreciate the distinction between absolute and relative differences,^{25,26} a failure that impedes the confident and correct communication of quantitative risk information.

Additional Challenges

Common Errors in Risk Interpretation. As noted herein, patient perception of risk is a complicated phenomenon, laden with personal values and biases that challenge attempts to ensure the "correct" interpretation of risk information (TABLE 2).^{17,27,28} For example, patients are subject to anchoring bias, in which patients estimate their own risk from a given action based on another familiar risk; availability bias, in which patients overestimate a risk that receives substantial notoriety (eg, in the media); compression, whereby patients overestimate small risks and underestimate large risks; and miscalibration of confidence judgments, which leads to overconfidence in the extent and accuracy of knowledge.²⁷ Simply altering the scale in which a risk is placed can alter the perceived risk.^{16,29} Finally, the perceived lethality of an activity and the perceived invulnerability of some individuals may lead them to assess their own level of risk as less than the risk to others from the same activity.²⁷

Given the diverse difficulties in understanding risks, people frequently resort to powerful heuristic guides, or rules of thumb, that provide convenient shortcut answers to probability questions, answers that are themselves probabilistic in being right most but not all of the time.³⁰ These common interpretive errors pose tremendous challenges to physicians who

Error	Definition
Anchoring bias	A patient will tend to estimate his/her risk of an unwanted outcome based on the risk of some other related event or procedure already familiar to the patient
Availability bias	A patient will tend to overestimate a risk that receives substantial notoriety (eg, breast cancer in women)
Compression	A patient will tend to overestimate small risks and underestimate large risks
Miscalibration	A patient will tend to be overly confident about the extent and accuracy of his/her knowledge

may be struggling to define the risks and present them in accessible terms for patients from diverse backgrounds.

Reconciling the Average and the Individual. The biggest challenge may be to help patients reconcile averages derived from populations and their meaning at an individual level. For example, although lower serum cholesterol levels result in a reduction in the number of myocardial infarctions in a large population of patients, an individual patient may be chagrined to learn that he is paying a lot of money and possibly experiencing a reduction in his quality of life for a very small chance of individual benefit. Or, a patient may face a given treatment with the reassuring advice from a physician that the chances of a serious complication are only 1 in 100, but he/she may remain very concerned about whether he/she will be that 1 in 100. The angioplasty patient does not experience a 4% myocardial infarction complication; for each individual patient, the outcome is an all-or-none phenomenon. Thus, even if we can identify and describe risks, the information must ultimately be expressed in terms that are meaningful to individual patients and must allow them to make decisions with which they are comfortable.

Patient Preference and Frameworks for Medical Decision Making. Two related issues overlying any discussion of medical risk and implicit throughout this article are the ascertainment of patient preference and the choice of a framework for medical decision making.^{1,31,32} Patient preference may vary not only for the relative value of diverse outcomes but also for the amount and type of information patients want to be given, the manner in which it is given, and the degree to which they participate in and control the decision-making process. The physician may be inclined to prefer 1 of several different frameworks for decision making, ranging from one in which the paternalistic physician controls the decision to one in which patient and physician share responsibility or to one in which the autonomous patient entirely controls the decision. Yet another framework that may assume more importance in the era of managed care is one in which some decisions are removed from the realm of the patient-physician re-

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lationship all together and claimed as the prerogative of corporate entities. Although a full discussion of these issues is beyond the scope of this article, we believe that ascertaining patient preferences and fostering a participative mode of decision making are of paramount importance for most situations in the practice of medicine.

NEW POSSIBILITIES FOR RISK COMMUNICATION

Given that one quarter of the US population has only rudimentary reading skills and another quarter has limited reading skills,³³ there appears to be a need for alternative formats that can be readily understood by most patients, regardless of sophistication in numbers. For instance, recent studies examining the use of graphic data displays found that many patients were able to use and interpret graphic information.^{34,35}

Another possibility, which could be studied empirically, might be to take advantage of the natural anchoring bias to which patients are subject by relating medical risks to known everyday nonmedical risks, things from day-to-day life that people face frequently.⁴ For instance, one might equate the risk of dying from a given therapy with the risk of dying in an automobile crash or the risk of injury from a different therapy with the risk of injury from participation in a particular sport. By relating medical risks to nonmedical risks, the medical risk would be placed within the larger perspective of a person's life, together with activities for which they have an established sense of acceptability.

The best strategy may ultimately be a multifaceted and flexible approach that would, after describing the unwanted outcome, describe the frequency of the outcome using a combination of techniques, such as a qualitative term, a numerical expression, a graph, and an example from everyday life. One might let each patient determine which of the 4 formats is most helpful and build the discussion around that. This strategy would have the advantage of accommodating patients with diverse preferences and abilities for understanding risk information. Such a strategy would also accommodate our difficulty as physicians to vary our presentation styles to fit different situations.36

Regardless of the challenges noted herein, physicians must do the best they can in a difficult area and strive to edu-

cate patients about the risks of all reasonable alternatives for a given situation. It is not often as simple as saving that the chance of dying from the operation is 1 in 100; at the very least, the patient should know the risks of not having the operation. Although we may not be able to get it absolutely right, we can certainly try. In addition to considering the challenges noted herein, physicians should encourage further investigation of innovative means of communicating risk information. Because much of the research on risk communication takes place either in nonmedical situations or using hypothetical scenarios, it will be important to ascertain the best means of communicating risks to real patients facing real decisions. Only by helping our patients to understand the implications of their (and our) medical decisions will we fulfill our obligations as doctors-a word, after all, that stems from the Latin docere, "to teach."37

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