

Risk Communication: Problems of Presentation and Understanding

Rebecca Jean Gordon-Lubitz, *University of California, Berkeley*

ALTHOUGH PATIENTS FREQUENTLY MAKE DECISIONS ABOUT THE risks of medical treatments, their understanding of such risks may not be completely objective. Risk perception is affected not only by individual factors such as the patient's sex, prior beliefs, and past experience,^{1,2} but also by how the risk information itself is presented.

Identical risk information may be presented in different ways, resulting in "framing bias." Perceptions of risk are particularly susceptible to framing effects.³ For example, patients are much more likely to favor radiation treatment over surgery when radiation is presented as having a 90% survival rate than when it is presented as having a 10% mortality rate. Although both numbers describe identical risks, the latter is perceived as more dangerous.⁴ Another common framing effect involves absolute and relative risks. For example, if a medication reduces an adverse outcome from 20% to 15%, then the absolute risk reduction is 5% and the relative risk reduction is 25%. Although the absolute and relative risk estimates are derived from the same data, patients are more strongly persuaded by the larger changes in relative risk.⁴

The impact of framing on risk perception is often overshadowed by the effects of low numeracy. Numeracy refers to the ability to use numerical concepts and to perform basic probability operations. In one study of randomly selected women at a Veterans Affairs hospital, 46% could not correctly answer how many coin flips out of 1000 would turn up heads. Among these women, numeracy scores were related more strongly than framing effects to their ability to interpret risk estimates correctly. After controlling for demographic factors and whether the risk was framed as relative or absolute, women with high numeracy scores were 13 times more likely to interpret risk estimates correctly than women with low numeracy scores.⁵

Despite this propensity to misinterpret statistical risk information, patients often prefer quantitative over qualitative explanations of risk.² Preferences for numerical risk estimates may stem from an inaccurate perception that these numbers represent some objective certainty. In one study of risk communication in genetic counseling, only 3 of 46 counselees understood that their risk estimates involved a degree of uncertainty.²

For patients with low numeracy skills, qualitative explanations may improve understanding. Despite variation in people's understanding of words like "rarely," "sometimes," and "often," these descriptors can be contextualized by comparing them to everyday risks like being involved in an automobile crash.³ This allows patients to compare the medical risk with risks whose severity and frequency they already understand.⁶ Narratives about risks facing people who are simi-

lar to the patient are also useful in helping patients contextualize risk. For example, personalized accounts by HIV positive people have been shown to lead to increased perceptions of risk among at-risk patients who identified with the individuals depicted in the stories.⁷

There are instances when it is difficult to avoid a quantitative discussion of risk. In these situations, clinicians can employ various techniques to improve patient understanding. Individualized risk estimates use the individual's personal risk factors (eg, age, sex, race) to compute the probability of developing a specific health problem in a given period of time.⁸ Individualized risk estimates have been shown to influence patients' treatment choices more strongly than presenting general risk information, and may also result in increased screening behavior.⁹ Visual displays of risk information may also increase patient understanding more than qualitative or quantitative explanations alone. These include risk ladders, which place risks in decreasing order of magnitude alongside equivalent comparisons of everyday risks, and the Wall of Balls, in which a risk of 1 in 1000 would be presented as one colored dot on a page with 999 different dots. Such displays improve understanding of the difference in magnitude between risks.¹⁰

The goal of risk communication is to help patients make informed decisions about treatment options, medication regimens, and lifestyle changes. To make such communication a useful decision-making aid for the patient is thus an arduous task, but one that can be aided by employing a mix of techniques that accommodate the varying preferences and abilities of different patients.

REFERENCES

1. Shiloh S, Saxe L. Perception of risk in genetic counseling. *Psychol Health*. 1989; 3:45-61.
2. Hallowell N, Statham H, Murton F, Green J, Richards M. "Talking about chance": the presentation of risk information during genetic counseling for breast and ovarian cancer. *J Gen Counseling*. 1997;6:269-285.
3. Edwards A, Elwyn G. Understanding risk and lessons for clinical risk communication about treatment preferences. *Quality in Health Care*. 2001;10:i9-i13.
4. Malenka DJ, Baron JA, Johansen S, Wahrenberger J, Ross JM. The framing effect of relative and absolute risk. *J Gen Intern Med*. 1993;8:543-548.
5. Schwartz LM, Woloshin S, Black WC, Welch HG. The role of numeracy in understanding the benefit of screening mammography. *Ann Intern Med*. 1997;127: 966-972.
6. Bogardus ST, Holmboe E, Jekel JF. Perils, pitfalls, and possibilities in talking about medical risk. *JAMA*. 1999;281:1037-1041.
7. Rothman AJ, Kiviniemi MT. Treating people with information: an analysis and review of approaches to communicating health risk information. *J Natl Cancer Inst Monogr*. 1999;25:44-51.
8. Benichou J, Gail MH, Mulvihill JJ. Graphs to estimate an individualized risk of breast cancer. *J Clin Oncol*. 1996;14:103-110.
9. Edwards A, Hood K, Matthews E, et al. The effectiveness of one-to-one risk communication interventions in health care: a systematic review. *Med Decis Making*. 2000;20:290-297.
10. Lipkus IM, Hollands JG. The visual communication of risk. *J Natl Cancer Inst Monogr*. 1999;25:149-163.

Advance Directives and Patient-Physician Communication

Michael E. Hahn, Weill Medical College of Cornell University and The Rockefeller University, New York, NY

ADVANCE DIRECTIVES PROVIDE A LEGAL MEANS FOR PATIENTS to state treatment preferences in advance, should they later become unable to participate in decisions about their care. In 1990, Congress adopted the Patient Self Determination Act, which sought to increase the use of advance directives. However, a 1999 study of members of a health maintenance organization found that only one-third of patients aged 65 years or older reported having filed an advance directive.¹ Although such decisions may later be made by others acting as proxies, their judgments of patients' treatment preferences may not be accurate.² Through communication with their patients about advance directives, physicians can play a key role in making advance directives a more effective part of patient care.

In the previously cited study,¹ only 15% of patients reported having been asked about their advance care preferences by a physician or nurse, although patients were 3 times more likely to establish an advance directive if they have been asked about their wishes. Many physicians fail to initiate such discussions because they may worry about spending too much time on them,³ but in fact such discussions average less than 3 minutes in length.⁴ Physicians may also fear that patients are uncomfortable discussing issues surrounding their own mortality.⁵ In contrast to this assumption, one study found that 93% of outpatients and 89% of the general public were interested in discussing advance directives, with young and healthy individuals expressing as much interest as older, less healthy people.⁵ A retrospective study of decedents in a Midwestern community found that 85% had had advance directives, and suggested that the unusually high rate of use was the result of an extensive educational program on end-of-life planning.⁶ This implies that advance directives can be both widely used and effective, provided the resources exist to increase patient awareness.

While increasing advance directives is an important goal, a greater challenge lies in modifying them to better reflect patient preferences. Advance directive forms that are standard in US health care facilities ask patients general questions, which may or may not be applicable to a patient's individual circumstances. In addition, patients often misunderstand their options to refuse or withdraw treatment or to choose palliative care.⁷ It is possible that even with an advanced directive in place, patients may not receive the care they would want.

Patients must be educated about treatment options in order to make well-informed decisions about their future care. A simple way to accomplish this goal is to focus on the acceptability of potential treatment outcomes to the patient. A recent qualitative study of elderly individuals found they

were more concerned with functional outcome than with the medical techniques used to achieve that outcome.⁸ One method of assessing the acceptability of treatment is to use scenario-based decision aids describing different treatment options and their potential outcomes.⁹ Assessing patients' understanding and willingness to accept potential treatment outcomes increases the likelihood of informed consent and enhances the utility of advance directives.

In some cases, advance care decisions are made by someone other than the patient. The accuracy of proxy judgments can be enhanced when the patient and his or her proxy have discussed advance care issues.² This is in accord with research demonstrating that patients consider planning advance care to be a social interaction between loved ones, rather than simply a matter of signing forms.¹⁰ Promoting collaboration between family members and loved ones may minimize the ambiguity often found in advance directives, and may better prepare surrogates to make treatment decisions. Physicians can take an active part in this process by encouraging their patients to discuss advance care issues with their chosen surrogates.

Although systemic changes such as computerized reminders can encourage physicians to integrate advanced planning directives in their routine patient care,¹¹ such discussions will still require meaningful communication with patients. Through such discussions, physicians have the opportunity to play a central role in increasing both the effectiveness and use of advance directives.

Acknowledgment: This work was supported by Medical Scientist Training Program Grant GM07739 from the National Institutes of Health.

REFERENCES

1. Gordon NP, Shade SB. Advance directives are more likely among seniors asked about end-of-life care preferences. *Arch Intern Med.* 1999;159:701-704.
2. Sulmasy DP, Terry PB, Weisman CS, et al. The accuracy of substituted judgments in patients with terminal diagnoses. *Ann Intern Med.* 1998;128:621-629.
3. Emanuel LL, von Gunten CF, Ferris FD. Advance care planning. *Arch Fam Med.* 2000;9:1181-1187.
4. Goldblatt D. A messy necessary end. *Neurology.* 2001;56:148-152.
5. Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EJ. Advance directives for medical care—a case for greater use. *N Engl J Med.* 1991;324:889-895.
6. Hammes BJ, Rooney BL. Death and end-of-life planning in one midwestern community. *Arch Intern Med.* 1998;158:383-390.
7. Silveira MJ, DiPiero A, Gerrity MS, Feudtner C. Patients' knowledge of options at the end of life. *JAMA.* 2000;284:2483-2488.
8. Rosenfeld KE, Wenger NS, Kagawa-Singer M. End-of-Life decision making: a qualitative study of elderly individuals. *J Gen Intern Med.* 2000;15:620-625.
9. Dales RE, O'Connor A, Hebert P, Sullivan K, McKim D, Llewellyn-Thomas H. Intubation and mechanical ventilation for COPD. *Chest.* 1999;116:792-800.
10. Singer PA, Martin DK, Lavery JV, et al. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med.* 1998;158:879-884.
11. Dexter PR, Wolinsky FD, Gramel-Spacher GP, et al. Effectiveness of computer-generated reminders for increasing discussions about advance directives and completion of advance directive forms: a randomized controlled trial. *Ann Intern Med.* 1998;128:102-110.