

Risky Business

EDITORIAL

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To make informed decisions, patients need to know something about the likelihood of the relevant outcomes. For example, if a patient with type 1 diabetes is trying to decide whether to pursue conventional or intensive therapy, he might want to compare the chance for complications with conventional therapy with the chance for complications with intensive therapy. Ultimately, shared decision making requires that physicians learn more about risk communication.

There is a wide range of issues to learn about. A basic question is: *When should we communicate risk?* Clearly, some discretion is needed. Not all decisions are equally important, and not all outcomes are equally relevant. Then there is a very broad question: *How should we communicate risk?* Statements about chance may not always need to involve numbers; instead, the magnitude of risk may sometimes be better conveyed by using words. The choice probably hinges on the specific decision and the specific patient. When numbers are involved, there are numerous issues about presentation—for example, the effect of measure (odds, probabilities, or rates) and the effect of framing (positive vs. negative, absolute vs. relative). And then there is the pragmatic question: *How well are we communicating risks currently?* How do real patients perceive their own risks?

In this issue of *ecp*, Meltzer and Egleston¹ shed some light on this subject. There are several reasons to believe that the 139 patients they examined would want to be involved in decisions about their own care. First, they have a disease that impacts their lives daily—type 1 diabetes. Second, they are already very involved in their own care (94% adjusted their own insulin dose daily). Finally, they are at considerable risk for complications (as estimated from the control group of the Diabetes Control and Complications Trial)—in the next 20 years roughly 17% will become blind, about 9% will develop end-stage renal disease, and 2% will require a lower-leg amputation. This is obviously a group that should have a strong interest in knowing the risks they face.

In general, these patients overestimated their chances of developing complications over the next 20 years. The average patient estimated that, with conventional therapy, the chance for becoming blind was 32%, for developing end-stage renal disease 34%, and for requiring a lower leg amputation 25%. There was also a small group of patients (about 15% of the sample) who believed that their 20-year risk for each complication exceeded 50%. The patients also overestimated the risks for these complications under intensive therapy. By comparing the perceived risks of each therapy, the investigators extrapolated the perceived benefit of intensive therapy. Although patient perception of benefit was in the right ballpark in relative terms (i.e., the ratio of risks of intensive vs. conventional therapy), the perception of benefit was substantially overestimated in absolute terms (i.e., risks of conventional therapy minus risks of intensive therapy) (see **Primer**).

Could the source of these overestimates be the medical profession itself? Perhaps we should ask Meltzer and Egleston to repeat their work—this time on a sample of internists. Don't get me wrong; This isn't the type of pop quiz I would look forward to (for the record, nor would I want to be asked the name of the new Pakistani general or how to spell "potato"). But it is possible that our current focus on preventing the complications of diabetes has given us all an exaggerated sense of these risks. And it is important to know what patients are learning from their health care providers. The first step in shared decision making may not be providing risk information to patients—but to their clinicians.

Reference

1. Meltzer D, Egleston B. How patients with diabetes perceive their risk for major complications. *Eff Clin Pract.* 2000;3:7-15.

This paper is available at ecp.acponline.org.