

# How Patients with Diabetes Perceive Their Risk for Major Complications

**CONTEXT.** To educate patients with diabetes about their illness and to motivate these patients to pursue intensive treatment, physicians often inform them about their risk for serious complications. However, little is known about patient perceptions of these risks.

**OBJECTIVE.** To compare patient perceptions of risk for major complications of diabetes with actual risk for these complications.

**DESIGN.** Structured interviews were done to obtain the patient's estimate of their risk for complications. To generate estimates of actual risk for each patient, we used a simulation model based on the Diabetes Control and Complications Trial (DCCT).

**SETTING.** Four university-affiliated diabetes clinics in the midwestern United States.

**PATIENTS.** 139 patients with type 1 diabetes mellitus.

**MAIN OUTCOME MEASURES.** Probability of blindness, end-stage renal disease (ESRD), and lower-leg amputation over 20 years.

**RESULTS.** Participants were young (mean age, 30 years) and reported having had diabetes for an average of 15 years. Seventy-nine percent reported their current diabetic therapy to be "intensive." Ninety-eight percent had completed high school, and 51% were college graduates. The patients' estimates of their risks far exceeded the DCCT estimates for all three complications. The mean patient estimate of the risk for blindness was 31.6% (DCCT estimate, 17.0%), of the risk for ESRD was 33.7% (DCCT estimate, 8.7%), and of the risk for amputation was 25.1% (DCCT estimate, 1.9%). Similarly, patients overestimated the benefit of intensive therapy. They estimated, on average, that intensive therapy would result in a 17.0% absolute risk reduction for blindness (DCCT estimate, 12.2%), an 18.1% risk reduction for ESRD (DCCT estimate, 7.0%), and a 14.2% risk reduction for amputation (DCCT estimate, 1.2%).

**CONCLUSION.** Patients with diabetes overestimated their risk for major complications and the benefits of intensive treatment.

Patients with diabetes are at risk for numerous severe complications, including blindness, end-stage renal disease (ESRD), and lower-leg amputation.<sup>1</sup> The Diabetes Control and Complications Trial (DCCT) has shown that intensive therapy with the goal of tighter control of glucose levels can reduce or delay the onset of these complications in patients with type 1 diabetes mellitus.<sup>2</sup> However, many patients do not choose intensive therapy or adhere to its requirements.<sup>3</sup>

For physicians and others who care about the welfare of patients with diabetes, this low rate of adherence to intensive therapy is clearly a concern. Although it is certainly recognized that intensive therapy can have adverse side effects and is not the

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*Edited by Lisa M. Schwartz,  
MD, MS*

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right choice for every patient, most physicians recommend intensive therapy to their patients.<sup>4</sup>

Concern about low rates of compliance with intensive therapy and other preventive health behaviors has motivated much research into the psychology of preventive health behaviors. This research has generated a wide range of theories about the factors that may affect a person's decisions, but a common theme has been that perception of vulnerability to illness and efficacy of therapy may be important determinants of preventive health behaviors.<sup>5-8</sup> Several studies have found that these perceptions are important predictors of compliance with medical regimens for a variety of medical conditions, including diabetes.<sup>9,10</sup> In particular, some studies have found that patient perceptions of the magnitude of risk conferred by a disease or toxic exposure are associated with decisions about treatment or prevention.<sup>11,12</sup>

Despite the importance of perceptions of vulnerability to illness and efficacy of treatment, whether diabetic patients' estimates of risk for complications with various therapies match the risks reported in the literature has not been examined. If patients underestimate their risk for complications or the efficacy of treatment, this may explain the low compliance with intensive therapy and may suggest an approach for increasing compliance. If patients overestimate the probability of complications or the efficacy of treatment, they may be unnecessarily fearful of complications or feel pressured to adopt intensive therapy; in this case, educating patients might not increase their compliance, but it might improve their subjective well-being.

Indeed, diabetic patients may either underestimate or overestimate risk and benefit. Studies of patients with diseases other than diabetes have found mixed results about the accuracy of an individual's perceptions of risk. Weinstein and colleagues,<sup>13</sup> for example, found that people underestimate the danger that radon exposure poses to their health. Conversely, Iglehart and coworkers<sup>14</sup> found that women who have had breast or ovarian cancer overestimate the possibility that they are hereditary carriers of predisposing genetic mutations.

Our study examines the extent to which the views that patients with type 1 diabetes mellitus have about their risks for complications with conventional and intensive therapies match the risks reported in the literature.

## Methods

### Study Sample

Data for our study were drawn from a sample of patients interviewed for a larger study on the beliefs and preferences of patients with type 1 diabetes. The larger

study included 271 diabetic patients who were treated between June 1997 and December 1998 at four diabetes clinics affiliated with academic medical centers in the midwestern United States. Because we calculated actual risks from a model based on the DCCT, we attempted to limit the study sample to patients who would have been eligible for the DCCT. Thus, we excluded persons who were older than 39 years of age (82 patients), had severe preexisting complications (27 patients), or were missing important variables (3 patients had incomplete data on health status; 20 patients were missing risk estimates). Because most patients (84%) had had diabetes for longer than the limit specified in the DCCT (<5 years for the primary cohort), we did not exclude patients on the basis of duration of diabetes. Thus, 139 of the original 271 participants were eligible for our study. A comparison of these 139 patients with those excluded from the study revealed no significant differences with regard to race, education, or income.

### Estimated Risk for Complications

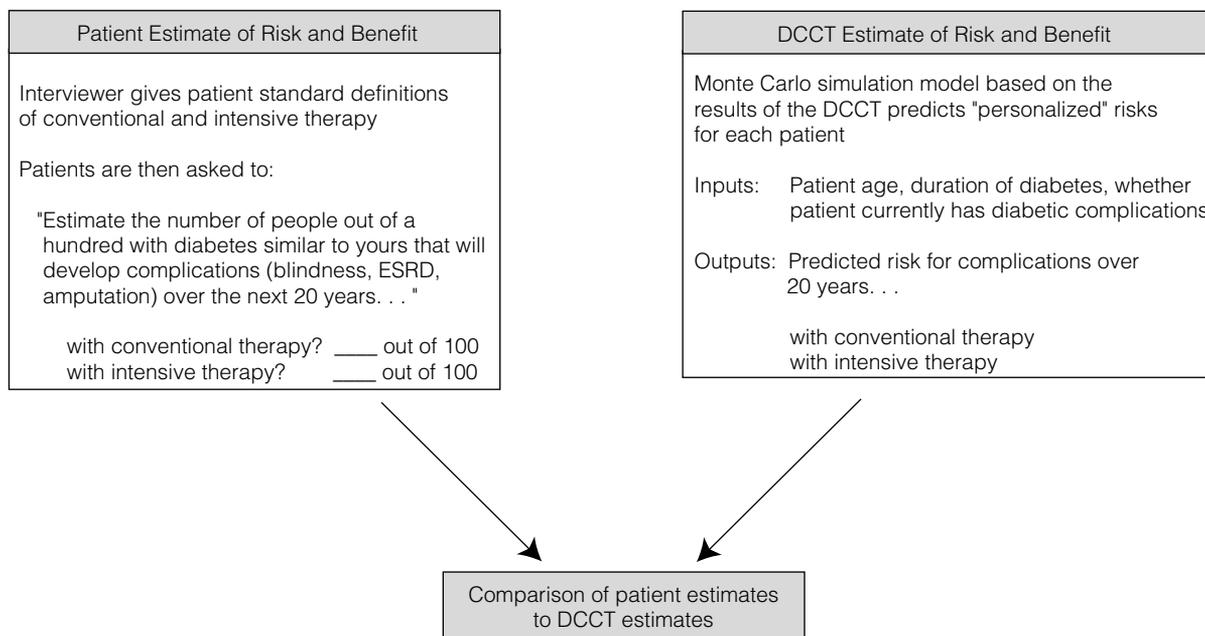
As **Figure 1** shows, estimates of risks for major complications of diabetes were obtained from patients and from a model based on the DCCT.

#### Patient Estimates

Trained interviewers asked patients how likely they thought they were to develop three diabetes-related conditions—blindness, ESRD, and lower-leg amputation—over the next 20 years if they received conventional or intensive therapies. Interviewers explained the differences between intensive and conventional therapy to reduce differences in patient definitions of the two treatments. A frequency-based approach to subjective probability assessment was used because it has been reported to generate more accurate reports than does the direct elicitation of probabilities.<sup>15,16</sup> Patients were asked to estimate how many of 100 persons who had diabetes similar to their own would develop each of the three complications over the next 20 years if they followed intensive therapy and if they followed conventional therapy. If a response was between 0 and 1, the interviewer asked the patient to estimate how many of 1000 persons with diabetes would develop complications. Trained research assistants extracted chart information on patients that indicated the presence and duration of any diabetes-related complications at the time of the study.

#### DCCT Estimates

We calculated patient-specific estimates of the actual risk for complications derived from a previously report-



**FIGURE 1. Methods for determining patient estimates of risk and Diabetes Control and Complications Trial (DCCT) model estimates of risk. ESRD = end-stage renal disease.**

ed Monte Carlo simulation model based on the DCCT.<sup>17</sup> Criteria for inclusion in the DCCT included age younger than 39 years at study entry and, at most, moderate nonproliferative retinopathy and minor nephropathy. In the primary cohort, patients with no retinopathy or nephropathy had to have had diabetes for 1 to 5 years; in the secondary cohort, patients with retinopathy and nephropathy had to have had diabetes for 1 to 15 years. Although the patients in the DCCT were followed for a mean of 6.5 years, the simulation model used progression rates based on the DCCT to predict the progression of complications over a person's lifetime. The model produced estimates of the 20-year risk for complications for each patient on the basis of the patient's age, duration of diabetes, and initial complications.

### Analysis

The 20-year probabilities of complications were calculated from the DCCT model for each person according to patient age and whether preexisting complications warranted inclusion of the patient in the primary cohort or the secondary cohort. For the purposes of this study, we assumed that the way in which we asked the questions caused people to report probabilities of complications over 20 years, assuming that they survived at least that long. Thus, we calculated the probabilities of complications by using the model with the assumption that

the probability of death within 20 years was 0. We used paired *t*-tests to compare the mean estimates of complication rates from the DCCT model with the mean patient estimates. We also tested whether patient estimates were related to well-known risk factors for progression, such as early signs of complications, to see whether patient estimates showed evidence of construct validity.<sup>18</sup>

## Results

The average age of our study sample was 30 years (Table 1). Fifty-six percent of the patients were female, 87% were white, and 85% had had at least some college education. About one fifth of the sample used an injection pump instead of injections, most knew about intensive therapy and had discussed it with their physicians, and 79% classified themselves as following intensive therapy.

### Perceived Risk for Complications

Figure 2 shows the distributions and means of the patient estimates and the means and ranges of the DCCT estimates of the chance that each complication would occur within 20 years with conventional therapy. In general, patient estimates far exceeded DCCT estimates. The largest absolute overestimate was in the risk for ESRD: The mean patient estimate of risk was 33.7%,

TABLE 1

## Patient Characteristics\*

VARIABLE	VALUE (n = 139)
<b>Demographic characteristics</b>	
Mean age $\pm$ SD, yr	30.1 $\pm$ 6.0
Female	56%
<b>Race</b>	
White	87%
Black	9%
Asian	1%
Hispanic	1%
Other	1%
<b>Education level</b>	
Less than high school	2%
High school graduate	13%
Some college	34%
College graduate	51%
<b>Income per annum</b>	
\$0–\$25,000	19%
\$25,001–\$50,000	32%
\$50,000+	49%
<b>Diabetic history</b>	
Mean age at onset $\pm$ SD, yr	15.4% $\pm$ 8.4
Mean hemoglobin A <sub>1c</sub> $\pm$ SD	8.5% $\pm$ 2.2
<b>Patient report of diabetic therapy</b>	
Mean daily glucose checks $\pm$ SD, n <sup>†</sup>	3.2 $\pm$ 1.1
Using insulin pump	22%
Using injections	78%
Administer insulin once a day	2%
Administer insulin twice a day	26%
Administer insulin three times a day	31%
Administer insulin four or more times a day	41%
Adjust insulin dose daily	94%
Patient's therapy meets DCCT criteria for intensive therapy	54%
<b>Patient knowledge</b>	
Knew of intensive therapy option	78%
Had discussed intensive therapy with physicians	81%

\*DCCT = Diabetes Control and Complications Trial.

<sup>†</sup>4 was used in the calculation if the number of checks exceeded 4.

and the mean DCCT estimate was 8.7% ( $P < 0.001$ ). This was followed by estimates of risk for lower-leg amputation: The mean patient estimate was 25.1%, and the mean DCCT estimate was 1.9% ( $P < 0.001$ ). Patients estimated a mean risk for blindness of 31.6%; the DCCT estimate was 17.0% ( $P < 0.001$ ). **Figure 2** shows that only about 5% of patients underestimated their risk for ESRD or amputation. In contrast, approximately one quarter of patients underestimated their risk for blindness.

## Perceived Benefit of Intensive Therapy

The patients believed that intensive therapy would reduce their risk for complications, but they substantially overestimated the benefit of this therapy relative to the DCCT model. **Figure 3** shows the absolute reduction in complication rates due to intensive therapy as estimated by patients and by the DCCT model. Patients estimated that intensive therapy would reduce the likelihood of ESRD by 18.1 percentage points (DCCT estimate, 7.0%;  $P < 0.001$ ), amputation by 14.2 percentage points (DCCT estimate, 1.2%;  $P < 0.001$ ), and blindness by 17.0 percentage points (DCCT estimate, 12.2%;  $P = 0.001$ ). For all three complications, the absolute differences as estimated by the patients translated into a relative risk reduction from intensive therapy of about 60% (DCCT relative risk reduction estimates were 81% for ESRD, 64% for amputation, and 73% for blindness). Thus, patients tended to substantially overestimate the absolute risk reduction from intensive therapy, but they were somewhat better calibrated with respect to the relative risk reduction.

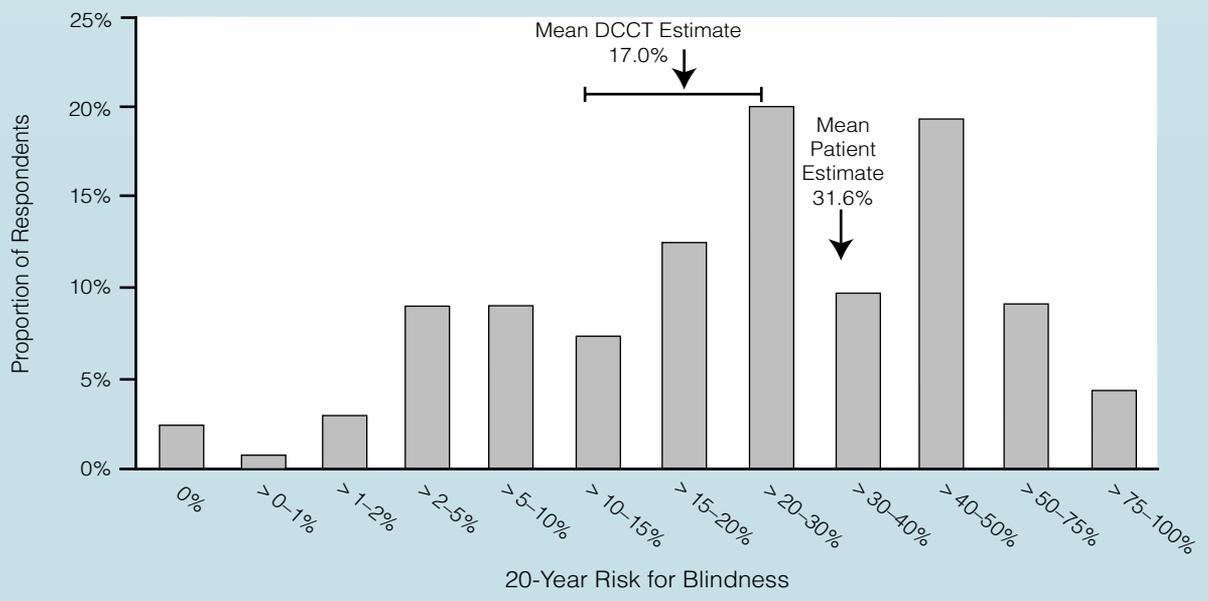
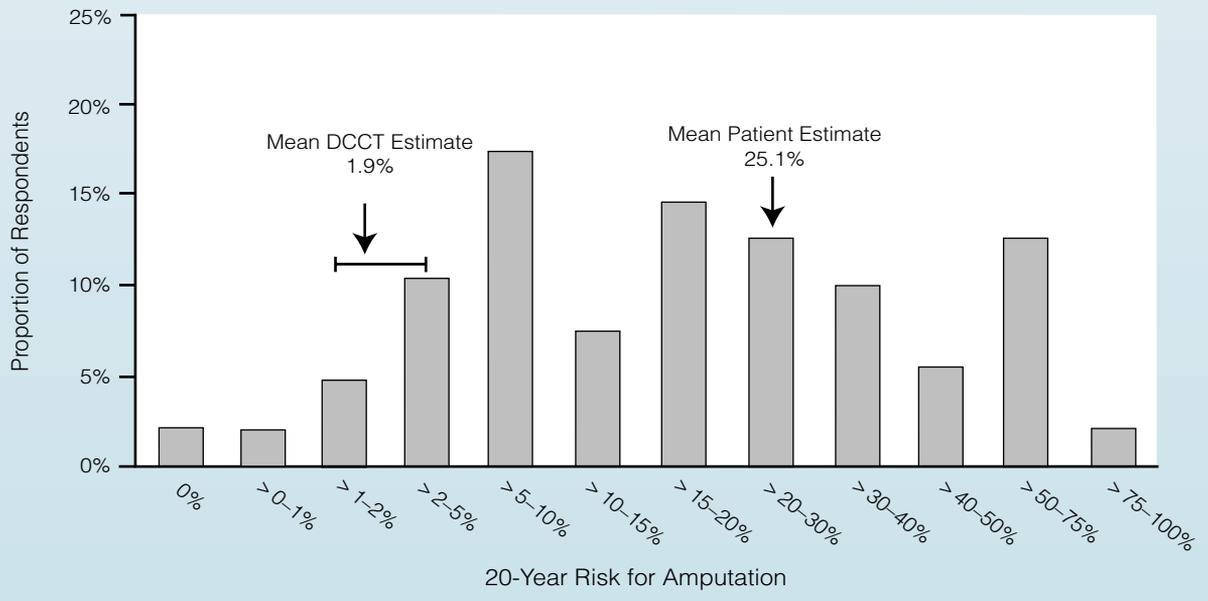
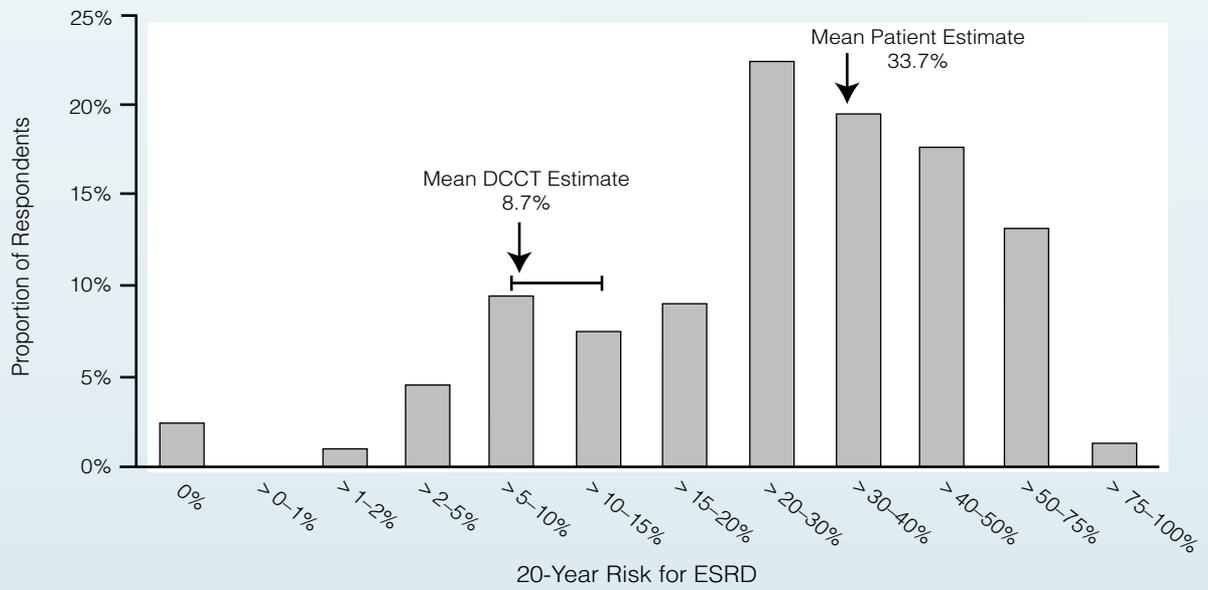
## Construct Validity

In our examination of construct validity for the probability estimates, we had too few patients with foot ulcers ( $n = 3$ ) or albuminuria ( $n = 4$ ) to assess whether the presence of these early-stage complications correlated with a greater subjective probability of having major complications. However, the presence of background retinopathy increased the mean probability estimate for blindness from 29.9% to 37.8% ( $P = 0.07$ ).

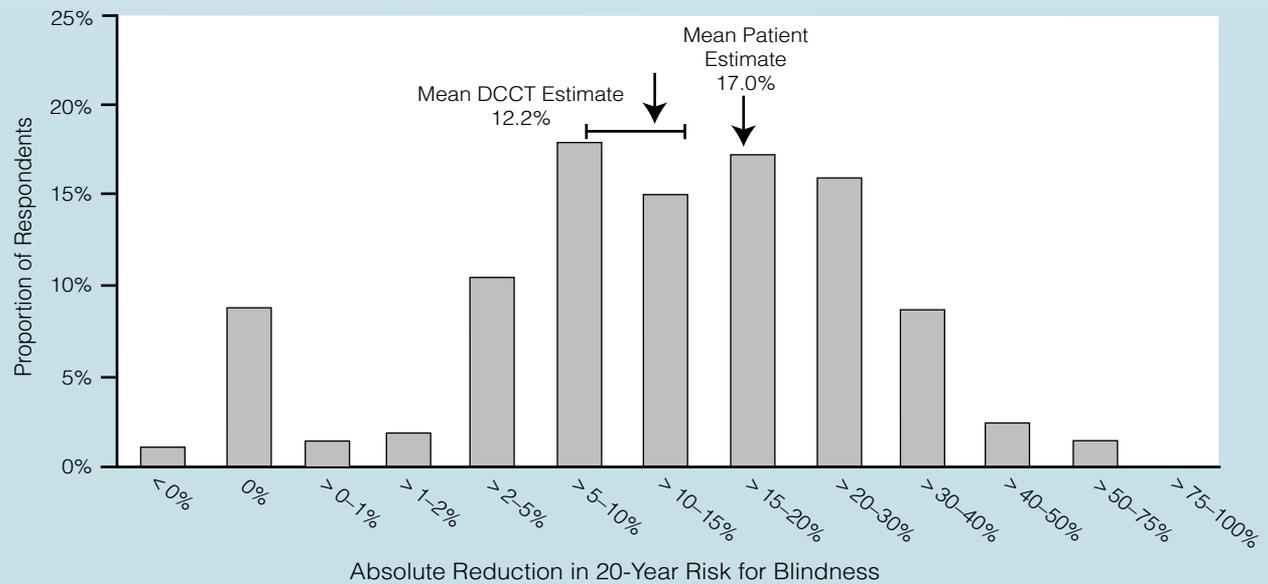
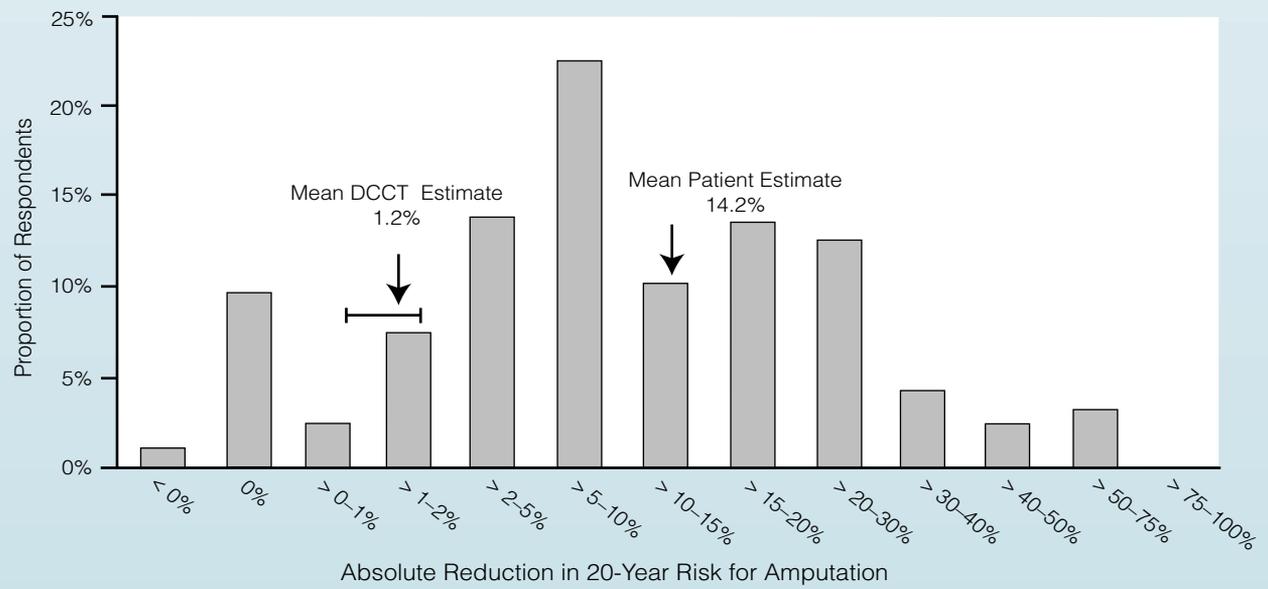
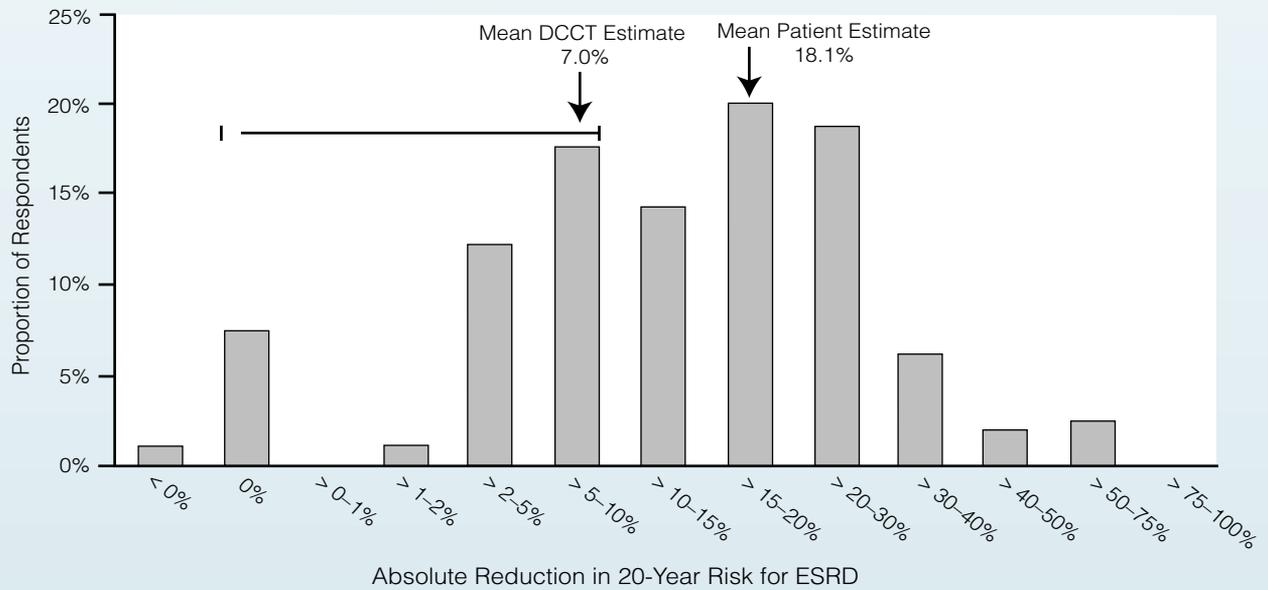
## Discussion

The results of our analysis suggest that patients with diabetes significantly overestimate their risk for diabetes-related complications. Patients also significantly overestimate the reduction in risk for complications produced by intensive therapy in absolute percentage terms and to some extent in relative terms. The pessimism of patients with regard to prognosis is our most striking finding. The average patient believed that with conventional therapy, he or she was more than 1.5 times more likely to become blind, 4 times more likely to develop ESRD, and 13 times more likely to have lower-leg amputation than the DCCT estimates indicated.

If these estimates of patient perceptions of risk are accurate, several important implications are evident. First, overestimating the likelihood of complications may increase the probability that a patient will follow intensive therapy. Solely from the perspective of whether complications are minimized, this may seem desirable. However, if patients do not know their actual risks for complications, they may not make choices that reflect their own values about risk



**FIGURE 2.** Distribution of patient estimates of their risk for three diabetic complications while receiving conventional therapy. DCCT = Diabetes Control and Complications Trial; ESRD = end-stage renal disease; — = range of DCCT estimates.



**FIGURE 3. Distribution of patient estimates of the absolute reduction in risk while receiving intensive therapy.** DCCT = Diabetes Control and Complications Trial; ESRD = end-stage renal disease; — = range of DCCT estimates.

reduction and quality-of-life trade-offs with competing medical regimens. From a more holistic perspective on patient decision making, this may not be desirable.

Second, overestimation of the likelihood of complications could lead to increased anxiety. Some evidence suggests that patients with diabetes have higher levels of anxiety and depression than other persons do<sup>19-22</sup> and that fear of hypoglycemia due to diabetic therapy is associated with increased anxiety.<sup>23</sup> Increases in distress caused by concern about the development of complications could also negatively affect patient welfare. In addition, because psychiatric illness has been associated with poor metabolic control in diabetic patients,<sup>24</sup> excessive fear of complications might adversely affect treatment. Although general anxiety unrelated to diabetes might cause increased fear and subsequent overestimation of diabetic complications, no evidence in other contexts suggests that persons with anxiety are more likely to overestimate the likelihood of the events that cause them anxiety.<sup>25</sup>

Our results are consistent with reports in the literature suggesting that people are often poor at predicting their risk for developing disease.<sup>26,27</sup> Indeed, the ordering of the magnitude of our patient estimates is not consistent with that of the DCCT estimates: Patients perceived ESRD to be the most likely complication, whereas blindness is actually the most likely. One possible explanation for this is that people may overestimate risk in proportion to their perception of the severity of that illness.<sup>28</sup> Patients in our study may have been very worried about developing the complications about which they were asked and, consequently, may have increased their risk estimates as a result of this fear. Consistent with this, our patients assigned the lowest quality-of-life ratings to ESRD.

The format of our probability questions may have confused some respondents, and other methods of assessing risk beliefs might have been easier for people to understand. For example, some authors have attempted to measure risk by using subjective rankings on scales that range from high risk to low risk.<sup>29,30</sup> However, because the responses to such scales are subjective, it is impossible to know whether one person's definition of high risk corresponds with another person's definition. Our study elicited actual probabilities to reduce such subjectivity. Furthermore, the fact that the patients' estimated probabilities did not differ across educational levels suggests that educational factors that might affect a person's understanding of probability did not significantly alter our results. Nevertheless, because the mean patient estimates for all three complications were similar (despite large differences in the DCCT estimates), more work is needed to assess the validity of techniques for eliciting subjective probabilities.

Additional issues must be considered in the interpretation of our study. First, our patients were selected from diabetes clinics with academic affiliations. It is pos-

sible that patients who have an increased fear of diabetic complications are more likely to enroll in such specialized care centers and thus are not representative of diabetic patients as a whole. Second, most of the patients in our analysis did not meet the requirements for duration of diabetes necessary for enrollment in the DCCT. Because the duration of diabetes was longer for most of our sample than for the patients in the DCCT, our patients' estimates may reflect a valid expectation that they have an increased risk for complications. However, the evidence on whether the probability of these complications over a given period increases with the duration of diabetes is mixed,<sup>31-33</sup> and the DCCT model that we used captured the effects of duration of illness to the extent that they are known. Thus, the estimates from the model should reflect known effects of duration of illness.

If these findings are confirmed in future analyses, better approaches to help patients understand their actual risks for complications may be needed. Indeed, methods exist for improving patient knowledge of risk estimates. Kreuter and Strecher<sup>34</sup> found that personalized risk assessments coupled with feedback led to more realistic risk estimates by patients with overly optimistic estimates of their risk for stroke and overly pessimistic estimates of their risk for cancer, although the assessments did little to change the patients' views of their risks for heart attacks and motor vehicle accidents. Murphy and colleagues<sup>35</sup> found that elderly patients substantially overestimated their probability of surviving cardiopulmonary resuscitation and were substantially less willing to undergo this procedure once they had been informed of the actual probability of survival. Similarly, physicians and other health professionals who work with diabetic patients could provide risk information when discussing treatment options. An encouraging finding is that educational interventions for patients with diabetes that attempt to increase their knowledge about their disease seem to be very effective.<sup>36</sup>

Beyond the challenges involved in conveying risk information in ways that are meaningful to patients, one barrier to promoting more realistic discussions of risk with diabetic patients is that physicians may not sufficiently appreciate the level of concern that their patients have about complications of diabetes. One study asked diabetic patients about their greatest concerns about diabetes and then compared the patients' answers with physicians' views of patients' concerns. Complications were listed first by patients but sixth by endocrinologists.<sup>37</sup>

Another challenge to acceptance of the practice of giving patients more detailed risk information is that physicians will have to accept the possibility that this practice may increase the likelihood that patients will choose conventional rather than intensive therapy. Although many physicians may believe this to be undesirable, it is

clearly supported by views of the ideal physician–patient relationship that emphasize the provision of accurate information to support informed patient decisions. From this perspective, the physician’s goal should be to help a patient make choices that maximize the patient’s welfare given the patient’s competing concerns about overall well-being, quality of life, and extension of life. Even if excessive fear of complications due to overestimation of risk motivates patient to choose a treatment that could delay complications, the increased anxiety and side effects associated with such treatment may not ultimately benefit the patient. It is worth noting that a recent American Diabetes Association training manual on the education of diabetic patients contains no discussion of the possibility that patients may have unnecessarily pessimistic views of their prognosis or that such views might have adverse consequences.<sup>38</sup>

We do not know how increasing patients’ knowledge of actual risk for complications will affect their decisions about management of diabetes or their feelings about the fact that they have diabetes. Many people find risk to be a difficult concept to grasp, and their reactions to knowledge about risk may not always seem consistent.<sup>39</sup> Moreover, perceived risk is only one factor in the motivation of health behavior. Still, the possibility that excessive concern about risk for complications may inappropriately alter a patient’s decisions and impair his or her sense of well-being deserves further consideration.

## Take-Home Points

- **To motivate diabetic patients to pursue intensive treatment, physicians often inform them about their risk for serious complications: blindness, end-stage renal disease, and amputation.**
- **It is not known whether patients have a realistic sense of their risk for these complications.**
- **We interviewed patients with type 1 diabetes mellitus to learn how they perceived their risks for major complications, and we compared these perceptions with actual risk for the complications as estimated from a large randomized trial.**
- **The average diabetic patient believes that he or she is 1.5 times more likely to become blind, 4 times more likely to develop end-stage renal disease, and 13 times more likely to have lower-leg amputation than he or she really is.**
- **Improved information about actual risks for complications might enhance patient welfare by reducing concern and allowing for more fully informed therapeutic choices.**

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**Correspondence**

David Meltzer, MD, PhD, 5841 South Maryland Avenue, MC 2007, Chicago, IL 60637; telephone: 773-702-0836; fax: 773-834-2238; e-mail: dmeltzer@medicine.bsd.uchicago.edu.