

# Virtual Mentor

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## ETHICS CASE

### **Discounting a Surgical Risk: Data, Understanding, and Gist**

Commentary by Peter H. Schwartz, MD, PhD

Dr. Feng had purposefully scheduled Ms. Reid to come into the office at 4:15 PM on a Friday. Despite the fact that her office staff would be trying to make it home as soon as possible, Dr. Feng had imagined that Ms. Reid might need extra time to discuss her biopsy results: there was a chance that the lump on her neck that she'd felt when tying a scarf might be cancerous.

Ms. Reid had been in the waiting room for an hour already by the time Dr. Feng called her in, trying to keep an eye on her two young sons, who were tipping over towers of cardboard blocks into the aisles between seats.

"Well, Ms. Reid," Dr. Feng started. "I'd hoped that we'd have a clearer answer for you today, but the pathology results from the aspiration of thyroid nodule are unclear. Some of the cells do look concerning for malignancy. We could repeat the aspiration, but I think that we should remove a piece of your thyroid at this point, to be safe."

"Is this a big surgery? Do I have to stay in the hospital?" Ms. Reid asked. With her job as a teacher and her kids, an inpatient stay would be difficult.

"No, no. It's a day surgery, and one I do routinely. The complications we might see are mainly bleeding and infection. We can control bleeding by cauterizing blood vessels or tying them off, and if there are signs of infection, for instance, if the wound becomes red or if you begin to have fever, we will start you on an antibiotic. There is always a slight risk of injuring a nerve to your vocal chord, but I've done this surgery many times and that's very rare. What questions do you have for me about the procedure?"

Ms. Reid said, "I'm ready to have this lump gone. Let's go ahead with the surgery."

"OK, then, visit with the scheduling nurse out front, and set up a time that works for both of us. You might want to schedule it before one of those occasions when your school has a 3-day weekend, like Easter or Memorial Day. The surgery isn't urgent."

Mrs. Reid scheduled the surgery, and it went as planned.

A few days after the surgery, Ms. Reid came in for an emergency appointment with Dr. Feng. It was obvious that she was irate, but her voice could barely be heard above the noise of the clinic.

“I thought you said this was rare,” she said, shaking a printout of a journal article on the subject. “My recurrent laryngeal nerve was injured. I’m a teacher, and I have children! I need my voice. I would have never done the surgery if I knew there was a 4 percent risk that I would lose my voice!” Was Dr. Feng negligent in explaining the risks of surgery to Ms. Reid? Was she required to use precise percentages of risk?

### **Commentary**

Something went seriously wrong in the way that Ms. Reid chose to undergo surgery. But the problem was not necessarily that her doctor failed to tell her that there was a 4 percent chance of damage to her voice. The problem was that Ms. Reid did not understand that that this injury was a real possibility and that either of her options (surgery or further testing) carried complex risks and benefits. Disclosing the exact probability of the injury and other possible outcomes might have helped her, and other patients, make a good decision, but it can also hinder that process. Research has shown that quantitative information can confuse and mislead as well as inform, challenging the assumption that disclosing such information is always ethically required [1].

### **The Complexity of the Decision**

During her meeting with her doctor, Ms. Reid must decide whether to have surgery immediately or postpone it and pursue more testing, most likely another fine-needle aspiration. The choice is not a simple one.

The benefit of having surgery is finding out definitively whether there is cancer in the nodule and, if there is, taking care of the problem (unless it has already spread, which is unlikely). At the same time, the surgery carries risks, including the damage Ms. Reid suffered to her voice but also other dangers, such as bleeding and infection. Although the doctor downplays these, they may of course be significant.

The main benefit of putting off the surgery is that further testing could show that there is most likely no cancer, allowing Ms. Reid to avoid undergoing surgery. In fact, she might benefit even if the testing shows a high chance of cancer, if it eases her decision about having surgery and thus reduces the likelihood of regret over negative outcomes, such as the one she experienced.

The downsides of pursuing more testing are the time, discomfort, and other burdens of the procedure, as well as the usual chances of bleeding and infection. Importantly, there is always the possibility that the testing will not clarify her risk. Also, even if the additional testing indicates that the chance of cancer is low, allowing her to avoid surgery, the nodule will still need to be checked by ultrasound 6 to 18 months later, and then in 3 to 5 years, according to standard guidelines [2]. If certain types of growth have occurred at these times, more testing and possibly surgery would be needed. It’s especially important to remember that any biopsy can fail to identify some cancerous or precancerous cells that can become a problem in the future—the so-called risk of a “false negative.”

Given all this, a significant downside of undergoing more testing rather than surgery is that Ms. Reid will need to live with at least some uncertainty, possibly for an extended period. The surgery has the benefit of providing certainty. In fact, this appears to be a key motivation for both Dr. Feng and Ms. Reid, as when she announces her decision with, “I’m ready to have this lump gone.”

### **The Advantage of Giving the Numbers**

As we know from the case, things did not turn out well, and Ms. Reid complains that she would never have had the surgery had she been told that the risk of injury to her voice was 4 percent. She feels that Dr. Feng’s description of this side effect as “rare” led her to underestimate its importance. Interestingly, when the European Union issued guidelines for using words to convey risk, they pegged the word “rare” to a risk of 1 in 1,000 to 1 in 10,000 [3], much lower than the risk that Ms. Reid faced.

At the same time, studies show that laypeople associate the word “rare” with probabilities that are much higher than the numbers favored by the EU, often equal to or greater than the 4 percent risk of the injury that Ms. Reid suffered. Subjects in one study guessed that the “rare” side effect of a hypothetical medication would occur 0 percent to 70 percent of the time, with about half of the individuals choosing a number between 5 percent and 20 percent [3]. Another study found that patients came up with a similarly wide range of interpretations for words like “rare” and “likely” when applied to the risks of surgery [4].

Due to the variable understanding of such words, many experts have argued that patients should always be given the numbers instead [5-7]. These experts reason that patients should receive full information and make their own determinations about whether a risk is “rare” or not, as part of a process leading to an autonomous decision.

To clarify the ethical issues, it is helpful to consider two criteria for what should be disclosed during informed consent. The *subjective standard* requires that each patient should be given all the information that he or she would find important in making the decision at hand [8]. Ms. Reid says that she would have found the 4 percent risk relevant, so, according to the subjective standard, it seems she should have been told of it.

The subjective standard has been criticized as being unfair to clinicians because it requires them to determine exactly what information each patient wants. This problem has led many to prefer the *reasonable person standard*, which requires only that the clinician should disclose the information that a reasonable patient would want [8]. Still, given the research about variable interpretation of words like “rare,” it seems that the reasonable person standard would require disclosure of the specific risk of 4 percent.

The subjective standard and reasonable person standard help clarify the ethical basis for Ms. Reid’s complaint, but they also provide a framework for exploring its weaknesses [9].

### **Numeracy, Heuristics, and Biases**

The idea that a *reasonable person* would want to know the specific probability of the risk raises the question of whether such a person would be able to understand the number. Studies show that more than 20 percent of adults in the United States have only basic mathematical skills like counting and another 33 percent are limited to simple arithmetic. Less than 50 percent of adults comprehend the more complex mathematical concepts of frequency and percentage that are central to probability [10, 11]. One could argue that we cannot assume that the “reasonable” person is numerate and thus cannot conclude that the reasonable person standard requires disclosure of such information [1].

Even those who understand probability may irrationally discount a risk such as 4 percent. For example, when told that a negative outcome will be suffered by 4 out of 100 people, some people will be unreasonably confident that they will *not* be one of the unfortunate ones due to the “optimism bias” [12]. Psychologists and economists have demonstrated a large number of such “heuristics” and “biases” in human thought, often related to rare outcomes. For instance, when making a decision, people often fail to account for the difference in importance of an event that will occur 1 in 1,000 times and one that will occur 1 in 100 times [13].

Other research has shown that people respond to probabilistic information differently based on how it is described or framed even when those descriptions are mathematically equivalent. For instance, people interpret a danger as being more likely when it is stated using positive framing (e.g., saying that 4 percent will experience it), than when stated using negative framing (e.g., saying that 96 percent will not experience it) [14]. Some guidelines recommend that doctors provide both positive and negative framing of outcomes to avoid causing bias [15]. This approach, however, can be quite confusing, especially for those who have limited numeracy, and presenting the negative framing allows people to focus on the chance that the risk will not occur, resulting in the optimism bias.

### **Emphasizing a Risk and Balancing Risks**

If Dr. Feng wanted to make sure that Ms. Reid understood the risk of injury to her voice, she might have chosen to state its probability using only positive framing (4 percent) or employing other means to make sure that Ms. Reid takes the chance seriously. But the challenge is not just of making sure she recognizes the risk, but, more importantly, helping her comprehend the risk in a way that allows her to choose rationally between surgery and further testing.

And for her to do that, it appears that she must understand other probabilities as well, perhaps most importantly the chance that there is cancer present in her thyroid that could spread and prove lethal. The case doesn’t tell us the probability of this

outcome but, given what her doctor says, the finding on her initial biopsy could have been “follicular lesion of undetermined significance,” or something similar. According to the literature, this finding carries a 5-10 percent chance of malignancy [16].

Other numbers that are clearly relevant include the probabilities that the repeat testing will show that there is minimal chance of cancer (and thus that she can forgo surgery without concern) or produce no change in the risk estimate (leaving her with the same uncertainty about how to proceed) or show that there is probably cancer present (and thus that she should have surgery). Further, if the biopsy is reassuring, it would seem important to know the chance of a false negative, i.e., her chance of facing further problems with thyroid cancer.

If before the operation, Dr. Feng had disclosed the exact chance of damage to Ms. Reid’s voice, it appears she should have provided these other probabilities as well, in a way that allowed rational evaluation and balancing among them. But it is unclear how she should do this, given the existence of widespread innumeracy in the population and common heuristics and biases in human thought [17]. Finally, she may not even have good numbers for some of these possible outcomes—such as whether the further testing will help clarify Ms. Reid’s risk—or what the chance of a false negative would be.

### **Conclusion**

These considerations suggest that disclosing a specific probability of a risk is less important than helping patients understand that there is a difficult decision to be made, and comprehend in some way the sort of complex and incommensurable tradeoffs involved. Providing exact numbers is not clearly required or even helpful for specific patients or overall, for a theoretical “reasonable person.”

This conclusion fits with “dual process” theories of human thought about risk, which hypothesize that *verbatim memory* encodes specific numbers, while *gist representations* classify outcomes in terms such as “important,” “rare,” and so on [18]. According to dual process accounts, *gist* plays a much more important role in decision making than *verbatim memory*. And from this perspective, the questions of whether doctors should disclose numbers and when depend on whether doing so can help patients form accurate and effective *gist representations*.

Finally, the process of informing a patient and explaining that a difficult decision must be made is not equivalent to demanding she make the decision alone. If Ms. Reid understood the complexity of the tradeoffs involved in her surgery, it is possible that she, like many patients, would ask the doctor what she recommends [19]. In fact, Dr. Feng provided her recommendation in a thinly veiled and persuasive way, with her interpretation of the risks and benefits of surgery. But she failed to emphasize the existence of a difficult choice to be made, and thus she failed to give Ms. Reid a chance to make her own decision, or to decide in an informed way

to rely on the doctor's recommendation. Her failure to disclose the specific probability of damage to Ms. Reid's voice was not the problem.

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