It’s Not What We Don’t Know That Hurts Us: It‘s What We “Know” That Isn’t So

written by Robert McNutt, M.D. | July 27, 2017

Making a decision is a—or really—“the” fundamental activity of life. The decisions we make, the consequences of those decisions, our feelings about the consequences, our interpretation of whether we made a good or bad decision based on those consequences, in total, form the basis of our life’s experiences, and, often, how we decide the next time.

My children used to say, “Duh,” to my muttering an obvious observance like, “It sure is hot today,” because the temperature just hit 100 degrees. The opening sentence of this blog may seem so obvious that it may trigger a similar response.

Making a decision in medical care is, however, not a “Duh” experience. It is a difficult, sometimes grueling experience. In fact, it is so grueling, that many people resign their responsibility for choosing to others, like their physicians. Making a decision is tough, for certain, but the process for making a decision should be routine, or, at least, “a” routine.

The routine is this: when you are ill and a diagnosis is made, you will have options for treatment. The options must be compared in terms of how much benefit they impart and how much, simultaneously, harm they produce. The key word in this last sentence is, “compared.” Medical decision-making is a routine of comparing one option for your care versus another.

We Must Understand the Real Tradeoffs Between Treatment Outcomes and Doing Nothing

Medical researchers study the outcomes of diseases. There are consequences when you have a disease. For example, your disease may threaten your life expectancy or your quality of life. Medical care aims to reduce the chances of those detrimental outcomes. Some treatments may be better at reducing the chance of the disease-related outcomes than another. There will be, hence, a difference in the percent chances of outcomes. You must know how big that difference is.

But, here’s the rub: a treatment that reduces, compared to another, the chance of detrimental outcomes associated with disease almost always produces added harmful outcomes caused by the treatment. When a patient learns the differences in both the outcomes of disease and treatment, she can assess if the value to gain in terms of disease outcomes is worth more than the value to lose from treatment outcomes. That trade-off is the essence, the routine of medical decision-making.

A brief, classic example may clarify—treatment for early stage prostate cancer. Surgery, compared to no surgery, reduces from 8 to 6 percent the chance of dying of prostate cancer over the next 10 years. The benefit is the difference, or 2 percent. On the other hand, surgery increases the chance of being impotent from about 10 percent to 60 percent; a 50 percent added difference, or harm. That is a 2 percent (benefit): 50 percent (harm) trade-off, or 1:25. In other words, harm is 25 times more likely than benefit with surgery, but benefit outcomes are life/death, and harm outcomes affect quality of life, not length. That is a tough balance choice to make, but the numbers of added benefit and harm inform the value debate for a patient.

No Medical Choice Should Be Made If Nothing Is Known

These trade-offs, in fact, are a requirement for making a medical decision. The marginal differences in outcomes of disease and treatment are based on science, hopefully appropriate for an individual’s choice, and required in order to balance one option versus another. Without those known differences in outcomes, no choice can be made, as no appropriate routine for choosing is available.

That is a radical statement in medical care, so I will say it again; no choice can (should) be made if nothing is known. Physicians often ask me, “What if I don’t have the data?” By this they mean that they do not know if there is a difference in disease outcomes because definitive studies have not been done. In that situation, no comparison of treatments can be made and, hence, no decision. This includes doing nothing versus doing something for a patient. Before any decision can be broached, there must be knowledge about how much better is doing something over nothing, for instance.

It is said that only about 20 percent of medical interventions have been studied in rigorous randomized scientific designs for us to know the numbers of benefit and harm. I don’t believe this number. First, we don’t really know how many possible interventions or combinations there are; any given disease may have only a limited set of options available and many treatments don’t require a randomized controlled trial to know they work. For example, the effectiveness of the polio vaccine was so obvious, we did not need a randomized study. Some treatments provide obvious benefits because they are nearly 100 percent effective. My point is that, in reality, we know more about the benefits and harms of treatments than just what the randomized trials tell us.

However, some use the 20 percent number to legitimize the need to suggest untested choices for the other 80 percent of the possible options for care. Some assume, even, that they can “intuit” what is better and offer based on beliefs. Belief-based decision-making is not new; but it is a different routine. It only uses values without knowing anything about the marginal differences in numbers of outcomes, much like the debates regarding health care in Washington, D.C.

If the title to this blog is correct, it is better to not know and not act than to act. Medical care must be a science. Patients must be the decision makers but it is our job to make sure they have evidence upon which to base their choice. So, if we don’t know what is best, it will always be better to study our ideas rather than treat based on our best guesses. Perhaps, one of the reasons medical care is so expensive is that many of the things being proposed are assumed to benefit when they do not. When we don’t have a known trade-off, we can’t inform patients, and making decisions without knowing leads to valueless care.

Founded as ICLOPS in 2002, Roji Health Intelligence guides health care systems, providers and patients on the path to better health through Solutions that help providers improve their value and succeed in Risk. Roji Health Intelligence is a CMS Qualified Clinical Data Registry.

Image Credit: Cindy Tang