For Patients, “Trust Me” Is No Longer Good Enough for Medical Decision-Making

written by Robert McNutt, M.D. | February 22, 2017

It’s time to rethink ideologies of medical care that no longer make sense. The following may sound revolutionary, but are nonetheless true:

> Patients are the future leaders in medical care.
> Patients must and can make their own medical decisions after being informed.
> Patients can and must learn to discern useless from useful information.
> Science must improve to match the increasing abilities of patients.

At present, none of these concepts are fully embraced by the business of medicine and, in fact, may be a 180-degree reversal from the way things work now. So, why are these statements important? Because getting the best health outcomes, those that weigh benefit and cost, depends on a new role for the patient as decision-maker.

Unfortunately, in the current environment, it is very difficult for patients to make those decisions. That must change. This is the first in a series of occasional posts about what consumers need for intelligent and cost-conscious health decisions.

Treatment Option Discussions Require Reliable Data, Not Emotionally-Laden Words

Patients need to understand their medical problems and related choices for managing their health. But discussion of “treatment options” is often superficially used with patients. They are often simply told why a proposed test or treatment is best. A patient recounted that her oncologist proposed radiation for breast cancer because it would “clear tumor,” and it was “imperative” to clear tumor to “limit” the chance of recurrence. This conversation can be viewed as offering reasons; “clearing tumor,” “imperative” and “limit” are words of size and intent.

These words conveyed nothing, however. She asked, “What do you mean by limit?” The physician said, “Reduce the chance of recurrence from 50 to 10 percent, a 40 percent difference.” That sounds like better information; it is numeric, it is tangible and it has meaning. But it was incorrect (the actual difference for this patient’s chance of recurrence was 5 percent, and the physician had either forgotten or exaggerated the results.).

Presenting information with numbers instead of non-specific words is essential, but not the standard for communicating with patients. The reason it is not a standard is that the numbers may be useless. For example, what if benefit information is derived from weak studies? What if the information is based on average population estimates rather than an individual’s peculiar circumstances? Population health, after all, should be the accumulation of best decisions made by individuals.

It will benefit patients to become aware of what medical information is most likely true, as much is not. This is a bold statement; many claim that patients can’t and shouldn’t need to understand medical information. They should trust the medical system to provide tests and treatments that are proven to produce more benefit than harm from the patient’s perspective. Unfortunately, this is a specious argument. There are too many conflicts of interest for those interpreting medical information.

Even a High School Student Can Learn and Understand Medical Information

It is my belief that patients can attain the skills needed to scrutinize and assess the quality and relevance of medical information as a basis for informed decisions about their treatment options.

I requested a high school student to assess a paper suggesting that patients cared for by a woman physician while in the hospital have a lower chance of dying in 30 days after being admitted. I gave the student some ground rules for thinking about a research study:

1. A study must ask a reasonable question.

    The question, if answered, must have a “do something about it” solution.

2. Consider problems with measurement; if compromised, science is precarious.

    First, examine how the study population’s data was collected.

        What is the source of data?
        How was the data sampled and collected?
        Was the data for the study obtained with the question in mind or does the study expediently use data collected for other reasons?
        How many people are in the study?
        Do the characteristics of the patients in the study resemble you?

    Second, are the items being studied and the outcomes measured accurately and reproducibly?
    Third, what personal, patient factors, if not balanced in compared groups, may make one option look better than it really is?

3. Does the study type assure that the item being studied is solely responsible for the better outcome?

    Is it a randomized study? If not, the study is likely not clinically credible.

4. What is the average and range of estimates for the absolute difference between the compared options?

    Is the difference clinically significant?

5. Interpret the study results.

    Is the study result likely true or false?

After discussing these guidelines, I told the student about the study and showed her the tables and the abstract. Here were her answers to the above questions about the study:

1. Study question?

   This is not an actionable study question. What could we do if we found that a woman physician's care for a hospitalized patient might lead to better outcomes? Would we demand only women care for admitted patients?

2. Measurement issues?

   Women and men are likely correct measures.
   Women cared for only 30 percent of the patients. Physicians, then, could not have been randomized to days of care in the hospital.
   The student noted it is not certain if the named physician actually cared for the patient. She told me of her experience. Her mother's hospital bill was from a physician who saw her only one of the four days.
   The student also asked if residents took care of the patients. Recounting her mom's care again, she said that only residents spent time with her mother. (In fact, in the study, 29 percent of women worked in academic medical centers versus 21 percent of males, raising the possibility that women physicians more likely had residents sharing in care.)

3. Study design issues?

   The student asked about the data; I told her that it was not collected for the explicit reason of the study question.
   She noted that the patients were all over 65 years of age and wondered if it would be the same for other patients.
   The study was not a randomized trial (cross-sectional, observational trial).

4. Difference in outcome?

   The difference in the main outcome measurement, 30-day mortality, was minuscule and rounded to equivalent mortality rates for patients treated by women versus men (11.07% [women] versus 11.49% [men]).

5. Interpretation?

The language used in the study suggested women were better physicians, despite the study design not being able to determine that.

The student thought the study showed equivalent care but thought there were measurement problems, so she could not be sure. She did not believe care was better with women.

She summarized: there is nothing we could improve if the study is true, the data were not collected for the question at hand, and the difference in mortality was “really small.”

In short, she nailed it. These astute and correct “critical appraisal comments” were made by my high school student after one half-hour chat about medical studies.

Patients Have a Right to Know the Truth and Applicability of Data for Decisions

I am using this example to reveal the goal of medical care communications. Each of us must learn to critically assess information provided by physicians or the media. The media took to this study like a duck to water and discussed it as factual, which it is not (we can’t say for certain that care is better with women).

Patients, when being informed about their care options, should be taught how to discern useless from useful information. It is equally important that patients know if the information they use is true for them as well as how to use the information for their decisions.

Patients, in my view, have the right and the ability to be discerning. If patients were taught to be discerning, they might open a path to a more obliging system of care. Patients may demand better studies and become aware of biased interpretations. Indeed, patients, in my experience as a physician, are better at knowing the value of information than those in the “system” who are promoting it. Patients, after all, face the consequences of their choices; no one in medical care can share a patient’s outcomes. As we shift who is in control of medical decision-making from physicians to patients, we will need to ensure that patients are educated in the skills of medical decision-making. Informed patients making educated decisions is a requisite step to better care.

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