Informed Choice in Cancer Screening

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I’VE ALWAYS KNOWN SHARED DECISION MAKING INVOLVES real work, but recently the challenge really hit home. A few days after I was invited to write this editorial, I visited my 80-year-old mother in Colorado. (Note: this is pure coincidence, both events are rare. . . .) She had just learned that she had carotid artery stenosis. She was asymptomatic and was being asked to consider angiography and possibly surgery. Her physician and I wanted her to make an informed choice. She asked me to write the relevant information on a single sheet of paper, so she could read it, think about it, and read it again. I struggled with the assignment. The primary data source was clear: the ACAS (Asymptomatic Carotid Atherosclerosis Study)1 and the mortality rate observed in the real world.2

But there were a lot of questions dealing with the 1-page presentation. My mother and I went through multiple drafts.

My tables failed miserably. “OK, let me see if I’ve got this right: 5% of the people who had strokes got surgery?” I wanted to limit the number of outcomes I gave her to avoid information overload. But which ones? I wanted to present the investigator’s primary outcome (ipsilateral stroke or any perioperative stroke or death), but that was tough: “Let me see if I’ve got this right—5% of the people having surgery had a stroke on the same side as the surgery, while 11% of the aspirin group. . . .” Gilbert, I thought you told me the aspirin group didn’t get surgery!” And then the inevitable question, “Why would I care which side my stroke was on?”

Shared decision making sounds great, but there is much to balance. Physicians want to provide a comprehensive picture of the decision without providing so much detail that our patients are overloaded. Physicians want to communicate the probabilities for various end points without being

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overly precise (particularly given the imprecision of most estimates). We also want to communicate the downsides of various therapies without scaring patients. Perhaps most important, physicians want to try to really share the decision, not simply step aside (“It’s really your decision”) and abdicate the responsibility as advisor. I tried to find this balance with my mother in making the decision about endarterectomy.

In this issue of The Journal, Walter and Covinsky provide a framework to help clinicians find this balance with elderly patients in making the decision about cancer screening. Perhaps the authors’ biggest contribution is their effort to help clinicians estimate the expected benefit of screening for a specific individual. Although they chose the reciprocal of the absolute risk reduction (the number needed to screen) as their metric of benefit, others are possible, such as change in 10-year probability of death from the target disorder or change in life expectancy. Learning which measure patients best understand is an important area for future work. No matter how it is expressed, however, the benefit of screening will seem small. One thousand people need to be screened to avoid 1 death, an absolute decrease of 0.1% in death in the next 10 years, or a 2-day increase in average life expectancy. It is important to convey to patients that these are averages and that most individuals will get no benefit while a few may benefit tremendously.

But no matter how small (or how rare) the benefit, if there are no downsides, there is no need to inform the decision. Why wouldn’t patients want to be screened? The prevailing medical culture has tended to downplay the downsides of screening. To have a more balanced view, physicians and patients all ought to be clear about what those downsides are.

**Screening Tends to Miss the Most Aggressive Cancers**

Many might argue this is not a downside to screening, simply a limitation. And, in fact, this is the 1 downside that is already factored in the measure of benefit. But it is very important that it be explicitly communicated so that people have realistic expectations. Patients should understand that cancer can appear during the interval between screening tests. These are the cancers that are not detectable at 1 screening test, yet are clinically obvious before the next. Not surprisingly, interval cancers are the fastest growing tumors. They are among the worst of cancer, more deadly than those detected by screening. Understanding that screening misses these cancers is important so that patients do not give up on screening if others develop cancer despite screening and also is important because it invalidates a common belief: anyone who dies of cancer and was not screened would have been saved if only he or she had had the test.

**Patients May Receive an Ambiguous Result and Undergo Cascade of Testing**

Physicians need to communicate that diagnostic tests are imperfect. Patients with abnormal screening test results often do not have cancer. But before they are pronounced “cancer free,” they may have to go through multiple tests—some of which are unpleasant and some of which can have serious complications. Additional testing may even become a regular event. Throughout the entire process, many will worry about whether they have cancer.

Most physicians have developed some language to prepare patients for false-positive test results. For instance, an explanation for fecal occult blood testing might be something like this: “This card will test the stool for small amounts of blood. If it’s positive, it doesn’t mean you have cancer, it just means we need to look further.” But physicians are not as good at preparing patients for the reality that extra testing may become quite invasive and go on for a long time—perhaps indefinitely. More and more are undergoing colonoscopies every 2 to 5 years; undergoing additional pelvic examinations, colposcopies, and cryoauterizations; and having repeat prostate biopsies. Patients should understand that more frequent testing can be a consequence of screening.

**Patients May Be Treated Unnecessarily**

This is the central harm of screening. Screening can detect pseudodisease: an abnormality that meets the pathologic definition of cancer but either does not progress or grows so slowly that an individual dies from another cause before the cancer ever causes symptoms. Mounting evidence suggests that a cancer reservoir exists in humans that is much larger than what is known to be clinically relevant, particularly for breast and prostate cancer. As screening tests become increasingly sensitive, the detection of pseudodisease is bound to become an increasingly common problem.

Patients who have pseudodisease detected cannot benefit from early treatment. Instead they only experience the morbidity of a cancer diagnosis and the morbidity (and occasional mortality) of our cancer therapies. There is no group for whom this harm is more relevant than elderly patients. As patients become older, their competing risks for death increase, making pseudodisease more likely. Given the common definition of cancer, however, the concept of pseudodisease is unfamiliar to most patients. But with the increasing detection of prostate cancer, internists and geriatricians have gotten some experience trying to describe it: “Some men die from cancer, many more die with it.”

**Some Pathologists Will Say That an Abnormality Is Cancer, While Others Say It’s Not**

To be fair, most physicians are rarely ever made aware of this downside. But that speaks more to the fact that few biopsy specimens are read by 2 pathologists than the frequency of disagreement. When investigators look for disagreement, they generally find it. The problem is not that pathologists disagree about large obvious cancers that are invading surrounding tissue. Instead they disagree about the subtle abnormalities—the very abnormalities most commonly identified with screening. Physicians and patients...
Physicians May Be Distracted From Other Issues That Are More Important to Patients

In the past, physicians came to most clinic visits without a preset agenda. Now, we increasingly have one: “You are due for A, B, and C, and we also recommend that patients do X.” And much of that agenda relates to screening. There is a lot of appeal to screening from the physician’s perspective. Screening is a concrete service (it can be written in the patient’s plan), and it identifies actionable lesions. Discussing screening concerns, on the other hand, can feel ethereal and frequently concludes with sympathy, not an actionable plan. Given the limited time for clinic visits, one service may compete with the other. However, this downside of screening is not frequently discussed, and the evidence that it exists is anecdotal. But I believe it’s real. The more time we spend describing, ordering, communicating results, and following-up abnormal findings, the less time there is to spend dealing with the patients’ concerns.

As I reflect on these potential downsides, I cannot imagine trying to communicate all these ideas to my mother (or any other patient) in a 15-minute visit. Because screening has been so effectively promoted as a uniform good, these ideas may be seen as heretical to most. So is there any other approach? There is, but it involves larger organizational units than the physician. Because screening is a population-based strategy, the responsibility to inform the choice falls on the larger system: managed care organizations, insurers, governmental agencies, and professional medical societies. This education may be an ideal part of the curriculum for group visits. However, the educational approach needs to shift. Most educational efforts to date have focused on persuading people to be tested, not informing them of the trade-offs involved.

Moreover, quality managers need to seriously rethink the idea that ordering a screening test somehow represents high-quality health care. Managers like to use screening tests as performance measures for 3 reasons. First, preventive services are good for public relations (read: marketing). Second, screening tests are easy to measure—they either happen or they do not, and they tend to be readily identifiable in electronic data systems. Third, the prevailing mindset is that the decision of whether or not to be screened is a “no brainer” and that a 100% compliance is a laudable goal.

That mindset needs to change. Walter and Covinsky contribute to the literature by making clear that the decision about screening is a matter of individual choice. The choice hinges on the probability of various outcomes and how patients feel about them. The truth is that screening has multiple effects on patients. A few may have their lives saved, a few will die of cancer anyway. Many more will face testing cascades and uncertainty, some will be treated unnecessarily, and a few may die from treatment. And all can be distracted from more important health pursuits. In short, for many patients, whether or not to be screened is a close call.

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