BEHAVIOR MATTERS

15 Years of Health Behavior Advocacy

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CHAPTER 7

How Science and the Media Undermine Behavior Change

As part of a symposium about whether the quantity of information has an impact on the quality of knowledge, I was asked to talk about the bottom end of the scientific information food chain; that is, how individuals make sense of and decide to act on science-based information, in this case, information about cancer screening. For example, should my 80-year-old mother get a mammogram? Should my 49-year-old brother get a colonoscopy?

Evidence tells us that people are healthier when their efforts to care for themselves are guided by a basic accurate cognitive model of benefits and threats to their health that allows them to maximize the former and minimize the latter.

Cancer screening would be more effective if individuals were both more knowledgeable about the benefits and risks involved and more motivated to act on them.

These questions resonate now because current trends in health care are such that there are dire consequences for those individuals who do not take caring for themselves, including such screenings, seriously enough.

Recent trends in health care delivery point to a new reality: Increasingly, you and I and our family members will make complicated decisions about our health and health care on our own. Often, we'll make these decisions in the absence of information about cost or quality—and, in many cases, without a basic understanding of how to evaluate health claims.

This is an interesting plan, if we can so dignify the convergence of fashion, policy, secular trends, desperation of employers and other institutional payers and politics that put individuals in the driver's seat of their health care without a map.

15. This essay examines how the normal processes of scientific discovery and journalism work together to undermine the use of scientific knowledge in health decision-making.

Or perhaps without a steering wheel. There is no evidence that this plan will work. In fact, there is significant evidence that it may not. Yet it is the direction of health care in this country and is thus a reason to think carefully about what it will take to engage people to seek and act on scientific information.

For illustrative purposes let's think about two of the most popular kinds of cancer screening: tests for breast cancer and colorectal cancer. I will touch on the vast and diverse body of information we have gathered about how to turn this information into knowledge that is acted upon by all adults.

But my main aim is to discuss how the likelihood of such action is profoundly undermined by the very nature of scientific inquiry and the nature of the journalism that reports scientific advances to the public.

Some Basic Facts

Currently, our government, the American Cancer Society and health professional groups all recommend the combination of three tests to detect early signs of breast cancer: mammography, clinical breast exam and breast self-examination.

To find polyps or early colorectal cancer, those same groups recommend that people over 50 should be screened using a combination of fecal occult blood testing, sigmoidoscopy and colonoscopy, determined in consultation with a physician.

In each case, recommendations are accompanied by information that would help individuals generally assess their level of risk and direct them to more specific actions.

Current rates of use of these tests look like this:

- In 2003, 70 percent of women age 40 and older had a mammogram within the past two years.
- In 2003, 23 percent of people age 50 and older had a home FOBT within the past two years.
- In 2003, 44 percent of people 50 and older had ever had a colorectal endoscopy.
- In 2003, 52 percent of people 50 and older had ever been screened for colorectal cancer using any of the tests.

Cancer screening guidelines were first among efforts to take stock of available scientific evidence and develop empirically derived and institutionally agreed-on guidance for health professionals and the public. The screening guidelines are widely available. The government (NCI, AHRQ, CDC), health voluntaries (American Cancer Society) and other cancer groups (the National Breast Cancer Coalition, the Colorectal Cancer Coalition) make it their business to tell the public to participate in screening.

They recruit celebrity spokespeople. They sponsor events. They do what they can to raise the visibility of the problem these tests can prevent.

So far, so good. There is broad scientific consensus about which screening tests adults should receive for breast and colorectal cancer, and this information is accessible to individuals directly as well as through their health care providers and insurers.

There is also a substantial body of information about how to make it more likely that this information will be acted upon.

A recent systematic review on communicating with patients about evidence found that information about evidence for the lay public is best understood when (1) it is tailored to the audience's specific interests and interactive, (2) probabilities are represented as natural frequencies in relevant groups of people, or are summarized as effect measures, and (3) information is illustrated using bar graphs and cartoons.

A review paper that appeared in *The Scientist* in February 2006 by the McDonnell Social Norms Group made these recommendations to public health communicators:

- Keep it easy.
- Don't underestimate peer pressure.
- Provide immediate feedback.
- Be understood; confront misinformation.
- Link to existing beliefs.
- Use effective presentation.

These reviews are two among hundreds from multiple disciplines, all shedding glimmers of light on how to communicate health information in persuasive ways to the public that will result in action on the part of individuals.

So Where's the Problem?

The process by which scientific knowledge advances provides a slippery base for action about screening in particular and health in general.

First, as we learn more about the diseases, and the number and accuracy of screening technologies increase, screening recommendations subtly shift.

We have seen this repeatedly in the past few years. Do you remember the tumult that resulted when, in 2000, a systematic review from Denmark cast doubt on the value of regular mammography to reduce mortality? This resulted in task forces, commissions and a public debate, much of it carried out in the media, about whether the existing guidelines should stand or be changed. Millions of dollars were at stake; many oxen were ripe for goring; safety and risk were hotly debated and methods of systematic review came under close scrutiny. After two years of uproar, this resulted in the U.S. Preventive Services Task Force changing its recommendation from annual mammograms for women starting at age 40 instead of age 50. The other institutional players and guideline producers soon followed suit.

The development of the virtual colonoscopy and its relative advantages similarly raised a continuing series of questions about the need to modify the guidelines.

The confidence with which health care professionals and public health officials promote cancer-screening guidelines is also challenged by critics of screening who consistently raise caution about the limitations of current technologies.

The argument I am describing has been most clearly articulated by Gilbert Welch and his colleagues at the Dartmouth Medical School and the Department of Veterans Affairs. These watchdogs of the screening industry believe that the benefits of screening have been widely overstated and the harms have been largely

ignored. Early detection technology was so primitive that it could only identify large tumors, so there was little ambiguity about the finding of cancer. But now screening technology allows for the identification of a few abnormal cells that may meet the pathologic criteria for cancer but that would never bother patients if they were left alone.

Breast cancer isn't one disease. Colorectal cancer isn't one disease. Cancer is a spectrum of diseases. Some of them can be very rapidly fatal. The trick is to be able to distinguish them and to treat them accordingly—and evidence is only slowly emerging to support such decisions.

So most abnormalities are now treated as though they will develop into cancer, inflicting unnecessary suffering—surgery, anxiety, radiation, depression, chemotherapy and fear—though we are not certain for which individuals the suffering is totally unnecessary. In the meantime, the best fix is a thoughtful, careful discussion about one's personal risks and preferences with a trusted care provider.

The point here is not the specifics of Welch's critique of cancer screening; rather, it is the existence of a compelling argument from reputable professionals that is attracting attention from those trying to present a more accurate picture of cancer screening.

A third and more general concern is the stream of events and practices within the scientific community that have been rightly reported on by a vigilant press watching out for the public's money and the public's trust. Whether it is the industry sponsorship of ghostwritten journal articles, lack of transparency about conflict of interest or outright misrepresentation of facts about scientific findings, this is news. The public wants and needs to know when its trust in objective, unbiased scientists has been violated. Institutions, including medicine, don't have the public respect they once did. Rebuilding a reliable reputation is an ongoing challenge.

People probably recognize that there are good scientists and bad ones. But they don't know how to tell the difference and don't know how deep the problem is. And so science is sprayed with the faint grime of corruption that currently envelops institutions generally, undermining the credibility of scientific messages.

Journalism and Science

Journalism and scientific research are professions that share some traits: Practitioners of each search for novelty; they see their work as iterative and self-correcting; they are skeptical; and their underlying aim is the betterment of the human condition through understanding.

But they are also very different. Science reveres expertise and precision. Journalism is wary of both. Science is a slow process with an ongoing search for truth that ultimately provides an increasingly accurate perspective of reality. Journalism believes that every day is a new day. Science is dependent on history and context. Journalism, in its quest to deliver a terse, new message, often ignores both.

Science and journalism coexist in a marriage of necessity. For all the moaning by scientists about inaccurate reporting on complex science, news is the vehicle by which citizens and policy-makers learn of scientific progress and come to support

it. But when the issue involves convincing people to change their behavior on the basis of information, this partnership is less salubrious.

We know that the public wants and needs binary information about health actions like cancer screening. Just as the answer to the question "What kind of life insurance should I buy?" is "term and invest the difference;" just as the answer to "What should I do with my 401K plan?" is "an indexed mutual fund;" just as the answer to, "Should I stop smoking" is "Yes!" responses to questions on health actions should be simple and clear. "Should I get a mammogram?" "Yes." "I'm over 50, do I need a colonoscopy?" "Yes."

This kind of pronouncement creates problems for both journalism and science. The scientist demands answers with footnotes ("In many cases, this may be true but..."). Journalism is also tentative ("That's true today, but we may come up with an exciting new truth tomorrow.").

Both journalists and scientists are addicted to change. Citizens are often paralyzed by it.

People want quick answers that aren't subject to continuing subsequent review. They don't want to have to repeatedly assess the value of every routine test. We can't ask them to devote their lives to being good shoppers for information they don't feel qualified to understand. They are willing to get the test, but they don't want it to be laden with additional perceptions of risk and questions about whether it is necessary. They are busy. They have to finish the report, take the kid to karate lessons, fix supper and take the car to the garage.

Pregnancy tests meet this standard. Either you are or you aren't. But they're the exception. There are a few people who want to know more, who will dispute the advice and re-frame the question and make the effort to match their risk profiles to their actions. Visit any cancer-related Web site and you'll find a wealth of information about how to do this. But the methods of good science—and the methods of good journalism—are inimical to the cancer screening information needs of the general public.

The idea that our ability to screen for cancer with greater accuracy will improve over time is something that the public enthusiastically endorses. So it shouldn't be a surprise that emerging evidence casts doubt on current practices. This is not atypical in health. We had great fanfare about the changing risks associated with drugs to treat inflammation—Vioxx, for example, and a series of conflicting findings about the suicide risk posed for adolescents by antidepressants. More recently we have already witnessed the dashing of the shibboleth about the effectiveness of a low-fat diet to prevent heart disease and cancer. And we have learned that calcium supplements appear to have no effect on bone density. But it appears the public wants—and needs—one without the other. It wants better early detection and faster cures without the confusion that is part and parcel of scientific progress. For them, science is like legislation. They want a positive result they can understand, but they have little enthusiasm for the process (of watching the sausage be made).

Binary Desires, Nuanced Data

We are already headed for trouble here—because binary action cannot digest nuance.

The future of health care is in the nuance. Advances in genetic medicine and personalized medicine—eventually the treatments for most conditions—are going to challenge people to become engaged in their health in ways far more profound than consumer-driven health care ever will.

What does this mean about cancer screening for breast cancer and colorectal cancer?

It means that the definitive answer to the question, "Should I get this test?" is undermined by the steady stream of science news that makes the answer a qualified, "Maybe; it depends." People want a black box that will allow them to cut to the chase.

"But wait a minute," you say, "isn't the critique that maybe you don't *want* to be screened because of all the false positives?"

The people who don't seek screening—because it is too complicated to figure out whether such tests are personally relevant or because they are unaffordable—are not the same as those who choose not to get screened because they have talked to their doctors, looked at their own risk profile and made an informed decision. For one thing, there are a lot more of the first kind of person.

And the problem is that in order for screening to be successful as a strategy in a population and for these particular screening technologies to be effective for individuals, the latter must be standard practice. Otherwise, the resources we invest in cancer screening will not move the needle on saving lives.

What Should Be Done?

I'm not sure. It is ironic that as research supplies us with new answers about the determinants of health and disease, health care providers seem ever less available to help us personalize the new evidence to guide our decisions. Often new evidence floats away, not used by many people because it is too complicated to apply to their own situation without an available expert to assist.

This paradox must be solved if we are to fully capture the value of health research.

Maybe health plans and employers will recognize the need for and value of careful, thoughtful, personal informed consent (as opposed to a postcard from your health plan) to help people understand their unique risks so they can make decisions that match their own preferences for screening. This is most likely to occur in insurance programs like Medicare where beneficiaries make long-term commitments.

Maybe there will be a cohort effect as we age and as the public becomes more health literate, savvier about the use of health services and less passive about health and health care than our parents seem to be.

Maybe people will become more educated about both the possibilities and the limitations of science and will begin to celebrate the rhythms of discovery and self-correction.

Maybe journalists and their editors will take greater care to avoid inflated language, exercise more caution in their claims and recognize the need to describe the context into which new findings fit.

Maybe scientists will, even when there is so much money and fame resting on their findings, temper their claims.

And maybe someone will invent a magic pill that we'll be able to buy for a dime that will guarantee that we'll live without pain until we die quietly on our hundredth birthday.

But these are fixes that will take place over time and in response to demands and contingencies beyond those we can conjure or control.