

# BEHAVIOR MATTERS

*15 Years of Health Behavior Advocacy*

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BEHAVIOR MATTERS: 15 Years of Health Behavior Advocacy  
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## CHAPTER 6

# Promises and Pitfalls on the Way to Transforming Consumer Health Decision-Making

People with hammers have a tendency to see their world as a collection of nails. There's a tendency to seek universal solutions that will solve any problem. So, some suggest that removing vending machines from grade schools will solve the childhood obesity problem; that Paxil is going to fix your marriage, your job, your bad mood and your truck. And that tax cuts will stimulate the economy, reduce the trade deficit, stabilize immigration, improve the nation's schools, and increase research and development in the United States.

While the impulse to try out a good hammer on a lot of nails—to try to apply a solution to related problems—is both normal and often useful, there is *always* a point of diminishing returns, a point where the solution is not sufficiently flexible or robust to be effective. *The trick is to find the optimal match between problem and solution: finding the right tool for the job.*

I think that this ubiquitous hammer-and-nails aphorism provides a good metaphor with which to understand how to better support individuals in making the right decisions for themselves about their health and health care.

So, first I'll make some observations about *nails*—that is, people—consumers—whose attention we are trying to capture, whose behavior we hope to change. Then I'll say a few words about the *hammers* we use on those nails—the interventions, the programs, the applications through which we attempt to support consumer health decision-making. I'll reflect a little about some trends that encourage me about the future of this enterprise and I will end by talking about the relationship between hammers and all those nails.

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14. This essay is adapted from a keynote address at the annual meeting of the Center for Information Therapy in Park City, Utah, in September 2005.

First, the *nails*—how the varied characteristics of consumers present a challenge to the construction of effective interventions.

I recently completed a book that involved interviews with about 200 people—patients and their families—about how they made use of scientific information after receiving a devastating medical diagnosis. There is probably no point in one’s life when it is more important to make judicious use of good information—and there is probably no point when people feel less able to actually do that.

I am deeply enthralled with the vividness of the stories I heard. I feel as if over the years, my ears had become numb to the meaning of terms like “health literacy” and “cultural preference.” They had become dense shorthand that for me had lost any nuance or valence and were just variables to be accounted for.

These interviews have brought me up short, cracked open these coded terms, shone a light on the complexity of human experience and forced me to think carefully and differently about the “project” of getting people to act on the basis of good information.

It humbles you to listen to people whose lives depend on finding and using good information describe how they approach this task—whether they are talking about trying to identify the right doctor, determine whether they are getting competent care or choose among treatment options. It requires immense effort, energy and resourcefulness to do this when you are in shock—when you have just heard that your life is irrevocably changed by the diagnosis of ALS or MS or cancer or stroke.

Here are four observations that I have taken from these interviews:

**People’s preferences for health information in response to stress become more inflexible as stress increases.**

I have always thought of Suzanne Miller’s work on blunterners and monitors as an elegant heuristic that defined extreme ends of a continuum. Miller has identified these inherent preferences for seeking information about health risk and found that people fall into a bi-modal distribution of *blunterners*—people who find that they do better with a minimum of information—and *monitors*, those who energetically track down the details about the molecular structure of their sarcoma, for example. She has found that blunting is a pretty stable style, but that monitoring, because it tends to rouse anxiety, is more malleable—it can be reined in and self-managed, the acquisition of information self-titrated as a person learns more and gains experience in learning about their disease and its treatment.

In listening to people describe their approach to seeking and using information, I have come to see these differences as pretty meaningful. Under stress, people become more extreme and more set in their preference for learning about their conditions. If you are a blunter, you may actively resist learning more. If you are a monitor, you may spin out on the glut of information available to you, desperate that you are missing that single last piece of information that will make the difference between your life and your death, unable to stop searching, unable to make a decision.

So, for example, one classic blunter told me: “I would be insulted if some yobbo read 15 papers on theoretical physics, my own field, and then came in and asked

me to help him design an experiment. And I expect the same of my doctor. I pay her. Let her sit down and tell me exactly what I need to know—what are my choices and what do they mean? That’s her job. I have other things to do.”

Another young woman described applying all her legal research skills to figuring out her choices and then being unable to think sufficiently clearly to weigh the meaning of her choices and their consequences. Despite having physicians as parents, she was unable to make a decision and eventually sought help from a psychotherapist—not for psychotherapy but because that was the only person she could think of who had no stake in her answer. The surgeon said “have surgery,” the oncologist recommended chemotherapy, the radiologist insisted on radiation, her parents were each pushing a different approach. And the weeks were washing by. Only a psychotherapist with no expertise in the disease could be trusted to listen to her reason it out without imposing his or her own values.

It was interesting hearing about how even extreme blunters were aware of that *someone* needed to learn about their condition and make informed decisions. So I heard from the man who said, “Look, I’ll supply the body and my wife will work with my doctor to do the rest. I have no interest in the details.”

I heard many stories like this where couples and families had different information preferences and it worked out: Someone would do the research and the other would participate as necessary—teenagers performing Web searches for grandparents, a distant cousin who is a nurse researching the right doctors. But I also heard heartbreaking stories where the difference in style of seeking and using information was the straw that broke the camel’s back—the young woman dying of liver cancer estranged from her husband because he wanted to examine and expound on every journal article, every blood count, while she wanted to spend her energy having the limited life she could. Or the elderly couple responding to the husband’s stroke divided by his faith in doctors and science and her faith in God.

What does this mean for us? It means that individuals’ behavior doesn’t change, even when life is at risk. Some will be sophisticated and analytical while others will simply reach for the first box they see.

But it also points to the unit of interest—the “nails” we want to whack at with information—as being not only the person with the risk or the disease, but also that person’s sisters, mom, adult kids and teenagers, distant relatives, boyfriend and neighbors.

### **A person’s receptivity to new information ebbs and flows unpredictably.**

Suppose you went to your doctor tomorrow and she told you: “Surprise! You have this disease that is going to shorten your life considerably and disable you in the next couple of years.” What would you do? How many nanoseconds would it be before you hit Doctor Google to figure out what was up?

I, like you, have this notion that people get a bad diagnosis and then they immediately go out and learn all about it. And I don’t think this is *completely* wrong, but I am confident that this is not the only—or even the most common—response.

A man just diagnosed with an aggressive leukemia described doing exactly what I would do—he took a look at the first three Google hits about his disease, decided that it was too complicated for him right then and that he would focus on strengthening his immune system, an activity that completely preoccupied him for the next nine months, after which he felt ready to learn about his disease and his treatment. Or the couple—both of whom are nurses—who, when one of them was diagnosed with ovarian cancer, came home from the hospital and downloaded hundreds of articles during the first two hours, none of which they ever read. One of them told me, “We felt that by downloading the articles, we had been good consumers but we couldn’t take in any information. None. PDQ scared us to death. And we continued for the next year, every once in a while taking a little sip of new information—but only about the specific details about next thing we were facing—the transplant, the surgery, the chemo. It was too overwhelming to read and try to figure out what all those population-based numbers meant for us.”

Or on a smaller scale: “All of a sudden in the middle of the night, it occurred to me that one of the implications of my diagnosis might be that I would lose bowel function. WHAT? No one mentioned that, but I was sure it was true. What was I going to do? What would make the difference? How would they decide? What would it be like? Would life be worth living? Should I be worried about this? How come no one mentioned it? Should I kill myself tonight or tomorrow?”

What does this mean for us? It means that there is no discernable logical order in people’s needs for information. It means that the right information at the right time is a reflection of deeply personal differences that are superimposed on a general orientation toward seeking and using information to inform action.

### **All health information has a personal, emotional impact that distorts how it is processed.**

The associate dean for medical education at a New York medical school was in the middle of describing how they train students to deliver bad news. He paused for a moment and said, “Well you know, most health news is bad news.” That’s not surprising. Journalists know well that there’s no news like bad news. The more personal bad news is, the greater power it has to generate an emotional response that distorts how it is processed. Most medical news involves a reminder that you are resident in an imperfect body that will cause you inconvenience, if not serious discomfort. Misery doesn’t necessarily love company. Some people are encouraged to realize that they are not alone and that others have confronted—and even conquered—similar problems. But others see membership in a larger group as trivializing what they view as a personal and unique situation.

A man with multiple myeloma told me about receiving seven copies of Lance Armstrong’s *It’s Not About the Bike: My Journey Back to Life*. “I’m sure my friends thought it would be inspirational for me to read about him—you know, it would give me hope and courage—and also help me figure out how to cope. But I’ll tell you, I read the first couple chapters and quit. It is his map of suffering. I have my own map and it scares me enough to think about that.”

Or the man diagnosed at age 43 with diabetes: “I started learning about controlling my blood sugar and felt like I lost my life as I had known it. I went into a deep depression and really struggled to find my way out. Where was I going to find time to have this disease? I knew that I would have to devote hours of time learning to manage this if I want to stay alive. I have no interest in this disease but figuring it out it is the only way I can hang on to the things I love.”

We make the mistake of thinking that “just the facts, ma’am” is our business, that the information itself will be the transformer. We are kidding ourselves. Every fact becomes surrounded in a rich web of meaning and value, wherein an individual will, over time, accept, reject, use, or discard it.

### **Health literacy is more complex than comprehending ideas and instructions.**

This comes not from my interviews but rather from watching the aftermath of Hurricane Katrina unfold. The notion of consumer-driven health care is that the vast majority of people can and will make choices based on good cost/risk assessments and that such choices will be generally available to everyone. For example, the idea of Health Savings Accounts for the Medicaid population is an expression of confidence in the idea that a combination of threat and incentives will be sufficient to inspire responsible health behavior.

Some people simply have access to more tools than others, as we were reminded during Hurricane Katrina.

One writer compared two families struggling to flee New Orleans in the flood’s aftermath: one white and middle class (though hardly affluent), the other black and poor. The first family quickly found comfortable accommodations in a northern Louisiana hotel, then a semi-permanent home in a nearby town. But the second family spent months shuffling from one endless line to another—hungry, unshowered, unsure of its next move.

The matriarch of the middle-class family, a local court clerk, tapped a cousin to secure a low corporate rate at the Lafayette Hilton. She paid for it with her American Express card. The woman then worked connections in local government and churches to land a scarce rental property. She even won a dispensation from local authorities to sneak back into her abandoned house in a quarantined area so she could rescue some televisions and furniture.

The other family didn’t have such options. The husband had never been out of New Orleans before; the wife had never flown on a plane. Neither had contacts capable of assimilating them into another community. They did have \$2,000 in savings, but lacked a bank account. Their money burned up in a fire that followed the flood.

While money would have helped this family, coping skills and broader community ties like a banking relationship could have been more important.

This story reminds me of our facile assumptions about the skills and acculturation required to navigate an unfamiliar system. Being a patient in the United States is like being drop-kicked into a foreign country. You don’t know the language, you don’t have a map, you can’t tell who is in charge, and all you want to do is go home. I

have talked to highly educated, sophisticated people who are flummoxed by entering into the all-encompassing world of the ill—the whirlwind of tests and procedures and specialists required to make a diagnosis.

Just as it took more than money for that one family to weather the storm, it takes more than information to actually be able to negotiate the complicated series of personal and professional interactions required to get good treatment.

It is convenient—and probably commercially necessary—for us to carve out of the problem of general illiteracy the sub-problem of health illiteracy for special attention, but I fear it encourages us to forget the broader deficits in capacity and experience that erode the possibility of good health for many in our country.

So, thinking about the nails we hope to affect through our hammers—the consumer audience, the people whose actions we hope to influence and shape by providing them with systematically gathered information—these observations are important for several reasons:

- They remind me of the diversity and complexity of human behavior.
- They make me look hard at my ideas about what indicators of change will show that any given intervention makes a difference.
- They make me marvel at the grand ambition of the work those of us here are engaged in.

Now let me talk a little about hammers—the interventions, the applications, the “fixes” that we think are going to make the difference in consumer health decision-making.

How many reading this have a BlackBerry? How many like their BlackBerry? This story is for you.

I was at an international science and technology meeting in Kyoto and had breakfast with Rick Lazaridis, the inventor of the BlackBerry. Now the BlackBerry is an extraordinary example of mass diffusion: At the beginning, he had 200 employees and no customers. Now he has millions of subscribers for a device that works nearly everywhere in the world. Mr. Lazaridis waxed poetic about the potential of his BlackBerry and he said, “Information is soon going to be more important than reality!”

“How so?”

The answer is summed up as “access.” Those who have access to all the information in the world will prosper and those who have not, will not.

I really appreciate the genius of the BlackBerry. And I really, *really* appreciate the reality of the commercial enterprise, which requires Mr. Lazaridis to pack every conceivable function—phone, Web, e-mail, TV, whatever—onto his elegant little hammer so that he can whack as many communications nails as possible.

But information *isn't* going to be more important than reality. At best, it is merely a representation of reality.

And the BlackBerry is only a device, a little computer. It will only be *one* of the tools we use to communicate with one another, to send and receive information. It will never be the only one. The needs of human beings are too varied, our preferences too strong, our abilities too diverse for one device—one hammer—to suffice.

Ultimately the BlackBerry, like the screwdriver, is a tool that can help in certain situations. But neither will do much for a hungry person unable to buy food.

At the same Kyoto meeting, Dan Goldin, the former NASA Administrator, cautioned, “We must at all cost avoid the zero-point solution. I learned that in spades at with the Space Shuttle. You always need *redundant, flexible, varied* solutions to any given problem, whether that is in planning a response to a natural disaster like Hurricane Katrina, a terrorist attack or curing cancer. Take avian flu. Everyone is obsessed with how many vaccine doses can be produced in the days and weeks after an outbreak is detected. But there are many equally important other strategies to contain an outbreak that we are *not* talking about, from isolating high risk individuals, using face masks and hand-washing, selective quarantines, public education campaigns about avoiding exposure and so on. Hand-wringing about the political vicissitudes of producing and distributing the vaccine simply cannot be the only solution to this oncoming pandemic.”

Here’s the interesting dilemma for those of us interested in consumer health decision-making: How do we find the balance between our interest, on one hand, in developing powerful, trusted, clear tools for decision support for health decision-making—the one-stop information source—and the diminishing effectiveness of a tool or system that cannot accommodate the nuances of individual needs? The promise of the Internet, which remains unproven, is that it can create an affordable, high-tech, high-touch environment.

It strikes me that the economic incentives for most of you here are on the side of packing more stuff into each program or intervention—more different types of information, more different approaches to accessing it, more portals, better tailoring, more whatever. And the challenge for you is that there is some point past which the hammer is not hitting the nails but whacking senselessly at everything in sight, and at that point people cannot and will not use your program or product. But such combinations involve inevitable tradeoffs, which comes as no surprise to anyone who’s ever retired their recording television just because the VCR within died.

Finding the right nails and using the right-sized hammer demands hard work, vast experience, patience, attention to detail and a willingness to innovate and take risks.

Ultimately, I see two challenges to consumer health decision-making.

First, the need to continually acknowledge the complexity of the task we take on when we seek to provide the right information to the right people at the right time to support their decisions about their health. And second, in response to that understanding, recognizing that there is no “killer app” for what we are doing. There is no single program or solution that will do everything; the trick is to find the balance between efficiency and effectiveness.

But improved consumer health decision-making is also promising, particularly in three areas.

The first two areas I would put in the category of “clouds with silver linings:”

I think that the growth of consumer-driven health care is an extraordinary opportunity, with Health Savings Accounts and insurance trends that place more responsibility for health care on individuals.

I am skeptical about some claims made by advocates. I fear that the trend toward consumer-driven health care will damage the health of those already disadvantaged by our economic and educational systems, and that the net effect on the nation's health has already proved negative.

But I also believe that this is the road the country has taken and that there are ways to make it less rough, less unfair. I also believe in taking the long view. I see that the *mere threat* of this trend accelerating has stimulated unprecedented action. Money has been allocated to research on decision-making, has led insurance companies to invest in consumer decision support products, and has vastly increased access of most people to useful information about their health risks and health care.

Having advocated—fruitlessly to date—for increased resources and attention for health behavior on the grounds of good science and quality care, I am mightily impressed by the effectiveness of market forces in galvanizing resources to support consumer participation in health care. And I am even more impressed by the entrepreneurial efforts undertaken by our colleagues and competitors all over the country.

Whether or not consumer-driven health care is your idea of a positive direction for health insurance, you have to admit that in the past three years, the availability and use of information to support consumer decision-making has been transformed.

The second promise is the unexpected upside of the tragedy of Hurricane Katrina: My sense is that for all the misery and despair that it has caused, it will also cause a huge voltage hike in the availability, diversity, acceptability and use of communications technologies among the population at large. A simple example: listening to the people at Google talk about how they worked night and day to figure out how to put a net around all the Web sites that listed missing people in the Gulf states so that those sites could be searched without searching the entire Web.

Necessity is the mother of invention and this disaster has provided a new set of problems that will *electrify* the effort to find solutions. And from this outpouring of energy and creativity will come innovations in communication, in parsing and searching for and delivering information that will not only greatly enhance the tools available for health decision-making, but will also change the expectations and skills of the public about what they can *do* and *learn*.

The third promise is one that those of us who focus our work so tightly on identifying and solving problems tend to forget, but I was reminded of it by a conversation with Paul Wallace. I was talking with him about how he, as an oncologist, handled information and decision-making with patients, and I remarked on how many people I had talked with who had felt abandoned by their doctors in that time immediately after a devastating diagnosis. And Paul said, “The thing that really amazes me is how consistently people, despite our naïve and clumsy efforts, are able to move on and do OK.”

He is right. The promise of consumer health decision-making in part rests on the ability to put together easily navigable maps of information. But it rests far more heavily on the responsiveness, resilience and the resourcefulness of individuals to get the information they need to reduce their pain, to get their mom the right

treatment, to make sure their kid's asthma doesn't keep her from playing basketball, and to live for as long and as well as they can.

They are a messy crew, those consumers, and they have their limitations, but on the whole, they are feisty and impatient, and are going to respond to the tools we provide to help them make decisions. If those tools work, they'll use them. If not, they won't. Individuals acting as consumers of the information we provide will force excellence in the products we develop to support their decisions.

I want to return to the problem of the person with the hammer for whom everything looks like a nail, and to contrast that person with the task faced by those of us who attempt to construct an entire toolkit of robust, flexible, redundant methods, approaches, programs and applications that will be responsive to the known variations in human learning and behavior.

Our interest is not in hammering. It is in finding the right tool to do the job.

One of the occupational hazards of being a hammer-maker is the tendency to fall in love with your product. Like Rick Lazaridis, the inventor of the BlackBerry, it is easy to become intrigued by all the neat tricks your device can do. And it's all too easy to confuse solving the technical problems of the hammer with the larger challenge in consumer health decision-making, of actually hitting the right nails—solving the problem of helping people to easily find and use the right information when they need it.

This is understandable. Fiddling with the program or the application is easier: The hammer is yours—it's the thing you can control. But those nails—those pesky consumers—are wily and unpredictable.

The success of our efforts to support consumer decision-making depends on our abilities to improve our aim.