

The Fragility of Evidence: Why Study Health Behavior Now?

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I am grateful to be invited to such an esteemed institution, the Bloomberg School of Public Health. While I have gone through Baltimore twice a week for 14 years as I have commuted from New York to Washington, DC, this is my first time getting off the train in Baltimore in many years. It wasn't so long ago that the only matter of note for this city was that it led the nation in gonorrhea -- and chalk outlines. Today, there is a turn-around, and it is the practitioners of public health who have had a lot to do with that.

In a big city, human health and human life can be fragile. In the ivory towers of academia, we recognize that science -- the evidence we seek -- is also fragile.

I would like to speak today about the fragility of evidence -- how the results of the nation's investment in health research will be limited so long as we fail to devote enough resources to understanding how to get institutions, people and policy to transform new knowledge into routine action.

And I will try to persuade you to enthusiastically endorse an innovative and expansive vision for studying health behavior now.

To do so, I am addressing my remarks to three audiences that I expect are present today.

The first audience is those of you who have devoted your careers to studying health behavior. I hope to vindicate your choice of topics and to recognize the courage and persistence it has taken to succeed in this field over the years. Health behavior has historically been the ugly stepchild of the NIH and other funders - a problem that may have negatively influenced your status in the university, in hospitals, and in public health departments. The decision to establish a department of health behavior here at Johns Hopkins -- and the generous endowment that makes it possible -- is visionary and offers you opportunities for leadership and growth.

A second audience for my remarks is composed of those of you who are cool to the idea of studying health behavior and who are here ex officio -- or perhaps because of the snacks. I hope to persuade you that there is no more vitally important set of topics to address than those that cluster around health behavior. Health behavior rivals the human genome in its complexity -- and it will take a similar level of investment to attract and produce the caliber of researchers required to make significant progress in understanding and shaping it. You may be disappointed with the research findings produced by scientists in this field to date, and it is true that progress has been uneven. But the media, Congress, and public and private decision makers have begun to realize that behavior is the frontier that must be conquered if we are to solve the major health problems of our time.

New resources are coming, along with new expectations. It's time to transform your critical judgments about the study of health behavior into positive suggestions for the next generation of researchers.

The third audience, of course, is students. I want to make the case that you should seriously consider a career studying health behavior and applying what you learn to improve the way we prevent, treat and manage disease. The rising demands for evidence-based approaches to changing health behavior and the new methodologies and technologies that make powerful new types of

analysis possible mean that you will be entering a field that is in the midst of reinventing itself. It may be messy, but it will undoubtedly be both entertaining and challenging. If you are a tough critic, analytically savvy, and wildly creative, studying health behavior is for you.

The idea that human behavior is a critical link between scientific knowledge and improved health outcomes is not new, but it is substantially undervalued. I realize that I am talking here to a number of people who persist in believing - evidence to the contrary -- that behavior can be changed by mailing out peer reviewed journal articles to busy clinicians and by sitting in darkened hotel ballrooms watching PowerPoint presentations.

Besides, it's not as though scientific knowledge HASN'T substantially been transformed into changes that improve health even if it lacks a focus on health behavior. If I did believe in Powerpoint data slides, I would show you that 23 percent of the population smokes, down from 42 percent in 1964. And I'd show you that medical care for cataracts, for example, conforms to science-based standards 79 percent of the time.

As a nation, we *are* generally healthy. People mostly know what they need to do to stay healthy; the public health infrastructure, while tattered and underfunded, is doing all right; and healthcare is pretty good for many people, although expensive even for those who do have health insurance.

Despite this, I will argue today that the tradition of undervaluing the study of health behavior is no longer an option. Rather, it is absolutely critical that we focus our vision, resources, and energy on it -- on increasing our knowledge of how social, economic, cultural and environmental factors affect the behavior of individuals and populations. And, in turn, how behavior gets "under the

skin” to affect health. The challenge is then to figure out how to use this knowledge to design policies and programs that increase the likelihood that individuals and groups will benefit from the scientific advances in which our society -- and the world -- has invested its research dollars. We simply cannot afford *not* to do so.

Why study health behavior? There are two main reasons: First, because converging trends in the United States make it likely that more individuals are being forced to assume more responsibilities for more aspects of their health -- and with fewer protections.

Most of us are unprepared to make the complex, high stakes decisions we will be asked to over the coming years. We need effective, evidence-based strategies to ensure that all of us have the supports we need to make good choices for ourselves and our families -- and particularly, that those who are vulnerable because of illness, lack of skills and limited opportunities do not suffer disproportionately from this increased responsibility.

The second reason to study health behavior now is because we daily learn more about how scientific advances in protecting health and treating disease disappear into the Bermuda Triangle of research, policy and practice -- and thus do not benefit anyone.

We study health behavior because the actions of individuals and professionals form the link between what is known and what the health outcomes are:

- The act of putting vaccines in kids’ arms -- or *not*.
- The 7-11 clerk carding the kids trying to buy cigarettes -- or *not*.
- The health worker teaching people with HIV to take antiretroviral medications -- or *not*.

The thing we are learning more about daily is how often the “*not*” is the case.

Let’s look at the first reason for studying health behavior more closely -- the growing responsibilities individuals face in making health decisions -- and examine some trends, all of them familiar to you:

Number 1. The increase in health problems that result from behavior. The rising rates of childhood and adult obesity -- and their impact on Type II diabetes and heart disease -- have finally captured the attention of the media, the government and private industry. And the message is penetrating consciousness: People who until recently thought they were just a little heavy are beginning to see themselves and their kids as having serious -- and intractable -- health problems that, unless they take action, threaten their lives and prospects.

Number 2. The rising number of people with chronic conditions. This number will continue to grow as the Baby Boom generation approaches 65. Most people with chronic conditions spend most of their days far from the oversight of health professionals and thus serve as their own primary care physicians or depend on a family member to serve in that role. Learning how to manage symptoms, prevent decline, and avoid complications is a lifelong learning -- and behavioral -- challenge.

Number 3. The lack of health insurance. Currently 43.6 million people do not have health insurance in this country, meaning that they rely heavily on their own judgment, abilities and good luck to protect themselves and their families from harm -- to care for themselves for as long as they can without professional help. Of these, 7.8 million are children and 30 percent of them are immigrant children. That’s a lot of parents making a lot of health decisions for a lot of kids without access to professional counsel.

Number 4. A broken health care delivery system. For all of the innovation of the past decade, the delivery system remains fragmented and uncoordinated. The high cost of care pushes individuals and their employers to switch plans frequently. That would be disruptive anyway, but a system that lacks a cumulative medical record results in confusion for patients and health professionals alike. The result is we all wind up acting as our own diagnosticians and medical historians as we piece together care that works for ourselves, our kids and our parents.

Number 5. The pace of development of new pharmaceuticals. There is an explosion in prescription and over-the-counter drugs and in food supplements -- vitamins, enzymes and so on -- giving both individuals and physicians a wealth of alternative substances to choose from in treating illness. Direct-to-consumer advertising of prescription and over-the-counter drugs fills the airways, the internet and the e-mail in-box, promising everything from growing hair to improving your sex life to curing you from diseases that don't exist. And we are the ones who seek, purchase and adhere -- or fail to adhere -- to recommended doses and uses.

Number 6. The assault on public health from Washington. In addition to losing access to professional advice from physicians, the government protections that have been essential to public health in this country are eroding. In the past three months, the Bush administration and the Republican Congress have

- overturned ergonomics regulations in the workplace
- refused to raise taxes on cigarettes
- ignored the rising urban asthma rates when considering revisions to the Clean Air Act and continued to insist, all evidence to the contrary, that condom distribution promotes promiscuity.

In addition, the administration has stood by silently as the Republican Congress has gone after research on sexual behavior -- as if their constituents don't have any.

And it has weakened the regulations so that producers of food supplements -- vitamins, herbs, enzymes and other products -- can make health claims identical to those of over-the-counter drugs without conducting any tests for safety, efficacy or purity.

In short, risk of preventable illness in the population is increasing while simultaneously people have more choices, less recourse to advice and an erosion of public health protections.

When I look at these trends, I am struck by the flimsiness of the link that we depend on to transform the extraordinary advances of modern science into improvement in peoples' lives.

Think about it. Each trend points to individuals increasingly being on their own with regard to their health at a time when their health concerns are rising. The trusted sources we once relied on to help us make health decisions and protect us from harm are less effective in doing so, less available and less trustworthy.

Each trend points to the need for the behavior of health care and public health professionals to change as well. We have to accommodate the twin demands of planning and caring for an aging and increasing chronically ill population while integrating the scientific advances arising out of the billions of dollars invested in new technologies, pharmaceuticals, basic health research and the genomic revolution.

So how are we going to manage this? I know my mom and dad are bewildered about how to coordinate my dad's six doctor's recommendations right now. How about you? And we are the ones with the education, the contacts, and the training to negotiate the public and health care establishments. What about those who know less, who have less, or who face a myriad of other barriers to finding useful information and help because of their proximity and relationships to health authorities?

As the repercussions of these trends reverberate throughout the population, knowledge of health behavior will be critical to finding ways to support individuals' health choices to prevent the erosion of their health and the health of the public at large.

Which brings us back to the second reason we need to make health behavior a more robust field of study. I mentioned the Bermuda Triangle of research, policy and practice. We have invested deeply as a nation in learning more and more about human health, yet we are continually brought up short when we find that the fruits of that research are not routinely integrated into public health and health care practice and policy.

On World AIDS Day, it is fitting to remember that during the past two decades 22 million people worldwide have died of AIDS and 40 million are now infected with HIV. Millions will perish in the coming years if they don't receive antiretroviral drugs.

The lack of political will and resources to pay for these drugs is a tragedy - but no less problematic is the tragedy recently reported in the New York Times of health workers in China handing patients bottles of antiretroviral medication with no instructions about how to take them.

All over the developing world, millions of lives are needlessly lost to malaria, tuberculosis and diarrheal diseases due to similar failures. And within healthcare delivery in the United States, the RAND study by Elizabeth McGlynn and her colleagues in June showed that patients received care consistent with evidence-based recommendations only 55 percent of the time -- and that included acute, chronic and preventive care across the functions of medicine, including screening, diagnosis treatment and follow-up.

Recently I have been talking with people who run publicly funded breast and cervical cancer screening programs in local communities and they are frustrated as hell trying to figure out how to get women to come get screened. They provide a good example of what I am talking about: mammography and PAP tests are reliable, valid, useful technologies.

Under this program, these services are offered free to eligible women -- as is treatment if a malignancy is diagnosed. The professionals who run these programs are breaking their backs to get a 50 percent return rate each year -- and only 10 percent of the women who are eligible come in the first place.

Think of all the research that was conducted to discover and develop the PAP test. How much time to figure out how often and which women should be tested? How much money to persuade insurers, educate physicians, market the test, develop laboratory capacity and integrate PAP tests into routine care for women?

And then we depend on postcard reminders to connect this magnificent technology to the women who need it?

In each of these examples, there are effective, potentially life-saving interventions available. Yet in each, it is the actions of individuals -- of individuals, health workers, administrators, health educators, program

managers, doctors -- that mute the benefit of scientific advances and contribute to suffering, disability and death.

I look at these two constellations of facts -- the first about how people are increasingly on their own when making choices about health, and the second about how professionals and individuals struggle to make good use of effective interventions -- and I see a powerful, smack-it-out-of-the-ballpark argument for studying health behavior.

Just a word about the “now” part of the title of my talk: “The Fragility of Evidence: Why Study Health Behavior *Now?*”

I, like many of you, spend my days trafficking among those who are working hard to figure out what it will take to improve health outcomes. And I am bemused by the clarity of focus of my colleagues:

- “What we really need to do is focus on universal access to care.”
- “What we need is free antiretroviral drugs world-wide.”
- “What we really need to improve quality is great health IT - you know, decision support and electronic medical records.”
- “What we really need is a cure for juvenile diabetes.”

And I agree with each of them. But it reminds me of that old saying “when a wife locks her husband out of the house, the problem is not just with the door.”

Each of these solutions relies on the development of new technologies or information or economic arrangements. And not one of them formally takes into account how individuals will act as they respond to or interact with or implement it. The success of each of these solutions requires close and systematic attention to the behavior of individuals -- how we respond to

incentives, how we operate within systems, how we act in response to what kind of information.

The field of health behavior in its current incarnation has a lot to offer each of these solutions. These solutions are being sought *now*. Health behavior researchers and experts should be working on these problems with their colleagues *now*.

As long as I am going to nag at health behavior researchers to get involved with these very applied inquiries, let me formally address what I see as the historical --- and narrow --focus of the health behavior field.

As a long-time advocate for health behavior research, I am frustrated both by the topic being ignored by those outside the field and, from within the field, by a myopic absorption with health promotion and disease prevention and the general unwillingness to address health behavior outside our borders. This focus is certainly important, but its narrowness serves to shrink the tables at which health behavior researchers are invited to sit and limits the value and depth of the potential contribution of looking at how individual and group actions affects all other aspects of health and illness.

The academic study of health behavior in schools of public health has made important advances, I will be the first to admit. But the world outside of the academy has taken a much more utilitarian view of the problem and has developed a multitude of creative and effective strategies to changing health behavior, using sophisticated, multidisciplinary, evaluated approaches.

All efforts to change health-related behavior are not necessarily aimed at improving health. It is time for the academic study of health behavior to break

out of the current fixation with finding policy and programmatic fixes to encourage moderate eating, drinking, exercising, sun tanning and use of tobacco in the United States.

The study of health behavior includes those things, plus the entire range of human behaviors that go into fully capturing the value of health research both here and internationally.

That range is characterized by the blending of two domains: The first domain consists of understanding the forces within a society or community that affect the behavior of individuals -- and how they might be modified to influence behavior that in turn improves health. And the second, how behavior “gets under the skin” to produce health -- or disease and disability, that is, understanding the biological substrate of behaviors.

The best model for an expansive vision for the study of health behavior is one that is, for all my enthusiasm for taking on new topics, deeply familiar to you: tobacco use. Although the field of health behavior claims only minor credit for its richness, I think it exemplifies the potential for the lens of health behavior to serve as an agent of coherence and progress.

Research on tobacco use both domestically and internationally, has been conducted to understand the external forces -- advertising, social norms, price sensitivity, supply and access -- as well as how the product gets “under the skin,” the etiology of addiction to tobacco and the psychophysiology of quitting.

Conducting this work has required the expertise of the full spectrum of disciplines.

It has been built on partnerships -- some holy, some not -- with the advertising and pharmaceutical industries, with governments and with politicians, among nations, and with a wide variety of voluntary and not-profit interests. And over time, it has yielded a wealth of knowledge about changing behavior and some successes in doing so.

Tobacco-use research blends the perspectives of the social and behavioral scientists, for whom the relevant determinants of behavior are exclusively external, with those of the molecular biologists and geneticists, for whom the relevant determinants of health are biological.

Tobacco-use researchers recognize the tremendous power of commercial interests and do not depend solely on government fixes to make progress, nor do they fail to recognize where the free market is at loggerheads with the goals of a healthier world.

And tobacco-use researchers recognize that in the middle of the production arc from crop subsidies to lung cancer, you still have the kid buying the cigarettes and lighting up. The determinants and sequelae of that kid's actions are the behaviors that we are ultimately trying to understand and to influence.

Building on the example of tobacco, what it is going to take for people -- you, me, people all over the world -- and our doctors, our health workers, our employers, our politicians and our bureaucrats -- to make the best possible use of what we know about the prevention, onset, progression and treatment of disease?

It will take solid evidence-based approaches for intervening with individuals, with groups and with populations to build systems that make the right behavior the easiest behavior. It will mean establishing policies and practices that

increase the probability that everyone, not just those with extraordinary internet skills, are able to make fully informed choices.

For individuals, it means figuring out how to negotiate complex information and demands, from adhering to multi-drug regimens to choosing among benefits in a defined contribution benefit plan.

For health professionals, it means figuring out how to best use precious time with patients, how to make use of new equipment and pharmaceuticals, how to build “systems” that help field workers, and busy doctors, nurses and technicians make evidence-based judgments and keep track of what they have done.

It means finding effective ways to efficiently communicate evidence-based innovations in public health practice to those who need to know them when they need to know them; and it means gaining a systematic understanding of what “implementation” requires of professionals and the public.

But it also means recognizing that ultimately, health and illness happen to individuals who make complicated calculations, only some of which have to do with scientific evidence.

The size and scope of this challenge are far beyond the fairly modest health education and prevention focus the academic field of health behavior apports itself in most Schools of Public Health. In preparation for this talk, I looked through this fall’s course offerings in the health behavior departments in six schools of public health. I saw a plethora of missed opportunities.

I began today talking about the fragility of evidence. But I have almost persuaded myself now that maybe it isn't that the evidence that is fragile, but rather the means by which we use it, is fragile.

Gosh! Knowledge about health behavior is finally being recognized as the missing solution to the major health problems of our time! What an incredible opportunity!

So what is it going to take to seize that opportunity?

It will require inviting in many disciplines, many of which do not see health behavior as a central concern. It will draw generously from health services research, organizational psychology, ergonomics, behavioral economics, nursing, sociology, marketing, communications science, media studies, information processing, health policy, human factors design, psychology, anthropology, environmental sciences, epidemiology, biology, genetics, operations research, evaluation research and the law. Each of these fields accounts in some way for behavior and has tools, ideas, energy and expertise to offer.

The new study of health behavior will be multi-, inter- and transdisciplinary. It will bring together people with expertise in their own fields to bring their skills and curiosity to research that focuses on the determinants and sequelae of health behavior across disciplinary - and national - boundaries. Among them are adherence to complex drug regimens, childhood obesity and rehabilitation after brain injury.

The new study of health behavior will make use of advances in statistical modeling, new methods of studying complex phenomena, and the use of new behavioral and physiological monitoring technologies and brain imaging to link behavior to the biological substrate.

The new study of health behavior will live not only within a school of public health but within medical, dental, nursing and other professional schools. It will be viewed by them as a critical resource, adding value to the benefits of their own research and service delivery.

The new study of health behavior will welcome the perspectives of advertising and of marketing. It is possible to find common ground and develop partnerships with these experts in health behavior, and it is time to stop avoiding them out of fear of being co-opted or jealous pique that they are doing so well.

The new study of health behavior will be funded by the Centers for Disease Control and Prevention and various institutes and offices at the NIH, by the Agency for Healthcare Research and Quality, by the Health Resources and Services Administration, the Department of Agriculture, the Veteran's Administration and the National Science Foundation. But *shame* if it is not funded also by foundations, by private individuals, by the insurance industry, the food industry, the restaurant industry and others. Corporate dollars are not dirty dollars. We must find ways to work with private industry that don't compromise our scientific independence and integrity.

You have been given a large endowment to establish this new department of health behavior. With it comes prominence, visibility and the opportunity to provide the leadership and focus necessary to make less fragile the links between *what we know* about health and improvements in health outcomes both in the United States and abroad.

My purpose today is to remind you that biology matters, genes matter, germs matter and machines matter. But what's most important is realizing that behavior *really* matters.