

BEHAVIOR MATTERS

15 Years of Health Behavior Advocacy

JESSIE GRUMAN, PH.D.

BEHAVIOR MATTERS: 15 Years of Health Behavior Advocacy
Copyright © 2008 by Jessie Gruman, Ph.D.
All rights reserved.

No part of this book may be used or reproduced in any matter whatsoever without written permission from the publisher except in the case of brief quotations embodied in critical articles or reviews. For more information address: Health Behavior Media, Center for the Advancement of Health, 2000 Florida Avenue, NW, Suite 210, Washington, DC 20009.

Published by Health Behavior Media

Health Behavior Media books are published by
the Center for the Advancement of Health.

Library of Congress Cataloging-In-Publication Data

ISBN: 978-0-9815794-0-5

Visit CFAH's website at www.cfah.org.

First U.S. Edition 2008

CHAPTER 1

Why Study Health Behavior Now?

America makes major investments in health research, yet fails to devote adequate resources to understanding how institutions, people and policies transform new knowledge into positive behavioral change. The study of health behavior is key to using scientific evidence to improve health outcomes. Without it, new research findings—and the technologies, practices and drugs they yield—will fail to achieve their potential. My goal is to persuade you to enthusiastically endorse an innovative and expansive vision for studying health behavior.

My thoughts are addressed to three groups.

The people who comprise the first group are **those studying health behavior**, which has historically been the less-loved stepchild of the NIH and other funders. Their indifference may have negatively influenced your professional status. I hope to vindicate your choice and to recognize the courage and persistence it has taken to succeed in this field over the years.

A second group comprises **those who are cool to the idea of studying health behavior**. I hope to persuade you that there is no more vitally important set of topics. 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 this discipline. You may be disappointed with the research 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 our major health problems.

New resources, along with new expectations, are in the pipeline. It is time to transform critical judgments about the study of health behavior into positive support for the next generation of researchers.

2. This essay was adapted from a talk delivered as part of a symposium on health behavior at the Bloomberg School of Public Health, Johns Hopkins University in Baltimore, Maryland, in November 2003.

The third group is **students**. Students should seriously consider a career studying health behavior and applying what they learn to improve the way we prevent, treat and manage disease and improve health. The rising demands for evidence-based approaches to changing health behavior and the new methodologies and technologies that make powerful new types of analyses possible mean that this field is reinventing itself. Entering this perhaps messy arena will undoubtedly be both entertaining and challenging. If you are a tough critic, analytically savvy and wildly creative, studying health behavior is for you.

Why Is Health Behavior Important Now?

The idea that the study of human behavior provides a critical link between scientific knowledge and improved health outcomes is not a new concept, but not an adequately respected one either. Many people persist in believing—despite evidence to the contrary—that they can change behavior by mailing peer-reviewed journal articles to busy clinicians or by giving PowerPoint presentations to researchers in darkened hotel ballrooms. And while that may yield some enhanced status, it won't do anything to create a healthier nation, which is, I suggest, our ultimate shared goal.

Scientific knowledge can be translated in ways that benefit the public. Today 22 percent of the American population smokes, down from 42 percent in 1964, and medical care for cataracts, for example, conforms to evidence-based standards 79 percent of the time.

As a nation, we *are* generally healthy. Mostly people know what they need to do to stay healthy; the public health infrastructure, while tattered and underfunded, is ambling along; and health care is fairly good for many people, although expensive even for those who have health insurance.

Unfortunately, American society undervalues the study of health behavior even as the need obviously grows. It is absolutely critical that we focus our vision, resources and energy on increasing our knowledge of how social, economic, cultural and environmental factors affect the behavior of individuals and populations. We must then use this knowledge to design policies and programs that increase the likelihood that individuals and groups will benefit from the scientific advances our society has sponsored. We simply cannot afford any other course.

As research and technology become more sophisticated and narrow, the need for intermediaries to involve the public, which is asked to take on growing responsibilities in this area, grows.

Most of us are unprepared to decide among the complex, high-stakes prevention and treatment choices that we will encounter. We need effective, tested strategies to ensure that we all have the support we need to make good choices. This is particularly important for those who are most vulnerable and who find it especially challenging to make informed decisions about their health because they are ill and alone or lack the cognitive or physical abilities. Those who face the hardest decisions are often among those least prepared.

Meanwhile, each day the odds of scientific findings translating into public benefits become longer for several reasons. There are more of them than there used to be and they tend to be narrower and harder for a lay audience to understand.

We study health behavior because what *we* do determines *whether* what is known has a positive impact on health. Messages—about the dangers of smoking, which drug treats this disease at which dose and how to use diagnostic and screening technologies—improve health only when actually acted upon appropriately by individuals and health professionals. The forces that shape our behavior determine, for example, whether we are

- vaccinating—or not vaccinating—kids;
- carding—or not carding—teenagers trying to buy cigarettes; and
- teaching—or not teaching—HIV-infected people to take antiretroviral medications.

Daily, we are learning how frequently “*not*” is the case.

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 become obvious to much of our population. People who until recently thought they were just a little overweight are beginning to see themselves and their kids as having serious, intractable health problems that could threaten their futures.

The rising number of people with chronic conditions

Continuing progress against acute diseases will inevitably cause the number of people with chronic conditions to grow as members of the baby boom approach age 65. Most people with chronic conditions spend most of their days far from health professionals and thus rely on their own judgment and that of friends. Learning how to manage symptoms, prevent decline and avoid complications is a continuing challenge.

The lack of health insurance

Currently, 46 million people do not have health insurance in this country. They must rely heavily on their own judgments, abilities and good luck to protect them from harm as they care for themselves without professional help for as long as possible. Of these, 7.8 million are children, with immigrant children accounting for 30 percent of this group. Insuring them won't eliminate the problem of inadequate care, because those in the insured population are being asked to take increasing responsibility for their health and care. On the other hand, if those now insured took better care of themselves, it could free medical resources to care for those now uninsured.

A fragmented health care delivery system

America's health care delivery system remains fragmented and uncoordinated. The high cost of care pushes individuals and their employers to frequently switch health plans. The lack of a readily available, cumulative medical record results in confusion

and needless duplication. So we all spend time acting as our own diagnosticians and medical historians as we piece together care that works for us, our kids and our parents.

The pace of drug and supplement use

There is an explosion in the number of prescription and over-the-counter drugs being taken and in the number of nutritional supplements, such as vitamins, herbs

EATING YOUR HEART OUT

Anyone who has survived a brush with death deserves to celebrate. And so, on Robert Tools' one-month anniversary of getting the first self-contained artificial heart, with his doctor's blessings, he celebrated by eating ice cream and cheesecake.

With two previous heart attacks, bypass surgery, and congestive heart failure behind him, Mr. Tools was, in that moment, the very picture that illustrates both the triumph of American medicine and its Achilles heel.

The triumph is that our romance with the quick fix for health has come true. Want your muscles to ripple without touching the weights? Load up on legal megadoses of creatine. Sat on your couch all your life and your heart is giving out? Sign up for a self-contained cardiac implant. Ate yourself into blimpdom? Get medically safe gastric bypass surgery. High-tech medicine not working? Join the 42 percent of Americans who spend \$27 billion annually on alternative therapies.

And the romance continues to grow and thrive as scientists promise cures for devastating and costly diseases, such as cancer and Alzheimer's disease, pending the investment in, first, the decoding of the human genome and, now, stem cell research.

Don't get me wrong. The potential of modern medicine to improve health is breathtaking. But Robert Tools, with his ice cream and cheesecake, is the symbol of medicine's Achilles heel—human behavior, the thing that stands between the promise of biomedicine and its fulfillment.

Behavior—mine, yours, our families', our doctors', our health plan administrators', our politicians'—mediates the use of all health science information, all evidence-based health care interventions. Whether it is taking the right medicine the right way, adhering to a complicated drug regimen or having access to and making the best possible use of an expensive artificial heart or a precious human one, capturing the value of health research depends on behavior.

While we know quite a bit about behavior, we still have a tremendous amount to learn and apply. Only 10 percent of the NIH budget for research is spent on behavioral and social sciences. Given the potential of behavior to make good use of effective, evidence-based interventions to improve health—and its potential to do the opposite—is a 10 percent solution enough?

and enzymes being purchased. 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 diseases as yet undiscovered. And we seek, purchase and adhere—or fail to adhere—to recommended doses and uses of these substances with the aim of improving our health and quality of life.

Declining help from Washington, D.C.

Government protections that have historically safeguarded the American public's health are being eroded. Recent events suggest that Washington is a fickle protector, at best. In recent years, our government has

- overturned ergonomics regulations in the workplace,
- ignored the rising urban asthma rates and potential fetal damage when considering revisions to the Clean Air Act,
- weakened regulations governing protection from environmental tobacco smoke,
- denied decades of government research documenting the health impact of mercury, and
- continued to insist, all evidence to the contrary, that condom distribution promotes promiscuity.

Congress has also weakened the regulation of food supplements, so companies 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 just when people have more choices—but less time to discuss advice with their doctors. And this is all occurring against the backdrop of a weakened system of public health protections.

The Imperative for a Focus on Health Behavior

The links that we depend on to transform the extraordinary advances of modern science into improvement in our lives are weak.

Think about it. Each trend points to individuals being increasingly responsible for their health care at a time when the population is aging and health concerns are multiplying. The trusted sources we once relied on to help us make health decisions and protect us from harm are less effective in doing so, and sorting the good information from bad requires considerable skill.

How are we going to manage this? My mom and dad are bewildered about how to coordinate the recommendations of my dad's four doctors, and I'm sure many others have the same concerns. Some of us have the education, the contacts and the training to negotiate the public and health care establishments. What about those who know less, who have fewer resources or who face a myriad of other barriers to finding useful information and help because of their lack of proximity to and relationships with those with health expertise?

As the repercussions of these trends reverberate throughout the population, knowledge of health behavior will be critical to finding ways to help people make smart health choices.

This brings us back to the second reason for investing more robustly in health behavior. We have invested deeply as a nation in learning more and more about human health, yet we constantly fail to make the suggested changes to public health and health care practice and policy. We're not getting the return on our investment we could and should.

During the past two decades 22 million people worldwide have died of AIDS and 40 million people are now infected with HIV. Millions of people will die if they don't receive antiretroviral drugs. The lack of political will and resources to pay for these drugs is a tragedy, as are shocking missteps signaled when health workers in China hand patients bottles of antiretroviral medication with no instructions about how to take the drugs.

Throughout the developing world, millions of lives are needlessly lost to malaria, tuberculosis and diarrheal diseases due to similar failures of communication and the availability of the right resources. Within the United States alone, the RAND study by Elizabeth McGlynn and her colleagues in June 2004 showed that patients received care consistent with evidence-based recommendations only 55 percent of the time.

I have recently talked with people who run publicly funded breast cancer and cervical cancer screening programs in local communities and who are extremely frustrated in their efforts to encourage women to be screened. The best idea they have had so far is to send the women an annual postcard reminder about the importance of the tests and their availability at no cost.

This is a good example of what I am talking about: Mammography and PAP tests are reliable, valid, useful technologies, but they are not being used optimally. Through such local programs, these services are offered free to eligible women, as is treatment if a malignancy is diagnosed. The professionals who run these programs are working very hard to get a 50 percent return rate each year, yet only 10 percent of the women who are eligible are screened even once.

Consider everything that's gone into the Pap test—all the research conducted to discover and develop it and the time and effort required to determine which women should be tested and at what intervals. Think about how much money was spent to persuade insurers to cover the cost of the tests, educate physicians and nurses to perform it, market the test, develop the laboratory capacity and integrate Pap tests into routine care for women.

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

For HIV/AIDS, breast cancer and colon cancer, there are effective, potentially lifesaving interventions available. Yet in each case, the actions of individual health care providers, administrators, health educators and program managers mute the benefit of scientific advances and contribute to unnecessary suffering, disability and often even death.

When I look at how people are increasingly on their own when making choices about their health—and how professionals struggle to make good use of effective interventions—I see a powerful, smack-it-out-of-the-ballpark argument for studying health behavior and for doing it *now*.

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

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

Although I agree with each of these statements, I am reminded 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, information or economic arrangements. None takes into account how individuals will respond and interact with these new technologies. The successful implementation of each of these solutions depends on close and systematic attention to the behavior of individuals—how we respond to incentives, how we operate within systems, how we seek information and how we act in response to the threat posed by risks.

The field of health behavior in its current incarnation can contribute a great deal to ensuring the efficacy of these solutions. Researchers are seeking to solve medical and financing problems *now*. Health behavior researchers and experts should be working alongside their colleagues on these problems *now*.

What Is Required to Meet Current Challenges?

The field of health behavior has had a narrow historical focus. As a longtime advocate for health behavior research, I am frustrated by the fact that the topic is ignored by those outside the field and within and by a myopic absorption with health promotion and disease prevention. I am bothered by the general unwillingness to address health behavior related to the numerous other tasks involved with finding and making use of good quality health care. A focus on health promotion and disease prevention is certainly important, but such a narrow approach decreases the opportunities for health behavior researchers to share their expertise about how individual and group actions affect all aspects of health and illness.

The academic study of health behavior in schools of public health has made important advances, but outside of the academy, the understanding of the problem is much more utilitarian. Indeed, in the marketplace, sophisticated, multidisciplinary, evaluated approaches have been used to develop many creative and effective strategies for changing health behavior. For example, Coca-Cola and Burger King seem to know quite a bit about how to change behavior.

It is time for the academic study of health behavior to expand the narrow focus of finding policy and programmatic fixes beyond those that encourage moderate eating and drinking, increased exercise and reduced sun-tanning and tobacco use in the United States. Although the study of health behavior includes these goals, it also includes studying the entire range of human behaviors needed to fully capture the value of health research both in the United States and internationally.

That range is characterized by the blending of two domains. The first domain consists of understanding the behavioral determinants of individuals and how these forces might be modified to improve behavior and health. The second domain involves understanding the biological substrate of behaviors: how behavior “gets under the skin” to produce either health or disease and disability.

The best model for an expansive vision for the study of health behavior is tobacco use, which shows the potential for the lens of health behavior to serve as an agent of coherence that will enable us to make progress.

Research on tobacco use both domestically and internationally has been conducted to understand how the external forces of advertising, social norms, price sensitivity, supply and access and the characteristics of the product itself are intertwined in the etiology of tobacco addiction and the psychophysiology of quitting.

Conducting this work has required the expertise of the full spectrum of disciplines. This work has been built on partnerships with the advertising and pharmaceutical industries, governments and politicians, and a wide variety of voluntary and not-for-profit interests. Research about tobacco use blends the perspectives of social and behavioral scientists, for whom the relevant determinants of behavior are exclusively external, with those of molecular biologists and geneticists, for whom the relevant determinants of health are biological.

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

These researchers also know that in the middle of the arc from crop subsidies to lung cancer is the kid buying the cigarettes and lighting up. The determinants and sequelae of that kid’s actions are the behaviors that we are trying to understand and influence.

How can we build the experience of tobacco use research to determine what is needed for the public, health and social decision-makers, health professionals, employers, politicians and 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, groups and populations to build systems that make the right behaviors the easiest behaviors. It will mean establishing policies and practices that increase the probability that everyone, not just those with good Internet skills, are able to make fully informed choices.

Individuals must learn how to negotiate complex information and demands, from adhering to multidrug treatment regimens to choosing among benefits in a defined-contribution benefit plan.

Health professionals must learn how to best use precious time with patients; how to make use of new equipment and pharmaceuticals; and how to build “systems” that help busy field workers, doctors, nurses and technicians make evidence-based judgments and track what they have done.

We must find effective ways to efficiently communicate evidence-based health innovations to those who need to know them when they need them and to gain a systematic understanding of what “implementation” requires of professionals and the public. We must also recognize that decisions about health and illness are often the result of complicated calculations in which scientific evidence carries feather-light valence.

The size and scope of this challenge are far beyond the fairly modest health education and prevention focus the academic field of health behavior apporitions itself in most schools of public health. Looking at course offerings in the health behavior departments at six schools of public health, I saw a plethora of missed opportunities.

Seizing the Opportunity

There are a few signs that health behavior may receive the kind of recognition it deserves. The proliferation of health pages in newspapers, health segments on broadcast news, and the flood of health Web sites all signal that there is a growing appetite for good health information. The accelerating rise of disease management and chronic care programs is another. Increased attention by employers, insurers and health plans to providing the right information to their constituencies at the right time means that they understand that individuals’ actions have a critical role in health.

These trends add up to an opportunity to ask—and answer—important questions about health behavior.

But to seize this opportunity will require inviting in many disciplines, many of which do not see health behavior as a central concern. It will mean drawing generously from the results of health services research and drawing on the tools, ideas, energy and expertise of experts in 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.

The new study of health behavior will:

- Bring together people with expertise in diverse fields who can focus on the determinants and sequelae—both external (social, environmental) and internal (biological, genetic)—of health behavior across disciplinary boundaries. Some topics that could benefit from such an approach are adherence to complex drug regimens, childhood obesity and rehabilitation after brain injury.

- Use advances in statistical modeling, new methods of studying complex phenomena and new behavioral and physiological monitoring technologies and brain imaging to link behavior to the biological substrate.
- Occur not only within schools of public health but also within medical, dental, nursing and other professional schools. It will be viewed by these faculties as a critical resource, adding value to the benefits of their own research and service delivery.
- Welcome the perspectives of advertising and of marketing. It is possible to find common ground and develop partnerships with commercial experts in health behavior, and it is time to stop avoiding them because of fear of being co-opted or out of a political commitment that holds commerce in contempt.
- Be funded by the Centers for Disease Control and Prevention (CDC) and various institutes and offices at the National Institutes of Health (NIH), by the Agency for Healthcare Research and Quality, by the Health Resources and Services Administration, the Department of Agriculture, the Department of Veterans Affairs and the National Science Foundation. But it would be a shame if such research it is not funded also by foundations, private individuals, and the insurance, food and restaurant industries. Corporate dollars are not dirty dollars. We must find ways to work with private industry that do not compromise our scientific independence and integrity.

Departments of health behavior at schools of public health across the country have the prominence, visibility and opportunity to provide the leadership and focus necessary to strengthen what we know about health behavior and to ensure the implementation of that knowledge to achieve the improvements in health outcomes.

The public, researchers and health professionals believe that biology matters, genes matter, germs matter and machines matter. What's most important *now* is for all of them to realize that behavior *really* matters.