

Health Behavior: From Paradox to Paradigm

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Editor's note: This article is adapted from the address of the American Diabetes Association President, Health Care and Education, given in June 2000 at the Association's 60th Annual Meeting and Scientific Sessions in San Antonio, Texas.

In preparing to speak with you today, I did a great deal of thinking about what I wanted to share. And I kept coming back to behavior. Health behavior is fascinating. How people make decisions is truly a puzzle. Each one of us has only to look at our own informed health decisions to realize that there are many paradoxes in health behavior. We end up murmuring to ourselves about our own food choices or lack of exercise. What was I thinking? Indeed, *was I thinking?*

The following dialogue is an example of why I believe health behavior remains a puzzle . . . Imagine that you are seated in an airplane, and you overhear this conversation between two women near you.

First woman: "...Did you tell him that?"

Second woman: "I don't know what I told him. I'm never in control of what I say to doctors, much less what they say to me. There's some kind of disturbance in the air."

First woman: "I know exactly what you mean. It's like having a conversation during a space walk, dangling in those heavy suits."

Second woman: "I lie to doctors all the time."

First woman: "So do I."

Second woman: "But why?"¹

Why? Yes, that is the question that fascinates us. And it may surprise you that I found that conversation reprinted in the *Annals of Internal Medicine* several years ago.

Please come with me on a brief personal journey. First, we will look at some paradoxes in diabetes health behavior. We will then look forward

to an emerging paradigm for diabetes care. And from there, we will attempt to construct a vision of how leaders and members of the American Diabetes Association can give health behavior the integral, no, the *central* place it deserves in diabetes care and research. Along this journey, there will be more questions than answers. But that is the fun of it!

Consider a definition of "paradox" from the *Oxford English Dictionary*: A paradox is something that is discordant with, or contrary to, that which is held to be the established truth.² So, what is the established truth?

I believe many have accepted the following as the truth about diabetes: that people don't know what to do to attain good diabetes control or that people don't have access or adequate coverage for it—and that is why they are in poor glycemic control. These notions are true, or course, for many people, and so improved knowledge and greater access would be appropriate goals. However, additional explanations for poor glycemic control include: that some people simply don't have positive health behaviors as a priority, that taking care of their diabetes it is not number one on their "to do" list each day, and that the community may not support, and in fact may hinder, their efforts to lead a healthier lifestyle.

Let's explore three examples of what I call paradoxical issues. The first one is *Healthy People 2000*.³ This was a major public health initiative in the 1990s, involving the Centers for Disease Control and Prevention and the National Institute of Diabetes and Digestive and Kidney Diseases, with input from the American Diabetes Association (ADA) and many other groups. In the 1990s, attainment of the targeted goals for diabetes was disappointing. Some indicators got worse; that is, the data went in the wrong direction. Moving away from the target, not toward it!

More specifically, in *Healthy People 2000*, diabetes-related goals such as lowering the age-adjusted death rate for diabetes and reducing the prevalence of diabetes were, by the end of the initiative, even worse than at baseline. The age-adjusted prevalence of overweight or obesity also increased in the 1990s. The rates for diabetic retinopathy screening are moving toward the target, but certainly are not at goal yet.

In our research at the Albert Einstein College of Medicine's Diabetes Research and Training Center, we found that our powerful telephone intervention could double the rate of screening for retinopathy in an African-American population, when compared to a control group. However, a large percentage of the group still did not get screened, even when access was no longer an issue. Puzzling!

Was the inability to meet *Healthy People 2000* goals just measurement error? Was the bar set too high? Or were we lacking in dedicated effort? What is the explanation?

It's not so simple. An increase in some numbers, such as the incidence of diabetes, may in fact indicate success in other types of public health initiatives, such as American Diabetes Alert and other nationwide ADA programs for detecting the undiagnosed. Were the goals not met because success was dependent on provider or consumer health behaviors or community support of the initiatives? With all of the scientific advances in the last half of the 20th century, it's hard not to come back to behavior as a major factor to explore.

The new *Healthy People 2010* builds on past initiatives as it outlines a comprehensive health promotion/disease prevention agenda for the first decade of this new century. This initiative focuses on increasing quality and years of healthy life and eliminating health disparities. We must take the

negative direction of some measures in the 1990s as a challenge to unravel the paradox of health behavior.

Still on our journey, we continue with the paradoxes; let's go, however, from the big picture to some particular examples in diabetes care, education, and research. The first is risk perception, that is, perception of risk for developing diabetes or risk of diabetes complications.^{5,6}

We devote ADA resources and our professional time as clinicians telling people that "Diabetes is serious, costly, prevalent—an epidemic." But diabetes is also a self-management disease. People with diabetes can do many things for themselves to control their blood glucose. So a person may think, "How serious a disease is diabetes, if I can manage it myself?" Perhaps that person needs some help sorting through these mixed messages.

Some may characterize certain patient choices as risk-taking behavior. For example, people with distal neuropathy may choose to go barefoot. Now, if we intervene with information alone, these people with diabetes may not have much success in altering their risk-taking behavior, especially if going barefoot is a quality-of-life issue.

We must also ask: What are their competing risks and priorities, other than the risks of diabetes? Are there significant environmental risks? Is community support, or a lack of it, an issue? Are there risks from other diseases?

If our patients choose "risk-taking" behaviors, perhaps we, as providers, can think about health communication as "risk-talking" behaviors. I don't mean that we should frighten them or threaten them. But we should ask some pertinent questions: Am I telling my patients enough about their risks to get their attention? To allow them to make an informed choice? To help them give positive health behavior a higher priority? Am I telling my patients enough about their risks to activate them? The zone of indecision is often where people get stuck.

Here is one of the many reasons that diabetes is serious. Despite its self-management components, indeed because of its dependence on self-management or individual behavior for good outcomes, there are no magic bullets or simple cures. There remain tremendous uncharted regions

in health behavior. We must further explore how to help people make informed choices for the quality of life they desire.

Let's move from risk perception to my second example, medication adherence.⁷ There is no question that we are in an era of pharmacological innovations. But if our patients don't take these new medications as prescribed, they probably won't have improved diabetes outcomes.

Let's think about this. Is "adherence" an appropriate term for this situation? From my clinical experience, here's what I think the word adherence conveys:

Let's say a woman who has type 2 diabetes comes to see me because she wants to improve her diabetes control. She's been taking an insulin secretagogue but asks, "What else can I do to get my blood sugars to come down?" We discuss her lifestyle and what she's willing to do. She's already decided she is not yet ready to take injections. I suggest the option of adding another diabetes medication that may help her in a different way. But this one should be taken twice a day. She says, "O.K., as long as I don't get those embarrassing side effects and no more weight gain!" And so our diabetes team prescribes a second medication for her.

Think about this. She asked for something specific. We discussed all sides of the issue. She said she could handle taking an additional drug, and then she walked out of our office with the prescription. When we discuss her therapy by phone between visits, she is reluctant, but eventually tells me that she never took the new pills. I do think of her self-reported behavior as a measure of adherence to our mutually agreed upon goal of taking two different medications for diabetes. "Adherence" or "sticking to" something we had previously agreed to. People know what that means.

People don't always know *why* they have difficulty following through. She says, "No problems; no reasons." "I'm lazy," says she. (I know she's not lazy.)

Here's the paradox: our patient asked for medication; she got it. She didn't take it; she doesn't know why. We may need to work with her ambivalence in a brief behavioral intervention. In the Diabetes Prevention Program,⁸ where two-

thirds of our active participants take a preventive medication, we train our staff to use what is called motivational interviewing.⁹ It's a brief technique to work with patients' ambivalence about taking a preventive medication.

I believe a person's ambivalence in health behaviors such as medication taking may be part of the paradox. And unless we face this problem squarely, study it, and implement programs to help patients and providers cope with it, many opportunities for improving health and quality of life may be lost.

We've looked at these diabetes care puzzles from several perspectives: the large perspective of the *Healthy People* initiatives and the more specific perspectives of risk perception and medication adherence. I'd like now to look forward, as others have done, to an emerging paradigm for diabetes health care. Let's talk "paradigms."

In 1962, the philosopher Thomas Kuhn published his small but powerful book, *The Structure of Scientific Revolutions*.¹⁰ Kuhn postulated that preconceived ideas really control the observations of scientists. Paradigms, he said, are universally recognized scientific or methodological frameworks that, for a time, provide model problems and solutions to a community of practitioners. Simply put, a paradigm is a way of experiencing the universe. Within a paradigm, we find out how to test a hypothesis, what is important to measure. How to analyze is also a tool of the paradigm. Everyone looks at the world through similar lenses.

It's difficult to break out of a paradigm, because it has become "normal" science. Everything else is suspicious or abnormal. When new ideas come up against the current thinking, they "hit a wall." For example, we are slowly emerging from the acute care medical model, and I say "emerging" with a sense of optimism.

So many basic tenets of our health care culture are rooted in that paradigm of how to cure disease and treat acute problems. But diabetes is a chronic condition. So breaking out of or shifting the paradigm takes a revolution of sorts. Questioning, eccentric, radical, fringy people are often just the sort to move us along. (Know anyone like that?) If there is a paradigm shift in diabetes health care, one that would address many of the paradoxes

in health behavior, what could the new paradigm be?

I believe we need a new paradigm that will integrate ongoing clinical care with brief behavioral interventions, including continuing opportunities for diabetes self-management education. I'll attempt to describe a new paradigm that moves away from the acute care medical model. In this chronic care paradigm, health care professionals use brief behavioral interventions and communication technologies along with their clinical skills. Behavioral measures will be integral to care and outcomes, not just nice to do, if there's extra time.

The new paradigm has many potential supports in chronic disease management, including group self-management education, community health workers, peer counseling, lifestyle coaches, telephone interventions, telemedicine, and Internet interventions. Above all, the new paradigm for ongoing diabetes care will require a clinician, perhaps an advanced practice clinician, who may come from one of a variety of disciplines. But care must be structured to facilitate excellent team communication wherever team members physically practice.

The clinician must be someone with good interpersonal skills who implements principles of diabetes self-management education and lifestyle change skills, as well as diabetes management and prevention of complications. (Know anyone like that?) This clinician can be trained in brief behavioral interventions and group counseling and given tools, technology, and efficient and effective communication systems to help support these interventions. Training programs for these clinicians would be designed and implemented with input from diabetes medical experts, nutrition and physical activity experts, psychologists, and other behaviorists in health promotion.

But the crucial integrated work, the work in the field, the patient-provider interactions for diabetes management, are done by this clinical-behavioral person, with the consultation, guidance, expertise of a Bruce Zimmerman or a Jerry Bernstein—an endocrinologist. There is so much work for each one of us to do!

This vision is all well and good, but there must be insurance coverage and reimbursement for such a health care paradigm.

Remember the dialogue between the two women that I shared at the beginning of this journey? Well, these things that patients tell us, that they didn't tell other providers, it simply takes a lot of time to be receptive to these messages. In this new paradigm, we should not have to explain or justify one more time that diabetes self-management education is good and necessary. The essence is this: self-management is in the individual's and the community's attitudes and behaviors, based on knowledge and skill. Perhaps we need to more clearly define the complex concept of "diabetes self-management education" and forever put to rest the didactic "This Is Your Pancreas" lecture.

From paradox to paradigm—so many questions. I conclude by bringing the discussion back to the ADA. If any of you share the vision I've articulated, that is, my vision of the centrality of health behavior, we can make this happen by working to put health behavior squarely in the center of a new paradigm and the work of the American Diabetes Association. We must collaborate for appropriate funding for research related to health behavior and to mentor new behavioral and educational researchers. Let's continue to support clinical trials that have incorporated behavioral interventions and measures. We don't want to say in 2010 that it is such a shame that we didn't adequately fund studies to incorporate behavioral science into the design.

All of this relates to the mission of the ADA for the new century. You are the ADA, and if you desire change, you must be proactive in working for change. Your challenge, and your choice, is to work diligently toward this vision. Believe me, it will not be handed to you or to me.

Diabetes research, care, and education are truly done in a community, a community made up of families. I wish to extend warm and heartfelt thanks for the support of my family: my husband, Vern Walker; our children, Teddy and Amanda; and Amanda's fiancée, Matthew Daloisio. Thanks also to my ADA family, especially my partners: Edward Hawthorne, always rational, warm, and direct; Bruce Zimmerman, the quintessential diabetes physician; and each member of the national Executive Committee. John Graham,

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The psychologist Wlodkowski said that education "is a dimension, not something one practices or performs, but something one enters and lives."¹¹ Congratulations to all of us who enter and live the role, among our many roles, of the diabetes self-management educator.

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