

On the Shoulders of Giants

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Editor's note: This article is adapted from the address Dr. Marrero delivered as the recipient of the American Diabetes Association (ADA) Outstanding Educator in Diabetes Award for 2008. He delivered the address in June 2008 at the association's 68th Annual Meeting and Scientific Sessions in San Francisco. A webcast of this speech is available for viewing at the ADA website (www.diabetes.org) under "For Health Professionals and Scientists." Click on the icon for the 68th Scientific Sessions Presentation Webcasts.

I would like to start my remarks by thanking the American Diabetes Association for selecting me for this special recognition. I am deeply honored.

I want to explain the title of my talk. Once, when Sir Isaac Newton was being given an award, the person introducing him suggested that he had seen "further than others" in the field of science. To this Newton replied, "If I have seen further it is by standing on the shoulders of giants."

Now trust me, I am not trying to compare myself to Sir Isaac Newton. But I do appreciate what he was trying to say; the reason that I am here today is ostensibly for recognition of my achievements in diabetes education. But my accomplishments are, in part, because of what I have learned from so many others, some who have stood here before me and many others who deserve to be recognized as I am today. So this morning, I want to tell you a bit of my story and how so many people have helped to shape my experience, influenced what I chose to do with my life, and taught

me to see farther than perhaps I would have by myself.

My story begins with my own discovery of type 1 diabetes. In 1977, while I was in graduate school at the University of California, Irvine, I had a weekend job in a hardware store. One day, during a break, a group of us employees were talking in the break room. The cashier, Patty, pulled out a bottle of ketodiastix. Being the inquisitive boy that I was, I asked what they were. She explained that she was a "juvenile diabetic," and she used these to test her control. Remember, this was 1977; "type 1" wasn't a term, and home glucose meters had not yet arrived. Up until this point, I had never talked to a person with diabetes.

I asked, just for laughs, to try one. The strip changed from blue to dark brown. When I asked what this meant, she said, "It means you have diabetes!"

Because I did not manifest any symptoms and had no family history, I was skeptical. But I was also bothered, so I called my father, who was a primary care doctor, and told him what happened. He said that he didn't like the sound of this, but told me there were other possible explanations and asked me to come to his office fasting the next morning. So I did; got blood drawn (again, in the era of no point-of-care testing) and was told to go down the street, get a big breakfast at Denny's, and come back for a follow-up.

When I got back, I asked where my dad was and was directed to his personal office. I went in and saw him lying down on his couch. I knew immediately that it was not good

news, and indeed, he confirmed that I had insulin-dependent diabetes.

My first exposure to diabetes education was through my father. As you might imagine, we talked about it often. He tried to explain to me the balancing act that was required to avoid acute problems. My father was a talented artist and used illustrations to try to show me the relationship between food intake, insulin dose, exercise, and glucose fluctuations. This was in the days before there were many patient education materials. Indeed, his were the first drawings I ever saw designed to explain diabetes therapy.

His attempts to illustrate the principles of diabetes therapy provided me my first valuable lesson that has served me well through the years: we all have different learning styles. Some of us are visual learners, and some do better with numbers and tables. My dad instinctively knew this and reinforced for me an important element of diabetes education, namely, *that we need to adapt our educational approaches to meet the needs and abilities of the learner.*

The next important event that influenced my career path happened shortly after my diagnosis. As I mentioned, I was in graduate school at UC Irvine studying social ecology. I was working on developing my dissertation topic, which I had decided would focus on the impact that institutional environments (in my case, prisons) had on health and behavior. So, in the middle of this, I suddenly discovered I had diabetes.

Like any good grad student, I went to the library to read up on what was known about how to cope with this disease. What I found was

a bit shocking; there were very few articles about the psychosocial elements of type 1 diabetes, and what was there had been produced in the 1950s. My personal favorite was the article that suggested that there was a “Freudian personality” that was probably the cause of diabetes. Tempting as it was to blame my mother, I realized that this perspective was not at all useful to me.

So one afternoon, I found myself bemoaning this fact to two of my dissertation advisors, Ray Novaco and Peter Scharf. Ray pointed out that perhaps I should consider changing the focus of my dissertation to something that was more personally meaningful: the process of coping with and adapting to diabetes. He pointed out that I had the training and skills to investigate this topic. I recognized the inherent logic of this recommendation and changed my dissertation to an investigation involving a group of adolescents who had histories of chronic poor diabetes control.

Now, when I say chronic poor control, I am talking about adolescents who averaged four hospitalizations for diabetic ketoacidosis per year. I spent 2 years with this group of 15 teens and their families, conducting interviews, administering psychometric tests, and trying to build an intervention to improve their situation. In this process, I learned several lessons that have helped shape my career and how I think about diabetes in general.

In collaboration with Dr. Michael Golden and Dr. Donald Orr, the physician mentors who helped me to meet and deal with what I later termed “my club,” I learned that *coping with diabetes, and in particular the lifestyle it imposes, is much more complex than simply following the demands of therapy or the instructions of a health care provider. It demands considerable energy on behalf of the person with the disease to cope with not only the required behaviors, but also the psychological demands.* Both Drs. Golden and Orr showed me that effective therapy in diabetes requires as much attention to psychosocial issues as it does to glucose.

My mentors and the teens also showed me that, often, *efforts to cope with the psychological and emotional demands of diabetes can appear to be destructive behaviors yet can actually be adaptive for patients as they struggle to cope with the emotions that diabetes therapy can instigate.* In this regard, I learned that sometimes denial can be an adaptive way to cope with an overwhelming emotional reaction. In some situations, it can be harmful to break down what is ostensibly an effective coping response without replacing it with something that can also help people deal with their emotions but may lead to a better health outcome.

My experience with the families of these teens was reinforced and expanded by the work of my friends Barbara Anderson, Tim Wysocki, Alan Delamater, and several others who have illustrated the *crucial importance that families play in helping people adapt to diabetes and how diabetes can become a crucible for mediating conflicts that extend way beyond the disease.* I have seen that diabetes can be used to avoid dealing with developmental issues in youth and relationship issues in adults. These colleagues and others have shown me that we need to attend to these issues if we are to both understand the forces that influence adaptation to diabetes and help others to find more effective strategies for coping.

My early exposure to the teens in my research group and my personal experience have also taught me a lesson that my friend Richard Rubin has so eloquently written about: *that to effectively adapt to diabetes, you need to struggle against it a bit, to try and “psych it out.”* As Richard always reminds me, such efforts may not always be easy, but they can be achieved, especially with the support and help of others.

My understanding of coping was deepened by the work of my friend Bill Polonsky, who gave voice to what many of us with this disease know, but could not always articulate: *that coping with diabetes can not only be difficult, but indeed can lead to diabetes burnout and that it*

is sometimes necessary to learn how to regulate the well-meaning intentions of others as we figure out how best to cope. His discussion of the “diabetes police” touches on an issue that many of us with this disease have experienced yet have not always known how to deal with. He reminds us that *to help with the education of people with diabetes, we sometimes need to see it from their perspective.*

This theme and my education have continued with the work of my friends Bob Anderson, Marti Funnell, and others who suggest that *to help others, first as an educator you have to let go of your own agenda and really listen to what others are telling you is important to them.* They have helped me and others to understand that the majority of diabetes care is provided by patients; therefore, patients are the focus of control and decision-making in the daily treatment of diabetes. The primary mission of the health care team is to help patients make informed decisions to achieve their goals and overcome barriers by providing ongoing diabetes expertise, education, and psychosocial support. They have reinforced my belief that people are much more likely to make and maintain behavior changes if those changes are personally meaningful and freely chosen. I worry that too many health care providers continue to labor under the acute care model of health care delivery under which they feel that they need to make a diagnosis and prescribe a cure and that their view is the correct one.

My experience has also been shaped by some remarkable physicians who are scholars as well as healers. I have learned from Charles Clark Jr., Frank Vinicor, Sue Kirkman, Alain Baron, Ed Fineberg, and many others that *to understand how to best help people with diabetes, we need to apply the best science, strive for the most precise answers, and base our advice on evidence and not just beliefs or personal prejudices.* I am proud to have worked with so many physicians who truly embrace a key element of the Hippocratic oath: “I will remember that there is art to medicine as well as science, and that warmth,

sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug."

I have learned valuable lessons from the many dietitians I have been privileged to work with, notably Lynn Wheeler, Marion Franz, and Hope Warshaw. For too many years, we tried to get patients to follow a diet that was often difficult and not terribly gratifying. They helped me and others to understand that *you don't have to deny yourself gratifying foods, but you need to understand how to make them work for you. As people, we all have unique differences that are reflected in our dietary habits, and we need to recognize and work with this.*

I have also learned a valuable lesson from my friend Steve Edelman who has created the Taking Control of Your Diabetes movement. He has helped me and many others to see that *we, as people with diabetes, can take control of our disease, that there is phenomenal power in sharing our experiences together and in seeking support and guidance from others who walk our path, and that making connections and examining experiences can strengthen us all, patients and providers alike.*

From Red Hiss, Russ Glasgow, Ed Fisher, and others I learned that *we need to consider diabetes treatment and education in a broader context—one that extends beyond the patient-provider interaction. We need to view diabetes in terms of community, considering how the environments in which we live either facilitate or inhibit the goals of treatment.* In this context, we need to design our approaches to treatment so that they account for not only how, but also where, people live.

I just returned from the 5th World Congress on the Prevention of Diabetes and Its Complications. This meeting helped me to better appreciate a lesson that I have learned from Kelly Acton, Frank Snoek, Norbert Hermanns, Hotoshi Isshi, and many others: that *diabetes is not a U.S. disease. Rather, it affects all people everywhere.* Importantly, how different people respond to the disease is significantly influenced by both culture and socioeconomic factors.

If we are going to effectively stand in the way of this worldwide epidemic, we need to carefully consider how best to individualize both education and treatment and make it responsive to individuals' needs. Clearly, this is not a one-size-fits-all disease.

From my good friend and collaborator Ron Ackermann and many of my colleagues with the Diabetes Prevention Program, I continue to learn about what I see as the future of our field: the primary prevention of diabetes. In recent years, research has illuminated the incredibly powerful role that lifestyle plays in reducing the risk of developing diabetes among people with increased risk. *We are now faced with the important task of translating the results of this research to the public health.* This effort will require that we address several issues, many of which I have alluded to already: that getting people to adopt healthy lifestyle behaviors is much more complex than simply telling them to lose some weight; that diabetes has considerable psychological demands that are influenced by family, friends, and environment; that we will need to tailor our approaches to how and where people live; and that, to do so, we will need to listen to what is important and difficult for those we help.

We also need to become stronger advocates for policies that will play a vital role in getting effective primary and secondary prevention efforts truly integrated into public health. This is a lesson that I continually learn from Ann Albright and others who struggle daily to get better recognition and coverage for diabetes prevention and treatment.

Finally, I need to acknowledge a few other people who have helped me to pursue the work on which I have focused my energies. My colleagues at the Diabetes Translational Research Center at Indiana University: Paris Roach, Usha Subramanian, Kieren Mather, Jackie Baker, Susie Kelly, Marcia Jackson, Brenda Hudson, Susanna Williams, Emily Anderson, and Angela Hadden, who remind me every day that there are many who share my passion and my concerns. These are people who are willing to

work incredibly hard because they know that what we do is truly important. I also have to thank them for the difficult task of keeping me in line and on schedule.

The most important group I need to thank is my family. I wish to thank my wife, Kay, who reminds me daily that we all must try and see the positive in what we do and never succumb to the forces that say it can't be done; my son, Grayson, who always reminds me that you need to keep a sense of wonder and humor when tackling serious issues; my mother, who always taught me to strive for excellence and pay attention to what really needs to be done and who has taught me more than any other that life is not a proposition of playing with good cards but of learning to play a poor hand well; and my stepfather, Karl, who always reminds me to measure twice and cut once and that *it's attention to detail that can make the difference between a good idea and a plan that works.*

Finally, I started this talk with a story about my father, who was my first diabetes educator. Unfortunately, he passed away 2 years ago and cannot be here with me today. He would have gotten a real kick out of this. However, I am very happy that my stepmother, Kay, could be here this morning to help channel his spirit.

In closing, what I hope is obvious by now is that, while I might be honored here this morning, I really represent everyone here, because we all share a concern about diabetes, a passion to help those with the disease, and a commitment to do whatever it takes to make a difference.

If I was chosen this year as the Outstanding Educator in Diabetes, it is because I have stood on all of your shoulders—the shoulders of giants. Indeed, all of you have stood on the shoulders of our community and learned to see how we might make a better tomorrow. I thank each and every one of you and both applaud and celebrate this award, which I accept for all of us.

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